Palliative and Hospice Care in South Africa: The Confluence of Context and Education

by

Carla Daun Loeppky Ens

A Thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfilment of the requirements of the degree of

Doctor of Philosophy

Department of Community Health Sciences
Faculty of Medicine
University of Manitoba
Winnipeg, Manitoba, Canada

Copyright © 2009 by Carla Daun Loeppky Ens

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES

*****

COPYRIGHT PERMISSION

Palliative and Hospice Care in South Africa: The Confluence of Context and Education

By

Carla Daun Loeppky Ens

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of

Manitoba in partial fulfillment of the requirement of the degree

Of

Doctor of Philosophy

Carla Daun Leoppky Ens©2009

Permission has been granted to the University of Manitoba Libraries to lend a copy of this thesis/practicum, to Library and Archives Canada (LAC) to lend a copy of this thesis/practicum, and to LAC's agent (UMI/ProQuest) to microfilm, sell copies and to publish an abstract of this thesis/practicum.

This reproduction or copy of this thesis has been made available by authority of the copyright owner solely for the purpose of private study and research, and may only be reproduced and copied as permitted by copyright laws or with express written authorization from the copyright owner.

Abstract

The aims of this study were twofold: 1) to describe, from the perspective of patients, family care providers and health care workers, how palliative and end-of-life care in South Africa is both perceived by the public as well as by hospice and other health care organizations, with a specific focus on the role of the medical doctor in providing this care, and 2) to assess the University of Cape Town's palliative care distance education program in terms of its' perceived ability to impact palliative care delivery as described by graduates and current students.

Four questions framed the research project and were best methodologically approached in two distinct parts. Part 1 (The Context of Palliative Care in South Africa), corresponded to the questions "How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?" and "How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?". Part 2 (Evaluation of UCT's Palliative Care Distance Education Program) was a response to the questions "What are/were the positive and negative aspects of the palliative care program as described by current and former students?" and "How do former and current students evaluate the influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?" Parts 1 and 2 are intrinsically connected, since an informed evaluation of the distance education program at UCT is best understood within the broader context of palliative and end-of-life care in South Africa.

Informed by interpretive description, a mixed methodology was used within the study. In Part One--the investigation of palliative and end-of-life care within South Africa--structured observations, interviews and a Health Care Provider Survey (1) were applied to the research questions. Fifteen hospices and two state hospitals served as project and observation sites. One hundred and sixteen participants including nursing sisters[i] (n=18), other health care providers (n=15), medical doctors (n=48), family care providers (n=13), and patients with life threatening illness(es)(n=22) were interviewed. In South Africa, the main medical conditions associated with palliative care are HIV/AIDS, cancer, and other chronic diseases; the disease profile of the participating patients reflected this national disease distribution. Seventy-five of the health care workers interviewed also completed the Health Care Provider Survey.

Three themes described the qualitative data: 1) Two Solitudes: Participant versus Public Notions of Palliative Care, 2) Accessing Palliative Care, and 3) The Changing Face of Palliative Care. Viewed together, the three themes and their attendant sub-themes identified how palliative and hospice life care was fragmented and difficult to access within South Africa. Factors such as ability to pay and proximity to care were described as affecting palliative care experiences.

In the Health Care Provider Survey, participants ranked the importance of various palliative care elements in an educational program for medical doctors. There were 36 statements pertaining to 11 domains of palliative care: 1) Pain, 2) Symptom

---

[i] In South Africa, a professionally trained nurse with a Bachelor of Nursing is referred to as a "nursing sister". The terms "nurse" and "nursing sister" are interchangeable.

Control, 3) Bereavement, 4) Psychosocial Aspects of Death, 5) Professional Issues, 6) Ethics, 7) Establishing a Palliative Care Program in the Community, 8) Principles of Palliative Care, 9) Communication with the Patient and Family, 10) Interdisciplinary Communication, and 11) Personal Ability to Cope with a Dying Patient. Although 94.2% of the time respondents selected the ratings “very” or “somewhat” important, the five categories with the highest overall scores were “Pain Management” (2.97 out of 3, SD=0.16), “Communication with Patient and Family” (2.96, SD=0.20), “Pain Assessment” (2.96, SD=0.20), “Control of Symptoms Nausea and Vomiting” (2.94, SD=0.23), and “Principles of Palliative Care”(2.94, SD=0.23). Those that scored the lowest overall were related to “Pain and Neurophysiology” (2.53, SD=0.56), “Pain and Comprehensive Therapies” (2.42, SD=0.60), “Research in Palliative Care” (2.41, SD=0.55), and “Euthanasia” (2.22, SD=0.83).

In Part Two--the investigation of UCT's distance education palliative care post-graduate program--three surveys were used to evaluate the program. Eighty-three individuals representing 66.4% of all possible participants completed the General Survey and 41 (65.7%) of the program's graduates completed the Graduate Survey. The Pre-post Workshop Survey, measuring attitudes and competencies before and after having finished the UCT palliative care training, was also completed by a small portion of the workshop participants (2006 n=6; 2007 n=8). In general, students perceived the course material and their experiences to be meaningful in furthering their understanding of palliative care. The Graduate Survey gave insight into the strengths and weaknesses of the program; communicating with patients, family care providers and other health care workers was described as being particularly well taught, as was learning to deal with challenging encounters. Graduates praised the program but also stressed the need to develop a curriculum that incorporated a practical component.

This study has highlighted two integrated areas--context of care and palliative care education—which will be central to further development in the field of hospice and palliative care. Two recommendations arose from this study: 1) to improve accessibility to palliative care and hospice services by addressing barriers to care present in HPCA hospice programming and 2) to increase the content of palliative care in undergraduate and post-graduate medical training as well as professional development aiming for uniform inclusion of palliative care curricula and a compulsory component of medical education. To increase accessibility, referral processes for existing hospice and palliative care services will need to be improved along with further government support. To address the education agenda, it is recommended that palliative care education target undergraduate medical students, practicing medical doctors and the general public. The benefits of the post-graduate distance education palliative care program are limited to a small group of practitioners and it is important that the principles of palliative care gain prominence more broadly.

Acknowledgements

I am grateful for all of the people and organizations who provided support throughout this study.

First, I would like to acknowledge the support of the various funding bodies that helped finance my doctoral research:

- Social Sciences and Humanities Research Council
- International Development Research Centre
- Western Regional Training Centre
- Manitoba Palliative Care Research Unit
- Community Health Sciences (David G. Fish Memorial Scholarship)

My humble thanks go to Dr. Harvey Chochinov who, in the midst of his own demanding research career, found countless hours to mentor me. Harvey's endorsement of my program of research has been very meaningful and I am thankful for all of the opportunities he has afforded me. I feel honoured to have had such an experience.

I have always known that I have a stellar committee. With individuals like Dr. Stephen Moses and Dr. Richard Harding- both researchers with remarkable careers - providing input, I have very capable minds guiding my work. Thank you both for your comments and assistance throughout this process; you have both challenged me to grow as a researcher and writer.

Two colleagues, both from the Manitoba Palliative Care Research Unit, that I would like to thank include Dr. Genevieve Thompson and Dr. Susan McClement. Genevieve was always willing to assist with this study whether it was in reviewing transcripts, editing manuscripts, or providing a break when it was needed. Thanks Gen for your friendship and guidance. Sue also assisted with reviewing the qualitative section of the dissertation and provided excellent feedback. Sue has a way of teaching and encouraging at the same time and her help was much appreciated.

Thank you also to Dr. John Bond, a mentor and friend, for his assistance with the project, particularly in its final stages.

I was welcomed in South Africa with open arms. Dr. Liz Gwyther, a woman who is incredibly dedicated to palliative and hospice care in South Africa, found time to introduce me to various stakeholders and answer the numerous questions I had. In the office at UCT, I was blessed to be working with three women whom I now regard as good friends: Thandi Mashao, Linda Ganca, and Naomi Fray. Our conversations pertaining to culture and race were particularly enlightening for me and I appreciated your openness to share with me on sensitive topics. Each of the women also assisted the project in different professional capacities and I am thankful for this. And finally, my gratitude reaches out to my very capable research assistant, Kate Jackson, who taught me so much about South Africa in our journeys to and from interviews.

I thank the participating hospices, staff and participants that gave of their time to this research endeavour. I also want to thank the Hospice and Palliative Care Association of South Africa for supporting the research and providing statistical summaries of hospice referrals.

I would like to thank and acknowledge the support of my families both in my time as a student and throughout our year in South Africa. It is a difficult decision to leave one's place of comfort; with the blessing of parents and siblings, the decision was easier to make. Prayers, visits, emails, calls, and letters were much appreciated and we felt carried along by the encouragement and love from home.

Lastly, I would like to thank my husband and children (Katarina, Henry and Harrison) for encouraging me to follow this dream and for making 2007 an unforgettable year. I appreciated how willing you all were to try something different, even if it was at times difficult to be far away from family and friends. I am proud of you all.

I dedicate this dissertation to my husband, Steve, for without his support, I would not be writing this today. There are many sacrifices to be made when a spouse is a student and these have not gone unnoticed. In South Africa, Steve filled the year with memories: as a venerable tour guide, as the "boss of the apartment", as head chef, and as my trusty chauffeur. I cannot imagine that our year could've been any better. With all my love, this one's for you.

Table of Contents

Appendices

TABLES

FIGURES

CHAPTER ONE: Introduction

1.1 Introduction

The Republic of South Africa, with a 2007 mid-year population estimation of 47.9 million people (2), is located at the southernmost tip of the African continent. The country is divided into nine provinces: Eastern Cape, Free State, Gauteng, KwaZulu-Natal, Limpopo, Mpumalanga, North-West, Northern Cape, and Western Cape (see Appendix 1 for a map of South Africa). In South Africa, 79.3% of the population are black, 9.3% are white, 2.5% are Asian, and 8.8% are colored[ii] (3). South Africa is considered an "upper middle-income country"[iii] (4). This is a deceptive title. The country's aggregate income masks extreme differences in wealth that coincide with racial divisions in the country: the white community of affluence and the black people with few economic resources (5,6). Approximately 13% of the people live in conditions similar to developed nations as opposed to the remainder who live in extreme poverty (6).

From 1948 to 1991, South Africa operated under a system of *apartheid*, or racial segregation, where citizens were legally classified by racial group which in turn determined their class and subsequent treatment (7). These racial groups, classified as whites, Indians, coloreds, and blacks (in order of perceived value), were often physically separated and colonized based on these legalized categories (7). In apartheid South Africa, the government sectors were tools to maintain white supremacy and ensure

---

[ii] black denotes a person of pure African ancestry and colored of mixed racial descent.(46)
[iii] the gross national income per capita is $3,595-$11,115 (US)

strict racial divide. For example, the government division for health care provided substantial funding to white communities and minimal funding to blacks (8,9). The system of apartheid ensured that vast differences in service provision and opportunities co-existed and that the black people of South Africa, although representing the majority of the people, were essentially without the ability to vote or influence societal change democratically (7).

In 1990, South Africa began the transition from apartheid rule to a national democracy (10,11). April 7, 1994 marked the official end of apartheid in South Africa; on this day, the populace voted in the African National Congress (ANC) and Nelson Mandela became president (8,10). It was the start of the "Rainbow Nation", a phrase coined by Archbishop Desmond Tutu to describe post-apartheid South Africa (3). However, this period was not a time of peaceful governance as the end of the apartheid regime was accompanied by intense violence and social dislocation (11). A huge influx of impoverished and unemployed people from the rural regions of South Africa made their way to the urban shacklands; poverty was intensified and there was a lack of social cohesion (12). Through it all, a democratic nation was born.

Undeniably, the legacy of apartheid is still obvious within South Africa today (13), and the process of change is slower than anticipated (14). The terms "black", "white", "colored" and "Indian" are still used in society to describe different population groups. However, the classification does not carry with it the weight of the apartheid system. Now, when the terms are utilized within the governmental sector, it is for statistical purposes, to evaluate trends within the systems to ensure that positive changes are occurring within society.

1.2 Health Care in South Africa

The health care system is a reminder of the polarities that exist in the country. Both a public and private health care system co-exist to provide health care for those living in South Africa. Approximately 85% of the population (corresponding with the poorest segment of society) is dependent on the public system with the remainder utilizing mainly the private medical services (15-18).

Although up to date information on health care utilization was not available, data collected by Statistics South Africa between 1995 and 1999 provide a fairly recent overview of health care usage (19,20). The data indicated that in 1998, 53.8% of survey respondents had used public health care services, 38.4% private sector, and 7.8% had visited traditional healers. As can be seen in Table 1.1, the largest proportion of state health care users were black and colored which is in contrast to white populations who relied heavily on private health care. Asian populations used both public and private health care services in fairly equal proportions. Traditional healers were visited most frequently by black South Africans.

Table 1.1: Utilization pattern by population groups, 1998 (20)

Ethnic Background	Public Sector (%)	Private Sector (%)	Traditional healer (%)
black	62.3	32.6	6.1
colored	57.3	42.4	0.5
white	22.4	77.1	0.5
Asian	44.9	54.7	0.4
Total	**53.8**	**38.4**	**7.8**

Even within the public health care system, access to care varies by socio-economic status; when health care was needed, people in low and middle class SES classes were found to access care significantly less often than those in higher SES classes (21).

In South Africa, a disproportionate amount of public money is used to fund private health care compared to the number of end users (18). As Benatar comments:

> *Over the past 30 years, expenditures for health care in the private sector have grown to consume a much larger proportion of the total national expenditure on health. In the 1970s, 30% of all health care expenditures were concentrated in the 20% of the population that had private insurance. Today, approximately 9% of the nation's GDP is spent on health care, with 60% of these funds going to care for the 18% of the citizens who have private insurance. Similarly, the percentage of physicians who work in the private sector and for patients with insurance has grown from 40% in the 1970s to 66% today (p. 81-82).* (9)

For the fiscal year 2003-2004, $5.3 billion, or 11% of the national budget, was allocated for primary, secondary, and tertiary public health care (9).

1.3 Life Expectancy in South Africa

A three-year overview of data from 2003-2005 by the World Health Organization (WHO) provided several population-based indicators of health for South Africa (see Table 1.2) (22). In 2002, the WHO noted that a *healthy life expectancy* (measuring a disability-free life expectancy (23)) at birth for South African males was 43 years and for females, 45 years. As the *regular life expectancy* (a measure that includes the quantification of morbidity across the life span (23)) was approximately 5 years longer, the implication is that a proportion of a South African's life will be spent in poor health.

It is important to recognize the impact that HIV/AIDS has made on life expectancy in South Africa. In a recent population-based study examining the implication of mortality transition in rural South Africa, the authors reported age-standardized death rates for four periods from 1992 to 2005. Their findings indicated that mortality rates have increased substantially since the mid-1990s primarily due to a six-fold rise in infectious and parasitic disease (24). Life expectancy in South Africa was on a steady upwards trajectory prior to the onset of the HIV/AIDS epidemic. As Tollman et al. assert, decreases in mortality were sustained until the mid-1990s when the HIV/AIDS epidemic took off and this induced a reversal in mortality for young adults and children. In fact, "by 2005, life expectancy at birth had fallen by 12 years for women and by 14 years for men" (p. 893) (24).

Table 1.2: Population-based Indicators for South Africa (based on data from the World Health Organization) (22)

	2003		**2004**		**2005**	
Population	45, 026, 000		47, 432, 000		Not available	
GDP per capita	$7,935		$8,506		Not available	
Total health expenditure per capita	$689		$660		$748	
Total health expenditure as % of GDP	8.7%		8.4%		8.6%	
	Males	Females	Males	Females	Males	Females
Life expectancy at birth (years)	48	50	47	49	50	52
Child mortality (per 1000)	70	61	72	62	68	68

1.4 Palliative and End-of-Life Care in South Africa

The World Health Organization describes palliative care as: 1) providing relief from pain and other distressing symptoms, 2) affirming life and viewing death as normal, 3) neither hastening nor postponing death, 4) integrating both spiritual and psychological aspects into care, 5) offering support systems to patients, 6) supporting families during illness and bereavement, 7) utilizing a multi-disciplinary team approach, and 8) enhancing quality of life, all element which should be applied over the entire course of the illness (25). The broad term "palliative care" subsumes palliative medicine as well as aspects of hospice care. A generally accepted view of palliative care is that it is the active total care of patients whose disease is not responsive to curative treatment. It encompasses all treatment modalities aimed at enhancing quality of life rather than curing disease (26). Palliative care can be regarded as an exercise in prevention, the prevention of ultimate suffering through timely diagnosis and expert management of physical symptoms and of psychosocial and spiritual concerns, at the earliest possible moment (27). Ultimately, excellent palliative care is anticipatory in nature, rather than reactive.

The literature differentiates between "palliative care" and "end-of-life care". While end-of-life care utilizes the principles of palliative care, it is specific to the care that patients and their families receive when patients are dying or near death. End-of-life care takes place during the last days or weeks of life and focuses on preventing suffering by attending to the physical, emotional, and spiritual comfort of the patient and family. End-of-life care is the specific application of palliative care interventions in the last hours, days or weeks of life (28).

Hospices are specific organizations where individuals with life threatening illnesses as well as their families are provided palliative care. Different hospice models are in existence around the world; South African hospices, based on a UK home care model, have been in existence since the early 1980s (29) and are primarily operated as NGOs. Within the physical space of a hospice, there are typically a small number of inpatient beds for the purposes of symptom control, respite for family caregivers, or (rarely) terminal care (30). In South Africa, the majority of hospice patients (96.5%) are cared for in their homes by hospice professional nurses or by trained non-professional carers supervised by a professional nurse (31).

A variety of factors have shaped care provision for individuals with life-threatening illnesses in South Africa. A lack of trained health care professionals (32), inadequate infrastructure (33-35), and difficulties in accessing medications (36) limit the ability to provide palliative care to those in need. Even though the health care sector's expenditures increase each year and the government has implemented a range of responses to the HIV/AIDS pandemic (37), it is apparent that the demand for health care services, and in particular palliative care, is greater than the resources available. Therefore, understanding the role of hospices and other health care organizations in providing palliative care in South Africa is important. The changing landscape of care, affected by factors like government policy and burden of illness, ensures that palliative care providers have a distinct part to play.

1.4.1 Location of Care

In South Africa, the majority of formal palliative and end-of-life care services are provided by hospices. Home-based care models are most frequently adopted whereby nurses and home-based carers visit patients and provide care within patients' homes. However, palliative and end-of-life care is also delivered in other settings such as hospital inpatient units (38,39). Originally designed to care for terminally ill cancer patients, hospices now administer care to many HIV/AIDS patients (30). For example, in a study of an Eastern Cape palliative care inpatient unit, 70% of the admitted patients had AIDS (40). Developing hospice programs has not eliminated the need for hospital-based services, but has greatly reduced the reliance on hospital care for patients at end of life (41,42).

1.4.2 Role of Health Care Providers

A variety of different professional health care providers are involved in palliative and end-of-life care in South Africa. For example, home based carers, social workers, nursing sisters, and medical doctors all have a role within the existing models of palliative and end-of-life care (39). The bulk of the physical care tasks is provided by home-based carers and nursing sisters (30,43). Although the literature emphasizes models of care that utilize trained nurses as administrators, nursing sisters provide a great deal of medical care and nurturance. Home-based carers, subordinates in the health care hierarchy, are most directly involved with the regular care tasks of the patients, such as feeding and bathing patients (42,43). Home-based carers employed in hospice settings typically receive training in a variety of areas (e.g. wound care, nutrition, and financial planning) and are assigned to patients by nursing sisters. For patients requiring a high level of assistance, the majority of their care would be provided by home-based carers. Home based carers receive their training from the hiring organization (e.g. Hospice and Palliative Care Association of South Africa) and typically work in their home community. In that way, the home-based carer is both familiar and accessible to the patients that he or she provides care to.

It is not clear from the literature what the role of medical doctors is in the provision of palliative care. There is some evidence that they may feel inadequately prepared to meet the changing needs of the dying patient (44,45) which may be due to a lack of preparation in medical training. Palliative care is ideally and typically delivered by a multidisciplinary team and it is commonly the place of the medical doctor to provide leadership and consistency for the network of professionals. Therefore, having doctors who not only understand the principles of palliative care but also employ them is paramount within the multidisciplinary model. As the role of the medical doctor is unclear, more investigation needs to be done; it is important to know if the team leader is adequately prepared to design and monitor palliative care plans for patients with life threatening illness(es).

1.5 Palliative Care Education

The field of palliative care is in its infancy in South Africa. As such, medical schools are only beginning to teach palliative care at the undergraduate level and do not uniformly offer post-graduate palliative care programs. In response to this dearth of educational offerings, in 2000, the University of Cape Town (UCT) began a post-graduate distance education program to train doctors in palliative care. Two streams were created: a Postgraduate Diploma in Palliative Medicine and a Masters of Philosophy in Palliative Medicine (45). Both programs incorporate learning modules, web-based learning, workshops, and personal learning portfolios. It is believed that these programs have benefited course participants thus enhancing their abilities to attend to palliative and end-of-life care patient issues. However, as the distance education training program has not been formally evaluated since its inception, it is unknown what affect it has had in the health care practices of the course participants or, more generally, in the community at large.

1.6 Aims and Objectives

The aims of this study were twofold: 1) to describe, from the perspective of patients, family care providers and health care workers, how palliative and end-of-life care in South Africa is both perceived by the public as well as by hospice and other health care organizations, with a specific focus on the role of the medical doctor in providing this care, and 2) to assess the University of Cape Town's palliative care distance education program in terms of its' perceived ability to impact palliative care delivery as described by graduates and current students. Four questions framed the research project and were best methodologically approached in two distinct parts. Part 1 (The *Context of Palliative Care in South Africa*), corresponded to the questions "*How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?*" and "*How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?*". Part 2 *(Evaluation of UCT's Palliative Care Distance Education Program*) consisted of two questions: "*What are/were the positive and negative aspects of the palliative care program as described by current and former students?*" and "*How do former and current students evaluate the influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?*". Parts 1 and 2 are intrinsically connected, since an informed evaluation of the distance education program at UCT is best understood within the broader context of palliative and end-of-life care in South Africa.

1.7 Methodology

The research project utilized a mixed methodology, inclusive of qualitative and quantitative approaches. To examine the more general and contextual questions pertaining to palliative and end-of-life care in South Africa, interviews of patients, family care providers, and health care providers were conducted. Structured observations in hospice and other health care organizations were also performed to provide related data on health care systems and delivery of care.

Data, both qualitative and survey responses from current students and graduates of the UCT distance education program in palliative care program, was obtained to respond to the third and fourth research questions. In this fashion, student and graduate feedback was available to analyze both their educational experiences and their understanding of how the distance education program shaped their medical practices.

1.8 Significance of the Study

This project should provide significant information pertaining to the provision of palliative and end-of-life care and palliative care education in South Africa. As this is currently not adequately addressed within the literature, this research will fill an important knowledge gap, thereby informing clinical practices, policy development, and education. An interpretive description based on the experiences of patients, family care providers and health care workers relating to palliative and end-of-life care in South Africa will broaden what is currently known about areas such as delivery of and satisfaction with care. In addition, the evaluative findings from the palliative care distance education program should help to strengthen UCT's current offerings; if students' feedback is acted on, then the course should be more reflective of the content areas and delivery methods that students perceived as important.

1.9 Organization of the Thesis

The thesis is organized into six chapters, each designed to provide detailed information about the research project. The primary aim of the first chapter was to introduce the main topics of the dissertation: South Africa's health care system, palliative and end-of-life care in South Africa, and palliative care education. Chapter One also briefly reviewed the purpose, methods, and significance of the project.

Chapter Two provides an in-depth literature review pertaining to South Africa's burden of disease (with a particular focus on cancer and HIV/AIDS), palliative care in South Africa, palliative care education, and methods of evaluation. The chapter concludes with the aims and objectives of the study.

In Chapter Three, the methodologies used in the study are explained. As the study consists of two distinct parts, each is described separately. This chapter provides an explanation of the sample, protocol, instruments, procedures and analyses.

The results of the study are presented in Chapters Four and Five. Part 1 of the project (The Context of Palliative Care in South Africa) is discussed in Chapter Four; these results include both the qualitative analysis of key stakeholder perspectives on palliative and end-of-life care in South Africa and the results of the Health Care Provider Survey. In Chapter Five, the results of Part 2 (Evaluation of UCT's Palliative Care Distance Education Program) including those of the three surveys- General Survey, Graduate Survey, and Pre-post Workshop Survey- are explained. Overall trends and comparison testing are expanded upon.

The final chapter provides an overview of the critical findings, study limitations and study implications. This includes a discussion about palliative care and end-of-life care in South Africa and the confluence of perception, need, and resources. These results are placed within the context of other research in the field of international health and palliative medicine. Given the relative paucity of empirical work in this area, this study should complement the existing empirical literature, hopefully promoting further dialogue on the issue of palliative care in South Africa.

1.10 Chapter 1 References

(1) Barnabe C, Kirk P. A needs assessment for Southern Manitoba physicians for palliative care education. J.Palliat.Care 2002 Fall;18(3):175-184.

(2) Statistics South Africa. Mid-year population estimates: 2007. 2007; Available at: http://www.statssa.gov.za/publications/P0302/P03022007.pdf. Accessed May 8, 2008.

(3) The Economist. Chasing the rainbow: A survey of South Africa. The Economist 2006 April 8, 2006:1.

(4) The World Bank. Country Classification. Available at: http://web.worldbank.org/WBSITE/EXTERNAL/DATASTATISTICS/htm. Accessed May 8, 2008.

(5) Igumbor EU, Kwizera EN. The positive impact of rural medical schools on rural intern choices. Rural Remote Health. 2005 Apr-Jun;5(2):417.

(6) The World Bank. South Africa Country Brief. 2005; Available at: http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/SOUTHAFRICAEXTN/0,,menuPK:368086~pagePK:141132~piPK:141107~theSitePK:368057,00.html. Accessed 05/03, 2006.

(7) History of South Africa in the apartheid era. 2006; Available at: http://en.wikipedia.org/wiki/Apartheid. Accessed June 26, 2006, 2006.

(8) Ngwena C. Substantive equality in South African health care: the limits of law. Med.Law.Int. 2000;4(2):111-131.

(9) Benatar SR. Health care reform and the crisis of HIV and AIDS in South Africa. N.Engl.J.Med. 2004 Jul 1;351(1):81-92.

(10) Klasen S. Poverty, inequality and deprivation in South Africa: An analysis of the 1993 SALDRU survey. Social Indicators Research 1997;41:51-94.

(11) Beall B, Gelb S, Hassim S. Fragile stability: State and society in democratic South Africa. Journal of Southern African Studies 2005 December 2005;31(4):681-700.

(12) Marks S. An epidemic waiting to happen? The spread of HIV/AIDS in South Africa in social and historical perspective. African Studies 2002;61(1):13-26.

(13) van der Walt HM, Swartz L. Task orientated nursing in a tuberculosis control programme in South Africa: where does it come from and what keeps it going? Soc.Sci.Med. 2002 Apr;54(7):1001-1009.

(14) Couper I. The future of rural medicine in South Africa. S.Afr.Med.J. 1997 Mar;87(3):290-292.

(15) Goosen J, Bowley DM, Degiannis E, Plani F. Trauma care systems in South Africa. Injury 2003 Sep;34(9):704-708.

(16) Ngwena C. Access to health care services as a justifiable socio-economic right under the South African constitution. Med.Law.Int. 2003;6(1):13-23.

(17) McKinley R, Cameron D. Differences in health care in South Africa and the UK. Br.J.Gen.Pract. 2004 Jul;54(504):546; author reply 546-7.

(18) Sekhri N, Savedoff W. Private health insurance: implications for developing countries. Bull.World Health Organ. 2005 Feb;83(2):127-134.

(19) Wadee H, Gilson L, Thiede M, Okorafor O, McIntyre D.
HEALTH CARE INEQUITY IN SOUTH AFRICA AND THE PUBLIC/PRIVATE MIX. 2003 September, 2003.

(20) Department of Health. South Africa Demographic and Health Survey - 1998. 1998.

(21) Lalloo R, Myburgh NG, Smith MJ, Solanki GC. Access to health care in South Africa--the influence of race and class. S.Afr.Med.J. 2004 Aug;94(8):639-642.

(22) World Health Organization. South Africa. 2006; Available at: http://www.who.int/countries/zaf/en/. Accessed June 12, 2006.

(23) Collerton J, Barrass K, Bond J, Eccles M, Jagger C, James O, et al. The Newcastle 85+ study: biological, clinical and psychosocial factors associated with healthy ageing: study protocol. BMC Geriatr. 2007 Jun 26;7:14.

(24) Tollman SM, Kahn K, Sartorius B, Collinson MA, Clark SJ, Garenne ML. Implications of mortality transition for primary health care in rural South Africa: a population-based surveillance study. Lancet 2008 Sep 13;372(9642):893-901.

(25) World Health Organization. World Health Organization definition of palliative care. Available at: http://www.who.int/cancer/palliative/definition/en/. Accessed May/ 05, 2006.

(26) Kim A, Fall P, Wang D. Palliative care: optimizing quality of life. J.Am.Osteopath.Assoc. 2005 Nov;105(11 Suppl 5):S9-14.

(27) de Lima L. IAHPC List of Essential Medicines for Palliative Care: Summary of Process for Editors of Pain and Palliative Care Journals. J.Palliat.Care 2006 Winter;22(4):300-304.

(28) Clark D. From margins to centre: a review of the history of palliative care in cancer. Lancet Oncol. 2007 May;8(5):430-438.

(29) Gwyther E. South Africa: the status of palliative care. J.Pain Symptom Manage. 2002 Aug;24(2):236-238.

(30) Gwyther L. Palliative care response to HIV/AIDS in South Africa. Int.J.Palliat.Nurs. 2005 Mar;11(3):112-113.

(31) Hospice and Palliative Care Association of South Africa. October 2007 Referral Statistics. 2007.

(32) Coughlan M. Pain and palliative care for people living with HIV/AIDS in Asia. J.Pain Palliat.Care.Pharmacother. 2003;17(3-4):91-104; discussion 105-6.

(33) Noah BA. AIDS and antiretroviral drugs in South Africa: public health, politics, and individual suffering: a review of Brian Tilley's It's my life. J.Law Med.Ethics 2003 Spring;31(1):144-148.

(34) Stein ME, Spencer D, Kantor A, Ruff P, Haim N, Bezwoda WR. Epidemic AIDS-related Kaposi's sarcoma in southern Africa: experience at the Johannesburg General Hospital (1980-1990). Trans.R.Soc.Trop.Med.Hyg. 1994 Jul-Aug;88(4):434-436.

(35) Tshibangu KC, Worku ZB, de Jongh MA, van Wyk AE, Mokwena SO, Peranovic V. Assessment of effectiveness of traditional herbal medicine in managing HIV/AIDS patients in South Africa. East Afr.Med.J. 2004 Oct;81(10):499-504.

(36) MacDonald N. Educational programs in pain and palliative care. J.Pain Symptom Manage. 1993 Aug;8(6):348-352.

(37) Department of Health: Republic of South Africa. Republic of South Africa: Progress Report on Declaration of Commitment on HIV and AIDS. 2005;March 2006.

(38) Harding R, Higginson IJ. Palliative care in sub-Saharan Africa. Lancet 2005 Jun 4-10;365(9475):1971-1977.

(39) Hospice Association of South Africa. Palliative care. S.Afr.Med.J. 2001 May;91(5):398.

(40) Jameson C. The role of a palliative care inpatient unit in disease management of cancer and HIV patients. S.Afr.Med.J. 2007 Sep;97(9):849-852.

(41) Uys L, Hensher M. The cost of home-based terminal care for people with AIDS in South Africa. S.Afr.Med.J. 2002;92(8 I):624-628.

(42) Crowe S. Home truths. Nurs.Times 2001 Sep 27-Oct 3;97(39):26-27.

(43) Demmer C. AIDS and palliative care in South Africa. Am.J.Hosp.Palliat.Care 2007 Feb-Mar;24(1):7-12.

(44) Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. BMJ 2003 Jul 26;327(7408):192-194.

(45) Gwyther L, Rawlinson F. Palliative medicine teaching program at the University of Cape Town: integrating palliative care principles into practice. J.Pain Symptom Manage. 2007 May;33(5):558-562.

(46) Coogan PF, Rosenberg L, Shapiro S, Hoffman M. Lactation and breast carcinoma risk in a South African population. Cancer 1999 Sep 15;86(6):982-989.

CHAPTER TWO: Literature Review

2.1 Introduction

The landscape of death and dying in South Africa has been shaped by many factors. For example, the societal (including government and public) responses to the HIV/AIDS pandemic such as AIDS denialism and delays in treatment (1), have had broad implications for systemic health care delivery. Palliative care initiatives, evident in both the formal health care setting as well as in non-governmental organizations (NGOs) like the Hospice and Palliative Care Association of South Africa (HPCA), have made visible the care needs for people with life threatening illnesses. The fact that many health care providers lack knowledge in palliative medicine is a critical concern (2), but as interest in palliative care continues to grow and as educational opportunities for health care providers become more readily available, the future landscape of death, dying and palliative care may be altered. The purpose of this chapter is to describe the burden of disease in South Africa (with a particular focus on HIV/AIDS and cancer), palliative care, and educational initiatives within the field.

2.2 Burden of Disease in South Africa

Due to the AIDS epidemic in South Africa, the burden of illness (estimated using a *modelling approach*[iv] due to high mortality and lack of comprehensive data) is expected to reduce the average life expectancy at birth from 50.0 years (as of 2005) (3)

[iv] The modelling approach projected the cause-of-death profile using information from the Actuarial Society of South Africa and estimations from sources including registered cause-of-death data (171).

to 41.0 years by 2010 (4). The provincial variations in life expectancy reflect the differing HIV prevalence rates[v]. In 2000, life expectancy was lowest in the provinces of KwaZulu Natal (male- 49.4 years; female- 53.8 years) and Mpumalanga (male- 50.7; female- 55.5), and highest in the Western Cape Province (male- 59.8; female- 67.0) (Appendix 2)(5). KwaZulu Natal also had the highest adult HIV prevalence rate with the antenatal seroprevalence rate measured at 40% (6,7). High HIV/AIDS prevalence rates, ranging between 27-31%, were also seen in the provinces of Eastern Cape, Free State, Gauteng, Mpumalanga and North West (8).

While HIV/AIDS is a major factor in calculating South Africa's burden of disease, other illnesses and causes contribute. In provinces described as "more poor and more rural", mortality due to pre-transitional causes[vi] were more pronounced (5). Conversely, injury mortality rates were highest in Western Cape and Gauteng, the provinces with large metropolitan areas (5). For males, the leading cause of injury death was found to be homicide, while for females it was road traffic accidents (5).

2.2.1 Cancer

Global cancer statistics indicate that cancer incidence and mortality are on the rise (9,10); in 2002, over 7.5 million people worldwide died of cancer (11). With about half of the world's new cancer cases occurring in developing countries, and approximately 80% of these cancer patients presenting at an incurable stage of the

---

[v] the total number of cases in the population divided by the number of individuals in the population

[vi] pre-transitional causes includes communicable diseases, maternal causes, perinatal conditions and nutritional deficiencies. These are generally related to underdevelopment and lack of health services (172).

disease, cancer is also an important part of South Africa's burden of disease equation (12). In developing countries, cancer mortality rates are generally increasing and are considered a major public health problem (10) as they are often related to various lifestyle factors (13). For instance, a portion of people with HIV/AIDS develop related cancers, with the most common being Kaposi's sarcoma (14).

Statistics from the World Health Organization state that, in 2002, the leading causes of death in South Africa were due to HIV/AIDS (355.4 per 100,000), cardiovascular disease (89.1 per 100,000), injuries (47.8 per 100,000), followed by malignancies (38.3 per 100,000). As shown in Table 2.1, lung, oesophageal, cervix, and breast cancers were the most common in the country. Furthermore, the disability-adjusted life year (DALY)[vii] measurement, a tool used by the WHO to inform priority-setting as health problems by order of potential for health gain, also identified the same four cancers as priority areas.

[vii] The disability-adjusted life year (DALY) is a health gap measure which "combines information on the impact of premature death, and of disability, and other non-fatal health outcomes" (173). The DALY was designed specifically for the Global Burden of Disease Study completed in 1992 by WHO at the request of the World Bank. It is frequently used to identify health care priorities; a higher DALY would be associated with a greater need.

Table 2.1: Estimated and Age-Standardized Cancer Statistics in South Africa, per 100,000, 2002 (15)

Non-communicable diseases	*Estimated total deaths ('000)*	*Estimated DALYs*	*Estimated deaths/100,000*	*Age-standardized death rates*	*Age-standardized DALYs*
Malignant neoplasms	**38.3**	**459**	**85.5**	**154.1**	**1,304**
Trachea, bronchus, lung cancers	5.9	63	13.1	23.5	190
Oesophagus cancer	5.3	60	11.8	20.9	180
Cervix uteri cancer	3.4	51	7.6	12.3	144
Breast cancer	3.1	39	6.9	12.5	114
Colon and rectum cancers	2.4	23	5.4	11.0	66
Stomach cancer	2.2	24	5.0	9.3	72
Liver cancer	2.2	28	4.9	8.5	77
Prostate cancer	2.1	14	4.7	10.6	41
Lymphomas, multiple myeloma	1.5	21	3.3	5.7	54
Leukaemia	1.3	25	3.0	4.5	55
Mouth and oropharynx cancers	1.3	16	2.9	5.0	48
Pancreas cancer	1.3	13	2.9	5.5	39
Melanoma and other skin cancers	0.6	6	1.2	2.3	18
Corpus uteri cancer	0.6	7	1.4	2.6	20
Ovary cancer	0.6	7	1.3	2.3	21
Bladder cancer	0.6	5	1.3	2.8	16

2.2.2 HIV/AIDS Pandemic

The HIV/AIDS pandemic in South Africa is changing the landscape of health care and has exacerbated a myriad of social, political and economic issues. For example, the lack of clear political leadership regarding the HIV/AIDS pandemic has served to intensify the differences in health status among rich and poor (16-18). Any post-apartheid achievements in health care have been overshadowed by both the South African government's refusal to accept HIV/AIDS and their poor response to the HIV/AIDS pandemic (1,19-21). In a Lancet editorial dated August 16, 2003, the government leaders in South Africa were described as "dithering and misguided" (p. 501) (22).

Recent political developments, however, shows promise for the health care system. As reported in a recent Lancet article, on September 25, 2008, the new interim president- Kgalmea Mtlanthe- replaced South Africa's Health Minister Manto Tshabala-Msimang with Barbara Hogan (23). Described as an anti-apartheid veteran, she is expected to usher in a progressive health agenda (23).

What follows is an overview of the disease and its particular relationship to palliative care and end-of-life care.

2.3 Description of HIV/AIDS

The acquired immunodeficiency syndrome (AIDS), defined as a "collection of symptoms and infections in humans resulting from the specific damage to the immune system caused by infection with the human immunodeficiency virus (HIV)" (24), first surfaced in the early 1980s in the United States (25,26) (see Appendix 3 for a review of HIV/AIDS episodes in an evolving epidemic). Three years later, an AIDS epidemic within the heterosexual population in Africa was discovered (25).

The transmission of HIV occurs through several different pathways: the direct contact of a mucous membrane or the bloodstream with a bodily fluid (e.g. blood, semen, vaginal fluid, or breast milk) containing the virus; exchange between mother and baby during pregnancy, childbirth, or breastfeeding; or exposure to one of the listed bodily fluids (24,27). Although antiretroviral treatments for AIDS and HIV exist to slow the virus's progression (28), there is no known cure (24).

2.3.1 Staging

The WHO staging criteria for HIV/AIDS identifies four clinical stages (29). In Stage One, the patient may be asymptomatic or experiencing swollen or enlarged lymph nodes. Stage Two, lasting an average of four to five years (30), is characterized by weight loss (less than 10% of body weight), chronic itchy skin, and / or recurrent sinusitis. In Stage Three, also termed “moderate disease”, symptoms include more obvious weight loss, unexplained and prolonged fever, oral candidiasis (more commonly known as “thrush”), pneumonia, and prolonged diarrhea. Stage Four, or AIDS, is characterized by multiple symptoms (e.g. tuberculosis, pneumonia, Kaposi’s sarcoma, HIV wasting syndrome, being bedridden). In this stage, individuals are prone to opportunistic infections and tumors (26,31). According to Lindegger and Wood, it takes approximately eight years to move from HIV infection to AIDS in South Africa without any form of antiretroviral treatment (32).

2.3.2 Pain

Patients with HIV/AIDS experience pain as often or more often than those with cancer (33,34). One North American study found that over 80% of people with AIDS, compared to about 40% of patients with cancer, experienced pain (35). Another estimated that 98% of adults with AIDS had pain (36). Studies conducted in developing countries show that patients with AIDS also have a high prevalence of pain (31,37-40). Pain can originate from a number of sources including the virus itself, related cancers, or the affects of opportunistic infections (34,36).

2.3.3 Prevention and Reduction of HIV/AIDS

There are proven methods to prevent or reduce the spread of HIV/AIDS and all rely on eliminating the transmission of bodily fluids. For example, transmission rates have been shown to decrease with condom use during sexual intercourse (41,42). In addition, different scientific discoveries have found significant ways to reduce transmission rates. For example, randomized control trials conducted in Kenya, Uganda and South Africa have shown that adult male circumcision significantly reduces the risk of HIV transmission (43-45). As Auvert et al assert, "Male circumcision provides a degree of protection against acquiring HIV infection, equivalent to what a vaccine of high efficacy would have achieved. Male circumcision may provide an important way of reducing the spread of HIV infection in sub-Saharan Africa" (p. 1112) (45).

2.3.4 HIV/AIDS in Sub-Saharan Africa

Slightly more than 10% of the world's population live in sub-Saharan Africa, yet about 64% of those infected by HIV/AIDS worldwide reside in the region (46). Of every ten women who are infected globally, eight reside in sub-Saharan Africa (47). Six of every ten infected men live in the sub-Saharan (47). In 2005, it was estimated that 3.2 million people in the sub-Saharan region became newly infected with HIV and 2.4

million people died of AIDS (48). In the sub-Saharan, HIV is spreading throughout the general population and is no longer confined to higher risk populations (46). HIV infection rates are higher in urban areas and the gender gap in HIV/AIDS prevalence continues to grow (46).

2.3.5 HIV/AIDS in South Africa

In 2007, the national HIV prevalence (monitored by the South African Department of Health through the public health sector's antenatal HIV and syphilis prevalence survey) was 29.1% (49). Provincial variation was also evident with the highest rates in KwaZulu Natal (39.1%) and the lowest rates in the Western Cape (15.1%). In a national survey of South African households, HIV prevalence was shown to be different among the different age groups which suggested different patterns of risk; HIV infection was higher among those in the late twenties and early thirties and lower among teenagers (6). Prevalence rates also varied by gender (6); in the age category 15-24 years, for example, it was found that over 15% of women were infected compared to less than 5% of men (8,50).

2.3.5.1 HIV Modes of Transmission and Epidemic Drivers in South Africa

Factors that have contributed to the high transmission rates include influences such as poverty, social instability, high levels of other sexually transmitted infections, an inadequate political response, a low status of women, and high mobility (1,8,51), several of which bear further explanation.

Poverty. A direct result of the apartheid regime was a high prevalence of poverty, particularly among the black population (52); approximately 70% of South Africans live below the poverty line (53). Poverty, with its strong correlation to ill-health, typically results in arduous and often hazardous work for people with low incomes, no power to influence change, and high levels of anxiety and stress (51). Of the nine provinces in South Africa, there is substantial provincial disparity in poverty rates which mirror the HIV/AIDS prevalence rates (52); provinces with the highest rates of poverty also have the highest rates of HIV/AIDS infections.

Employment does not always represent an escape from poverty. Agricultural workers, representing the highest proportion of workers, have the lowest incomes and are described as dependent on their employers for their family's needs (e.g. housing and education) (51). The mining industry also employs many vulnerable workers, often migrants originating from rural communities (51). As with agricultural workers, miners often support dependents who are heavily reliant on the mining wages (51).

Mobility and the Migrant Worker. It was thought that following apartheid, the role of the migrant worker would diminish, but as one author stated "for rural blacks, the mode of survival represented by labour migration became so deeply entrenched that the disintegration of apartheid did not end population mobility" (p. 19) (54). Rather, the end of apartheid was marked by the movement of even greater numbers of people. The negative health consequences of migrant labour have made a large impact in South Africa (54) particularly in the field of sexually transmitted diseases. In a typical route of transmission, an STD such as HIV is contracted in the region of employment. Then, following a return to the home community, the migrant worker transmits the disease to family networks (54).

Social Instability. The demise of the apartheid regime was accompanied by intense violence and social dislocation (54,55); it is estimated that between 1990 and 1993, approximately 9,000 people died due to political violence (56). The murder rate in South Africa remains high and ranges from 50-70 deaths/ 100,000 people (57); sometimes the country has the highest murder rate in the world. Domestic violence has also been described as a commonplace component of South African society (58-60); within certain boundaries of severity, gender-based violence has been shown to not only be tolerated but also accepted (61,62).

Social instability is also evident in the gender imbalance. Sexual relationships serve to exemplify the differences in the roles of men and women. Women have been described as relatively powerless in sexual decision-making (7). For example, a female would not request her partner to use condoms as that would imply either that she is infected or that she suspects infidelity (7,62). From a female's viewpoint, her self-esteem and social status have been shown to be linked to her relationship or boyfriend (7). In a study of adolescent women in South Africa, the vast majority of informants described assault as a regular feature of sexual relationships, with almost one third of the study participants reporting their first intercourse to be forced (62).

In the literature describing the male perspective, a “macho masculinity” is reported; a real man is defined by insatiable sexual urges (54). Sexual relationships are both a form of pleasure and a way to establish power within a relationship. Exclusivity is neither implied nor guaranteed if a male is in a sexual relationship (7). Therefore, it is not uncommon to have multiple partners and in some communities it is even encouraged. For example, in the Zulu language there are two terms to describe a man’s sexual experience: *isishimane* is a term to describe a man with one or fewer sexual partners whereas *isoka,* a term of respect, describes a man with multiple partners (62).

Low Status of Women. A progress report by the South African government for the United Nations Special Session on HIV and AIDS acknowledged the low status of women by stating that:

> *Women in South Africa, and especially black women, have been at the bottom rung in terms of participation in the economic, social, and political life of the country. They have for a long time experienced triple oppression on the basis of their class, race and gender. Some practical challenges facing women because of these three forms of oppression relate; violence and abuse, poverty, and poor health status in general. (p. 4)* (8)

In addition, women remain disproportionately affected by HIV (48); in 2004, almost 60% of adults living with HIV in sub-Saharan Africa were women (46).

2.3.6 Antiretroviral Therapy

Adherence to antiretroviral therapy (ART), a mainstay of Western medical treatment, can dramatically change the trajectory of HIV/AIDS (28). With highly active antiretroviral therapy (HAART)[viii], morbidity and mortality can markedly decrease (63). Without access to ART, however, "AIDS can be a rapidly fatal acute infectious disease characterized by multiple opportunistic infections, rapid deterioration and death" (p. 150) (64).

Until recently, it was felt that the costs of an ART program would overwhelm the public health care system in South Africa (65). According to a WHO bulletin, the South African Cabinet acknowledged for the first time, in 2002, that "antiretroviral treatments for HIV/AIDS —which stop the HIV virus multiplying in the body — may be a good idea for the one million people needing them in the country, and hinted that if it they are affordable it may provide them" (p. 921) (66). In 2005, it was indicated in a WHO Progress Report, that in sub-Saharan Africa, only 11% of people requiring ARTs were receiving them (67). The WHO described South Africa's progress in scaling up antiretroviral therapy as "slow overall, lagging behind performance commensurate with stated policy and available resources." (p. 17) (67).

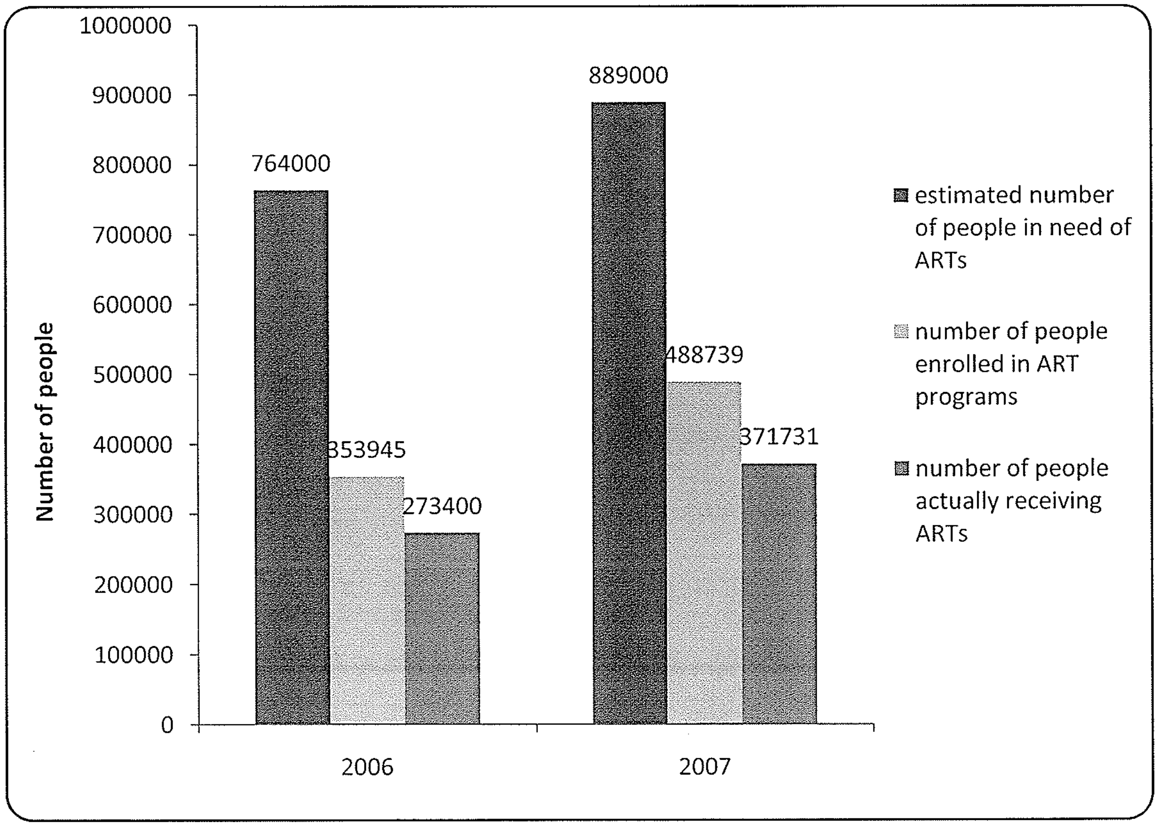
It has been suggested that it is difficult to provide comprehensive coverage in South Africa due to government tariffs (68), a lack of access due to either medication costs or geographic location (68), and the inability of the health care system to manage the complexities of treatment (28). However, as the costs of HAART for resource-poor countries has decreased markedly (in South Africa the cost is approximately $180 per patient-year) (65), continued growth in the South African HAART program is evident

---

[viii] Antiretroviral drugs are medications used in the treatment of infection by retroviruses, primarily HIV. When several (typically three or four) antiretroviral drugs are taken in combination, the approach is known as highly active antiretroviral therapy, or HAART (174).

(65). In fact, information from the most recent progress report on South Africa's declaration of commitment on HIV and AIDS prepared for the United Nations General Assembly Special Session on HIV and AIDS has shown positive developments in the scale-up process. As can be seen in Table 2.2, the estimated number of people in need of ARTs has grown from 764 000 in 2006 to 889 000 in 2007 (an increase of 125 000 people or 14%). However, the number of people enrolled in ARTs program or in treatment has grown proportionally greater. For example, the number of people enrolled in treatment has increased by 27.6% and the number of people receiving treatment by 26.5% (49) which is a promising trend.

Figure 2.1 Comparison of 2006 and 2007 Data on Need, Enrolment and Delivery of ART Programs in South Africa (49)



2.3.7 ARTs and palliative care

In South Africa, the department of health's treatment program is available free of charge to people with a CD4[ix] count lower than 200 or in Stage Four, as recommended by the WHO (69). Prior to the implementation of a national ART program, palliative care was considered the primary treatment option for people with HIV/AIDS. With the advent of ARTs in South Africa, the role of palliative care has altered but not diminished.

The data shown in Figure 2.1 (Comparison of 2006 and 2007 Data on Need, Enrolment and Delivery of ART Programs in South Africa) indicated that in 2007, approximately 42% of people eligible for ARTs were receiving them. This was a 6% increase from 2006. While ARTs are authorized for people at a specific stage in their illness, the fact is that they remain unattainable for many. This means that palliative care remains the only viable treatment option for many individuals. According to Defilippi et al., "while antiretroviral treatment is now officially available, poverty and the lack of infrastructure mean treatment remains beyond the reach of many who need it"(70) (p. 552). Additionally, the ART regimen is also difficult to follow and a variety of factors such as inadequate nutrition combine to make it difficult to remain on the strict treatment plan (71) and leads to reduced effectiveness due to progressive viral resistance (64).

[ix] A glycoprotein on the surface of helper T cells that serves as a receptor for HIV. Normal CD4 counts in adults range from 500 to 1500 cells per cubic millimetre of blood.

For those individuals on a treatment program, however, palliative care is still necessary; antiretroviral therapy has not obviated the need for palliative care (72). This has led to the emergent perspective that asserts the patient's entire being needs to be considered during therapeutic care; in addition to the antiretroviral regimen, pain management, psychosocial issues, and spiritual needs must be addressed (72). Therefore, as stressed by the literature, palliative care should be offered in conjunction with antiretroviral therapy (73,74). Ultimately, many or most of people with AIDS will still require palliative care, as treatment fails or treatment options become more difficult (Dr. Stephen Moses, personal communication, December 4, 2008).

2.3.8 The Role of the Traditional Healer

Some patients with HIV/AIDS may choose to forgo Western medical treatments. For some individuals seeking treatment, a traditional healer would be the first choice for health care. While the role of the traditional healer is not well documented, it has been reported that where both Western and traditional health modalities exist, many South Africans will consult traditional healers first (75,76). A traditional healer is described as having a holistic approach to health and illness, using herbal remedies to treat the "dis-ease" caused when the equilibrium of life has been disturbed (75). It has also been suggested that the decision to visit traditional healers may be influenced in part by the high cost and scarcity of essential Western medicines (76,77).

2.4 Palliative Care

The widely applied definition of palliative care by the WHO proposes that it provides relief from pain and other distressing symptoms, affirms life and views death as normal, neither hastens nor postpones death, integrates both spiritual and psychological aspects into care, offers support systems to patients, supports families during illness and bereavement, applies a multi-disciplinary team approach, enhances quality of life, and is applied over the entire course of the illness (78). A generally accepted view of palliative care is that it is the active total care of patients whose disease is not responsive to curative treatment. It encompasses all treatment modalities aimed at enhancing quality of life rather than curing disease (79). Palliative care can be regarded as an exercise in prevention, the prevention of ultimate suffering through timely diagnosis and expert management of physical symptoms and of psychosocial and spiritual concerns, at the earliest possible moment (80). Ultimately, excellent palliative care is anticipatory in nature, rather than reactive.

The literature differentiates between "palliative care" and "end-of-life care". While end-of-life care utilizes the principles of palliative care, it is specific to the care that patients and their families receive when patients are dying or near death. End-of-life care takes place during the last days or weeks of life and focuses on preventing suffering by attending to the physical, emotional, and spiritual comfort of the patient and family. End-of-life care is the specific application of palliative care interventions in the last hours, days or weeks of life (9).

2.4.1 Palliative Care in Developing Countries

A number of authors assert that palliative care should be viewed as an essential service regardless of place or country of residence (81-83). In developing countries, however, limitations may exist that hamper the ability to provide palliative care; a variety of factors make it difficult to ensure consistent and adequate levels of palliative care on a national level. For example, sometimes health professionals may need to choose between saving lives and alleviating suffering due to limitations within the system (40). Inadequate medical infrastructure is a commonly cited limitation in the delivery of palliative care services (77,84,85) as is a lack of trained personnel (34). While palliative medicine is ideally carried out across the entire trajectory of disease (86), cultural and medical practices may influence when palliative treatment is sought or applied. Other issues may include a lack of full access to analgesics for pain control, insufficient education of health leaders, and inaccurate public perceptions of palliative care (10). Furthermore, systemic issues like poverty can be major hindrances in the delivery of palliative care (84) as "controlling pain and leaving the patient with severe hunger pangs seems pointless as does empowering the family caregiver with basic nursing skills when they do not have the energy to turn the patient because they too are starving" (p. 108) (47).

2.5 Palliative Care in South Africa

The current body of literature relating to palliative care in South Africa is not extensive (see Appendix 4 for search criteria and retrieved articles). However, it is sufficient to provide an overview of many facets of palliative care, such as affiliated organizations, access to drugs, models of care, and location of death.

2.5.1 Health Care Professionals and Palliative Care

Care for patients with life-threatening illness throughout Southern Africa is typically home based and the majority of care is provided by family or community members. Professional palliative care for patients with life threatening illness is most commonly provided by nurses (39,87), trained volunteers (88), or home-based carers (88,89); typical models of care place the majority of the administrative tasks with the nurse and the physical care tasks with community carers, family members, or volunteers (88).

Little is documented on the role of the medical doctor in South Africa[x]. Little is known about: 1) their involvement with terminally ill patients; 2) if they feel adequately prepared to provide end-of-life palliative care; 3) what barriers and challenges, from their perspective, they face with respect to delivering end-of-life palliative care?; 4) what barriers and challenges medical doctors face, from the perspective of other stakeholders such as nurses, family members and patients.

There is some evidence that medical doctors in South Africa may feel inadequately prepared to meet the changing needs of the dying patient (90) and that

---

[x] A PubMed search on December 11, 2008 using the terms palliate*, doctor, physician, Africa, and South Africa yielded a total of 11 articles, three of which had direct relevance to South Africa. Of those articles, one was a single page study report, another an anecdotal description, and the third a comparative study examining sedation practices in South Africa, Israel, and Spain. When expanding the search to include the continent of Africa, six articles addressing some aspect of palliative care and physicians were located.

their knowledge of pain control may be insufficient (91,92). Furthermore, the attitudes of South African medical students towards terminally ill patients have been found to be significantly more negative in comparison to students from England (93); in a survey by Lloyd-Williams, differences were found in specialist preference (e.g. South African medical students wanted to work in a speciality where most patients were likely to be cured more often than their UK counterparts) and in attitude towards informing patients of a terminal diagnosis (e.g. South African medical students were not as willing to inform patients of a terminal diagnosis in comparison to their UK counterparts).

That health care providers have insufficient knowledge in pain control and palliative principles is a major concern in developing countries on the whole (94) and South Africa is no exception (91,92). Since palliative care is a necessary part of the treatment approach for patients in Africa (86,95), and as medical doctors appear to have a poor understanding of this treatment modality, the role and educational needs of the medical doctor within the field of palliative and end-of-life care deserves further exploration.

2.5.2 Drug Availability

It has been suggested that freedom from pain must be regarded as a human right (96,97). To redress inadequacies in pain control, in 1986, the WHO developed a three-step ladder to guide clinicians in the management of cancer pain. Designed to be both effective and inexpensive, the base (or first step) of the ladder is non-opioids (aspirin and paracetamol). The second step is mild opioids (codeine) and the top step is strong opioids such as morphine. The plan also recommends adjuvant drugs be administered and that drugs should be given "by the clock", opposed to on demand (98). Over the past two decades, research has shown that WHO's pain control ladder has been applied in a multitude of settings with high rates of effectiveness (99-104). It has also proven useful in patients with HIV/AIDS (105). It is regarded as a simple drug management plan, which is easily transferable between different countries, settings, and populations.

Morphine, a critical opioid for pain reduction, is not readily available in all health care centres in South Africa (92). One report from 2002 stated that the drug is typically only available in provincial hospitals and may only be available on certain days of the week (91). Even in large centres where pain control medications are readily available, pain is still often under managed (38,106). This may be due in part to a lack of knowledge in effective pain control techniques. However, without access to this opioid, doctors cannot prescribe according to the WHO recommendations.

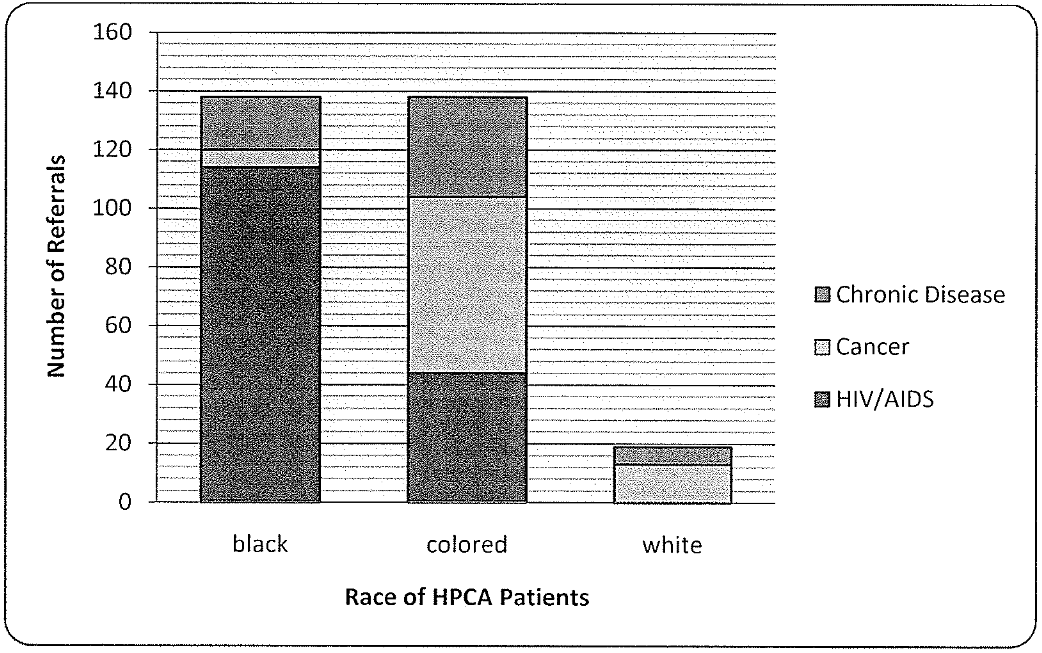
2.5.3 Palliative Care Organizations

In South Africa, there is a national organization that exists to provide consistent and regulated palliative care through its member hospices: the Hospice and Palliative Care Association of South Africa (HPCA). Developed in the late 1970s, the HPCA is involved in education, training, policy development and fundraising (107). There are about 70 different organizations in South Africa linked to the HPCA, each providing some form of hospice and palliative service within the community (107). Through

HPCA's member hospices, approximately 30,000 people are cared for per month (108). These services include, but are not limited to: inpatient care, home care, hospital support, orphan support, and education (75,107). The majority of the HPCA hospices are registered as both not-for-profit agencies (109) and NGOs. A small portion of the hospices' budgets may be provided for by the South African Department of Health but the majority of hospice operating revenues are raised through grants or local fundraising efforts (109).

Statistics for October 2007, collected from the 15 member hospices in the Western Cape Province, provide a snapshot of the patient population. In this month there were 295 new referrals: half of whom had HIV/AIDS, about 30% had other forms of non-HIV related cancer and approximately 20% a chronic illness such as Multiple Sclerosis (Figure 2.2). The majority of the 295 referrals were black or colored.

Figure 2.2: Patient diagnosis and race according to HPCA Western Cape statistics, October 2007 (110)



When hospices were first established in South Africa, patients typically had some form of cancer or other terminal conditions. Now, as is reflected in the HPCA statistics, the majority of patients have HIV/AIDS (88,111).

2.5.4 Home or Hospice-Based Care

One South African study reported that, according to HIV/AIDS patients receiving home-based hospice care, dying at home or in hospice was preferable to a hospital death (106). In fact, the most common service hospice and palliative care model is home-based (72). The infrastructure needed in a home-based model of care is minimal as space is only needed for administrative tasks. Home-based hospice employees spend the majority of their time in the community. While the majority of hospices provide only home-based care, some also operate inpatient units. These inpatient units typically have a small number of inpatient beds for the provision of symptom control, respite for family caregivers, or (rarely) terminal care (88). Home based carers, social workers, nursing sisters, and medical doctors all have a role within this model of care (112).

When a patient is admitted, an assessment nurse visits him or her to determine the patient's care needs. From there, the patient's care plan is developed and a number of health care workers may become involved in patient care. The home-based carer and the nursing sister are typically the most directly involved in patient care.

A home-based carer is a trained individual who provides in-home care for patients as defined by the patients' care plans. He or she will assist with physical care, household tasks, and will also have the ability to provide financial counseling and spiritual care (89,113).

Nursing sisters, the term used in South Africa to describe an individual with a university degree in nursing, will monitor a patient list; nursing sisters will visit patients according to the level of care that a patient requires need and will act as a link between patients and medical doctors. Nursing sisters will also supervise and educate the home-based carers. Nurses also evaluate patients' changing needs; with few exceptions, it is through nurses that patients' needs are relayed to doctors.

Other team members such as social workers, spiritual counselors, and medical doctors are involved primarily as resource people. While social workers and spiritual counselors may meet with patients directly, doctors are rarely involved in face to face patient care (88,92,113). Additional care is provided by other community members, including neighbours, extended family members, and community based organizations (88).

Studies evaluating the home-based care model have identified significant cost reductions in utilizing home-based care as compared to inpatient hospital services (114,115). However, it has also been identified that home-based care services can be inadequate due to a lack of specific training for health care providers (106). Developing home-based hospice programs has not eliminated the need for hospital-based services, but has greatly reduced it (113,115).

2.5.5 Hospital Based Care

It has been suggested that hospitals will not provide care without possible cure (90,116) and with the impact of HIV/AIDS on health care systems, it is now common practice for health care facilities to ration services to people who are HIV positive (117). In South Africa, hospital-based palliative care wards were described as rare due to the unsustainable costs (72) yet hospital palliative care wards have been operating in at least five major South African cities (Cape Town, Durban, Johannesburg, Port Shepstone, and Pretoria)(75,109). Moreover, these wards were employing multi-disciplinary teams in care provision (75,116). For example, at a hospital in the province of KwaZulu-Natal, palliative care team members include clergy, medical staff, nutritionists, and social workers, all of whom are available to deal with the variety of issues that may become apparent at end of life (116). A study investigating the role of a palliative care inpatient unit in disease management discovered that AIDS patients appeared to benefit from inpatient palliative care treatment, and suggested that patient outcomes (seen through decreased death rates) could improve with palliative care (118). As Jameson writes, "palliative care may improve the outcome of treatment [for AIDS patients] and result in patients moving from a terminally ill to a chronically ill state" (p. 849) (118).

2.5.6 Location of Death in South Africa

Only one research study has quantified location of death in South Africa; national statistics on location of death were not available. The study evaluated the location of death for patients enrolled in a home-based care program. Over half (52%)

of the patients enrolled in the program (n=150) died at home, 5% died in the hospice, and 43% died in hospital (106). Reasons cited for hospitalization were that care became too difficult to manage, family requested the move from home to hospital, or there were symptoms that the community carers could not control (106).

2.6 Palliative Care Education

Palliative care plays a significant role in the improvement of care for people throughout the trajectory of illness as well as when approaching death. This in and of itself is justification for ongoing palliative care education for all health care providers. However, another persuasive argument for the inclusion of palliative care in training programs is that incorporating it within the medical system could save resources; using palliative care may reduce other health care practices that are unnecessarily aggressive, costly, and unwarranted (119). Therefore, it is understandable that there has been a worldwide effort focused on increasing palliative care education.

2.6.1 Global Palliative Care Initiatives

Over a decade ago, the WHO challenged training institutions to ensure that palliative care was compulsory and given high recognition (119). While progress is evident, reviews of education programs in training institutions around the world have found palliative care programming to be patchy or nonexistent (120-128). This is true of the literature from developed (124-126,129,130) and developing nations (120,127). A case by case analysis of medical programs around the world has shown that some university programs have developed reasonable palliative medicine educational opportunities in both medicine and nursing faculties (131).

A variety of large-scale educational initiatives have been developed, as seen in the following illustrative examples:

Canadian Pallium Project. This project is described as an initiative to "support, mobilize and help individuals and organizations navigate the complexity of multiple systems and agents towards the constructive evolution of Canada's hospice palliative care capacity" (p. vi) (132). From its inception in late 2000, the Pallium Project evolved from supporting primarily rural health care practitioners to collaborating with regional health authorities and community-based, voluntary sector partners (132). The project was completed in March, 2008.

Educating Future Physicians in End-of-Life Care (EFPEC). With the advice and collaboration of many varied palliative care stakeholders across Canada, the primary objective of the EFPEC project was to design a common curriculum for medical students. The development of this national curriculum, based on common competencies for all undergraduate and clinical postgraduate trainees at all Canadian medical schools, facilitated the introduction of palliative and end-of-life care questions in medical licensing and certification exams.

End of Life Nursing Education Consortium (ELNEC). This program, developed in 2000 and funded by the Robert Wood Johnson Foundation, is an education program to improve end-of-life nursing care in the United States (133).

Comprehensive Advanced Palliative Care Education (CAPCE) Program. The CAPCE program, a Canadian initiative, is a 120-hour program designed so that learners will both extend palliative care knowledge into the hospice workplace and act as resources for the palliative care team. Developed in 2002, a recent evaluation indicated that the CAPCE program was relevant to clinicians and was found to have a number of positive effects for participants such as enhanced pain management and improved staff education (134).

Support, Education, Assessment and Monitoring (SEAM) Project. In 2003, the SEAM service model was developed in Australia for use in rural palliative care delivery. The education component was delivered to health care professionals, clients, and family members. The primary objective of the model was to "develop, implement and evaluate an integrated service model of palliative care that would focus on improving rural people's access to services" (p. 2) (135).

2.6.2 Palliative Care Education in South Africa

Palliative care education programs in developing countries, whether at the university or community level, appear to be uncommon (136,137) but increasing in number (138). One example is seen in Uganda, where palliative care education programs have been in existence for over a decade. In Uganda, training was originally provided through Mildmay International (an HIV/AIDS charity specializing in care, training and service development) and was extended to both the Hospice Association of Uganda and undergraduate medical programs (138). The African Palliative Care

Association (APCA), an organization for all of Africa, also facilitates training and education for member hospices and palliative care organizations. According to the APCA website (139), education and training objectives include developing standardized education and training programs, providing educational resources for partners, and assisting with technical needs during training and education.

Prior to the development of the post-graduate palliative care distance education course at UCT, there were five South Africans doctors who had received training in palliative medicine. All of these doctors had graduated from the University of Wales in Cardiff (127). In response to the dearth of palliative care training opportunities for doctors employed in South Africa (127), the UCT decided to offer a post-graduate distance education program in the field of palliative medicine (27). Since its inception in 2000, the program, offering a diploma in palliative medicine or a master's of philosophy degree in palliative medicine, has accepted up to 27 students per year (127). The program is designed so that students will complete the degree requirements over a two to three year period. Assignments are mailed to students (10 for Diploma and 12 for Masters) and are based on course objectives (see course objectives Appendix 5). According to the program description, "one personal learning portfolio[xi] is required for the Diploma programme and two portfolios for MPhil programme" (140). Students in

---

[xi] The personal learning portfolio is an opportunity for the student to describe her/his learning over the course of the Palliative Medicine Programme. Using illustrations from sources such as clinical contact or current research, the student is expected to produce something which reveals an evolution of thought, expression, knowledge and skill. There is no particular structure that a student is required to follow but it it is expected to be approximately 2500 words and to cover the following topics: contextual/Individual/family issues, clinical issues, psychosocial/spiritual issues, and application of palliative care principles including evidence of teamwork.

the master's program are required to complete a research project. As well, students attend two workshops, one in their first year of student and another in the second, where they receive face-to-face instruction (see workshop objectives Appendix 6).

2.7 Evaluating Palliative Care Education Programs

Evaluation is important for the development and success of any education initiative. While examples of educational assessment specific to postgraduate palliative medical training are infrequently cited in the literature, several examples are available. Typically, students studying palliative medicine are only evaluated within the particular course to assess outcomes of learning. Common assessment tools consist of essays or multiple choice questions (30). There is very little evidence describing effective educational assessment and even less to show if and how palliative care education influenced practice (141). The feedback from evaluation assists in keeping an intervention current, applicable to the needs present in the community and appropriate for the participants. Thus, it should not be considered optional.

2.7.1 Methods to Evaluate Palliative Care Education

Examples of educational assessment in postgraduate medical education are scarce in the literature. Typically students, including those studying palliative medicine, are evaluated within their particular course to assess outcomes of learning through tools like essays or multiple choice questions (30). Yet in general, there is very little evidence describing effective educational assessment and even less within palliative care education influencing practice (141). However, as evaluations of different educational initiatives, including some in palliative care, begin to be published, appropriate methods of assessing programs in palliative care can be determined.

It is difficult to measure the direct effects of a palliative care course or program on patients (142). Measuring effects may be difficult due to both patient characteristics and limitations of different evaluation techniques. Patient factors include, but are not limited to, difficulty in getting informed consent, deteriorating health of palliative participants, recruitment, or attrition rates (30,143). Although difficult, evaluation is necessary as educational programs must have evidence to indicate their impact on the health status of the population being studied (141,143,144).

A systematic literature review (see Table 2.2)[xii] showed that several different methodologies have been used to evaluate palliative care education programs. Quantitative measures including pre-post training surveys (143,145-149), questionnaires(150-157), chart reviews(158,159), and prescribing audits(160) have been completed. As well, qualitative studies involving interviews (161,162) and focus groups(157,161) have been conducted.

[xii] Four databases (PubMed, CINAHL, EMBASE, Google Scholar) were searched between April 15-May 3, 2006 and updated on March 3, 2008 for information relating to evaluation methods used in palliative care education initiatives. Hand searches of key articles were also completed. Different combinations of search terms (including "palliat*" "educ*" "train" "prog*","evaluate", "distance", "end-of-life", "medical", "South Africa", "Southern Africa","Africa") were utilized. Searches did not include work prior to 1985.

Table 2.2: Studies Evaluating Palliative Care Education Programs

Type of Study	*Study Authors*	*Additional Notes*	*Benefits*	*Limitations*
Pre-Post ***n=5***	Macleod, 1994(141), Hinkka, 2002 (146), Silverdale, 2005 (147), Fischer, 2003 (148), Adriaansen, 2005 (143)		Evaluates a specific intervention	Factors other than intervention may be producing change Measures perceptions May not predict potential for change Self-report and social desirability May overestimate effect of intervention
Pre-Post (Plus) ***n=9***	Hall, 1998(161), Hall, 1999 (157),Shipman, 2003 (162), Ward, 2004 (144), Reymond, 2005(163), Macleod, 1994 (141), Kristjanson, 1997(158), Schuit, 2000(160), and Myers, 2004(159).	interviews(162), a third evaluation (141,144,158,163), a "postponed" post evaluation (163), audit of prescribing patterns of participants (160), and chart audit (158,159) [170]. Two studies included: focus groups, pre-post survey, interviews, anonymous patient satisfaction surveys, informal input (157,161)	Applies more than one method to investigate the role of the intervention	Do not imply a direct measurement of intervention
Survey ***n=4***	Hopkins, 1997(153), Bruera, 1997(154), Weissman, 1998 (155), Koffman, 2005(156)		Evaluative tool Assists in program planning Can evaluate shortcomings or benefits in an intervention or program	Cannot measure change over time Self-report not entirely reliable
N=18				

Pre-Post intervention method. Of the 18 studies that evaluated a palliative care education program, the Pre-Post Intervention Method, or a variation of it, was the most popular technique chosen (77.8%). The goal of this method is to measure outcomes by analyzing results of the same survey completed both before and after an intervention. If there is a change in the scores, it is implied that these can be attributed to the intervention or education program (164). This type of study may include a second participant group, one not involved in the intervention that completes the baseline test for the purpose of comparing the intervention to a general population. This comparison enables the researcher to determine if the study population is uniquely different (e.g. has prior interest or education in the field being examines) than the baseline (141). As regional variations can affect results (165,166), participants are typically matched by location or other characteristics to ensure uniformity between subjects and baseline measures (165).

Five of the 14 pre-post studies used a "basic" version of the pre-post methodology where the same survey was used at the start and end of the intervention to evaluate palliative care educational programs (143,146-148,153). If a basic pre-post design is the only form of evaluation used to measure change in care practice, there can be some disadvantages. Firstly, it is not entirely accurate to attribute all observed changes to the program itself as other factors might have produced those changes (164). Second, although some authors rely solely on this methodology to evaluate changes in practice (146,165), it is not able to determine anything other than *perceptions* of change in practice. Thus, without additional data supporting results, the quantification of participants' opinions or confidence has limitations. While immediate post-course evaluations may be useful in commenting on the course structure or process, they cannot fully predict or explain any potential changes in practice (141). Finally, self-report has limitations related to social desirability, interviewer effects and self-selection (167).

Variations to the basic pre-post model exist to address some of the design limitations as well as provide additional assessment to inform the pre-post results. Nine of the 12 pre-post studies evaluating palliative care educational interventions used variations of the pre-post design. This evaluative approach attempts to "converge on an accurate representation of reality" (p. 164) (141) by examining an intervention from several different perspectives. Aside from the pre-post survey, studies evaluating education initiatives typically employed one or more of the following: a) focus groups (157,161), b) interviews (161,162), c) informal input (157,161), c) anonymous patient satisfaction surveys (157), d) a third evaluation (141,144,158,163), e) a "postponed" post evaluation (163), f) audit of prescribing patterns of participants (160), and g) chart audit (158,159).

Even when using two or more evaluative tools, authors still suggest that results do not imply a direct measurement of patient outcomes resulting from the educational program (157). Rather, program or educational initiatives found to produce change, are seen to be contributing factors in the care of the terminally ill (157). Using a complex evaluation strategy of several different methods will reach beyond simple learner satisfaction (157) and may tease out differences between perception and reality. For example, in an evaluation of an education program on morphine prescribing, the pre-post survey demonstrated an increase in knowledge scores (160). However, when this was compared to the prescribing patterns of attendees prior to and following the educational initiative, there were no significant changes (160). If the evaluation had relied on only the surveys, it might have been possible to conclude that changing attitudes did or would result in modified prescription practices. With the additional information, however, it was apparent that this was not the case. In the end, the overall conclusion was that the workshop format was simply ineffective (160).

A late or third period of assessment bears further discussion. Typically occurring between 3 and 12 months after the intervention, the late evaluation is meant to evaluate longer-term clinical outcomes (141,163), memory retention, or development of learning (144). By waiting a minimum of three months, time is given to integrate new knowledge (158). It is through this survey that course evaluators can determine change over time and this method appears to be effective. Direct impact of an intervention is frequently not apparent until participants have let the course material integrate within their with care practice.

Survey. Another form of evaluation that was employed in four or 22.2% of the studies (153-156) was the completion of a survey or evaluative questionnaire[c] following the educational intervention. Surveys evaluations were typically seen as preliminary to program development (157,165) but were also used in program evaluation. Koffman noted several challenges and limitations in survey methodology. First, unless there is a 100% response rate, the results will not provide a complete picture. Also, positive feedback in surveys may be evidence of student personalities (e.g. highly motivated) rather than course material. Finally, looking at factors such year of entry may provide useful data depending on what the survey's objective; if evaluating the effect of changes to a course, for example, knowing when a participant took the course would be meaningful (156).

The task of evaluation is important for the continuous refinement, development, and success of a palliative care educational program, whether it be a short course or a university diploma. Ongoing feedback from evaluation assists in keeping an intervention current, applicable to the needs present in the community, and appropriate for the participants. Several different methodologies have been applied to the evaluation of palliative care education programs. Quantitative measures including pre-post surveys, questionnaires, chart reviews, prescribing audits, and meta-analyses have been completed. As well, qualitative methods such as interviews, focus groups, and participant observation, have also been employed within evaluative projects. Combinations of quantitative and qualitative methods seem to have the strongest research design. The highest quality result was achieved with comprehensive and detailed research projects that used mixed methodologies; having layers of data to explore appeared to strengthen the results. For example, studies incorporating several data collection points (152,168) or mixed methods (qualitative and quantitative data collected concurrently) (169,170) were found to be the strongest and most revealing research designs as the confluence of data collected at different times or in different ways produced the most complete evaluation.

2.8 Study Aims and Objectives

The aims of this study were twofold: 1) to describe, from the perspective of patients, family care providers and health care workers, how palliative and end-of-life care in South Africa is both perceived by the public as well as by hospice and other health care organizations, with a specific focus on the role of the medical doctor in providing this care and 2) to assess the University of Cape Town's palliative care distance education program in terms of its' perceived ability to impact palliative care delivery as described by graduates and current students. Four questions framed the research project and were best methodologically approached in two distinct parts. Part 1 (The *Context of Palliative Care in South Africa*), corresponded to the questions "*How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?*" and "*How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?*". Part 2 *(Evaluation of UCT's Palliative Care Distance Education Program*) consisted of two questions: "*What are/were the positive and negative aspects of the palliative care program as described by current and former students?*" and "*How do former and current students evaluate the* *influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?*" Parts 1 and 2 are intrinsically connected, since an informed evaluation of the distance education program at UCT is best understood within the broader context of palliative and end-of-life care in South Africa.

Part 1 (*The Context of Palliative Care in South Africa*)

1) *How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?*

A number of more specific aims were subsumed under this broadly stated objective, which provided an operational framework to broach this research task. These include: 1) understand the perceptions of patients, family care givers, and health care providers with respect to how palliative and end-of-life care is delivered, primarily by hospice or other health care organizations; 2) describe the care that is provided by hospice or other health care organizations to patients with life threatening illnesses and their families; determine how care satisfaction is shaped by specific factors in the health care or hospice system; 3) describe doctors' experiences in providing end-of-life and palliative care within South Africa ; 4) describe different models of palliative and end-of-life care delivery 5) examine differences in perceptions of care from the perspective of various stakeholders i.e. regarding access and barriers to care, the hospice referral system, and informational needs of patients and families.

2) *How do health care providers articulate the palliative and end-of-life care*

educational needs of medical doctors?

Associated objectives include: 1) document the areas that health care providers (including medical doctors, nursing sisters, social workers, and others involved in the health care field) determine are vital elements of palliative care education for medical doctors in South Africa.

Part 2 (*Evaluation of UCT's Palliative Care Distance Education Program*)

3) *What are/were the positive and negative aspects of the palliative care program as described by current and former students?*

Associated objectives include: 1) assess different aspects of the distance education program including the workshops delivered to the first and second year students as well as the general program objectives through the use of survey methodology; 2) determine which areas are taught well from the perspective of students and those that need further development.

4) *How do former and current students evaluate the influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?*

This consisted of: 1) assessing graduates' perceptions of how the palliative care distance education program altered their own understanding of palliative care and 2) determining the ability of the post-graduate course to shape the provision of palliative and end-of-life care in South Africa.

What would the value be of the educational assessment if it was not contextually situated? Very little. Thus, the evaluation of UCT's distance education palliative care program offered to medical doctors could only be conducted if the contextual material accompanied it. It was important to understand both what the role of medical doctors was in the current landscape of palliative and hospice care, as well as the valuation by stakeholders (e.g. patients, family care providers, health care workers) as to this care. Although many tasks pertaining to palliative and hospice care in South Africa are provided by other members of the multi-disciplinary team, the doctor is an important team member. Only doctors can prescribe medications for the relief of pain or other symptoms which is an important component of palliative care.

In the process of evaluating the contextual role of the medical doctor, a general description of palliative care, including the roles of the various team members, was attained. Patients and family care providers described the care they received from a range of care providers and their satisfaction with that care. Observations of different care settings gave another layer of data describing palliative care in the country. Thus, it was necessary to keep the main focus on medical doctors in order to link the education program evaluation to the context of care. However, the qualitative data was useful in the broader description of palliative care delivery and more specifically in the role of hospice staff.

2.9 Summary

The literature review presented in Chapter Two highlighted the need for continued research in the field of palliative medicine and education within South Africa. In order to provide the necessary context for this research study, there was a particular focus on four areas: South Africa's burden of disease, global developments in palliative care, palliative care education, and methods of educational evaluation.

The available literature highlighted how the HIV/AIDS pandemic and the burden of illness due to cancer are shaping the landscape of care in South Africa, thus making palliative care programming imperative. Palliative care organizations in South Africa were described as functioning with limited resources and little (if any) government support. As palliative medicine plays a significant role in the improvement of care for people throughout the trajectory of illness as well as when approaching death, it is crucial that it is seen as a required component of care as opposed to optional. Therefore, inexpensive and effective models of delivery will be critical within South Africa's health care system.

Another part of the nation's response to the burden of illness must be in the field of palliative care education. UCT's palliative care distance education course was presented as a model or example of how a university can respond to a population-based need. Evaluation is important for the development and success of any education initiative; an evaluation of UCT's palliative care course is necessary in order to highlight successes and reveal shortcomings of the program, thus ensuring continued progress.

The literature provides a framework for both parts of this research project. As Part 1 (The Context of Palliative Care in South Africa) aims to understand how palliative and end-of-life is delivered and perceived by patients, family care providers, and health care workers, the findings will assist in the delivery of culturally appropriate models of care. Part 1 also evaluates the educational needs of medical doctors in the field of palliative medicine and it is anticipated that this will feed into current educational programming. Part 2 of the study (Evaluation of UCT's Palliative Care Distance Education Program) will determine the role and influence of the distance education program at UCT. It is expected that the culmination of the two parts will yield a rich data-set pertaining to palliative and end-of-life care in South Africa.

2.10 Chapter 2 References

(1) Achmat Z, Simcock J. Combining prevention, treatment and care: lessons from South Africa. AIDS 2007 Jul;21 Suppl 4:S11-20.

(2) Gwyther L, Rawlinson F. Palliative medicine teaching program at the University of Cape Town: integrating palliative care principles into practice. J.Pain Symptom Manage. 2007 May;33(5):558-562.

(3) World Health Organization. South Africa. 2006; Available at: http://www.who.int/countries/zaf/en/. Accessed June 12, 2006.

(4) Goosen J, Bowley DM, Degiannis E, Plani F. Trauma care systems in South Africa. Injury 2003 Sep;34(9):704-708.

(5) Bradshaw D, Nannan N, Groenewald P, Joubert J, Laubscher R, Nojilana B, et al. Provincial mortality in South Africa, 2000--priority-setting for now and a benchmark for the future. S.Afr.Med.J. 2005 Jul;95(7):496-503.

(6) Department of Health. National HIV and Syphilis Antenatal Sero-prevalence Survey in South Africa: 2004. 2005.

(7) Varga CA. Sexual decision-making and negotiation in the midst of AIDS: Youth in KwaZulu-Natal, South Africa. Health Transition Review 1997;7(supplement 3):45-67.

(8) Department of Health: Republic of South Africa. Republic of South Africa: Progress Report on Declaration of Commitment on HIV and AIDS. 2005;March 2006.

(9) Ahmedzai SH, Walsh D. Palliative medicine and modern cancer care. Semin.Oncol. 2000 Feb;27(1):1-6.

(10) MacDonald N. Educational programs in pain and palliative care. J.Pain Symptom Manage. 1993 Aug;8(6):348-352.

(11) Lingwood RJ, Boyle P, Milburn A, Ngoma T, Arbuthnott J, McCaffrey R, et al. The challenge of cancer control in Africa. Nat.Rev.Cancer. 2008 May;8(5):398-403.

(12) Torres I, Lopez-Zetina J. Morbity and mortality in developed and developing countries. In: Bruera E, De Lima L, Wenk R, Farr W, editors. Palliative Care in the Developing World: Principles and Practice. 1st ed. Houston, TX: IAHPC Press; 2004. p. 11.

(13) Morris K. Cancer? In Africa? Lancet Oncol. 2003 Jan;4(1):5.

(14) Mpanga Sebuyira L, Mwangi-Powell F, Pereira J, Spence C. The Cape Town Palliative Care Declaration: home-grown solutions for sub-Saharan Africa. J.Palliat.Med. 2003 Jun;6(3):341-343.

(15) World Health Organization, Measurement and Health Information. Death and DALY estimates by cause, 2002. 2004; Available at: http://www.who.int/entity/healthinfo/statistics/bodgbddeathdalyestimates.xls. Accessed June 26, 2008.

(16) Berger JM. Tripping over patents: AIDS, access to treatment and the manufacturing of scarcity. Conn.J.Int.Law. 2002 Spring;17(2):157-248.

(17) Farmer P. AIDS heretic. New Internationalist 2001 01//Jan/Feb2001(331):14.

(18) Benatar SR. Health care reform and the crisis of HIV and AIDS in South Africa. N.Engl.J.Med. 2004 Jul 1;351(1):81-92.

(19) Kapp C. Mantombazana Tshabalala-Msimang: South Africa's controversial health minister. Lancet 2005 Mar 26-Apr 1;365(9465):1131.

(20) Mbeki's colour scheme. Economist 2005 02/19/;374(8414):45-46.

(21) Kampfner J. A nice villa for a retired torturer. New Statesman 2003 01/13/;132(4620):18.

(22) Hope for South Africa--at last. Lancet 2003 Aug 16;362(9383):501.

(23) Kapp C. New hope for health in South Africa. The Lancet ;372(9645):1207-1208.

(24) AIDS. 2006; Available at: http://en.wikipedia.org/wiki/HIV/AIDS. Accessed June /20, 2006.

(25) World Health Organization. The World Health Report 2003: Shaping the future. 2003.

(26) Welsby PD, Richardson A, Brettle RP. AIDS: aspects in adults. In: Doyle D, Hanks GWC, MacDonald N, editors. Oxford Textbook of Palliative Medicine. 2nd ed. New York, NY: Oxford University Press; 1998. p. 1121-1148.

(27) Olweny C, Sepulveda C, Merriman A, Fonn S, Borok M, Ngoma T, et al. Global exchange. Desirable services and guidelines for the treatment and palliative care of HIV disease patients with cancer in Africa: a World Health Organization consultation. J.Palliat.Care 2003 Autumn;19(3):198-205.

(28) Harries AD. Management of HIV in resource-poor countries, with a focus on sub-Saharan Africa. Lepr.Rev. 2002;73(3):268-275.

(29) WHO Africa Region. Interim WHO clinical staging of HIV/AIDS and HIV/AIDS case definitions for surveillance. 2005.

(30) Doyle D. Oxford textbook of palliative medicine. 3rd ed. Oxford ; New York: Oxford University Press; 2004.

(31) Shvartzman P, Singer Y. Community education in palliative medicine. J.Palliat.Care 1998 Autumn;14(3):75-78.

(32) Lindegger G, Wood G. The AIDS crisis: review of psychological issues and implications, with special reference to the South African situation. S.Afr.J.Psychol. 1995 Mar;25(1):1-11.

(33) Sepulveda C, Habiyambere V, Amandua J, Borok M, Kikule E, Mudanga B, et al. Quality care at the end of life in Africa. BMJ 2003 Jul 26;327(7408):209-213.

(34) Coughlan M. Pain and palliative care for people living with HIV/AIDS in Asia. J.Pain Palliat.Care.Pharmacother. 2003;17(3-4):91-104; discussion 105-6.

(35) Breitbart W, Kaim M, Rosenfeld B. Clinicians' perceptions of barriers to pain management in AIDS. J.Pain Symptom Manage. 1999 Sep;18(3):203-212.

(36) Norval DA. Symptoms and sites of pain experienced by AIDS patients. S.Afr.Med.J. 2004;94(6 I):450-454.

(37) Merriman A. Uganda: current status of palliative care. J.Pain Symptom Manage. 2002 Aug;24(2):252-256.

(38) van Niekerk JP. Palliative care--from dream to mainstream. S.Afr.Med.J. 2003 Sep;93(9):625.

(39) Shawn ER, Campbell L, Mnguni MB, Defilippi KM, Williams AB. The spectrum of symptoms among rural South Africans with HIV infection. J.Assoc.Nurses AIDS Care 2005 Nov-Dec;16(6):12-23.

(40) Spence D, Merriman A, Binagwaho A. Palliative care in Africa and the Caribbean. PLoS Med. 2004 Oct;1(1):e5.

(41) Michelo C, Sandoy IF, Dzekedzeke K, Siziya S, Fylkesnes K. Steep HIV prevalence declines among young people in selected Zambian communities: population-based observations (1995-2003). BMC Public Health 2006 Nov 10;6:279.

(42) Agha S. Declines in casual sex in Lusaka, Zambia: 1996-1999. AIDS 2002 Jan 25;16(2):291-293.

(43) Bailey RC, Moses S, Parker CB, Agot K, Maclean I, Krieger JN, et al. Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial. Lancet 2007 Feb 24;369(9562):643-656.

(44) Gray RH, Kigozi G, Serwadda D, Makumbi F, Watya S, Nalugoda F, et al. Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial. Lancet 2007 Feb 24;369(9562):657-666.

(45) Auvert B, Taljaard D, Lagarde E, Sobngwi-Tambekou J, Sitta R, Puren A. Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: the ANRS 1265 Trial. PLoS Med. 2005 Nov;2(11):e298.

(46) UNAIDS. Fact sheet: Sub-Saharan Africa. 2006; Available at: www.data.unaids.org/pub/GlobalReport/2006/200605-FS-SubSaharanAfrica_en.pdf. Accessed 06/14, 2006.

(47) Defilippi K. Palliative care issues in sub-Saharan Africa. Int.J.Palliat.Nurs. 2000 Mar;6(3):108.

(48) UNAIDS. Sub-Saharan Africa. Available at: www.unaids.org/en/Regions_Countries/Regions/SubSaharanAfrica.asp. Accessed 06/14, 2006.

(49) South African Department of Health. Progress Report on Declaration of Commitment on HIV and AIDS: Reporting Period January 2006-December 2007. 2008.

(50) Pettifor AE, Rees HV, Kleinschmidt I, Steffenson AE, MacPhail C, Hlongwa-Madikizela L, et al. Young people's sexual health in South Africa: HIV prevalence and sexual behaviors from a nationally representative household survey. AIDS 2005 Sep 23;19(14):1525-1534.

(51) May J, Govender J. Poverty and Inequality in South Africa
Report prepared for the Office of the Executive Deputy President and the Inter-Ministerial Committee for Poverty and Inequality. 1998 May 13, 1998.

(52) Klasen S. Poverty, inequality and deprivation in South Africa: An analysis of the 1993 SALDRU survey. Social Indicators Research 1997;41:51-94.

(53) Carter MR, May J. Poverty, livelihood and class in rural South Africa. World Development 1999;27(1):1-20.

(54) Marks S. An epidemic waiting to happen? The spread of HIV/AIDS in South Africa in social and historical perspective. African Studies 2002;61(1):13-26.

(55) The darkening of white South Africa. Economist 1995 05/20/;335(7915):18-20.

(56) Ransdell E. The children on South Africa's front line. U.S.News & World Report 1993 03/15/;114(10):16.

(57) Beall B, Gelb S, Hassim S. Fragile stability: State and society in democratic South Africa. Journal of Southern African Studies 2005 December 2005;31(4):681-700.

(58) Elder GS. Hostels, sexuality, and the apartheid legacy : malevolent geographies. Athens, Ohio: Ohio University Press; 2003.

(59) Christofides NJ, Silo Z. How nurses' experiences of domestic violence influence service provision: Study conducted in North-west province, South Africa. Nurs.Health Sci. 2005 03//;7(1):9-14.

(60) Ross FC. Bearing witness : women and the Truth and Reconciliation Commission in South Africa. London ; Sterling, Va.: Pluto Press; 2003.

(61) Jewkes R, Levin J, Penn-Kekana L. Risk factors for domestic violence: Findings from a South African cross-sectional study. Social Science and Medicine 2002;55(9):1603-1617.

(62) Wood K, Jewkes R. Violence, rape, and sexual coercion: Everyday love in a South African township. Gender and Development 1997 June;5(2):41-46.

(63) Colebunders R, Verdonck K, Nachega J, Kothari P. Impact of new developments in antiretroviral treatment on AIDS prevention and care in resource-poor countries. AIDS Patient Care STDS 2000 May;14(5):251-257.

(64) Norval D. AIDS. In: Bruera E, De Lima L, Wenk R, Farr W, editors. Palliative Care in the Developing World: Principles and Practice. 1st ed. Houston, TX: IAHPC Press; 2002. p. 143-185.

(65) Badri M, Maartens G, Mandalia S, Bekker LG, Penrod JR, Platt RW, et al. Cost-effectiveness of highly active antiretroviral therapy in South Africa. PLoS Med. 2006 Jan;3(1):e4.

(66) Cullinan K. South Africa takes first steps to provide antiretrovirals. Bull.World Health Organ. 2002;80(11):921.

(67) World Health Organization. Progress of global access to HIV antiretroviral therapy: An update on "3x5". 2005 June 2005.

(68) Jones JS. Taxed to death. S.Afr.Med.J. 2005 Sep;95(9):642-644.

(69) Hausler H, Naidoo P, Schoeman H, Karpakis B, Godfrey-Faussett P. Implications of selection criteria for antiretroviral therapy in South Africa. Int Conf AIDS 2004.

(70) Defilippi KM, Cameron S. Promoting the integration of quality palliative care: the South African Mentorship Program. J.Pain Symptom Manage. 2007 May;33(5):552-557.

(71) Olweny CL, Borok M, Gudza I, Clinch J, Cheang M, Kiire CF, et al. Treatment of AIDS-associated Kaposi's sarcoma in Zimbabwe: results of a randomized quality of life focused clinical trial. Int.J.Cancer 2005 Feb 10;113(4):632-639.

(72) Harding R, Higginson IJ. Palliative care in sub-Saharan Africa. Lancet 2005 Jun 4-10;365(9475):1971-1977.

(73) Collins K, Harding R. Improving HIV management in sub-Saharan Africa: How much palliative care is needed? AIDS Care 2007 Nov;19(10):1304-1306.

(74) Barnard A. Palliative care is on the move--masihambe! S.Afr.Med.J. 2006 Feb;96(2):118, 120.

(75) Clark D. South Africa. Available at: http://www.eolc-observatory.net/global_analysis/southafrica.htm. Accessed May 03, 2006.

(76) Sukati NA, Mndebele SC, Makoa ET, Ramukumba TS, Makoae LN, Seboni NM, et al. HIV/AIDS symptom management in Southern Africa. J.Pain Symptom Manage. 2005 Feb;29(2):185-192.

(77) Tshibangu KC, Worku ZB, de Jongh MA, van Wyk AE, Mokwena SO, Peranovic V. Assessment of effectiveness of traditional herbal medicine in managing HIV/AIDS patients in South Africa. East Afr.Med.J. 2004 Oct;81(10):499-504.

(78) World Health Organization. World Health Organization definition of palliative care. Available at: http://www.who.int/cancer/palliative/definition/en/. Accessed May/ 05, 2006.

(79) Kim A, Fall P, Wang D. Palliative care: optimizing quality of life. J.Am.Osteopath.Assoc. 2005 Nov;105(11 Suppl 5):S9-14.

(80) MacDonald N. Palliative care--the fourth phase of cancer prevention. Cancer Detect.Prev. 1991;15(3):253-255.

(81) Doyle D. Palliative medicine training for physicians. J.Neurol. 1997 Oct;244 Suppl 4:S26-9.

(82) Adenipekun A, Onibokun A, Elumelu TN, Soyannwo OA. Knowledge and attitudes of terminally ill patients and their family to palliative care and hospice services in Nigeria. Niger.J.Clin.Pract. 2005 Jun;8(1):19-22.

(83) The Palliative Care Trainers Declaration of Cape Town--November 13, 2002. J.Palliat.Med. 2003 Jun;6(3):339-340.

(84) Noah BA. AIDS and antiretroviral drugs in South Africa: public health, politics, and individual suffering: a review of Brian Tilley's It's my life. J.Law Med.Ethics 2003 Spring;31(1):144-148.

(85) Stein ME, Spencer D, Kantor A, Ruff P, Haim N, Bezwoda WR. Epidemic AIDS-related Kaposi's sarcoma in southern Africa: experience at the Johannesburg General Hospital (1980-1990). Trans.R.Soc.Trop.Med.Hyg. 1994 Jul-Aug;88(4):434-436.

(86) Harding R, Karus D, Easterbrook P, Raveis VH, Higginson IJ, Marconi K. Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. Sex.Transm.Infect. 2005 Feb;81(1):5-14.

(87) World Health Organization Regional Office for South East Asia. Facts Sheets HIV/AIDS for Nurses and Midwives. 2002.

(88) Gwyther L. Palliative care response to HIV/AIDS in South Africa. Int.J.Palliat.Nurs. 2005 Mar;11(3):112-113.

(89) Uys LR. The practice of community caregivers in a home-based HIV/AIDS project in South Africa. J.Clin.Nurs. 2002 Jan;11(1):99-108.

(90) Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. BMJ 2003 Jul 26;327(7408):192-194.

(91) Gwyther E. South Africa: the status of palliative care. J.Pain Symptom Manage. 2002 Aug;24(2):236-238.

(92) Demmer C. AIDS and palliative care in South Africa. Am.J.Hosp.Palliat.Care 2007 Feb-Mar;24(1):7-12.

(93) Lloyd-Williams M, Dogra N, Morake R. A comparison of attitudes of medical students in England and in South Africa towards patients with life-limiting illness. J.Palliat.Care 2003 Fall;19(3):188-191.

(94) Aranda S. Global perspectives on palliative care. Cancer Nurs. 1999 Feb;22(1):33-39.

(95) Olweny C, Sepulveda C, Merriman A, Fonn S, Borok M, Ngoma T, et al. Desirable services and guidelines for the treatment and palliative care of HIV disease patients with cancer in Africa: a World Health Organization consultation. J.Palliat.Care 2003 Fall;19(3):198-205.

(96) Marco CA, Buderer N, Thum SD. End-of-life care: perspectives of family members of deceased patients. Am.J.Hosp.Palliat.Care 2005 Jan-Feb;22(1):26-31.

(97) Brennan F. Palliative care as an international human right. J.Pain Symptom Manage. 2007 May;33(5):494-499.

(98) 20 World Health Organization. Cancer pain relief. Geneva: World Health Organization ; Albany, NY : WHO Publications Center USA distributor; 1986.

(99) Otsuka K, Yasuhara H. Toward freedom from cancer pain in Japan. J.Pain Palliat.Care.Pharmacother. 2007;21(3):37-42.

(100) Zyczkowska J, Szczerbinska K, Jantzi MR, Hirdes JP. Pain among the oldest old in community and institutional settings. Pain 2007 May;129(1-2):167-176.

(101) Barakzoy AS, Moss AH. Efficacy of the world health organization analgesic ladder to treat pain in end-stage renal disease. J.Am.Soc.Nephrol. 2006 Nov;17(11):3198-3203.

(102) Azevedo Sao Leao Ferreira K, Kimura M, Jacobsen Teixeira M. The WHO analgesic ladder for cancer pain control, twenty years of use. How much pain relief does one get from using it? Support.Care Cancer 2006 Nov;14(11):1086-1093.

(103) Klepstad P, Kaasa S, Cherny N, Hanks G, de Conno F, Research Steering Committee of the EAPC. Pain and pain treatments in European palliative care units. A cross sectional survey from the European Association for Palliative Care Research Network. Palliat.Med. 2005 Sep;19(6):477-484.

(104) Maltoni M, Scarpi E, Modonesi C, Passardi A, Calpona S, Turriziani A, et al. A validation study of the WHO analgesic ladder: a two-step vs three-step strategy. Support.Care Cancer 2005 Nov;13(11):888-894.

(105) Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative Care: the World Health Organization's global perspective. J.Pain Symptom Manage. 2002 Aug;24(2):91-96.

(106) Uys LR. Aspects of the care of people with HIV/AIDS in South Africa. Public Health Nurs. 2003 Jul-Aug;20(4):271-280.

(107) HPCA. Hospice and Palliative Care Association of South Africa. 2006; Available at: http://www.hospicepalliativecaresa.co.za/index.htm. Accessed June 22.

(108) Hospice and Palliative Care Association of South Africa. Statistics for July, 2007. 2007.

(109) Clark D, Wright M, Hunt J, Lynch T. Hospice and palliative care development in Africa: a multi-method review of services and experiences. J.Pain Symptom Manage. 2007 Jun;33(6):698-710.

(110) Hospice and Palliative Care Association of South Africa. October 2007 Referral Statistics. 2007.

(111) Merriman A, Kaur M. Palliative care in Africa: an appraisal. Lancet 2005 Jun 4-10;365(9475):1909-1911.

(112) Hospice Association of South Africa. Palliative care. S.Afr.Med.J. 2001 May;91(5):398.

(113) Crowe S. Home truths. Nurs.Times 2001 Sep 27-Oct 3;97(39):26-27.

(114) Uys LR. Evaluation of the Integrated Community-Based Home Care model. Curationis 2001 Aug;24(3):75-82.

(115) Uys L, Hensher M. The cost of home-based terminal care for people with AIDS in South Africa. S.Afr.Med.J. 2002;92(8 I):624-628.

(116) Larsen JV. Palliation of recurrent carcinoma of the cervix in a district hospital. S.Afr.Med.J. 2001 Mar;91(3):182, 184.

(117) Russel M, Schneider H. A Rapid Appraisal of Community-based HIV/AIDS Care and Support Programs in South Africa. 2000.

(118) Jameson C. The role of a palliative care inpatient unit in disease management of cancer and HIV patients. S.Afr.Med.J. 2007 Sep;97(9):849-852.

(119) Scott JF, MacDonald N, Mount BM. Palliative medicine education. In: Doyle D, Hanks WC, MacDonald N, editors. . 2nd ed. Oxford: Oxford Medical Publications; 1998. p. 1169-1200.

(120) Krasuska ME, Stanislawek A, Mazurkiewicz M. Palliative care professional education in the new millennium: global perspectives--universal needs. Ann.Univ.Mariae Curie Sklodowska.[Med]. 2002;57(1):439-443.

(121) Yuen K, Barrington D, Headford N, McNulty M, Smith M. Educating doctors in palliative medicine: development of a competency-based training program. J.Palliat.Care 1998 Autumn;14(3):79-82.

(122) Schulman-Green D, McCorkle R, Cherlin E, Johnson-Hurzeler R, Bradley EH. Nurses' communication of prognosis and implications for hospice referral: a study of nurses caring for terminally ill hospitalized patients. Am.J.Crit.Care 2005 Jan;14(1):64-70.

(123) Oliver D. Training and knowledge of palliative care of junior doctors. Palliat.Med. 1998 Jul;12(4):297-299.

(124) Lloyd-Williams M, Carter YH. General practice vocational training in the UK: what teaching is given in palliative care? Palliat.Med. 2003 Oct;17(7):616-620.

(125) Kelley ML, Habjan S, Aegard J. Building capacity to provide palliative care in rural and remote communities: does education make a difference? J.Palliat.Care 2004 Winter;20(4):308-315.

(126) Cairns W, Yates PM. Education and training in palliative care. Med.J.Aust. 2003 Sep 15;179(6 Suppl):S26-8.

(127) Bateman C. GP'S vision kick-starts palliative training. S.Afr.Med.J. 2002;92(12):936-937.

(128) MacDonald N. A proposed matrix for organisational changes to improve quality of life in oncology. Eur.J.Cancer 1995;31A Suppl 6:S18-21.

(129) Lloyd-Williams M, MacLeod R. A systematic review of teaching and learning in palliative care within the medical undergraduate curriculum. Med Teach 2004;26(8):683-690.

(130) Aulino F, Foley K. Professional education in end-of-life care: a US perspective. J.R.Soc.Med. 2001 Sep;94(9):472-6; discussion 477-8.

(131) Kelly D, Gould D, White I, Berridge EJ. Modernising cancer and palliative care education in the UK: insights from one Cancer Network. Eur.J.Oncol.Nurs. 2006 Jul;10(3):187-197.

(132) Aherne M, Pereira J. A generative response to palliative service capacity in Canada. Int.J.Health Care Qual.Assur.Inc.Leadersh.Health Serv. 2005;18(1):iii-xxi.

(133) Coyne P, Paice JA, Ferrell BR, Malloy P, Virani R, Fennimore LA. Oncology End-of-Life Nursing Education Consortium training program: improving palliative care in cancer. Oncol.Nurs.Forum 2007 Jul;34(4):801-807.

(134) Harris D, Hillier LM, Keat N. Sustainable practice improvements: impact of the Comprehensive Advanced Palliative Care Education (CAPCE) program. J.Palliat.Care 2007 Winter;23(4):262-272.

(135) Buikstra E, Pearce S, Hegney D, Fallon T. SEAM--improving the quality of palliative care in regional Toowoomba, Australia: lessons learned. Rural Remote Health. 2006 Jan-Mar;6(1):415.

(136) Omar S, Alieldin NH, Khatib OM. Cancer magnitude, challenges and control in the Eastern Mediterranean region. East.Mediterr.Health J. 2007 Nov-Dec;13(6):1486-1496.

(137) Abu-Saad Huijer H, Dimassi H. Palliative care in Lebanon: knowledge, attitudes and practices of physicians and nurses. J.Med.Liban. 2007 Jul-Sep;55(3):121-128.

(138) Downing J. Palliative care and education in Uganda. Int.J.Palliat.Nurs. 2006 Aug;12(8):358-361.

(139) African Palliative Care Association. African Palliative Care Association. 2008; Available at: www.apca.co.ug. Accessed 09/15, 2008.

(140) Programmes in Palliative Medicine. 2004.

(141) Macleod RD, Nash A, Charny M. Evaluating palliative care education. Eur.J.Cancer.Care.(Engl) 1994 Dec;3(4):163-168.

(142) Adriaansen MJ, van Achterberg T. A test instrument for palliative care. Int.J.Nurs.Stud. 2004 Jan;41(1):107-117.

(143) Adriaansen MJ, van Achterberg T, Borm G. Effects of a postqualification course in palliative care. J.Adv.Nurs. 2005 Jan;49(1):96-103.

(144) Ward C, Wright M. Fast-track palliative care training to bridge the theory-practice gap. Nurs.Times 2004 Mar 23-29;100(12):38-40.

(145) van Staa AL, Visser A, van der Zouwe N. Caring for caregivers: experiences and evaluation of interventions for a palliative care team. Patient Educ.Couns. 2000 Aug;41(1):93-105.

(146) Hinkka H, Kosunen E, Metsanoja R, Lammi UK, Kellokumpu-Lehtinen P. General practitioners' attitudes and ethical decisions in end-of-life care after a year of interactive Internet-based training. J.Cancer Educ. 2002 Spring;17(1):12-18.

(147) Silverdale N, Katz J. The impact of a distance learning death and dying course: an analysis of student self-reported changes. Nurse Educ.Today 2005 Oct;25(7):509-518.

(148) Fischer SM, Gozansky WS, Kutner JS, Chomiak A, Kramer A. Palliative care education: an intervention to improve medical residents' knowledge and attitudes. J.Palliat.Med. 2003 Jun;6(3):391-399.

(149) Sullivan AM, Lakoma MD, Billings JA, Peters AS, Block SD, PCEP Core Faculty. Creating enduring change: demonstrating the long-term impact of a faculty development program in palliative care. J.Gen.Intern.Med. 2006 Sep;21(9):907-914.

(150) Low J, Cloherty M, Wilkinson S, Barclay S, Hibble A. A UK-wide postal survey to evaluate palliative care education amongst General Practice Registrars. Palliat.Med. 2006 Jun;20(4):463-469.

(151) Landmark BT, Wahl AK, Bohler A. Competence development in palliative care in Norway: A description and evaluation of a postgraduate education program in palliative care in Drammen, Norway. Palliat.Support.Care. 2004 Jun;2(2):157-162.

(152) Baughcum AE, Gerhardt CA, Young-Saleme T, Stefanik R, Klopfenstein KJ. Evaluation of a pediatric palliative care educational workshop for oncology fellows. Pediatr.Blood Cancer. 2007 Aug;49(2):154-159.

(153) Hopkins MJ. A palliative care education model for the hospital setting. Eur.J.Cancer.Care.(Engl) 1997 Dec;6(4):280-290.

(154) Bruera E, Selmser P, Pereira J, Brenneis C. Bus rounds for palliative care education in the community. CMAJ 1997 Sep 15;157(6):729-732.

(155) Weissman DE, Ambuel B, Norton AJ, Wang-Cheng R, Schiedermayer D. A survey of competencies and concerns in end-of-life care for physician trainees. J.Pain Symptom Manage. 1998 Feb;15(2):82-90.

(156) Koffman J, Higginson IJ. Assessing the effectiveness and acceptability of interprofessional palliative care education. J.Palliat.Care 2005 Winter;21(4):262-269.

(157) Hall P, Weaver L, Hupe D, Seely JF. Community-based palliative care education: can it improve care of the terminally ill? Acad.Med. 1999 Oct;74(10 Suppl):S105-7.

(158) Kristjanson LK, Dudgeon D, Nelson F, Henteleff P, Balneaves L. Evaluation of an interdisciplinary training program in palliative care: addressing the needs of rural and northern communities. J.Palliat.Care 1997 Autumn;13(3):5-12.

(159) Myers B, Parry CD, Pluddemann MA. Indicators of substance abuse treatment demand in Cape Town, South Africa (1997-2001). Curationis 2004 May;27(2):27-31.

(160) Schuit KW, Otter R, Stewart R, Sleijfer DT, Meijler WJ, Meyboom-De Jong B. The effects of a postgraduate course on opioid-prescribing patterns of general practitioners. J.Cancer Educ. 2000 Winter;15(4):214-217.

(161) Hall P, Hupe D, Scott J. Palliative care education for community-based family physicians: the development of a program, the evaluation, and its consequences. J.Palliat.Care 1998 Autumn;14(3):69-74.

(162) Shipman C, Addington-Hall J, Thompson M, Pearce A, Barclay S, Cox I, et al. Building bridges in palliative care: evaluating a GP Facilitator programme. Palliat.Med. 2003 Oct;17(7):621-627.

(163) Reymond L, Charles M, Israel F, Read T, Treston P. A strategy to increase the palliative care capacity of rural primary health care providers. Aust.J.Rural Health 2005 Jun;13(3):156-161.

(164) Bureau of Justice Assistance. Assessing program performance: Pre-experimental (pre-post) design. Available at: http://www.ojp.usdoj.gov/BJA/evaluation/guide/ap5.htm. Accessed June 22, 2006.

(165) Shipman C, Addington-Hall J, Barclay S, Briggs J, Cox I, Daniels L, et al. Educational opportunities in palliative care: what do general practitioners want? Palliat.Med. 2001 May;15(3):191-196.

(166) Barnabe C, Kirk P. A needs assessment for southern Manitoba physicians for palliative care education. J.Palliat.Care 2002 Fall;18(3):175-184.

(167) Schulman-Green D. How do physicians learn to provide palliative care? J.Palliat.Care 2003 Winter;19(4):246-252.

(168) Paice JA, Ferrell BR, Coyle N, Coyne P, Callaway M. Global efforts to improve palliative care: the International End-of-Life Nursing Education Consortium Training Programme. J.Adv.Nurs. 2008 Jan;61(2):173-180.

(169) Fineberg IC, Wenger NS, Forrow L. Interdisciplinary education: evaluation of a palliative care training intervention for pre-professionals. Acad.Med. 2004 Aug;79(8):769-776.

(170) Sullivan AM, Lakoma MD, Billings JA, Peters AS, Block SD, PCEP Core Faculty. Teaching and learning end-of-life care: evaluation of a faculty development program in palliative care. Acad.Med. 2005 Jul;80(7):657-668.

(171) Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, et al. Initial burden of disease estimates for South Africa, 2000. S.Afr.Med.J. 2003 Sep;93(9):682-688.

(172) Scott V, Sanders D, Reagon G, Groenewald P, Bradshaw D, Nojilana B, et al. Cape Town Mortality, 2001 Part II: An equity lens, lessons and challenges. 2003 November, 2003.

(173) The World Bank. *World Development Report 1993: Investing in Health.* New York: Oxford University Press; 1993. p. 1-51.

(174) Antiretroviral drug. 2008; Available at: http://en.wikipedia.org/wiki/Antiretroviral_drug. Accessed 05/05, 2008.

CHAPTER THREE: Methodology

3.1 Introduction

The purpose of this chapter is to describe the study's methodology in detail. As this project has two distinct parts--Part 1 (The Context of Palliative Care in South Africa) and Part 2 (Evaluation of UCT's Palliative Care Distance Education Program)--the sample selection, study protocol, instruments, procedures, and analysis used by each are presented separately. The chapter concludes by discussing the ethical considerations critical in a study such as this.

3.2 Interpretive Description

The approach used to address the two study aims was informed and guided by interpretive description. First proposed by nurse researchers Thorne, Reimer Kirkham and MacDonald-Emes in the early 1990s (1), the principles of interpretive description have been refined over the last two decades.

In the past, social science approaches (e.g. grounded theory, phenomenology and ethnography) have been used by health researchers when conducting qualitative inquiries. While each methodological approach has a role to play within theory development, none are fully compatible with the pragmatic demands of the applied health disciplines. In the social sciences, research studies may not have the same potential or necessity to have immediate impact that it does in the health sciences; health research often can and should be translated into practice very quickly. Thus, health research needs to be a blend of both the objective and the subjective, deriving data from a range of data sources in order to best respond to the research enquiry. Interpretive description was developed to provide a meaningful framework for the development of protocol for use in the health field (2).

Descriptive research has often been depicted as the least valuable form of research. However, in the health field, description is an important element in learning about the complex world of human health and illness (3); description is and will remain an extremely important element in making practitioners aware of phenomena, in creating an empirical basis from which new questions can be generated, and for taking note of the manifestations of the complex and messy world of human health and illness. Interpretive description values the descriptive element of research and views it as an integral component of health research. However, interpretive description does not stop with description; it incorporates both careful and systematic analysis and the transposition of that analysis back into the context of the practice field (2).Rather than producing just description, the health researcher seeks to discover associations, relationships and patterns within the phenomena that have been described (2). As a health researcher seeks to discover associations, relationships and patterns within a particular area, the interpretation of the patterns extends beyond simple documentation and into "sense-making" (2). Thus, interpretive description is valuable as a qualitative research approach to address aims that derive from both health care practice and the contextual data.

Interpretive description is not particularly prescriptive in that texts on the methodology do not provide a "recipe" for the researcher to follow. However, the authors of interpretive description present a methodological framework within which a range of options for design decisions can be enacted and justified. As Thorne has emphasized, "interpretive description is ... about ensuring a solid and auditable logic for what you did and why that was an appropriate thing to do" (personal communication, March 17, 2009). For example, the application of content analysis, a process typically adhered to in grounded methods, is appropriate within interpretive description if content analysis has been determined to be the most useful and effective analytical tool. As Thorne et al. state,

> *"[Interpretative Description] is a grounded approach to articulating patterns and themes emerging in relation to various clinical phenomena. This method provides direction for qualitative description and allows for its extension into the realm of interpretation and explanation in the context of qualitative credibility criteria."* (4) *(p. 8).*

In this study, interpretive description was used as a logic model to inform the design decisions (e.g. in data collection and analysis) in order to address the research aims. As the study focused on the health care experiences surrounding palliative and hospice care, interpretive description was a natural fit. In her most recent text, Thorne identifies seven foundational tenets: 1) conduct the research in a setting that is as natural as possible and in a way that ensures respect for participants, 2) view both the subjective knowledge and experiences of participants as fundamental sources of health research, 3) examine carefully both the commonalities and differences in participants' experiences, 4) describe and reflect on issues that are not bound by time or context while at the same time reflecting on the factors of time and context, 5) acknowledge that human experiences are in part socially constructed and thus need to be examined in that way, 6) recognize that human experiences are constructed of multiple realities which may be contradictory, and 7) acknowledge that the interactions of the researcher and the participants may influence one another (2).

Although interpretive description studies may differ one from another in how data is collected and analyzed, the philosophical underpinnings ensure a coherence that distinguishes the products of interpretive description from those derived from blended approaches or from generic qualitative description. Each foundational tenet was considered carefully within this study on palliative and hospice care in South Africa.

This chapter contains a description of the protocol, sample, and analysis used in the study. Specific references to how interpretive description both informed and guided the study will be made throughout.

3.3 Study Overview

The aims of this study were twofold: 1) to provide an analysis of palliative and end-of-life care in South Africa as it is currently provided within hospice and other health care organizations and 2) to assess the palliative care distance education program offered through the University of Cape Town (UCT). Four questions framed the research project and were best methodologically approached in two distinct parts. Part 1 (The *Context of Palliative Care in South Africa*), corresponded to the questions "*How* *do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?*" and "*How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?*". Part 2 *(Evaluation of UCT's Palliative Care Distance Education Program*) consisted of two questions; "*What are/were the positive and negative aspects of the palliative care program as described by current and former students?*" and "*How do former and current students evaluate the influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?*" Parts 1 and 2 are intrinsically connected, since an informed evaluation of the distance education program at UCT is best understood within the broader context of palliative and end-of-life care in South Africa. (See project overview in Figure 3.1).

Part 1: The Context of Palliative Care in South Africa. The two questions, *How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?;* and *How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?* formed the basis for Part 1 of the project. A mixed methodology, utilizing both qualitative and quantitative approaches, ensured the collection of comprehensive data in response to the research questions. Qualitative data was collected in three ways: a) structured observations, b) interviews of patients, family care providers and health care providers, and c) field notes. Quantitative data, in the form of a Health Care Provider Survey, was collected from a subset of those health care providers that were interviewed.

The interview and observation frameworks were developed to examine the personal and social environment, structure of care, process of care, satisfaction with care and quality of life. (See Appendix 9 for framework of key observations points that were tracked during fieldwork). Interview data was collected from a wide range of stakeholders involved in palliative and end-of-life care, in order to both describe the experiences of various populations as well as to facilitate comparisons between groups. Field notes were generated throughout the data collection period and were useful to capture the researcher's different observations, reactions to and by participants, and perceptions of emerging themes over time.

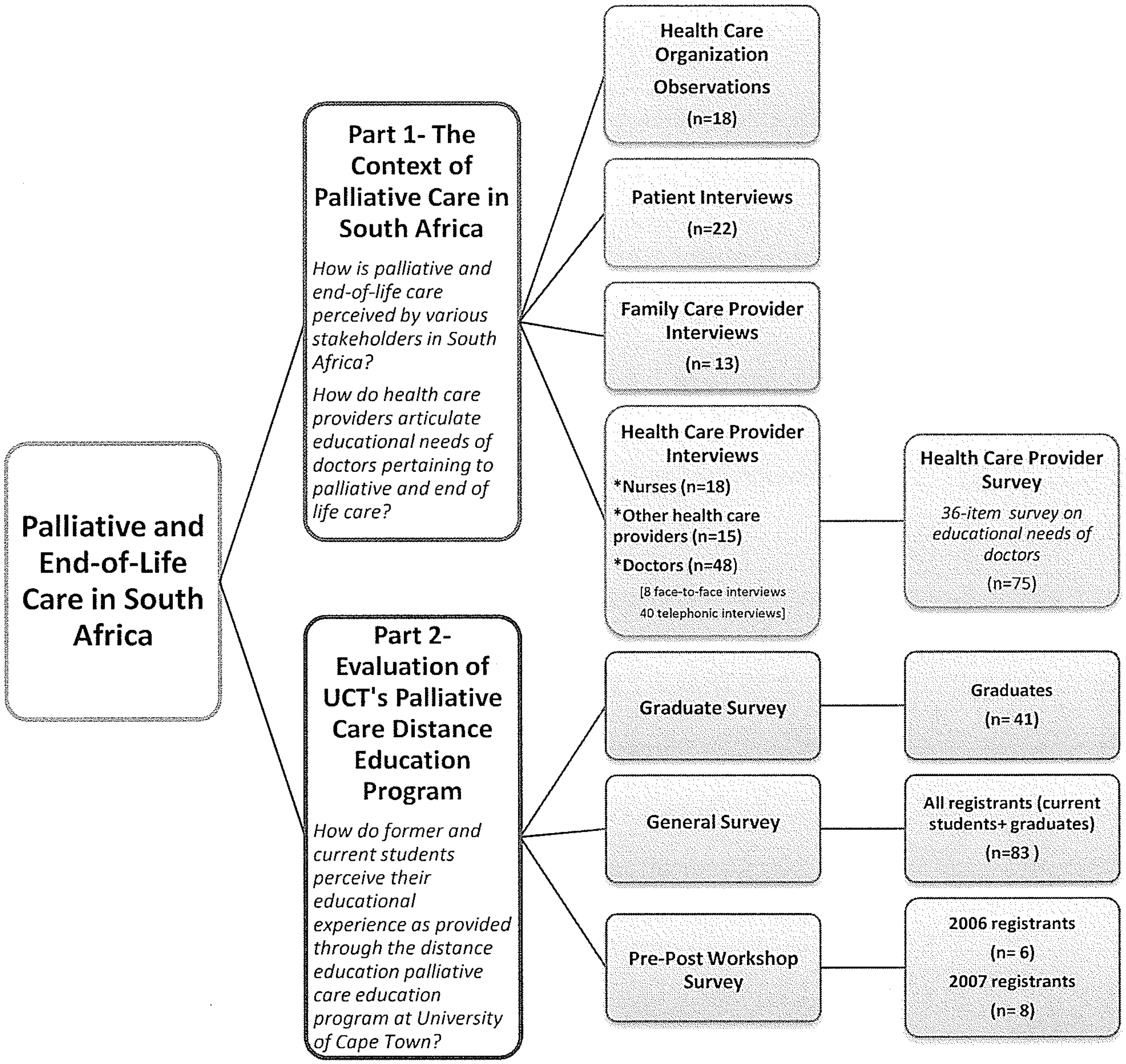
The Health Care Provider Survey evaluated the palliative care educational needs of medical doctors in South Africa and was completed by a range of health care practitioners including doctors, nursing sisters, social workers, and home-based carers. To reflect the multidisciplinary team concept used in the delivery of palliative care, a range of health care workers were asked to participate. In this way, it was possible to examine the similarities and differences between the groups; different perspectives on the educational needs of doctors were explored. Also, because Part 2 was focused on physician education and as Parts 1 and 2 were thematically linked, it was felt important to be consistent in this physician focus, albeit inclusive of a multidisciplinary perspective.

Part 2: Evaluation of the UCT Palliative Care Distance Education Program. The research questions, *What are/were the positive and negative aspects of the* *palliative care program as described by current and former students?*" and "*How do former and current students evaluate the influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?* were the foundation for Part 2 of the project. This program was based at UCT in the School of Public Health and Family Medicine. Three surveys: the General Survey, Graduate Survey, and Pre-post Workshop Survey, were used in Part 2 of the study in order to examine different components of the course.

The General Survey was developed from the course objectives by the lead investigator (CE) to examine how effectively the overall course objectives were taught, and was completed by current students and graduates. The purpose of the Graduate Survey was to examine the experiences and perceptions of graduates; it explored if and how the course altered the graduates' medical practices. The third survey, the Pre-post Workshop Survey, was designed to evaluate the onsite three-day workshop offered to first and second year students in the program. In this study first year students were those that began the course in 2007 and second year students were those that enrolled in 2006. All of the workshop participants were asked to complete the Pre-workshop Survey before the start of their workshop weekend; Post-workshop Surveys were mailed out to participants four months following the completion of the workshop to assess perceived changes in behaviour or competence.

The sample sizes were defined by the number of course participants and thus were relatively small. However, as multiple tools and approaches were used to evaluate the program, this allowed for some triangulation of results i.e. drawing conclusions based on the convergence of multiple sources of data. The analysis of these three surveys allowed for greater insight into how trainees experienced this program and the viability of this program in shaping the provision of palliative and end-of-life care in South Africa.

Figure 3.1 Palliative and End-of-life Care in South Africa: Study Overview



3.4 Methodology for Part 1: The Context of Palliative Care in South Africa

3.4.1 Introduction

Interpretive description locates itself within a philosophical tradition that explores the search for truth from multiple vantage points; exploring meaning from the perspective of a number of different stakeholder groups and using different methods to gather data, for example, are believed to strengthen the results of scientific enquiry (2). The experiences with and perceptions of patients, family care providers, and health care workers regarding palliative and end-of-life care were explored in Part 1 (The Context of Palliative Care in South Africa). In addition, an investigation into the educational needs of medical doctors pertaining to palliative care was completed. A description of the methodology applied in Part 1 will include an overview of the sampling approach, instruments, procedures, and data analysis steps.

3.4.2 Sample

A variety of different types of organizations are involved in providing palliative and hospice care to individuals residing in South Africa. While patients receive palliative care most frequently at hospices, other models of care, including but not limited to NGOs delivering home-based care or hospitals, exist to provide palliative care services in South Africa. Therefore, the sample for Part 1 consisted of individuals, hospice organizations and other health care organizations.

A framework of observations (see Appendix 9) was used to describe the organizational structures, infrastructure, available personnel and accessibility to medications within health care organizations providing palliative care. In order that the data reflect a range of health care organizations providing palliative care services, several different types of organizations were observed. A total of 18 formal observations were conducted at hospices, state hospitals, and private residences between February 1st and September 14, 2007[xiii]. Field notes were also made throughout the data collection period; most typically, field notes were written after an interview or organizational visit, but they were also formulated whenever the researcher wanted to capture an idea or experience emerging within the context of the study.

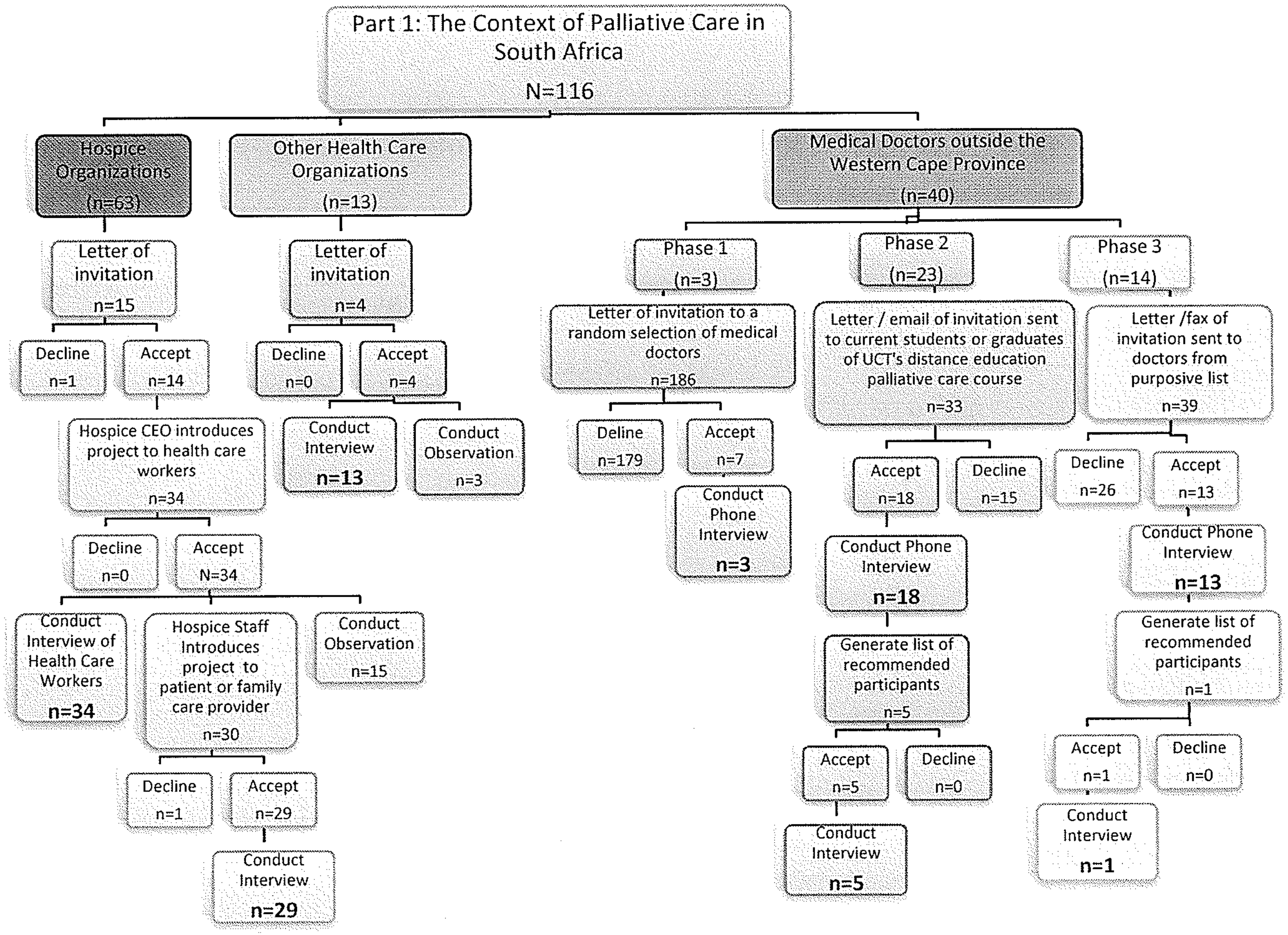
The study sample was derived from three different sources: hospice organizations, other health care organizations, and medical doctors outside the Western Cape Province. Figure 3.2 provides an overview of the recruitment process. (A detailed overview of how contact was made will follow in sections 3.4.2.1-3.4.2.3 and section 4.2). In interpretive description, an essential requirement of sampling is to apply a transparent sampling logic and report the findings in keeping with what this sample is understood to represent (2). In this study, both purposive sampling—where the settings and specific individuals were recruited by virtue specific characteristics--and

---

[xiii] Participating health care organizations: Cotlands Hospice, Bolands Hospice, Drakenstein Hospice, BRAM Care Centre, Breede River Hospice, St. Luke's Kenilworth, Heldeberg Hospice, St. Luke's Lentegeur, Groote Schurr Public Hospital, Bethesda Hospice, Knysna Hospice, Franschoek Hospice, Tygerberg Hospital, St. Luke's Kalk Bay, Belville Hospice, Living Hope Community Centre, St. Luke's Khaleyitsha and St. Luke's Gugulethu

convenience sampling—where participants were chosen based on availability— were used. Using these types of samples, both necessary within the time frame and objectives of the study, has implications for the generalizability of the study.

Figure 3.2 Flowchart of Study Recruitment Process for Part 1 (The Context of Palliative Care in South Africa)



3.4.2.1 HPCA Hospice Organizations (Face to Face Interviews and Structured Observations)

The 15 Western Cape hospices registered with the Hospice and Palliative Care Association of South Africa were invited to participate in the project. First, a letter containing a project overview and invitation to participate was sent to the hospice managers or CEOs of the HPCA hospices located in the Western Cape province of South Africa (Appendix 7). Approximately one week after the letter of invitation was sent, a follow-up phone call was placed by CE to determine the interest level of the hospice manager or CEO in participating in the project. Of the 15 organizations, 14 agreed to take part and one, by virtue of non-response, did not. Once a commitment was made by the hospice manager or CEO to participate, the researcher would explain the two ways a hospice could participate. Namely, hospices were asked to assist in generating research participants as well as be a site for a structured observation.

The majority of the patient, family care providers, and health care workers who participated in the study were recruited through HPCA hospice organizations.

Patients. Interviews with patients (n=22) took place between February 8th and August 7th, 2007. Of the 22 patients, 17 were recruited through HPCA hospices. The recruitment of the other 5 participants will be explained in section 3.3.2.2 (Other Health Care Organizations). To be considered for the project, patients had to be: a) dealing with a life-threatening illness, b) able to complete a 30-minute interview, c) a minimum of 18 years old, d) willing and able to provide informed consent, and e) able to communicate in Afrikaans, English or Xhosa.

Patients were recruited through hospice organizations by nursing sisters. First the project was explained directly to the administrators of the hospice organizations who then passed on recruitment information to the nursing sisters. Conversely, the primary investigator would present the project details at a staff meeting, thus providing the recruitment details for all the medical staff. Then, based on the recruitment criteria, nursing sisters would determine which of their patients might be suitable to be study participants. Nursing sisters would proceed to contact patients directly to determine level of interest. All of the patients contacted were interested in participating with one exception. After patient interest was determined, the nursing sister would then put the names of the patients on a list for the researcher to review. When the researcher made a formal hospice visit with the purpose of conducting interviews, additional screening would take place; the nursing sister would verbally describe the patient to the interviewer and if the patient met the recruitment criteria, he or she would be put on the interview list. Depending on where the patient was receiving care, interviews were held either at the hospice or patient's home. Details on patient demographics can be found in Chapter Four.

Family care providers. Interviews with family care providers (n=13) were conducted between March 7th and September 14th, 2007. To be considered for the project, family care providers needed to be: a) caring for a relative with a life-threatening illness (not necessarily the primary caregiver but involved in care-giving tasks on a regular basis), b) 18 years of age or older, c) competent to provide valid informed consent, and d) able to speak Afrikaans, English, or Xhosa. Of the 13 family care providers interviewed in the study, 12 were recruited through HPCA hospices.

As the nursing sisters had frequent contact with family care providers, they would refer participants meeting eligibility criteria to the project. Family care providers were recruited in the same manner as the hospice patients. After the nursing sisters received information about participant recruiting, they would determine eligible family care providers. Nursing sisters would then contact family care providers directly to ascertain interest level. All of the family care providers approached about the study were interested in participating. The nursing sister would then put the names of the patients on a list for the researcher to review. When the researcher made a formal hospice visit with the purpose of conducting interviews, additional screening would take place; the nursing sister would verbally describe the family care provider to the interviewer and if the family care provider met the recruitment criteria, he or she would be put on the interview list.

One participant was identified through word of mouth; when a family care provider learned about the research topic through a friend of the researcher, she asked if she could participate. Contact information was provided to the researcher and a phone call determined participant eligibility.

The location of the interview was determined by the family care provider. If the interview was to take place in conjunction with the nursing sister's visit, then the nursing sister would make the necessary arrangements. If the interview was to be conducted at a time and place separate from the nursing sister's visit, then the family care provider's contact information would be given to the researcher and she would call the family care provider directly to make the necessary arrangements. Most frequently, as the family care provider would be involved in the daily care of his or her family member, the interview would be at the home of the patient. However, the interview site was determined based on the caregivers available and preference.

There were seven instances where both the patient and his or her family care provider were interviewed; of the 22 patients interviewed, the family care givers of seven also participated. Therefore, six of the family care providers and 15 of the patients interviewed participated independently.

Health Care Providers. Interviews of health care providers (N=81) were conducted between February 1st and December 2nd of 2007. To be included in the study, health care providers needed to be: a) providing care for patients with life-threatening illnesses, b) able to complete an interview of up to one hour, and c) able to communicate in English.

The category "health care providers" consisted of nursing sisters (n=18), other professional health care providers such as social workers or home based carers (n=15), and medical doctors (n=48). Seventeen nursing sisters, ten "other health care workers", and seven medical doctors were recruited through HPCA hospice organizations in the Western Cape Province. Doctors outside the Western Cape (n=40) were recruited in a different manner, a process described in section 3.3.2.3 (Medical Doctors Outside the Western Cape Province).

The research study was introduced to the administrators of the hospice organizations who then passed on study details to the hospice's health care staff. If a staff member was interested in participating in the research study, he or she would inform the hospice administrator. When the researcher would visit the hospice, therefore, a number of eligible health care workers would be available to be interviewed.

Interviews were typically conducted in the administrative section of the hospice organization. The only exception was when an interview was conducted en route to a hospice organization; a home-based carer wished to be interviewed and, as the schedule did not permit a stop, the interview was held while the home-based carer drove the researcher and research assistant back to the administration buildings.

3.4.2.2 Other Health Care Organizations (Face to Face Interviews and Structured Observations)

"Other Health Care Organizations" was a category consisting of two state hospitals (Groote Schurr and Tygerberg) and two hospice organizations not registered with the HPCA (BRAM Care and Sun Valley). The intent behind the inclusion of these organizations was to attain a different perspective on palliative care provision in South Africa. The recruitment strategy similar to that of HPCA hospice organizations was utilized and can be seen in Figure 3.2. At the state hospitals, four social workers were interviewed- three at one site and one at the other. A total of five patients, one nursing sister, one home-based carer, and one medical doctor were interviewed at the non-HPCA hospices.

These organizations were contacted in the following way. First, a letter containing a project overview and invitation to participate was sent to the three organizations. At the state hospitals, the researcher contacted the head social workers in the oncology departments. At the hospice organization, the researcher wrote to the administrator. A follow-up phone call was then placed to determine the interest level of the letter recipient. Of the three organizations contacted, all agreed to participate in the project. During the visit to each organization, a structured observation was also conducted.

3.4.2.3 Medical Doctors outside the Western Cape Province (Phone Interviews)

Of the 48 doctors interviewed for the research study, 40 were conducted with doctors who worked outside the Western Cape Province in the eight remaining South African provinces of Mpumalanga, Eastern Cape, Free State, Limpopo, KwaZulu Natal, Gauteng, Northern Cape, North-West. An interpretive description requires a sample that is representative of the larger body being studied. "Saturation" is a concept that is not encouraged in interpretive description; saturation implies that the researcher has tapped all relevant human variation, something that is not technically achievable. Given the difficulties that were encountered in recruiting medical doctors, three phases-completed in a sequential manner- were necessary to achieve a representative sample of medical doctors in South Africa. To achieve a sample that was reflective of a particular aspect of doctors in South Africa, it was felt that a total of 45 medical doctors (or 5 per province) would be appropriate. However, the design of the project was such that there was sufficient time in the project to increase sample size if it was felt that a representative sample had not yet been achieved.

Phase One: The study protocol indicated that eligible doctors would be randomly selected from an online list of medical practitioners working in South Africa and then contacted via mail. Although such a list was available, the information on it proved to be incomplete. Three attempts were made to contact doctors using this method, but the recruitment rate was too low to be considered effective; of 186 letters sent, seven individuals indicated interest in participating. Therefore, given the problems of recruitment in Phase One, other sampling approaches were used to achieve data saturation.

Phase Two: In the second phase of recruitment, students or graduates of the palliative care distance education program were approached. If student or graduates lived and worked in the provinces where more information was needed, they were sent a letter of invitation. In this way, 18 students (37.5% of the sample) agreed to participate in the study.

Phase Three: As the full complement of participants (five participants per province) was not reached after the recruitment procedures of Phase One and Two, a third phase was necessary. In several provinces, namely the provinces of Limpopo, Mpumalanga and the Northern Cape, recruitment was more difficult. Therefore, Phase

Three focused primarily on these three provinces in an effort to meet the recruitment targets. Using contact information provided by both the Rural Health Initiative of South Africa and the South African Yellow Pages, the researcher made direct contact with hospital managers within those provinces. By faxing or emailing project information to the hospital managers and then following up with a phone call, the full complement of participants within those provinces was reached.

3.4.3 Study Protocol for Part 1 (The Context of Palliative Care in South Africa)

Approval for the study was granted by the Research Ethics Boards at University of Cape Town, University of Manitoba and Hospice and Palliative Care Association of South Africa. Once participants were identified, the researcher would meet with them (or phone them), explain the study and provide them an opportunity to ask questions. After responding to questions, the researcher would review the consent form and provide them an opportunity to ask questions. Once participants had signed the consent form, the interview would proceed, in some instances, with the assistance of a translator.

3.4.3.1 Xhosa Translation

A number of the patient and family care provider interviews (n=10) were conducted with the assistance of a Xhosa translator. In these interviews, participants were encouraged to respond in the language they felt most comfortable speaking and often they would use both English and Xhosa to answer questions. The researcher would pose questions in English and the translator would echo them in Xhosa. At times, participants would not wait to hear the Xhosa translation and would respond, either in English or Xhosa, directly to the researcher's questions.

When participant responses were in Xhosa, the translator would summarize the comments briefly so that the interviewer, using an approach described by Twinn, could "process the meaning of the participant's comments and ... adjust questions and comments in response to unanticipated answers" (p. 573). (5). Having the Xhosa translator present allowed the lead researcher to continually shape the interview.

Aside from the pragmatics of the translation process, it the Xhosa translator was helpful both throughout the interviews and also in the interpretation of various behaviours. She would be able to interpret the cultural context of the participants for the researcher as well as offer comment on possible reasons for certain behaviour. From the participant perspective, the translator appeared to be a buffer; having her present made the interview process more comfortable for the participants.

3.4.4 Instruments

The following section reviews the instruments used to collect data within Part 1 (The Context of Palliative Care in South Africa) of the research study. Namely, the interview guides, observation guides, and the Health Care Provider Survey will be explained.

3.4.4.1 Interview Guides

The interview schedules for patients, family care providers, and health care providers (Appendix 8) were developed from Stewart et al.'s health care framework(6). While the framework was designed and tested in the United States, the field advisor (LG) and a sub-set of her selected colleagues deemed it relevant for use in South Africa, thereby helping to ensure face validity of the tool for the population of interest. Separate interview guides were developed for the different sub-groups of patients, family care providers and health care workers. In this way, the experiences of different groups could be assessed and compared.

In Stewart's framework, there are five specific categories (personal and social environment, structure of care, process of care with physicians, nurses, and social workers, satisfaction with health care, and quality and length of life) that combine to provide a comprehensive evaluation of end-of-life experiences. For this study, material pertaining to process of care and satisfaction with care were further developed. For example, the interview guides for patients and family care providers contained questions relating to types of care that was provided or received as well as satisfaction with this care. As can be seen in Figure 3.3, the interview questions are in direct alignment with the Stewart framework.

Figure 3.3 Interview Questions within Stewart Framework

Personal &Social Environment

Clinical status, case mix

Can you tell me about your illness? Can you describe symptoms that have caused you discomfort in the last 2 weeks? Are you able to control these symptoms?

Social support for patient

Can you describe for me the type of care that you provide? (physical, emotional) How often do you provide care?

Structure of Care

Access to Care within System

What is the referral process for patients with life threatening illness to be admitted into hospice care?

Do you feel that this is an adequate referral system?

What do you feel are the barriers and challenges to accessing palliative care?

HOW MANY WORKERS ON STAFF? (PHYSICIANS, NURSES, SOCIAL WORKERS, OTHER)

NUMBER OF PATIENTS UNDER CARE?

Organization of Care

Does your organization have sufficient resources to offer palliative care to all patients with life-threatening illnesses?

Has staff received training in palliative care? Please explain.

Is there adequate equipment?

Formal support services available

Are there other health care professionals that provide your family member with care? What type of care does he or she receive from him or her? Would you say that he or she satisfied with that care?

Who, outside of the health care professionals, looks after your family

Physical environment(s) of care

ABILITY TO HAVE VISITORS?

NOISE LEVEL (CONSTANT, INTERMITTENT OR INFREQUENT NOISE)

PRIVACY

Process of Care with Physicians, Nurses, Social Workers

Technical Process- Patient

While in hospice care, how often do you see a medical care provider (list in separate question). Would you like to see that health care provider more often? Less often? Please explain. What type of care do you receive from a medical care provider (each practitioner dealt with separately)? physical care? emotional care?

While in hospice care, how often does your family member see a medical care provider (list in separate question). Would he or she like to see that health care provider

Decision Making Process- Patient and Family

Can you tell me about your illness? When were you given this diagnosis? By whom were you given this diagnosis?

Interpersonal and Communication Style- Patient and Family

How are patients told of a life threatening diagnosis and what to expect?

How is the topic of death and dying dealt with in patients and families?

Information, Counselling- Patient and Family

Are patient's families instructed on how to care for patients with life-threatening illnesses?

Satisfaction with Health Care

Patient Satisfaction with Health Care

Would you say that you are satisfied with the care that you receive from your medical care providers (each practitioner is dealt with separately)? Please explain why or why not.

Family Satisfaction with Health Care

Would you say that you are satisfied with the care that your family member receives from the medical care providers (each practitioner is dealt with separately)? Please explain why or why not.

Quality and Length of Life

Quality of Life- Patient

Are you able to control your symptoms?

Quality of Life of Family and Loved Ones

Can you describe for me the type of care that you provide? (physical, emotional) How often do you provide care?

KEY:

Questions asked to patients

Questions asked to family care providers

Questions asked to health care providers

OBSERVATIONS

Interview Refinement.

Over time, the interview guide was refined and adapted. Guided by the tenets of interpretive description that stress the importance of examining both the commonalities and differences in participants' experiences as well as the need to continually reflect on contextual issues, it was decided that the more appropriate means by which to clarify, validate and expand upon the developing themes was to refine the interviews. It became apparent, based on the thrust of the initial interviews, that emerging themes were pointing towards issues which needed additional emphasis. Interview questions of health care providers were altered to draw out certain issues. For example, the original interview did not include a question relating to the participant's definition of palliative care. Although participants were not initially asked to describe what palliative care meant to them, during the preliminary concurrent data collection and coding, it was apparent that participants had varied understandings or descriptions of palliative care. To ensure that the perspectives of all participants could be compared and contrasted, a question was dedicated to the participant's definition or description of palliative care. Contextual questions were also added to the phone interviews to provide more background data given that a written survey approach was not offered to gather this type of data.

Conversely, it was found that the structure of the interviews was somewhat repetitious; re-structuring them created less repetition and a more natural, conversational flow. Interviews of patients and family care providers were also restructured so that the participants would focus on the care and satisfaction of one health care worker at a time, as opposed to discussing first the care tasks of each health care worker and then the satisfaction with each health care worker.

Finally, interviews were re-structured to streamline the process. For example, the original interview schedule incorporated a number of demographic questions such as “Where did you receive your medical training from?” and “Have you taken additional training in palliative care?”. Questions such as those were moved to the Health Care Provider Survey to allow for greater efficiency.

3.4.4.2 Observation Guide

A structured observation guide, based on the Stewart et al. framework (see Appendix 9) was developed to assess and document various elements of organizations that provide palliative care. During an observation, the researcher was typically accompanied by an organization employee who provided information relating to staffing, patient volume, or other areas of inquiry. The observation guide looked specifically at environmental characteristics (e.g. noise level, privacy, and the ability to have visitors) and availability of health care providers (e.g. number of medical doctors and nurses on staff). The length of the observations varied; the shortest observation period would have been approximately 30 minutes and the longest one hour.

3.4.4.3 Health Care Provider Survey

In 2002, Barnabe and Kirk developed a palliative care education needs assessment for use in Manitoba (Canada) (7). The purpose of their survey was to identify educational needs of practicing physicians in the field of palliative care. The survey covered a range of areas--pain and symptom control, bereavement and psychosocial aspects of death, and professional issues—and the topics covered universal elements of palliative care. Furthermore, Barnabe and Kirk's analysis doctors identified areas where they felt less competent (e.g. bereavement and psychosocial aspects of dying) which was useful data for educational program evaluation and planning. For those reasons, this same survey was used to evaluate the educational needs of doctors working in South Africa. Before use, it was vetted by a South African health care informant, (LG), who is a palliative care physician, to ensure relevance within a South African context (Appendix 11). The review of the survey resulted in no changes to the Health Care Provider Survey. The survey consists of 36-items and examined 11 categories: pain, symptom control, bereavement, psychosocial aspects of death, professional issues, ethics, establishing a palliative care program in the community, principles of palliative care, communication with the patient and family, interdisciplinary communication, and personal ability to cope with a dying patient. Respondents ranked the importance of each item from one (not important) to three (very important).

3.4.5 Procedures

The data for Part 1 was collected through interviews, structured observations and Health Care Provider Surveys. The procedures followed for each will be reviewed.

3.4.5.1 Interviews

During the study, 40 interviews were conducted by phone and 76 were conducted face-to-face. Face-to-face interviews were conducted with patients (n=22), family care providers (n=15), nursing sisters (n=18), other health care workers (n= 15), and medical doctors (n=8), all of whom resided in the Western Cape Province. All of the interviews were recorded digitally. Phone interviews were conducted with 40 medical doctors employed in the remaining eight South African provinces. The same interview guide (Appendix 8) was used for both the phone and face-to-face interviews.

Consent for the phone interviews was attained prior to the interview. For the phone interviews, the researcher would first fax or email project documents (including a study overview and a consent form). Then, the interview would be scheduled after the form was returned. In the few instances where the consent form was not received before the interview was scheduled, consent was obtained verbally at the start of the interview by reading a brief script to the participant (see Appendix 13). Before the start of each phone interview, a brief explanation of the study was also provided.

Before the start of the face-to-face interviews, the researcher would briefly explain the study, respond to any questions, and then review the consent form with each participant (Appendix 12). When interviews of patients or family care providers were conducted with the assistance of a translator, she would explain the consent form (translated into Xhosa- see Appendix 14) with each participant.

Several Xhosa-speaking participants expressed, either verbally or non-verbally, some discomfort with the study prior to the interview. Most commonly, they were somewhat reluctant to sign the consent form; this had not been an issue in the other patient or family care provider interviews. It was suggested by the translator that this had to do with either historical issues of trust (e.g. a black person would have difficulty trusting a white person) or low education levels. In cases where participants appeared particularly bothered by signing the consent form but still wanted to participate, we suggested to them that they could sign the consent form *after* the interview was completed. All participants willingly signed the form using this method.

Some Xhosa speaking respondents also seemed concerned with the use of the recorder, often stressing that they did not want to be on television. A simple review of the digital recorder would allay the fears of the participants as it was a voice recorder with no video capabilities. The fact that the interviewer was a female Caucasian (and a foreigner) also appeared to cause some discomfort for a small portion of the participants. Although the analysis of the transcripts did not suggest that the responses were different in these few cases, it did take some of the participants longer than others to warm to the interviewer. One example of this: a younger black man was participating in the interview and was fairly reserved throughout. During several points in the interview, the translator would appear to coax him to expand on his answers. However, at the end, when the opportunity came for the participant to ask questions, all of them were directed to the researcher: Why was she here? Where was she from? etc. And when he was satisfied with the responses, he broke into a huge smile and visibly relaxed. The fact that all of those items had been reviewed earlier in the consent form seemed immaterial; he had not grasped much from the consent form. It suggested two things: that the consent form was too detailed for participants, and secondly, that a certain level of anxiety will exist when different races communicate in South Africa.

At the conclusion of the all interviews, participants were thanked for their time. Participants were also asked if they would like a summary of the findings mailed or emailed to them once the study was completed.

The length of the interview was measured by the digital recording, which would begin with the first question and end with the last. This length did not accurately measure the amount of time spent with participants; an approximate 10-40 minutes would be spent with each person prior to and following each interview. During this time, the interviewer was able to build trust, develop rapport, and respond to any questions or comments. As written in the field notes of February 12 (2007), "an important part of the introduction was me telling about my family—in fact, it was requested. Are you married? Do you have children? The sisters were quite happy that they were able to meet Harrison and Steve [son and husband] later on in the morning." Becoming comfortable in the interview setting was a critical element of the process.

This data, although not recorded and transcribed verbatim, was pertinent to the study and was captured in the field notes.

There were two instances where the recorder malfunctioned due to factors such as low battery or lack of space which resulted in a cut off interview or no recording. One of those interviews was with a husband (patient) and wife (family care giver) and lasted about 90 minutes. It was unfortunate as the quality of the interview could not be fully captured in the field notes. In another instance, the recording stopped midway through the interview. Detailed field notes on the remaining three questions were emailed to the participant who then reviewed and returned them to the researcher. In this way, an accurate representation of the interview was attained.

3.4.5.2 Health Care Provider Surveys

A number of health care workers (n=75) also completed the *Health Care Provider Survey* (HCPS). When health care workers agreed to be interviewed for the study, they were also asked if they would complete the HCPS. Of the 81 interviewed participants, 75 completed the survey. The reason that some health care workers did not complete the survey was related to time; for example, several of the doctors commented that they would do either the interview or the survey but they did not have the time to do both.

Participants were given the one page survey to be completed at their convenience. Participants were asked to return the completed survey within one week of the interview. The researcher was not present while the surveys were completed but was available if there were any questions. Completed surveys were handed directly to the researcher, emailed in, faxed to UCT's office, or mailed to the researcher. Email reminders were sent to participants if the survey was not sent in after one week.

3.4.5.3 Structured Observations

A total of 18 structured observations were completed throughout the study. Fifteen observations were conducted at participating hospices (two structured observations were conducted at the same hospice on different dates), two at state hospitals, and one observation was conducted at a participant's home.

When the observation was conducted at an organization, most typically an administrator would give the researcher a tour. During the tour around the organization, the researcher would ask questions pertaining to the availability of health care staff and number of patients treated. After the tour was completed, the researcher would complete the observation form and attach additional comments. The observation conducted at a private residence was completed after the visit to provide context for home care patients. The researcher completed the form without the assistance of any other individual.

3.4.6 Analysis of Part 1 Data

The intent of interpretive description is to seek patterns and themes within the subjective human experience, both to understand what future behaviour is likely in health care practice and to develop some meaningful sensitivity around this behaviour

(2). Interpretive description includes some elements of concurrent data collection and analysis; constant comparative technique is used so that there is ongoing engagement with the data, allowing the researcher to confirm, test, explore, and expand on the conceptualizations that begin to form in the field (2). The respective methods used to analyze the data in Part 1 will be described.

Qualitative Data: All interviews were audio-taped, transcribed verbatim, and analyzed using the NVivo 7 software program. Transcriptions of English interviews were completed within two weeks of the interview to retain accuracy. Two Xhosa speaking translators assisted with the transcription of Xhosa interviews.

Xhosa translation was a three step process. To start, one Xhosa translator would translate the interview into English. The second translator would then review and edit the transcript. If there was a discrepancy, the translators would work together to find the accurate meaning. Following the advice by Twinn (5), it was more important to produce a meaning-based translation rather than a word-for-word product.

In Interpretative Description, analysis is process whereby the researcher works to understand the overall picture. There is no particular method that is championed by interpretive description; the most effective and useful tool needs to be determined for each study. In this study, content analysis was used to extract themes and sub-themes. However, the findings were extended into interpretation by linking the results of Part 1 and Part 2 in broader ways. Questions like, "what might this mean?" formed the interpretation that extended beyond a descriptive documentation (2). Therefore, as the analysis aimed to understand a comprehensive picture of the palliative care experience as reflected by informants and observations, thematic content analysis using phrase coding was used to generate themes and sub-themes. Then, questions such as "what is happening here?" or "what am I learning about this?" were used to extend and interpret the themes. In the discussion, the results of the study were articulated in relation to existing literature. Finally, a response to the findings and literature were presented as recommendations.

Quantitative Data: The survey data was analyzed using SPSS 11.0. To eliminate outliers, frequencies were run on the data. Cases with outliers necessitated reviewing the original questionnaire. In all cases, outliers were due to data entry error and were then corrected. Statistics, including means and frequencies of item responses, were calculated.

For analysis of the Health Care Provider Survey where the goal was to assess if significant differences existed between various groupings, Mann-Whitney tests were conducted. A nonparametric test was chosen for two reasons: 1) the data from the Health Care Provider Survey came from a small sample size and 2) the scores were not normally distributed (8). The primary disadvantage of using nonparametric tests is that the likelihood of finding a true difference when it exists is lower (8). A level of significance of $p<0.05$ was chosen for this study which means we were willing to accept a 5% probability of making a Type I error.

3.4.7 Rigour

A systematic approach to data collection, interpretation and communication was used to ensure scientific rigour. More specifically, the approach explained by Mays and Pope (9,10) was followed closely from design to analysis.

Triangulation, or comparing results from two or more different methods of data collection (9,10), was used throughout the study. Interview, observational, and survey data were all used to inform and describe palliative and end-of-life care in South Africa.

A clear exposition of methods of data collection and analysis was provided (9,10). As Mays and Pope posit "a clear account of the process of data collection and analysis is important"(9). Therefore, the procedures for the study were carefully designed to be transparent. In addition, during the period of field work, the dissertation committee assisted with clarifying the analysis process which also allowed for a stronger design.

Reflexivity, the act of self-reference within a research study, was applied throughout the study (9,10) . In an attempt to sustain objectivity as a researcher, the reflective process of preparing field notes were incorporated into the design. For example, the personal biases of the researcher and the effect of personal characteristics (e.g. race, sex, social class and professional status (9)) were reflected on to determine their effect on the study procedures and results.

Mays and Pope suggest that the research design should incorporate a range of perspectives to ensure an accurate and fair representation of a situation (9). As the study design indicated, the viewpoints of a wide range of participants were the basis of this research study; patients, family care providers, social workers, home-based carers, spiritual care providers, nurses and medical doctors had opportunity to participate in the study.

Several other steps were taken to ensure valid results. For example, Nvivo 7 was used throughout the project as computer-assisted coding and analysis as this is seen by some to enhance credibility (10). Additionally, a co-researcher- Dr. Genevieve Thompson- based in Winnipeg, Manitoba, assisted with the analysis by reviewing the data and addressing inconsistencies found in the early analyses. In this way, the co-researcher would examine the influence of bias upon the research findings as much as possible (1) and could address her concerns with the researcher as the study progressed. The interview recordings were reviewed and compared to the typed transcripts to check for accuracy. The translated interviews (see discussion on process in section 3.3.3.1) were independently verified by a qualified Xhosa speaking individual to ensure accuracy. Finally, the length of time in the field (11 months) allowed for prolonged engagement where the researcher was able to learn about the culture and social setting. It also provided the opportunity to develop rapport and trust with participants. It was felt that the systematic approach used in the study yielded credible results.

3.5 Methodology for Part 2: Evaluation of UCT's Palliative Care Distance Education Program

3.5.1 Introduction

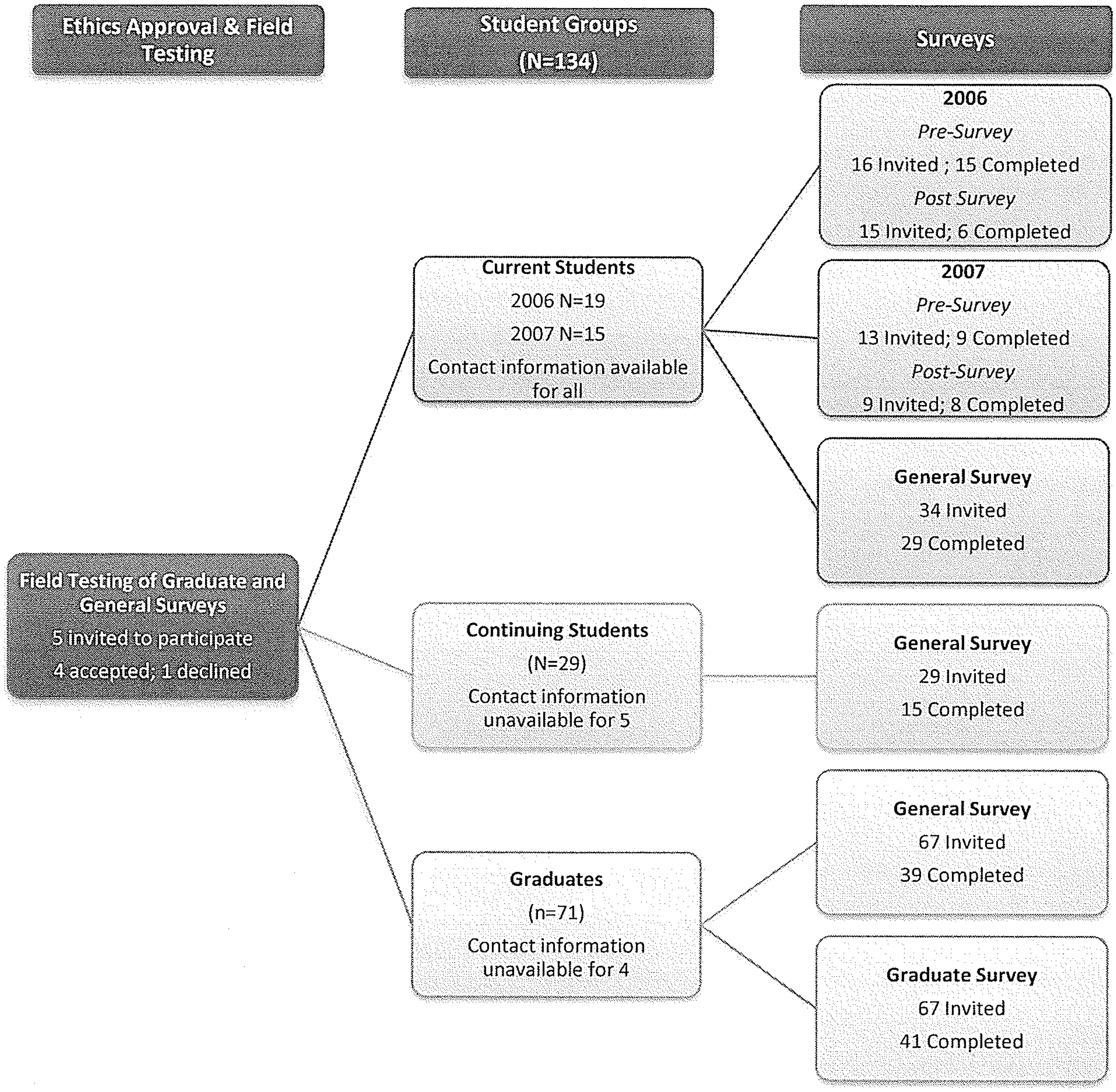
The primary aim of Part 2 was to assess the palliative care distance education program offered through the University of Cape Town (UCT). To achieve a full and data-rich overview, three surveys (General Survey, Graduate Survey, and Pre-Post Workshop Survey) were developed and administered over the course of the 2007 calendar year. Each survey was designed to examine a unique aspect or experience within the course. Current students as well as graduates were invited participate in the study.

3.5.2 Sample

All past and present course registrants (n=134) of UCT's distance education palliative care program were considered eligible for this part of the research study. Contact information was accessed through the administrative records at the School of Public Health and Family Medicine at UCT. Current records were not available for nine students, thus the eligible pool of participants was narrowed to 125. Demographic details on the participants can be found in Chapter Five.

Students were classified into three groups for ease of recruitment: 1) first and second year students, 2) continuing students, and 3) graduates. Recruitment, as seen in Figure 3.3, varied according to the classification of the student.

Figure 3.4 Recruitment Protocol for Part 2



A students' classification determined which survey(s) they were eligible to complete.

Surveys were mailed or hand-delivered to students between February and June of 2007.

First and Second Year Students. The first and second year students were eligible to complete both the Pre-Post Workshop Survey and the General Survey. This cohort of students attended two-day workshops, a program requirement, at the University of Cape Town campus. The 2007 workshops were held at University of Cape Town in late February and early March for the first and second year students respectively.

Having the students on campus provided the researcher the opportunity to have direct contact with the students. Thus, when students were attending workshops, the researcher was able to explain the project and hand out the surveys directly to students. At the start of the workshops, the research project was introduced and the students (n=25) were given both the Pre-Workshop Survey and General Survey. Students who were not in attendance were mailed the General Survey (n=5, March 22, 2007). The Post-Workshop Surveys were mailed on June 12, 2007, to the 25 participants who had completed the Pre-workshop Survey at the course workshop.

Continuing Students. Students who were registered in the program but had not yet graduated were considered to be "continuing students". These students were eligible to complete the General Survey only.

Graduates. Students who had successfully completed the distance education palliative care course were eligible to complete both the General Survey and the Graduate Survey.

3.5.3 Protocol

Approval for the study was granted by the Research Ethics Boards at University of Cape Town, University of Manitoba and Hospice and Palliative Care Association of South Africa (HPCA).

The surveys were developed in Canada and as such it was imperative that they were field tested in a South African context prior to use. Field testing began in late January, 2007. To ensure rapid feedback, the field advisor (LG) identified five doctors living in the Western Cape. The doctors, all of whom attended the palliative care course, were asked to review both the General Survey and Graduate Survey and comment on their cultural appropriateness. Four people responded.

A focus group was then held to review the comments and finalize the survey. The group consisted of three individuals: two palliative care physicians (LG and AB) and the researcher. The Graduate Survey was seen to be very relevant and culturally appropriate. However, due to lengthy statements, four changes were made to the Graduate Survey; where certain questions were perceived to contain too many elements to accurately respond to, the questions were split. There was more discussion around the General Survey. The original General Survey had a statement regarding "knowing when to recommend a shift to a comfort care approach" which was not seen to be relevant within South Africa. It was deleted. There was also discussion about the questions regarding pain specialists in South Africa, mechanical ventilation, IV hydration, and non-oral feedings. It was felt that the results of those questions might be interesting given the reluctance on the part of practitioners to use those medical options. Although it was felt that the content of those four questions was not entirely relevant within a South Africa context, the questions remained in the survey.

Students were introduced to the project either in person or by written communication. In both the verbal presentation and the written documents, the research study was explained in detail. Participants were given the opportunity to contact the researcher if they had questions. Prior to filling out the surveys, participants were required to sign a consent form acknowledging their willingness to participate in the study.

On February 21, 2007 the Graduate and General Surveys were mailed out to the continuing students and graduates of the distance education course; 30 packages containing only General Surveys and 66 with both the Graduate and General Surveys were mailed. Due to an error in compiling the address list, an additional six graduates were sent surveys on April 26th.

To increase the response rates, a second mailing- containing a letter of introduction, consent forms and survey(s)- was posted to those continuing students and graduates who had not responded to the first mailing. On May 1st, 22 people were sent a package containing the General Survey and 58 were sent a package consisting of both the General and Graduate Surveys. The second reminder came in the form of a telephone call; between June 18th and 20th, 2007, the research assistant telephoned continuing students and graduates to explain the project and invite participation. Of the

24 calls where direct communication with the intended recipient was achieved, 14 people requested to have the project documents sent out via email, seven stated that they were in the midst of completing the surveys, two provided a new mailing address, and one stated that he/she was too busy to complete the survey. An additional 27 calls were placed, but circumstances were such that direct communication did not occur.

The third and final reminder was sent via email; 48 people were emailed a project explanation, a consent form, and the appropriate survey(s). In addition, as some of the email addresses on file at UCT were found to be incorrect or discontinued, 19 individuals were mailed a final reminder letter.

3.5.4 Instruments

Data was collected using three instruments- General Survey, Graduate Survey and Pre-Post Workshop Survey- designed to evaluate specific aspects of the program (described below). Techniques proven to increase response rates (e.g. using short and simply worded titles, limiting length to four pages(11)) guided survey development.

General Survey. The General Survey (Appendix 15) consisted of 31 questions and was developed from the course objectives (Appendix 5). It was designed to evaluate student competence in the following five areas: palliative care activities, pain, assessment, changes in treatment, and general palliative care concepts.

Graduate Survey. The Graduate Survey was designed to assess graduates' experiences with and perspectives of the distance education palliative care course. It included 25 multiple-choice questions and eight open-ended questions in order to solicit information about perceived changes in care practice, benefits, limitations, and suggestions for change (Appendix 16).

Pre-Post Workshop Survey. In both the first and second years of the program, students are required to attend a 3-day workshop held at UCT. A 52-question Pre-Post Workshop Survey (Appendix 17) was developed to evaluate if the workshop objectives were adequately addresses and to determine if participants perceived that they had changed elements of their medical practice as a result of the workshop. The survey was based on the intended workshop objectives (Appendix 6) and all workshop attendees were considered eligible participants.

3.5.5 Procedures

The data for Part 2 was collected through three surveys (General Survey, Graduate Survey and Pre-Post Workshop Survey). Eligible people were either mailed the survey(s) or handed the survey(s) at a workshop. The researcher was not present while the surveys were completed but contact information was provided so that she could be contacted if questions arose. Completed surveys were handed directly to the researcher, emailed in, faxed to UCT's office, or mailed to the researcher.

Of the 125 current or past students eligible to participate in the study, 83 (66.4%) completed the General Survey. Of the 67 eligible graduates, 41 (65.7%) returned the Graduate Survey. Of the 20 students that began the course in 2006, there were 16 workshop participants. Fifteen of these students completed the Pre-workshop Survey and six completed the Post-workshop Survey. Of the 15 students who began the course in 2007, there were 13 workshop participants. Nine of these students completed the Pre-workshop Survey and the Post-workshop Survey was completed by eight of these students. Therefore, there were six matched surveys for 2006 students and eight matched surveys for students who began the course in 2007.

3.5.6 Analysis

The qualitative data found in the Graduate Survey and the quantitative data were analyzed separately. Each method will be described.

Quantitative Data: The survey data was analyzed using SPSS 11.0. To eliminate outliers, frequencies were run on the data. Cases with outliers necessitated reviewing the original questionnaire. In all cases, outliers were due to data entry error and were then corrected. Statistics, including means and frequencies of item responses, were calculated.

For analysis of the General Survey and Graduate Surveys where the goal was to assess if significant differences existed between various groupings, Mann-Whitney U and Kruskal-Wallis tests were conducted. Nonparametric tests was chosen for three reasons: 1) the data from both the General Survey and Graduate Survey came from a small sample size, 2) the scores were not normally distributed (8), and 3) the survey data was based on an ordinal scale. The primary disadvantage of using nonparametric tests is that the likelihood of finding a true difference when it exists is lower (8). A level of significance of $p<0.05$ was chosen for this study which means we were willing to accept a 5% probability of making a Type I error.

In the General Survey, a series of Kruskal-Wallis 1-way analysis of variance tests were used to evaluate the relationship between program level and survey scores. Significant findings were followed by Mann-Whitney U tests for pairwise comparison. In the analysis of the Graduate Survey, Mann-Whitney U tests were used to compare various groupings pertaining to number of years practicing medicine, number of patients, and year started in program.

Qualitative Data: Qualitative data obtained from the Graduate Surveys was analyzed using thematic content analysis. Student responses were typed into a main document to ensure all the responses to each question were grouped together. Following that, the responses were read over systematically in search of common elements. This method of thematic content analysis, as described by Shank (12), involved an ongoing search for patterns within the data towards the formation of themes. All responses to all questions were considered when determining themes and sub-themes. Phrase coding, as opposed to word counts, were utilized. A second rater (GT) examined both the data and the emergent themes developed by the researcher (CE) to determine appropriateness. Consensus was reached through discussion and continued review of the material.

The results of Part 1 and Part 2 were synthesized in the discussion chapter. Guided by the interpretive description approach— to systematically analyze and transpose the analysis into the health care context—the findings of each part were evaluated as a whole. The larger implications and meaning of the cumulative data produced a thorough description of palliative and hospice care in South Africa. This also provided a rich context within which to understand the challenges and opportunities pertaining to the field of palliative care education.

3.6 Ethical considerations

This study was carefully designed and adheres to the Declaration of Helsinki 2000 (13,14). The project did not involve deception and measures were taken to preserve anonymity and confidentiality. While the researcher had access to identifying information when gathering data by survey or interview, this information was not used in the dissemination of the project results.

All participants had the project explained to them prior to signing the consent form and were provided with a copy of the participant information sheet that outlined the purpose of the study and the expected role of the participant. The consent form was treated as only one level of consent and if a participant had asked to withdraw from the project at any time- his or her right- it was made clear to the participant that there were no negative consequences associated with that decision. Family members and patients were considered "vulnerable populations" so additional measures to ensure safe ethical practices were put in place: if at any time a participant indicated distress, the interview process was to be halted and offered access to social work services. At no point did any patient, family member or other project participate indicate distress; some patients did appear uncomfortable with certain aspects of the interview (e.g. signing a consent form) as discussed earlier, but these situations were dealt with satisfactorily.

All participants who signed a consent form completed the entire research protocol.

3.7 Chapter 3 References

(1) Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. Res.Nurs.Health 1997 Apr;20(2):169-177.

(2) Thorne SE. Interpretive description. Walnut Creek, CA: Left Coast Press; 2008.

(3) Sandelowski M, Barroso J. Writing the proposal for a qualitative research methodology project. Qual.Health Res. 2003 Jul;13(6):781-820.

(4) Thorne S, Con A, McGuinness L, McPherson G, Harris SR. Health care communication issues in multiple sclerosis: an interpretive description. Qual.Health Res. 2004 Jan;14(1):5-22.

(5) Twinn S. An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. J.Adv.Nurs. 1997 Aug;26(2):418-423.

(6) Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. J.Pain Symptom Manage. 1999 Feb;17(2):93-108.

(7) Barnabe C, Kirk P. A needs assessment for southern Manitoba physicians for palliative care education. J.Palliat.Care 2002 Fall;18(3):175-184.

(8) Norušis MJ, SPSS Inc. SPSS 10.0 guide to data analysis. Upper Saddle River, N.J.: Prentice Hall; 2000.

(9) Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. BMJ 2000 Jan 1;320(7226):50-52.

(10) Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ 2000 Jan 8;320(7227):114-116.

(11) Lund E, Gram IT. Response rate according to title and length of questionnaire. Scand.J.Soc.Med. 1998 Jun;26(2):154-160.

(12) Shank GD. Qualitative research : a personal skills approach. Upper Saddle River, N.J.; Columbus, Ohio: Prentice Hall; Merrill/Prentice Hall; 2002.

(13) World Medical Association General Assembly. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. J.Int.Bioethique 2004 Mar;15(1):124-129.

(14) Mamdani B. The Helsinki Declaration, 2000, and ethics of human research in developing countries. Indian.J.Med.Ethics 2004 Jul-Sep;1(3):94-95.

CHAPTER FOUR: Results of PART 1: Palliative and End-of-life Care in South Africa

4.1 Introduction

Two research questions formed the basis of Part 1: "*How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?*" and "*How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?*". The analysis of structured observations, the Health Care Provider Surveys, and interviews with patients, family care providers and health care providers, produced a comprehensive description of palliative and end-of-life care in South Africa. That analysis will be reported on here.

4.2 Participants

There were 116 participants--including patients (n=22), family care providers (n=13), nursing sisters (n=18), other health care providers (n=15), and doctors (n=48) --interviewed for this portion of the research study. A short description of the recruitment strategies and response rates follows.

Non-Doctor Populations. This group consisted of patients, family care providers, nursing sisters, social workers, and other allied health care providers. Doctor recruitment, particularly those participating by phone, followed different protocols and will be discussed separately.

Patients were approached by nursing sisters to participate in the study. Of the 23 people approached, 22 agreed to be in the study. The one individual who did not want to participate was not willing to discuss his illness in the context of a research study.

Family care providers were primarily approached by nursing sisters to participate in the project. The one exception was when the researcher contacted a family care provider directly. All family care providers contacted agreed to be a part of the study. It appeared that the family care providers welcomed an opportunity to discuss their role in the care of their ill family members and saw the interview as a time to express emotional aspects of being the primary care providers.

All of the nursing sisters, social workers, professional carers, and spiritual care providers who were asked to participate in the study did so.

Medical Doctors. It was more difficult to calculate the refusal rate for the medical doctors who participated in the study as doctors were contacted using a variety of different methods. However, when doctors explained their reasons for not participating in the study, it was due to time constraints or a belief that they did not treat patients who had life threatening illnesses. The following is a brief overview of how doctors were contacted and the estimated participation rates.

Doctors in the Western Cape were the first group to be contacted. In particular, eight doctors were approached to participate in the face to face interviews. All agreed to participate and thus eight interviews were completed. In the remaining provinces of South Africa where phone interviews were to be conducted, there was a much lower participation rate. As described in **Section 3.3.2.3** (Medical Doctors outside the Western Cape), there were three phases of participant recruitment (see Table 4.1).

Table 4.1: Phone Interview Participants by Province and Source of Referral

	Phase One	Phase Two	Phase Three	
	Letter Writing Campaign	Distance Education Course Participants	Recommendations	Other Sources (letters, emails, phone calls, word of mouth)
North West	1	2	2	0
Limpopo	0	0	0	5
Mpumalanga	0	2	2	1
Northern Cape	0	1	1	3
KwaZulu Natal	0	4	0	1
Free State	0	3	0	2
Eastern Cape	1	3	0	1
Gauteng	1	3	1	0
Number of Participants	**3**	**18**	**6**	**13**

In Phase One, 186 letters were mailed to medical doctors and seven were returned. Of the seven letters returned, six agreed to participate. An interview was coordinated with three of those six individuals.

In Phase Two, students and graduates of the distance education program were contacted to determined interest. Thirty-three people were contacted either by phone (n=5) or email (n=28) and 18 agreed to participate. Of the 15 people who did not participate, only one person stated that they were not willing to be in the study; the remaining 14 people did not respond at all. As such, the Phase Two refusal rate was 45.5%.

The intent was to interview by phone five doctors in each of the eight remaining provinces. To reach the full complement of participants, the researcher phoned, sent letters and emailed medical doctors practicing throughout the country. In addition, at the end of some of the phone interviews, study participants were asked to recommend colleagues that might be interested in participating in the study. This only occurred in provinces where recruitment was particularly difficult.

Aside from the participant recommendations, the most effective recruitment method was talking to doctors directly; mailing or emailing project information garnered very few participants. If a doctor was contacted by phone, the researcher would describe the project briefly and determine the doctor's level of interest. However, it took approximately six to eight direct communications to recruit one doctor. Using mail or email to contact eligible doctors was even less successful. One out of every 30 emails or letters would result in the recruitment of a single doctor. Therefore, the most successful method of recruiting doctors was through recommendations where an interview participant would recommend colleagues for the study. Having the ability to say that a colleague had completed the study and recommended (name of medical doctor) for the study as well, the response rate was very high. In approximately four out of five times that a recommended doctor was contact, he or she would agree to a phone interview. A view of the participant profile per province provides a better indication of how participants were recruited.

Of the five participants in the North West Province, two were graduates of the distance education program. One participant (M) was a participant contacted during Phase One recruitment. At the end of the interview with M, the participant recommended two colleagues for the study. Both were contacted and agreed to participate.

In Limpopo, all of the participating doctors were recruited by phone. Although 15 doctors were mailed or faxed letters, it was from the groups that had been phoned (n=9) that the participants were recruited.

Of the five participants in Mpumalanga, two were graduates of the distance education program. One of these participants provided the names of two colleagues, both of whom participated in the study. The final participant was found through a series of cold calls placed to medical doctors in the province.

In the Northern Cape Province of South Africa, three of the participants agreed to participate when recruited by phone. One of the participants (W) suggested a colleague who also participated in the study. The fifth participant from the province was a student of the distance education program.

Four of the five doctors interviewed in the province of KwaZulu Natal were graduates of the distance education program. The fifth doctor was contacted by phone. Similarly, in Free State, three of the five doctors were graduates of UCT's distance education program and two were recruited via cold calls.

In the Eastern Cape Province, three of the participants were from UCT's distance education program. One of the doctors was recruited through Phase One, and the fifth of the group was recruited by word of mouth. A South African friend of the researcher had a son who was a medical doctor. When the purpose of the research project was explained, it was suggested that the researcher contact the son. An email was sent to determine eligibility and describe the project after which he agreed to participate.

In Gauteng, three of the participants were current or former students of the palliative care program. One of the participants (V) was recruited through Phase One. At the end of the interview with V, he recommended a colleague for the study. That individual also agreed to participate.

Therefore, the recruits for phone interviews were from four sources: 1) Phase One, the initial letter writing campaign, 2) Phase Two, whereby students or graduates of the distance education course were recruited, 3) Phase Three, the recommendations of the interview participants, and 4) Phase Three, other sources such as word of mouth (see Table 4.1).

4.2.1 Patients

Patients were approached to participate in the project by the nursing sister who directed their care. They were invited to participate and it was clear that there were no ramifications if they chose not to participate. Many patients saw the interview as an opportunity to socialize but a few were more reticent of the process. It appeared that having a white foreigner interview them was either a novelty or a slight concern. By the conclusion of all the interviews, however, all patients appeared very comfortable with the process.

There were 22 patients interviewed in the study. Their ages ranged from 26 to 79 years with an average age of 51.3 years (SD=16.2). Forty-five percent of patients had

HIV/AIDS (with or without TB) and forty-one percent had some form of cancer (see Table 4.2). All of the patients were receiving hospice care and, depending on the hospice services, were receiving home-based care, inpatient care, or were attending the hospice daycare; 7 of the patients were interviewed in their homes, 13 in inpatient wards, and two at the daycare. Although the interview did not ask about patients' stage of disease, it was apparent that some were more ill than others; some were bed-bound whereas others were ambulatory.

The recorded portion of the interview was an average length of 10 minutes 30 seconds (SD 5.4). As discussed in Section 3.3.5.1, the length of the recorded portion did not accurately measure the amount of time spent with participants; an approximate 10-40 minutes would be spent with each person prior to and following each interview. During this time, the interviewer was able to build trust, develop rapport, and respond to any questions or comments. This data, although not recorded and transcribed verbatim, was pertinent to the study and was captured in the field notes.

There was some consideration given to the removal of the shorter interviews. In the shortest patient interview, for example, the participant had difficulty staying awake throughout and thus the responses were extremely short. However, it was felt that several of the participant responses indicated engagement with the research topic and thus the data was important to include. It was felt that each of the interviews, long or short, added a different perspective and thus deserved a place in the analysis.

4.2.2 Family Care Providers

There were 13 family care providers interviewed for the study, ranging in age from 26 to 70, with an average age of 53.9 years. Family care providers were asked to describe the person they cared for; ten were caring for cancer patients, two for people with HIV/AIDS, and one for an individual with Multiple Sclerosis. The kinship ties between the family care providers and patients were varied. Family care providers were caring for mothers (n=3), father-in-laws (n=1), husbands (n=3), wives (n=2), daughters (n=1), and uncles (n=1). One of the family care provider interviews took place at a school and the others were conducted at the home of the family care provider or patient. Three of the family care providers were employed outside the home setting. The other respondents were either retired or considered caring for the patients a full-time job.

The average length of the interviews was 9 minutes and 50 seconds (SD=5.31). If the shortest interview had been eliminated from the data, the average length of the interviews would have been over 11 minutes. However, as in the patient interviews, it was felt that each interview (including the broader experience and process) added something to the analysis.

There were seven instances where both the patient and his or her family care provider were interviewed; of the 22 patients interviewed, the family care givers of seven also participated. Therefore, six of the family care providers and 15 of the patients interviewed participated independently.

4.2.3 Nursing Sisters

There were 18 nursing sisters interviewed for the project; all of the nursing sisters approached to participate in the study willingly participated. The participants were all employed at hospices; four were working in inpatient units and 14 were employed as home-based care nurses. The dominant ethnic backgrounds of the nursing sisters were white (38.9%) or coloured (38.9%). Half of the participants spoke Afrikaans as their first language, 22.2% (n=4) spoke English as their first language and 11.1% (n=2) spoke Xhosa. All of the nursing sisters interviewed in the study were female. The average length of the interviews was 23 minutes and 15 seconds (SD= 12.4).

Home-based nursing sisters seemed to enjoy having the researcher accompany them on home visits; it appeared to provide them with the opportunity to socialize as well as highlight the work they were involved with.

4.2.4 Other Health Care Providers

There were 15 participants that represented "other" health care professions including social work (n=9), home-based care (n=5) and spiritual care (n=1). These participants ranged in age from 32 to 63 years (m=44.9, SD= 11.0). Eleven of these health care providers worked at hospices and four worked in public hospitals. The spiritual care provider was male and the other participants in this category were female (93.3%). Slightly over half (n=8 or 53.3%) of the participants were "white" compared to those who were "black" (n=3 or 20%) or "coloured" (n=4 or 26.7%). The first language of twothirds of the participants was Afrikaans. The average length of interviews was 20:44 (SD=11.6).

Table 4.2: Descriptive Statistics of Non-Doctor Participants

	Patients (n=22)		Family Care Providers (n= 13)		Nursing Sisters (n=18)		Other Health Care Providers (n=15)	
Characteristic	**Number**	***Percent***	**Number**	***Percent***	**Number**	***Percent***	**Number**	***Percent***
Sex								
Male	12	*54.5*	*2*	*15.4*	0	*0*	1	7.7
Female	10	*45.5*	*11*	*84.6*	18	*100*	14	93.3
Ethnic Background								
Black	11	*50.0*	*2*	*15.4*	3	*16.7*	3	20.0
White	6	*27.0*	*6*	*46.1*	7	*38.9*	8	53.3
Coloured	4	*18.0*	*4*	*30.8*	7	*38.9*	4	26.7
Indian	--	--	*1*	*7.7*	--	--	--	--
Not specified	1	*5.0*	--	--	1	*5.5*	--	--
Primary Language								
Xhosa	11	*50.0*	*2*	*15.4*	2	*11.1*	3	20.0
English	3	*13.6*	*4*	*30.8*	4	*22.2*	1	7.7
Afrikaans	5	*22.7*	*5*	*38.5*	9	*50.0*	10	66.7
Bilingual	1	*0.5*	--	--	1	*5.5*	--	--
Not specified	1	*0.5*	*2*	*15.4*	1	*5.5*	1	7.7
Other	0	*0*	--	--	1	*5.5*	--	--

4.2.5 Doctors

Forty-eight interviews were conducted with medical doctors. Of these, 40 were telephonic interviews and eight were conducted face-to-face. Doctors' ages ranged from 30 to 69 years and the average age was 47.9 years (SD=9.9). Thirty-one (64.6%) of the doctors were male and seventeen (35.4%) were female. The ethnic backgrounds varied provincially; overall there were 33 “white” doctors (68.8%), 11 “black” doctors (22.9%) and four Indian doctors (8.3%). There was a wide range of languages spoken amongst the participants including Xhosa, Sutu, Tswana, Venda, English and Afrikaans. The two languages most frequently described as the participants' primary languages were English (37.5%) and Afrikaans (35.4%). The average length of the interviews was 21 minutes and 35 seconds (SD=7.6). (See Table 4.3).

Table 4.3: Descriptive Statistics of Doctors (n=48)

	Western Cape (n=8)		*Northern Cape (n=5)*		*North West (n=5)*		*Gauteng (n=5)*		*Eastern Cape (n=5)*		*Limpopo (n=5)*		*Mpumalanga (n=5)*		*Free State (n=5)*		*KwaZulu Natal (n=5)*		*TOTAL (N=48)*	
	#	*%*	*#*	*%*	*#*	*%*	*#*	*%*	*#*	*%*	*#*	*%*	*#*	*%*	*#*	*%*	*#*	*%*	*#*	*%*
Sex																				
Male	4	*50*	4	*80*	4	*80*	2	*40*	2	*40*	5	*100*	3	*60*	3	*60*	4	*80*	31	*64.6*
Female	4	*50*	1	*20*	1	*20*	3	*60*	3	*60*	0	*0*	2	*40*	2	*40*	1	*20*	17	*35.4*
Ethnic Background																				
white	7	*87.5*	2	*40*	1	*20*	5	*100*	3	*60*	2	*40*	5	*100*	5	*100*	3	*60*	33	*68.8*
black	1	*12.5*	1	*20*	4	*80*	-	--	2	*40*	3	*60*	-	--	-	--	-	--	11	*22.9*
Indian	-	--	2	*40*	-	--	-	--	-	--	-		-	--	-	--	2	*40*	4	*8.3*
Primary Language																				
English	3	*37.5*	1	*20*	2	*40*	4	*80*	2	*40*	-	--	1	*20*	1	*20*	4	*80*	18	*37.5*
Afrikaans	4	*50.0*	2	*40*	-	--	1	*20*	-	--	2	*40*	3	*60*	4	*80*	1	*20*	17	*35.4*
Xhosa	1	*12.5*	-	--	1	*20*	-	--	2	*40*	-	--	-	--	-	--	-	--	4	*8.3*
Sutu	-	--	-	--	1	*20*	-	--		--	1	*20*	-	--	-	--	-	--	2	*4.2*
Tswana	-	--	1	*20*	-	--	-	--	-	--	-	--	-	--	-	--	-	--	1	*2.1*
Venda	-	--	-	--	-	--	-	--	-	--	1	*20*	-	--	-	--	-	--	1	*2.1*
Other	-	--	-	--	-	--	-	--	-	--	1	*20*	-	--	-	--	-	--	1	*2.1*
Unspecified	-	--	1	*20*	1	*20*	-	--	1	*20*	-	--	1	*20*	-	--	-	--	4	*8.3*

The project design did not specify that the doctor sample should mirror the demographics of doctors working in South Africa. However, statistics from the Health Professionals Council of South Africa provide evidence that the populations were similar (see Table 4.4). For a more extensive break-down of doctors by province, Appendix 18 contains a demographic overview of doctors employed in South Africa. Therefore, given that the study sample and the general doctor population data are similar, the findings of the study may be generalizable beyond the sample.

Table 4.4: Statistics from the Health Professionals Council of South Africa, updated November, 2007

	Asian			Black (& African)			Colored			White (& European)			Other			Total		
	Male	*Female*	*Total*	*Male*	*Female*	*Total*	*Male*	*Female*	*Total*	*Male*	*Female*	*Total*	*Male*	*Female*	*Total*	*Male*	*Female*	*Total*
Western Cape	254	143	**397**	91	62	**153**	127	72	**199**	2735	1302	**4037**	1477	571	**2048**	4684	2150	**6834**
Limpopo	43	11	**54**	343	140	**484**	0	0	**0**	225	58	**283**	164	45	**209**	776	253	**1029**
Mpumalanga	59	12	**71**	227	73	**300**	0	2	**2**	367	105	**472**	161	35	**196**	814	227	**1041**
Free State	25	7	**32**	169	50	**219**	10	2	**12**	650	269	**919**	309	103	**412**	1162	432	**1594**
Gauteng	750	374	**1124**	1324	703	**2027**	36	31	**67**	3577	1837	**5414**	1987	866	**2853**	7674	3811	**11,485**
KZN	1275	604	**1879**	425	195	**620**	29	16	**45**	1112	373	**1485**	1026	298	**1324**	3867	1486	**5353**
Northwest	59	19	**78**	127	55	**182**	5	2	**7**	342	93	**435**	155	37	**292**	688	206	**894**
Northern Cape	24	6	**30**	34	9	**43**	9	1	**10**	159	55	**214**	78	27	**105**	304	98	**402**
Eastern Cape	154	37	**191**	267	132	**399**	28	9	**37**	609	188	**797**	444	105	**549**	1505	471	**1976**
Foreign	60	20	**80**	40	12	**52**	3	4	**7**	560	176	**736**	378	95	**470**	1039	307	**1346**
GRAND TOTAL	2703	1233	3936	3047	1431	4479	247	139	386	10336	4456	14792	6179	2182	8458	22513	9441	31954
	8.4%	3.8%	**12.3%**	9.5%	4.5%	**14.0%**	0.8%	0.4%	**1.2%**	32.3%	13.9%	**46.3%**	19.4%	6.8%	**26.5%**	70.5%	29.5%	
Current Study			**8.3%**			**22.9%**			**0**			**68.8**			**0**	64.6	35.4	

4.3 Qualitative Results

Interpretive description was used to understand how different people experienced and described hospice and palliative care. It is a method that first explores health care concepts at a broad descriptive level and then interprets these findings in a meaningful way. Of particular interest was the role of the doctor in the provision of this care. The data collected in Part 1 made available several different layers of data for analysis. Interviews were coded into broader categories to examine the larger themes present in the data. Although the interview questions allowed for some organization of the data, the themes that were generated, though informed by Stewart et al.'s framework, were not unduly fettered by it. As is specified in the Interpretive Descriptive methodology, the data is examined in an overarching manner; all responses to all questions are considered when determining themes and sub-themes. A second rater (GT) examined both the data and the emergent themes developed by the researcher (CE) to determine appropriateness. Consensus was reached through discussion and continued review of the material. After consensus on the themes and sub-themes was reached, a descriptive discussion of the emergent themes was written. This interpretive piece is the culmination of the Interpretative Descriptive methodology and as such draws from all the material in the study, thereby allowing for a rich description of palliative and end-of-life care in South Africa.

Overview of Themes, Sub-Themes and Categories. The data was organized into three major themes which consisted of eight sub-themes and twenty-two categories. As can be seen in Table 4.5, a category is a distinct element particular to the corresponding sub-theme; a number of the sub-themes contain categories that assist with classifying and describing particular health phenomena.

Table 4.5 Overview of Emergent Themes and Sub-themes Based on Qualitative Interview Data

A) Theme	*B) Sub-Theme*	C) Category
Two Solitudes: Participant versus Public Notions of Palliative Care	*Through the Health Care Providers' Lens*	
	Social Perspectives on Palliative Care	
Accessing Palliative Care	*Access Routes*	Lack of Standardized Access Routes
		Lack of Knowledge Regarding Access to Palliative Care
	Barriers to Getting Palliative Care	(Lack of) Resources: Getting there costs money
		Staff Access & Safety
		Stigma: Hospice Care and HIV/AIDS
		Hospice Coverage: Too Few… Too Small
		Doctors' Perceptions: Blissfully Ignorant
		Public Attitudes: Fearfully Ignorant
		Racial Issues: Colour Matters
The Changing Face of Palliative Care	*Patient Care*	Patient and Family Care Providers' Description of Hospice Care
		Role of Health Care Providers
		Role of Medical Doctors
		Satisfaction with Hospice Care
		Patients in the General Population
	Educational Needs of Medical Doctors	Current status of educational programs
		Suggested Changes to Undergraduate Medical Curriculum
	Models of Palliative and End-of-Life Care	Hospice Organizations
		Hospital based Palliative Care Ward
		State Hospital Care
		Care by Family or Community
	Funding and Resources	Palliative Care Resources for private or state care
		Hospice Organizations

The purpose of the following section is to summarize how the qualitative data portrays palliative and end-of-life care in South Africa. This includes how palliative care is: experienced as a patient; provided by health care workers or family care givers; perceived by society; and taught within medical schools. Three major themes will be discussed: A) Two Solitudes: Participant versus Public Notions of Palliative Care, B) Accessing Palliative Care, and C) The Changing Face of Palliative Care. Each consists of several sub-themes.

In Appendix 19 is found the *theme dictionary*. It contains a brief definition of each of the themes and sub-themes, as well as a range of exemplars from the various data sources. By referring to this theme dictionary, the reader can experience greater detail of the themes and sub-themes through a wider range of participant exemplars.

Theme 1: Two Solitudes: Participant versus Public Notions of Palliative Care

The cumulative interview data produced a divergent portrayal of how participants described palliative care, how they perceived others to understand palliative care, and how the current state of palliative care in South Africa was affected by these different understandings. While the participants who were doctors, nursing sisters or social workers described palliative care using a range of terms, such as patient-centred care, tender-loving care, or pain management, there were many similarities in the overall meaning. However, the participants perceived themselves to have a much different concept of palliative care in comparison to the rest of society. As the theme's title suggests, what emerged in the data were clear differences in perception: from internally held views on the importance of patient focused care to the opposing public perception suggesting that palliative care was a waste of time. Thus, the first theme of "Two Solitudes: Participant versus Public Notions of Palliative Care" explores this concept of how individuals perceived themselves to have different values (pertaining to palliative care) compared to the wider public. Two sub-themes emerged within this theme (Sub-theme 1A: *Through the Health Care Providers' Lens* and Sub-theme 1B: *Social Perspectives on Palliative Care*) to further elucidate these divert perspectives.

Sub-theme 1A: Through the Health Care Providers' Lens

Approximately half of the health care participants interviewed in this study had received training in the field of palliative care. For example, all the nursing sisters had received intensive training through HPCA, all home-based carers had received on-site training in the principles of palliative care, and a number of the doctors in the study were in or had graduated from UCT's distance education program. A sample reflecting such a high level of palliative care training is not typical of the general medical population; the results, therefore, need to be interpreted with this in mind. However, the advantage of using a sample with an overrepresentation of trained practitioners was that it provided the ability to compare this cohort with those health care providers lacking palliative care education.

The World Health Organization's definition of palliative care incorporates pain and symptom management, the spiritual and psychological aspects of care, family support, multi-disciplinary care and quality of life. If comparing participant descriptions of palliative care to the WHO's definition, the responses by participants with palliative care training were much more similar than those without training. For example, one respondent- a doctor with 20 years of medical experience who had completed the palliative care course- noted:

"It's a form of medicine that's driven by the requirements of the patient as opposed to assessing the way in which we manage the disease. But focusing much more on what the patient thinks is important and a lot less on what the doctor thinks is important. I mean I think it's important for the science of medicine to control diseases, but I mean we used to have patients in our hospitals dying of cancer who haven't been given morphine, you know. So we're seriously missing the point when deciding what the patient feels is important" (D1).

The quote highlights that the participant perceives patient centred care as being central within palliative care model, similar to the WHO definition. Nursing sisters, all of whom had been trained in palliative care, described elements such as the team approach, patient centred care, and holistic care. They described working together with the patient and family to create a useful and suitable management plan. Caring for patients was the primary focus of their comments. In the words of a nurse who had worked in hospice for over 12 years:

"I think the main thing is looking at the person as a whole and also its very much team work. So one person can't be everything to everybody so you have to look at the person as a whole, understand them and where they are in their disease, and their family, what kind of disease they've got. You need to understand their past and look into their future so it's very much holistic for me" (NS14).

Again, the holistic concept of care throughout the entire trajectory of illness was evident.

Although there was an overlap in how participants described palliative care, doctors without training in palliative care conveyed a less specific idea or description of palliative care as applied in medical practice. The majority of their responses did not explicitly address the holistic elements of palliative care (e.g. patient centred care or the merge between body, mind and spirit), but rather, focused on specific methods they used to increase patient comfort through pain and symptom management. However, descriptions of palliative care did allude to the importance of a patient-centred focus and a change in the type of care that would be provided to those with life threatening illnesses. For example, when one oncologist from the Eastern Cape province stated, *"we explain it to them in nice terms" (D40)* it becomes apparent that a discussion with patients regarding their care is a part of palliative care. Or, as one of the doctors from the NorthWest province said, *"Palliative care, and I can only speak for that, that's in the form of tender loving care—TLC" (D34),* indicates that the type of care changes focus, moving from curative to palliative.

It seemed reasonable that descriptions of palliative care would differ according to training yet one common element continually surfaced in the data. Health care practitioners viewed symptom control as a central tenet of palliative care and perceived the primary objective of palliative care as keeping patients free of complaints. This can be seen in both quotes below, one from a home-based care nursing sister and the other from an oncology social worker:

> *"I would say this is a time of caring. Caring for, uh, the patient and family. And especially for the patient who needs to be comforted. Especially with the pain and other symptoms that might upset them. Just to walk along with them. And care" (NS10).*

> *"...now we're at a stage where we can't remove it [cancer] anymore but we can care for them, make them free of symptoms, help them with pain, and make the quality of living excellent" (SW7).*

What also became apparent was that all health care worker participants placed value on palliative care in his or her medical practice. While their perceptions of palliative care varied somewhat according to training and background, they all saw it as an important and vital part of their medical practice. Health care providers' lens' thus provided a glimpse into how practitioners viewed palliative care; although responses could be differentiated by training, similarities were evident in how participants portrayed the fundamental value of palliative care in South Africa.

Sub-theme 1B: Social Perspectives on Palliative Care

The second sub-theme-- Social Perspective on Palliative Care—identified a different and essentially opposite stance towards the value of palliative care. Individual health care participant's views on palliative care were described differently than those of the collective public. When reflecting on societal perceptions of hospice and palliative care, the health care participants consistently identified that: a) the public did not have a great deal of knowledge or understanding about the purpose or objectives of palliative care; and 2) if there was a public awareness of palliative care, it was primarily negative. These observations were made by all sub-groups of the health care worker participants.

Respondents frequently stated that their colleagues- none of whom had palliative care training-- had no interest in palliative care and that it was not a priority in a treatment plan. This was also evident in the observational data. For example, observation notes from February 1, 2008 state that "it is difficult to get the message of palliative care to doctors—there exists a philosophical disparity where doctors focus on curative care". Overall, participants felt that palliative care was not yet considered important in the care of patients with life threatening illnesses. One doctor who had attended medical conferences over the course of her career reflected on the absence of palliative care content as part of the scientific program:

> *"And in fact I've been going to physicians' conferences for the last 10 years and we have virtually nothing on palliative care. So the general population of physicians, they don't see it as a priority" (D1).*

By not including palliative care in the conference agenda, the implication was that it lacked importance. Other participants identified how colleagues perceived themselves to have no time to provide palliative care; the health care system, burdened by few resources and many demands, left no other choice but to abandon palliative care.

Participants felt there were a number of reasons contributing to the fact that palliative care was not widely practiced (or even understood). One reason given was that there were only a small number of opportunities for formal training in the field, which limited the ability to learn. The majority of the medical doctors had received no undergraduate training in palliative care—only recently had this been introduced into some of the South African medical curricula—and opportunities for further training were few. Also, the public health care system, characterized by high demand and limited resources, viewed palliative care more as a strain on the system as opposed to a dynamic way to offer care to patients with life threatening illnesses.

The students or graduates in the palliative care program were particularly unified in the opinion that palliative care was not highly regarded amongst the general medical community. As a whole, they felt that palliative medicine was regarded by the wider medical community as *"uninteresting"*(D15), a *"waste of time"*(D18), *"right at the bottom of the rank"* (D42), or *"unknown"* (D27). Some also felt that the lack of government interest or acknowledgement ensured that palliative medicine would continue to receive low priority in both educational and health institutions.

According to participant responses, public perception of hospice and palliative care remained negatively skewed. It was felt that society still linked hospice with death and that there was little understanding of the other critical roles that hospice played throughout a patient's illness. The sample of nursing sisters was particularly frustrated with how the public in general and medical doctors specifically, perceived hospice and palliative care. They frequently gave examples of situations where they felt doctors were inadequately prepared to offer palliative care due to a lack of understanding. One nursing sister, who had been working at a hospice for less than a year, stated that:

" one GP actually admitted to me that he cannot cope with a patient that is dying. He doesn't know what to do. They were trained to cure not to have to tell family. " (NS12)

Their responses contained descriptions of frustration: as nurses trained in palliative care, they felt that they could assist and teach medical doctors to better serve their patients. They described situations where doctors would persist in ineffective and possibly detrimental treatment due to both a lack of knowledge in palliative care and an unwillingness to learn from subordinates. However, due to the hierarchical structure of health care in South Africa (1), nurses informing doctors or sharing information was rarely done or seen as acceptable, as is evident in the following quotation:

"they don't want to take nurses' views on board and take into consideration your experience because you've worked longer than they have. I mean there are doctors who've just finished training who've never done any HIV/AIDS um... have no HIV/AIDS experience and you could actually tell them a thing or two but they just won't, they just won't receive it." (NS4)

On the whole, participants agreed that a mind-shift would be necessary in order for the greater public to accept and understand the role of palliative medicine within the realm of providing care to patients with life threatening or life limiting conditions.

The fascinating element of this overall theme was that the individual participant's views were described as the polar opposites of those in the collective public. Broadly speaking, participants saw the collective body of health care workers in South Africa as placing little value on palliative care which was different than how each individual participant saw things. That the individual perceived him or herself to place importance on the role of palliative care within the health care model, yet they didn't perceive colleagues to have the same ideals was an interesting development. It was like each participant viewed him or herself in solitude and with a different viewpoint than the rest of society. Because this was both a convenience and purposive sample and respondents may have been attempting to respond to questions in socially acceptable way, it is not certain if these findings are entirely consistent with practitioners' true beliefs. Indeed, the number of descriptions of situations where palliative care was regarded dismissively leads one to believe that the majority of health care workers in

South Africa do not regard it as a valuable element of patient care. Yet the number of participants that spoke to its value and importance leads one to believe that palliative care is perceived by some as a critical aspect of care.

Theme 2: Accessing Palliative Care

As palliative care programs develop in South Africa and as their importance has been proven, it is critical to understand accessibility. How do people access palliative care? Is it accessible for everyone who needs it? What are typical methods of getting palliative care services? Within the overall theme of "Accessing Palliative Care", two sub-themes were developed from participant responses: 1) Sub-theme 2A (*Barriers to Getting Palliative Care*), and 2) Sub-theme 2B (*Access Routes*). Within each sub-theme, several categories were developed. In the sub-theme Barriers to Getting Palliative Care, seven categories will be discussed. In the sub-theme on Access Routes, two categories will be expanded on.

Sub-theme 2A. Barriers to Getting Palliative Care: I Can't Get In!

Accessing palliative care through hospice programs was almost uniformly described by participants as complicated. Participants would frequently list barriers to accessing palliative care. From the responses, seven categories were developed: 1) (Lack of) Resources: Getting There Costs Money, 2) Staff Access & Safety, 3) Stigma: Hospice Care and HIV/AIDS, 4) Hospice Coverage: Too Few... Two Small, 5) Doctors' Perceptions: Blissfully Ignorant, 6) Public Attitudes: Fearfully Ignorant, and 7) Racial

Issues: Colour Matters. Each category explains a different perspective of the sub-theme relating to barriers to hospice care.

1) ***(Lack of) Resources: Getting There Costs Money.*** There is a deep economic divide between the rich and poor in South Africa. If you have money, you can receive health care on par with any well developed nation. Medical aide- the private insurance that is typically only available for the affluent- can ensure excellent medical care. Without resources, however, you are at the mercy of the state health care system, a system that provides care to a large number of people. This is explained in the words of one respondent, a rural home-based care nursing sister:

> *"I think the great divide in South Africa is between the people with medical aide and those who don't. And people with medical aide are usually, or are better off than the middle class and the HIV rate is much lower. So the poor, the vast majority of the population, don't have medical aide and so, you know, your average private practitioner would only see them for minor inter-current illnesses. But they certain wouldn't be able to go to them regularly" (D18).*

There is a large proportion of the population with high prevalence rates of HIV/AIDS that have few health care options.

Hospice programs typically charge minimal fees- structured according to ability to pay- or no fees at all. Even with low to no costs, hospice services remain outside the realm of possibility for a number of patients needing care. Just getting to a hospice is a barrier to access; the cost of transport was described as too high for many patients and families. Observations (February 2, 2007) also noted this. Social workers, in particular, highlighted the overwhelming transportation costs:

> *"We don't have a good public transport system and it's very expensive for the unemployed, the really poor people, it's really very expensive "(SW3).*

"Cost of transport is a significant barrier for patients. It is expensive to go to a doctor and so some of the people will be very late in their disease before they get diagnosed" (SW6).

Transportation was also described as an issue for staff. If using a home-based approach, staff members without access to transportation could spend hours getting to and from patients' homes. A number of hospices were attempting to address this with the purchase of bicycles, for example, to reduce transportation time and thus increase patient- caregiver contact time (Field notes, February 8, 2007).

2) ***Staff Access and Safety.*** In several instances, participants highlighted issues of staff safety; hospice workers could not enter into certain areas due to high crime rates. In addition, the fact that hospice workers carried medications made them targets of crime in some areas. One social worker described an incident where morphine had been stolen from a nursing sister. The "user" ended up dying from an overdose. Therefore, hospice organizations, in an effort to ensure staff safety, had determined geographical sites where hospice workers could not travel, even if the hospice was serving that particular catchment area. As one social worker stressed, hospices would look for ways to accommodate patients from the "unsafe" areas:

"There are a few geographical areas that are unsafe to send our staff members in. But if those patients are prepared to... move to relatives that are falling within our catchment area, we are prepared to look after them. It's not always working. Because when they reach the stage of being bed-ridden, then they would prefer to be in their own areas...we also have to be, cognizant of the safety of our staff: we can't send them into areas which is dangerous for them". (SW9)

In the observation notes of September 14, 2007, an experience was recounted:

"I was surprised that [the translator] asked questions about safety [to the nursing sister in the township we were visiting]. I had naively assumed that black people would feel

safe amongst other black people. The sister told several stories of muggings that made it clear that violence and crime are a natural part of life in the townships. She iterated that if you think about crime all the time, it will freeze you; you have to put it aside in order to work.

Issues of safety were ever present.

3) ***Stigma: Hospice Care and HIV/AIDS.*** A great deal of stigma surrounding HIV/AIDS still exists in South Africa. Hospice has become closely linked with HIV/AIDS care and thus has experienced a certain degree of stigma as well (Observation notes April 9 & 18, 2007). As such, patients might not choose to access hospice care due to either stigma with hospice care itself or with their disease. As the field notes that captured a doctor's comments stated "hospice will not be accessible to many people with AIDS as they would prefer to die with the disease rather than accept any outside help" (February 13, 2007).

At each hospice organization, at least one of the interviewees would describe an experience that demonstrated the stigma related to hospice organizations. Nurses would typically recount different scenarios where hospice was shunned. For example, patients or families would request that nursing sisters could visit on the condition that they would arrive incognito, without anything on the car or uniform that would attach them to the hospice. At times, patients would give an incorrect address so that hospice personnel would not go to the right place. In other instances, hospice staff would be asked to park a distance from the home so that people would not connect hospice to the particular person.

Hospice was also regarded by many as a place to die and a fair bit of stigma existed due to that limited definition. Respondents felt that both patients and family care providers were reluctant to be referred to hospice care if they viewed hospice as one step ahead of death.

Eliminating this stigma was described as a slow process and hospices were attempting to address this in different ways. For example, one of the participating hospices had chosen to rename it's organization to avoid the use of the term "hospice"; by calling themselves a "community centre" they hoped to address issues of stigma (Observation notes: May 22, 2007). As ARVs have changed HIV/AIDS care, the stigma of the disease is seen to be slowly decreasing. So too is the stigma attached to hospice care; as families and patients experience excellent palliative and end-of-life care, they spread this to others in the community. Over time, respondents had seen that the stigma is ebbing.

"Ja, well, the, the, the stigma with HIV will be there. But, uh, we're trying our best. Like here we're running support groups- there's my social worker who's running a support group on Tuesday and Wednesday, you know. And I see people coming in... the first day they are in denial, they won't be really keen to come but by the end of the month, you'll see that they wish they could be there. And they call the others, you know. So they're getting used to it now. I mean the stigma thing is also going down. Ja, they're learning to adapt to the situation. It's not like when this started really. Because they can see themselves being happy..."(NS17)

In fact, probably the greatest barrier that existed for many patients with HIV/AIDS was that they had difficulty accepting their illness. If the stigma surrounding the disease was greatly decreased, a greater proportion of people may feel comfortable accessing the care they need earlier in the course of the illness. But as one doctor said, *"A lot of people don't admit they've got HIV and they would rather die at home than admit they're HIV... If we know about all our cancer patients and all our HIV patients, the HIVs would be much much more. But in reality you won't see that because 90% of people HIV positive aren't going to admit it" (D47).*

4) ***Hospice Coverage: Too Few &Too Small.*** Many participants described the founders of hospices as retired nursing sisters who wanted to administer care to patients at end of life. As NGOs, funding for hospices in this study came from a variety of different sources including international sources like the Global Fund or President's Emergency Plan for AIDS Relief (PEPFAR). Local fund-raising efforts also accounted for a portion of each hospice's funds. As the hospices were not mandated or well funded by the South African government, the location and coverage of hospices appeared to be random; someone in a community had to initiate the creation of a hospice before it could be established. Therefore, hospice coverage could not be described as uniform throughout the country. This was difficult for those both within hospice organizations and those who lacked the service:

"...my main problem and concern is the people that are outside our boundaries. And our boundaries -we won't have telephonic correspondence within our area that ends at Veldriff. But further on there's a big area that is not covered by hospice at all. And, I mean, it's people that can be, because of where they're living, they're not able to get the quality of care as somebody that may be living in our area" (NS12).

Participants felt that there were too few hospices to meet the palliative care needs of the South African population. In the phone interviews with doctors outside the Western Cape Province, the participants often had difficulty describing local hospice facilities because they either did not exist or were so limited in scope that they were of little use to practitioners. It was not unusual for the closest hospice to be out of the patient's transportation range. Therefore, doctors often did not even consider referring their patients to hospice.

When a hospice organization was functioning in a community, it was frequently noted that there was not enough space to accommodate all the patients who could benefit from hospice care. Doctors who did choose to refer patients to hospice, therefore, were often frustrated with long waiting lists or a lack of space. As one doctor from the province of Free State said,

"I would say it seems like they [hospice] have something going and it seems like other people are benefiting from it. But it's not the people coming from this hospital. Meaning they say they've got 50 beds and the 50 beds are full. Obviously they're doing something for somebody, but it's not for me. I am unable to really access that service" (D7).

In short, the existing numbers of hospices was described as too few, and the services that each could offer was seen as too limited to meet the demand within South Africa.

5) ***Doctors' Perceptions: Blissfully Ignorant.*** As one hospice doctor from the Western Cape Province stated:

"It may sound a bit of a paradox in this day and age but there are still doctors who don't know what palliative care is and there are doctors that don't know the difference between a hospice and a hospital...And it's not the old doctors entirely, the modern generation is also blissfully ignorant" (D41).

Ignorance on the part of doctors was described as a barrier in the existing health care system. As the spiritual care provider described it, *"this is a bit of a minefield... because we don't necessarily have cooperating GPs who should maybe consider referral of their patients earlier" (SPC1).* Doctors were perceived to be unaware of palliative medicine, which eliminated a critical tool in their medical toolbox. This had negative ramifications for patients and family care givers who could have benefited from palliative care throughout the trajectory of illness. One nursing sister suggested that *"9 out of 10 doctors don't know what's going on" (NS7).*

Doctors' ignorance was perceived to be born out of a desire to be the only treating physician. As one of the social workers described it, "old school" doctors would wish to keep control of his or her patients from birth to death with nobody else interfering in patient care. Elements of palliative care were also described as distressing to doctors with no knowledge in the field. For example, although morphine is listed by the World Health Organization as an essential medicine to relieve patients' pain, some doctors remained convinced that using morphine would kill patients or lead to addiction. One nursing sister described a local doctor's perspective on morphine:

"He doesn't understand. He doesn't understand the, the morphine and he will say things like that you're killing the patient in front of the um um the relatives" (NS6).

Several of the participants felt that doctors cared for patients differently depending on the patient's disease. They felt that patients with cancer had greater access to palliative care services in comparison to those with HIV/AIDS. On a more positive note, participants that were employed at hospices also noted that due to either hospice or university education programs, doctors were becoming more aware of hospice services and the role of palliative medicine in patient care. And they felt that increased education balanced doctors' approaches to patient care regardless of disease.

6) ***Public Attitudes: Fearfully Ignorant.*** If doctors were seen as blissfully ignorant, then patients could be described as "fearfully ignorant"; willingness by the

public to latch onto myths surrounding hospice care and morphine use, had created a fear of hospice and palliative care. Participants felt that many people had associated death with hospice, a relationship that caused great fear. According to a hospital/community based palliative care social worker:

> *"The doctors invariably offer the patients [hospice] care. There is great resistance from patient point of view in South Africa to receiving hospice care. There's the belief that if you're referred to hospice, it will make you die. That you are actually going to die more quickly. So a tremendous number of patients refuse to be referred" (SW7).*

Another aspect contributing to patient ignorance was seen to be related to cultural differences in discussing death and attending to the dying. One of the doctors working at a community clinic in the more rural and generally less wealthy province of Mpumalanga said the following:

> *"One of the barriers I've battled with over the many, many years that I've worked is the cultural beliefs that basically nobody wants you ever to talk about someone dying... It's almost like if you do that, you are putting a curse on the patient and they are going to die. And I think that has always been for me very hard because you just cannot prepare children for their mother's death and you cannot talk to anybody about dying. It's just almost taboo. So that has been quite a challenge over the years. You know sometimes we can manage to get around it, but not so much" (D21).*

Finding a balance between a culturally appropriate response and the desire to provide adequate preparation was described as a great challenge.

Even though patients were described as ignorant, participants felt that getting the support of patients and families was not an onerous task. Often, it took a single and simple explanation; patients and families were often very grateful for the care they received once they understood hospice's role.

7) ***Racial Issues: Colour Matters.*** The issue of race is always near the surface of any problem in South Africa. It is also a delicate subject and one that contains a raft of

deep emotions. Most times, when the question "Do you think race is a barrier to accessing palliative care?" was asked, respondents responded in the negative. They would say that hospice was available to everyone, regardless of their racial and ethnic background. However, several respondents plunged into the race conversation before the question was asked. Two quotes in particular highlight the importance of the issue. The first was from a private practitioner, working in a small coastal community in the KwaZulu Natal Province:

> *"It depends on race, I would say, here. The problem being with black patients, if somebody dies at hospice they don't want to bring a patient to hospice again. If one of their family dies in hospital, they don't want to take another family member there again. Um, white people don't like hospice anymore because there's so many black people with AIDS in hospice so, I think that's part of the problem. Even with our fundraising it is sometimes now difficult to get the more affluent white people to donate money because they say 'that place now is just full of AIDS', you know. And which is not really the case because at any given time we've got maybe equal amounts of AIDS and cancer there so... We are working on the problem" (D16).*

The second quote was from a nursing sister, employed by a large hospice organization and working in a township:

> *"I want to be honest with you. There is the race issue...you cannot run away from it. There is. Even if you could see the structure of [hospice organization], that alone without any explanation, there is ... that is an issue. But- aaahhh—whatever it is man, I don't want to go deeply into it, uh huh, but the race issue is there". (NS18)*

The field notes also captured some perceptions on race. In those dated February 12 (2007) it was written *"The white women in the group (n=3) felt that they walked a fine line within the black communities; they did not want to appear judgmental and felt they had a guilt complex. The black women (n=3) were more able to go into the family and speak their minds freely"*. Race was an undercurrent in the hospice experience.

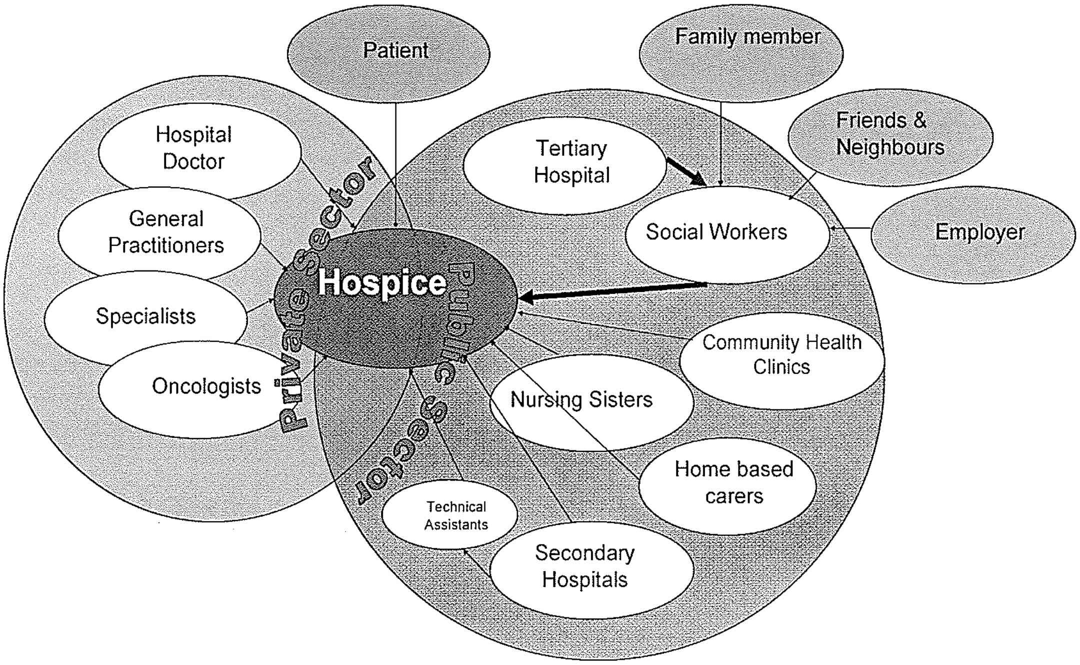
Sub-theme 2B: Access Routes

Patients typically accessed palliative care services through hospice organizations. To better understand the access routes- or the referral process- the health care workers who were interviewed were asked to describe the system and comment on both its effectiveness and usefulness. Based on their responses, a model describing referral sources was created (see Figure 4.2). Two categories: 1) Lack of Standardized Access Routes, and 2) Lack of Knowledge Regarding Access to Palliative Care, became apparent within the sub-theme dealing with access routes.

As seen in Figure 4.2, referrals to hospice organizations in South Africa typically originated within the public health sector as opposed to the private sector. While private practitioners did refer patients from time to time, referrals from the private sectors were typically described as a last resort (e.g. if private health care insurance was depleted) or due to excellent communication between the community's general practitioners and the hospice organization. The latter was described more frequently in smaller communities with long-standing hospice programs; if hospices had developed a strong communication network with health care practitioners in their area, they would regularly receive referrals from private doctors. Within the public health care sector, oncology departments of tertiary state hospitals took advantage of hospice programming most often. Most commonly the hospital social worker would be the critical person in the system as the direct link between the hospice and the tertiary hospital. Where good relationships existed between the social workers of large state hospitals and the referral nurses in hospice organizations, a large number of referrals were processed.

However, other “non-health care sources” (e.g. family, friends, and employers) were also identified as referral sources; some participants identified that as hospice organizations became better known and as a greater number of people receive care from hospices, more and more people self-referred. Here, either the individuals would present to the hospital social worker or directly to the hospice. If it was the case that a patient arrived directly at a hospice, part of the referral process would be to have a doctor fill in the required forms.

Figure 4.1: Source of Hospice Referrals in South Africa



1) ***Lack of Standardized Access Routes.*** The hospice referral system lacked standardization across the country. Even within the hospices certified by the Hospice and Palliative Care Association of South Africa, there was not a standard system in place. The process seemed characterized by the individual hospice's protocol, the disease profile of patients, as well as poor linkages between doctors and hospices.

Hospice protocol varied from place to place. Each hospice organization had its own specific referral system; forms were similar but not standardized across the province. Most hospices utilized a two form system for all patients: one form was for medical information, which was filled out by the patient's doctor, and the other form for personal information that was filled out by the patient and family. The patient/family form was seen as being critical within the hospice system as it signified that both the patient and family permitted the hospice to be involved in patient care. Without this form, hospice would not proceed with contacting the family.

The referral process was dependent on disease profile. The bulk of hospice patients could fit into two disease categories: HIV/AIDS and cancer. Most typically, the HIV/AIDS patients would enter the system from community-based clinics. Cancer patients, on the other hand, would be referred by oncologists in tertiary settings or private practice. HIV/AIDS patients could be referred by either doctors or nursing sisters whereas cancer patients required a doctors' sign-off. According to a nursing sister employed in a community hospice:

"The HIV patients can be referred by the sisters working at clinic. OK. There's a form there with all the details on it. And with the consent from the patient, they can refer the patient to us. And, uh, cancer patients it's only the doctors. Fill in the form and refer it to us, only doctors" (NS2).

It was not entirely clear why two forms were developed for these two distinct patient populations, but that was typical within the system. One doctor suggested that *"it works a little bit differently with the two kinds of patients"* (D46). Several respondents noted that the two "sides" did not function equally well. It was felt that the community health side (HIV/AIDS patients) worked better as the community nursing sisters had a good sense of their patient population. Conversely, the "medical side" (for cancer patients) was seen as having too much reliance on doctors. As stated by a hospice nursing sister, *"they're waiting so long for the doctors because the family is coming to us and saying there's a cancer patient, he's lying there, this and this and this is the problem, and then we must go to the doctor and explain what, what what and that is the problem. And we're waiting so long for the doctor's to fill because most of them are private practices. They've all the patients sitting there in the waiting room waiting for them so there's so much, no time for them. So maybe after hours fill in the forms. Sometimes we must go two, or three, or four times to the doctors to sit and wait for the forms. And that is why the treatment can't be continued and we're waiting for the doctor. If there can be another system where the patient can come to us and say 'We want our patient, my mother or my father, to like to be treated by the hospice'. Can't we go on like that?" (NS15)*

Poor linkages between hospital and hospice or various practitioners were a common element in the interviews. This contributed to the lack of standardization present in the system. One doctor simply stated: *"We haven't got a very good link with our hospice lot." (D7)* while another said, *"Yes, there are a number of hospices but we don't ever refer" (D32).* What was the cause of poor linkages between hospitals, doctors and hospice organizations? Several key factors were reported to negatively affect the efficiency of the system. Notable were poor linkages between hospital and hospice practitioners, systemic patient discharge issues that "lost" patients before a referral could be made, and difficulties in transferring patient management plans.

Perhaps, due to the increasing need for palliative care, hospital and hospice administrative structures were seen to be facing a losing battle. Without a good system in place, and without the resources to develop an effective system, changing the system did not appear probable. The words of the following doctor highlighted these points:

" There isn't, the structures aren't that well set up for patients to be referred from state to hospice. I think simply because, particularly with, you look at the our situation where we've got quite a number of HIV patients needing hospice or home care. There's such an overwhelming amount of them that on the hospice side of things, they just wouldn't be able to cope with all the referrals. So there aren't formal structures and stuff in place for that to happen" (D15).

On the one hand, it is understandable that an adequate system was not in place. Tertiary hospitals, for example, drew patients from large geographic areas. When curative treatment was completed and patient care had been transferred to the patient's local community, there were many possible ways that errors could happen. Although the state hospital would attempt to document a management plan for the patient upon discharge, this letter did not always make it to the patient's home doctor. It may be that the patient did not have a doctor to bring the letter to or it may be that the letter was mislaid along the journey home. An excellent system of communication would need to be in place for cross-provincial directives to be effective.

2) ***Lack of Knowledge Regarding Access to Palliative Care***. Health care participants frequently spoke of how there was a lack of understanding or knowledge about the palliative care referral system; both the general public and general practitioners were seen to have little understanding of how to access hospice care. Two quotes, one from an Eastern Cape medical doctor and the other from a Western Cape hospice nursing sister, express this:

> *And I think that a lot of people don't know about the referral process...There still is a misconception about what hospice provides them, you know the difficulty in what hospice traditionally was perceived to be and what we actually do do, what actually gets done by hospice. And uh, so there is that problem of referrals. (D3)*

> *All these doctors know about our referral system because we provide them with the forms. And our doctor goes and have meetings like once a month, on a Tuesday, with the hospital doctors and she has a separate time with the private doctors. It's a good relationship with them. (NS10)*

These two quotes encapsulate the two extremes that existed: those that had a strong understanding of the hospice system in general and the referral system in particular, and those that had limited knowledge. A good referral system was predicated on networks; the level of adequacy was dependent on partnerships built and maintained. Building relationships and developing an understanding of what hospices offered was an important element of a successful referral program.

Theme 3: The Changing Face of Palliative Care

The third and final theme that emerged from the data pertained to how palliative care in South Africa has evolved over time and continues to adapt according to need. Aspects relating to the burden of illness, the availability of health care providers, South Africa's health care system, and patient needs all factor into how palliative care is delivered. For example, palliative care organizations experienced an obvious change in the landscape of care due to the HIV/AIDS pandemic. Hospice care for HIV/AIDS patients began as terminal care and was transformed into care for the chronically ill; with the advent of a state-supported ARV program, patients with HIV were often be described as having a chronic, as opposed to terminal, illness. Hospices had gone from providing terminal care to all HIV/AIDS patients to monitoring patients; being on antiretrovirals did not eliminate the need for hospice support, but it had changed the course of care. The following quote by a medical doctor highlights the general theme of *"The Changing Face of Palliative Care"*:

> *"Especially now with the advent of ARVs because I mean we knew before. Because when I started working in '96 in HIV clinics, I was full of patients and I'd see them here because they'd die. There were no ARVs, you know? So that was different. But now, we know different...it's not the end of the road" (D45).*

The third theme contains four sub-themes relating to the changing face of palliative care delivery in South Africa: 1) Sub-theme 3A (*Patient Care*), 2) Sub-theme 3B (*Educational Needs of Medical Doctors*), 3) Sub-theme 3C (*Models of Palliative and End-of-Life Care*), and 4) Sub-theme 3D (*Funding and Resources*). Each sub-theme also contains several categories that expand on a particular area.

Sub-theme 3A: Patient Care

A description of patient care was generated from the interviews of patients, family care providers, as well as health care workers.

All of the patients were receiving hospice care at the time of their interview and were at different stages of their illnesses. Although the interview did not ask participants to describe details of their illness, it was evident that the patient population was not homogeneous; some patients were bed-bound while others were very active. The majority of the family care providers were also linked to hospice patients and all of the family care providers interviewed were the patients' primary care providers. Interviews of health care workers were helpful in describing more detailed examples of care tasks. There were five categories in the sub-theme relating to patient care: 1) Patient and Family Care Providers' Description of Hospice Care, 2) Role of Health Care Providers in Hospice Settings, 3) Role of Medical Doctors in Providing Palliative Care, 4) Satisfaction with Hospice Care, and 5) Patients in the General Population.

1) ***Patient and Family Care Givers' Descriptions of Hospice Care.*** Both the patients and the family care providers were asked to both explain the type of care they

received from a range of health care providers and then describe their satisfaction with this care. The two groups described health care provision similarly in terms of care provided as well as satisfaction. However, it was typical that the majority of the care tasks were completed by the family care providers which created an obvious strain. One participant described his care tasks by saying:

> *"I help her with her medicine. In the night time and my daughter's in the daytime. So she's doing it in the day, and I care for her in the night. At 6 o'clock in the afternoon she gets her morphine, 10 o'clock, 2 o'clock in the night, 6 o'clock in the morning so I'm giving her that... And food.... And, uh, I care for the house. Cleaning, cooking food because we got my daughter, my son's daughter here, living with us. And she's got uh... how can I tell you now, like a cripple. We care for her from it's 13, 14 years now. She's living with us. And she's getting.... on Saturday she's 21... I care for her also now. So it's a lot to do"(FCP7).*

In approximately one quarter of the interviews, family care providers would become emotional (e.g. tears would well in their eyes or they would sigh frequently) when describing their role. It was evident that respite care for the care givers was not readily available but necessary. Yet while providing care to the patient was emotionally and often physically taxing on family care providers, it was stressed that caring for their family member was a great honour and/or a family duty.

2) ***The Role of Health Care Providers in Hospice Settings.*** As the following quote emphasizes, an interdisciplinary team of health care professionals was valued in the hospice setting:

> *"The whole idea behind our hospice here is to have a multi-disciplinary team where you have a doctor, nurse, social worker and somebody from the religious part, the luminary or the pastor or whatever it is. And any other person that might come in, a family member or whatever. If we have a problem, we get the whole together and we solve it. But you also um, sort out the problem before hand so that you do not have the pastor sitting in on a medical problem or the social worker sitting in on the, well she could sit in on the pastoral problem (laughs), but you follow what I mean" (D42).*

When professional health care staff was involved with patient care, the amount of care and the type of person providing care would be dependent on the stage of the patients' illness. For example, if a patient was bed-ridden and the family care provider needed assistance with bathing him or her, then a home-based carer would be assigned to visit on a daily basis. A professional carer working in both an inpatient and home-based setting, described part of her day:

> *"So there we are doing home visits where we were caring for people in the community that are sick.... If I'm here in the ward, I must check all the bottles of urine. I must make sure, I must check that everything is clean. I must take all the bottles near the beds and go to the sluice room. To empty the urine and clean the bottles.... I must make sure I clean the beds. ... And sometimes, someone can call you and talk to you, and you have to advise her and encourage her spiritually" (C1).*

Conversely, if the patient was receiving ARVs and was responding well to the regimen, then the nursing sister would monitor the patient on a monthly or bi-monthly basis. Patients rarely were seen or visited by medical doctors even though this was desired by both patients and family care providers.

For home-based patients, it was most common that they would receive hospice care from nursing sisters and home-based carers. *"Anybody who would be at home would be under the guidance of the home-based carers which are then under the supervision of a professional nurse" (D39).* If it was deemed necessary by the nursing sister, a social worker would also assess the patient. It was unusual for a medical doctor to make a home visit. Spiritual care, described as a vital part of hospice programming in South Africa, was attended to by both hospice staff- including nursing sisters, home-based carers, and spiritual care providers- as well as congregants or clergy from the patient's faith community. It was not unusual to witness a nursing sister praying with her patient or to have church services included in daycare programs.

Nursing sisters carried out many roles within the hospice setting. For example, in addition to caring for their patients, they managed the home-based carers, assessed new patients, educated families on appropriate methods of care, addressed concerns by family members, attended folder rounds with the health care team, and hosted daycares. One of the family care providers described the hospice nurse's ability to communicate directly with the patient's doctors as invaluable; accessing medications became efficient and timely with the nurse's assistance:

> *"Because normally I have to phone the doctor and wait for him on the phone and so with her [hospice nursing sister], she speaks to him straight away and she phones me back. So that's nice" (FCP1).*

Inpatient hospice patients received a greater range of services. Nurse(s) would be on duty 24 hours a day, seven days a week and other professionals were available during regular working hours. Some patients likened their experiences at an inpatient unit to a holiday or hotel; they felt pampered by the level of care they received. The majority of the inpatient hospices that were observed in the study had two week limits on patient visits to allow for a greater number of patients to use the service. Inpatient hospices were designed primarily as respite services but were also a place where patients came in their final days of illness. Therefore, in situations where patients did not have family or friend to care for them, sticking to the two week limit became a struggle for hospice administrators. Certain patients were described as "bouncing around various community services", staying the maximum in each place and then moving on to the next organization. As one social worker described, families sometimes abandoned their ill relatives:

"When the doctor says '[SW8], this patient is going to discharge we must have a plan. Contact the family.' And the family is sometimes playing hide and seek (laughs) so you know... (laughs). That's all (SW8).

Inpatient hospice patients were also seen by medical doctors more often than home-based patients. Some hospices were fortunate to have a paid hospice doctor but it was more common for a community doctor to volunteer at the hospice. Having a doctor on salary was beneficial in many regards: nurses could be in direct communication with the hospice doctor to guide patient care, the hospice doctor could liaise with other community doctors thus educating them about hospice programming, and patients could be assessed regularly. If hospices were reliant on volunteers, then care was more fragmented: the time that doctors could give to the hospice was limited which meant that staff had to prioritize all concerns.

3) ***Role of Medical Doctors in Providing Palliative Care.*** As suggested earlier, the role of medical doctors in the provision of palliative and hospice care was varied and far from uniform. Patient and family care providers were asked to describe the care by doctors; their experiences were limited. Health care providers were also asked to describe the role of doctors in providing palliative care. Not surprisingly, participants who were employed in hospice organizations had a very specific view on both the role and importance of doctors in providing palliative care. Participants who were employed

in either public or private health care organizations, on the other hand, viewed palliative care as a small and sometimes insignificant part of their medical practice.

Although hospices were not the only location for palliative care, they remained the primary source. Therefore, the hospice doctors felt more comfortable in describing their role in providing palliative care. Typically, a doctor working in a hospice had several specific duties: a) to communicate with nursing sisters about patient needs and changes in patient care, b) to prescribe medications for patients, c) to lead chart rounds, and d) to provide medical care for patients. If hospices had an inpatient unit, the doctor would remain onsite, conducting ward rounds and liaising with home-based care nurses. Hospice doctors were also involved in educating hospice staff, and sometimes medical students or other colleagues. One doctor described her role at the hospice in this way:

"I'm available to all the nurses at anytime. To phone or SMS or discuss what we should do. We have, they, the hospice has monthly meetings where they discuss these sort of issues with the staff and on a couple of occasions they've called me in and said, you know, can you give a discussion in this area?" (D1)

Another suggested that a hospice doctor was like a *"jack-of-all trades" (D43).*

If a hospice was not able to employ a doctor, a volunteer doctor would be sought after. Depending on the amount of time a volunteer could provide to the hospice, the range of activities would be similar to those of a paid doctor. However, it would be unusual for a volunteer doctor to visit patients; chart rounds would be the most efficient way for patients to be managed. In a folder round, the health care team held a meeting to discuss individual patient's needs. Each nurse would present her patient concerns to the doctor and then he or she would then give suggestions or write a prescription for the nurse to fill. One nurse described a doctor's role in the following way:

"They are there to support us and the patient. And we are like telling them this is where the stage of the patient is and what they needs are and the doctor will prescribe pain medication" (NS10).

The nurses regarded the doctors as a critical support within patient care. While the doctor had the ultimate ability to prescribe medications, something not yet available to nurses in South Africa, he or she was more than a pharmacy to the nurse. In many hospices, the doctor helped to train the nurses. The doctor often provided emotional support to the staff. One nursing sister described the value of a hospice doctor:

"Once a month I sort of highjack my [hospice] doctor to go with me because it's nice for her to see the patients too. And it's nice to have a backer up, and then she checks if we're doing the right thing" (NS2).

Doctors working outside the hospice system were not as clear about their role in providing palliative care. It was not so much related to a lack of desire but rather a lack of time or perhaps ability. In the public health care system, doctors were described as the person who would disclose a terminal diagnosis to the patient (although other health care professionals did this as well), develop a short-term care plan, and then offload the patient. In the following doctor quote, it was clear that many different factors defined the type of care a doctor working in a state hospital could provide:

"You've got only so many minutes for each patient otherwise you don't get through the day, and how many people die in a day and everything. I mean every group we have has at least 3 deaths a day…on a Monday morning there's a stack of death certificates to write. And then usually they're in such a hurry to get the corpse into the grave that there's not a lot of time for thinking… she calls it "death overload". And unfortunately I think that is really what is happening here. The people they sort of capitulated, they've decided there are so many of these people that need this type of talk, and I've got so little time to give this type of talk. So they've decided I don't give this

type of talk at all. But even if they've got time to spend that little bit of extra time with the family or with the patient, they don't. And the less they do it, the more unfamiliar and uncomfortable they become when they have to talk to people that are crying and so on. You know, a lot of people believe that the doctor won't cry with the patient and that type of thing. And they feel unsafe with their own emotions so they'd rather dodge the issue or pass it on to somebody else. So I think it's a problem that most people are sort of ignoring to such an extent that everybody is sort of satisfied that we're doing what we can because what people expect of us in a palliative care sense, is out of our scope. You don't even feel bad about it because we've got lots of other stuff to do. And we try to do it to the best of our capability. But then this little thing gets neglected to a large extent. But that's my personal opinion. It doesn't talk nicely to what we do in the hospital but I think it is true" (D7).

The quote highlighted the issues of an overwhelming patient load, lack of time to attend to patient need, a desire to remain emotionally unattached, and "death overload". Those issues were discussed more frequently by doctors working in the public sector. Doctors in the private sector felt that palliative care was not a large part of their medical practice. A general finding was that those in small rural communities were much more involved in the direct care of the dying as compared to private practitioners in large urban settings.

All health care workers, including doctors, perceived the doctor's role within the provision of palliative care to be necessary and valuable. Their role in prescribing was critical for pain and symptom management, and their medical knowledge was important when determining a patient management plan. The medical doctor was also perceived to be the team leader, providing direction and leadership to the nurses, social workers, and other health care workers. Doctors did not express that their role should involve hands-on care of patients. This can be seen in the following quote by a medical doctor from the Northern Cape Province:

"I think the role of the doctor is very important. As far as the care of the patient is concerned, there the doctor isn't always necessary. But the moment you involve palliative care, I think the doctor is absolutely necessary and I think one should play a very important role there" (D38).

Participants regarded a doctor's advice as particularly useful and valuable. Patients, family care providers, and other health care workers regarded doctors as the ultimate source of advice. This was apparent in the following quote:

"Everybody looks up to a doctor. Not to say they don't look up to a social worker and so on. But if they see a doctor they say 'yes', you know, 'the doctor says so, we must do it'" (D40).

Although this happens to be a quote by a doctor, it was a sentiment expressed by a range of stakeholders including patients, family care providers, and other health care workers. The word of a doctor was unquestioned and very valuable. Thus, having a doctor visit a patient was expressed as a very important, yet lacking, component of the current system.

4) ***Satisfaction with Hospice Care.*** Patients and family care givers were highly satisfied with the hospice care that they received, particularly from the home-based carers and nursing sisters. Even though, for home-based patients especially, the amount of professional help they would receive was minimal, they were grateful for every visit. Hospice patients did not seem to fully understand the role of the social worker- their visits were described more as social calls- and so did not feel strongly one way or the other about social work care. The only time that patients or family care providers expressed some dissatisfaction was when they talked about doctor care.

As hospice doctors were rarely part of the care experience, patients and family care providers would typically describe their experiences with the community doctors.

Some were satisfied with their doctors, but others felt shortchanged. A Xhosa speaking man who was caring for his elderly uncle, for example, expressed frustration with the fact that, at their last visit to the clinic, the doctor did not even bother to do a physical examination of his uncle:

> *"But the [clinic] doctor didn't check him. He just asked 'what do you feel' and he says 'no, this one is painful' and they say 'OK, we're going to give you morphine, we've got nothing to do'. You see? They always just give the medicine, it's only to give the medicine" (FCP10).*

In the South African state health care system, block appointments are given to patients. This means that a patient is told to come on a specific day, but is not given a specific appointment time. On the appointment day, patients then try to arrive at the clinic or hospital as early as possible in order to get a good spot in the queue. It is not unusual for a patient to wait at the clinic or hospital for the majority of the day before they get to see a doctor. In one of the state hospitals where an observation was conducted, canteens were set up in the waiting rooms to accommodate people throughout the day. Thus, if a family care provider and patient perceived their medical treatment to be inadequate, the negative experience was compounded by the length of time it took to see the doctor.

5) ***Patients in the General Population.*** The 48 medical doctors that were interviewed were asked to describe the patients that they cared for. In this way, a broad description of patients in South Africa was produced. The descriptions appeared to mirror more broadly, those of patients utilizing health care services in South Africa. The majority of the people utilizing state health care services were indigents with few resources and the minority, those using private medical services, were most often white

and wealthy. They also described extreme differences in the available health care services for those with medical aide and those without. In the most surprising description, a doctor from the Limpopo province, which borders on Zimbabwe, talked about the affect of the influx of foreigners in their state hospitals:

> *"...quite a large number of them [Zimbabweans]. Quite a large number of them. And it is causing a big problem, you know. We are treating people who we don't know their identity...We don't know where they stay, they don't reveal. Some of them actually stay in the bushes here.... Of course now we treat them even then, but ...they have no permit to be here. So half of them are found and arrested, they are deported and then they would go through and they would be back again through [by the end of the week]. And then some of them actually come across the veld as criminals. The rest are clean. Lions devoured one of them- probably- they just left a few bones and a skull, finished. And there, it's not very far from here...these types of casualties are not uncommon. Sometimes they get the ideas to cross the Limpopo River.... But then of course there is the problem of crocodiles" (D23).*

Sub-theme 3B: Educational Needs of Medical Doctors

Doctors were asked to describe the current ability of education programs in providing palliative care education. A follow-up question explored if changes were needed in the current curriculum to provide a greater emphasis on palliative medicine. Many of the respondents were not familiar with the current curriculum; this did not preclude them from offering suggestions for program improvement. Two categories emerged within the sub-theme: 1) Current Status of Educational Programs, and 2) Suggested Changes to Undergraduate Medical Curriculum. Each will be discussed further.

1) ***Current Status of Educational Programs.*** Palliative care was described as a very minor part of the undergraduate medical curriculum. Respondents felt that

students may have some assigned readings in the area, but that without regular exposure or standardized exam questions, palliative medicine was perceived by students to lack importance. A curative model of patient care was considered the focus of medical training:

"I think palliative care is still taught very badly for doctors, and nurses actually, and your average medical student doesn't get too much exposure. They still, on the ward rounds, concentrate on the curative issues and symptom control is kind of viewed as a bit of TLC and it's trivialized by family doctors in the hospitals" (D18)

One doctor described current palliative care training:

"What we try to do now is train our medical students and the pre-graduates in their final year, their fifth year, we train them. We take them to the hospices, we lecture them, we show them how we do it in the hospital. And then post-graduate doctors we do have a course in palliative care as well" (D9).

However, the effort was seen as ineffective, for the most part, as respondents still felt that students regarded palliative care as insignificant.

2) ***Suggested Changes to Undergraduate Medical Curriculum.*** With the exception of one respondent, all felt that palliative medicine needed to be incorporated to a greater degree with the undergraduate curriculum. When pressed, respondents suggested that a foundational change in the current educational model was necessary; instead of learning only about cure, students should be engaged in holistic care principles.

"The principles of palliative medicine aren't sort of restricted to just palliative care. It should be across the board. This is how we should be treating all our patients.... I say we need to build an interest and one can do that if we introduce it early on in the medical program. I think by leaving it out, it's almost as if it's not important" (D15).

Palliative medicine fits well into a holistic model and should be regarded as important. A shift in the curriculum would allow for a shift in the mindset of students. More specifically, respondents felt that doctors needed to learn how to manage pain and counsel patients.

One respondent, however, was not convinced that a change was necessary:

" I think that the palliative treatment is very often a thing that develops with the character of the doctor. Not necessarily an academic thing" (D30).

Sub-Theme 3C: Models of Palliative and End-of-Life Care

In South Africa, palliative and end-of-life care is delivered in a number of different settings by a range of people, both professional and non-professional. In this section, different models of care (e.g. hospice organizations, palliative care wards, hospital care, and care by family or community) will be described. Data from both interviews of study participants and observations of hospice and other health care organizations were particularly useful in the development of these descriptions. Models of care will be described within four categories: 1) Hospice Organizations, and 2) Hospital Based Palliative Care Ward, 3) State Hospital Care, and 4) Care by Family or Community.

1) ***Hospice Organizations.*** Two models of care were evident in hospice organizations: home-based care and a combination of home-based care and inpatient services. Hospice organizations would care for both patients with private insurance and patients without. Hospices were not considered "state-run" organizations; while their

patient populations were similar to those found in state hospitals, they were typically non-governmental organizations.

Home-based care. As the name implies, home-based hospices delivered care to their patients in their homes. They would often host a daycare for patients as well. At daycare, patients were transported (by volunteers) to the hospice where they would do crafts, eat lunch, have tea, and perhaps attend a religious service. The primary purpose of daycares was to develop social networks in patients. However, nursing sisters also used the opportunity to talk with their patients; these weekly outings were also used for informal assessments.

The core staffing needs for a home-based hospice were nursing sisters and home-based carers. Other hospice staff might include administrators, doctors, social workers, and possibly spiritual care providers. All of the HPCA hospice employees were required to be trained in palliative care principles.

The nursing sister would be in charge of a number of patients, as few as 20 to as many as 40, as well as the home-based carer(s) assigned to her. As the nursing sister could not visit all of her patients daily or even weekly, a critical part of her task was to prioritize patient needs:

> *"I see my chronic patients once a month... the patients with the hypertension, diabetes, and so on, arthritis, um, I see them once a month. Where I do their blood pressure, and the diabetics I do the sugar test, the blood sugar level. And uh, the HIV and cancer patients I see once a week. But if there's problems, like we sometimes I see two times a week, a day" (NS11).*

The nursing sister was very involved in directing patient care. For example, if the hospice did not have a doctor or if the patient was still being seen by his or her general practitioner, the nursing sister would liaise between patient and medical doctor. In that capacity, she could contact the doctor directly for minor prescription changes, thus eliminating the need for the patient to visit the doctor. Hospice nursing sisters voiced many opinions about the community doctors they worked with: some doctors understood the role of hospice, whereas others were definitely more difficult to work with and, with respect to palliative care, were regarded as ignorant.

The home based carers were trained in a short palliative care course prior to making home visits. They were the "hands" of the hospice organization and were involved in a broad range of tasks including simple care tasks, financial planning, spiritual care, and household tasks. The salaries of home-based carers were slightly above that of a volunteer, which resulted in a large turn-over in staff. However, home-based carers were critical to the success of the system; nurses needed them to manage patient loads effectively.

The home-based carers often saw patients in the same community in which they lived. Thus, as they were considered to be locals, they were not regarded with suspicion when they visited people. This meant that they were also the "face" of hospice care; people associated hospice with a familiar person, which meant they were more open to hospice care.

If the hospice had enough funding, a variety of other staff members such as social workers, medical doctors, and spiritual care providers were hired. Social workers had an important job in the hospice program. At the request of nursing sisters, social workers would visit patients. They also spent a considerable portion of their time assisting patients apply for disability grants or personal identification numbers. A personal identification number was necessary to apply for governmental support. Without it, a person was not eligible for any support grants. In addition, they were also involved in counseling and family meetings. One social worker described her role as being a "listener"; in the telling of their stories, patients would slowly accept their illness.

As described earlier, the doctor's role was primarily to conduct folder rounds. If they were hired in more than a part-time capacity, a doctor would also be involved in many other aspects of the hospice organization, such as administration and education.

Hospices with Inpatient Units. Of the 16 participating hospices, eight had inpatient units. There was no one style that was consistent across all of them. If, for example, a house had been donated, the hospice would resemble a family home, with patients dispersed in a number of different rooms (Observation notes, March 1 & 14, 2007). Conversely, if a hospice was built to be efficient and cost-effective, it would consist of two large rooms, one for males and the other for females. All of the hospices had communal areas where patients would gather or visitors would congregate. The ability to have privacy varied, but there was usually a sitting room available designed for private meetings.

The demeanor of inpatient hospices was more comparable to homes than hospitals; handmade quilts were often on the beds, colourful artwork was on the walls, and fresh flowers were frequently in the rooms. All the hospices had televisions and most would be showing soap operas, which reflected a favorite past-time of South Africans. In hospices that housed primarily black patients, it was common to hear singing throughout the day.

Hospices that did not have inpatient services would often make arrangements with local old age homes or hospitals to use one or two beds for patient care. However, the use of other health care facilities was dependent on availability. A portion of the staff working at home-based hospices wished that they could have an inpatient unit:

"The need for me, personally, is an inpatient. You see we've got our carers at home, we've got the family, but sometimes its people, family don't want their people to die at home. You see. It's not everybody that can take it, that their people must die at home. You see. I think it will be nice to have an inpatient. That's my personal feeling" (NS11).

Even though inpatient units were described as helpful to provide family respite or end-of-life care, they remained very costly and out of reach for many home-based care hospices. In the observation notes dated April 10, 2007, inpatient hospices were described as "first-world" and very difficult to sustain. Given the increasing need for hospice services, it is likely that inpatient units will need to be regarded as luxuries as opposed to necessities.

2) ***Palliative Care Ward.*** Although rare, palliative care wards were included in some public or state hospitals in South Africa. This meant that people with private insurance and those without insurance could have access to a palliative care ward. However, respondents felt that people with private insurance would typically select a

private hospital or private nursing care, even though palliative care was not practiced in many of those settings. One described a ward in this way:

> *"The palliative care ward is in a separate part of the hospital which has been refurbished by private money, uh, as part of a grant. And what we have, we have 10 individual wards that accommodate one patient each and one of those we've actually converted into a chemotherapy ward so we can give IV chemotherapy" (D1).*

Another doctor described a unique partnership between the hospice organization and the state hospital:

> *"It's a public-private partnership. Um. We, six beds is really too small to run as an independent IPU, it's just not cost effective. So we're doing it in combination with the Department of Health. Ward A is the chronic care ward and we're just linking with them. They haven't really had palliative care experience or palliative care type interventions there so that's we're providing. And that link is its strengthening year by year. It was a very loose link initially but, ja, gradually that's growing. It takes a lot of effort though" (D43).*

Due to the different levels of palliative care experience amongst staff working in the chronic care ward and the hospice, there was much opportunity for hospice staff to educate hospital workers. This participant described how the close link was initially difficult, but that they were beginning to see benefits from the system.

State hospital doctors often referred to "step-down facilities" when asked to describe where palliative care was delivered. A step-down facility was explained to be a separate ward or building where primarily terminal HIV/AIDS or TB patients were cared for. Staff working in these facilities was not required to have an education in palliative care.

3) ***State Hospital Care.*** Doctors describing the current situation in the state hospital system seemed apologetic and defeated by the lack of resources. In particular, hospitals faced staff shortages which made caring for patients difficult:

"Because I mean you think about a provincial hospital there's 10,000 patients to see and 20 doctors to do it" (D16).

With the overwhelming need and a lack of human resources to address it, the result was overworked doctors who were increasingly frustrated with their situation. Furthermore, the situation for patients with HIV/AIDS was described differently than that of others. For example, HIV/AIDS patients were regarded as "incurable", and, in the words of one doctor:

"...in general wards people get a fair amount of neglect if they've got something that nothing can be done for, from a medical point of view" (D26).

The expense of caring for HIV/AIDS patients was a factor in the care that they received; due to the high costs of care, HIV/AIDS patients would be given a lower priority in comparison to patients with other diseases. So instead of admitting HIV/AIDS patients for necessary treatment and care, they'd be given a prescription and told to go home. In this way, hospitals managed to keep their costs lower.

4) ***Care by Family or Community.*** It was suggested that the most common care model was that of the family or community. In general, family members and the wider community were highly involved in palliative and end-of-life care. However, several factors affected their availability or desire to care for patients. For example, in the case of HIV/AIDS, the stigma surrounding the disease was sometimes too great for the family

to deal with and the patient would be disowned. Secondly, the lack of familial resources of the family sometimes made it impossible or extremely difficult to provide care. And finally, due to high death rates, family systems had changed, leaving fewer family members available to provide any care. Participants, in this instance a doctor, described situations where family was not available at all:

"Many of these people don't even have the people to care for them. They only have the neighbour, or a caregiver that just comes in once and a while to see them. So this person is very ill and cannot care for all those things" (D40).

Even considering those factors, it was still felt that family and community members were the primary source for caregiving at end of life. Culturally, it would have been viewed as a failure on the part of the family member if he or she did not make all efforts to care for the patient.

As one doctor stated:

"If there is an end of life situation, it would be handled by the family only. Sort of at home in the person's home, and the surrounding community people might go out and help these people" (D17).

This is not to imply that care by family members was ideal or even adequate. Many families in South Africa live in extreme poverty; providing food and housing is difficult for many people. The unemployment rate hovers around 40%(2) which does not accurately reflect the vast differences in employment rates between the wealthy and the poor. So being able to provide the nutritional and medical needs of a dying person was described as extremely difficult.

Infrequently, doctors described how communities would work together to provide care:

"In our community where we live, course it's a very rural area, people are very compassionate. So all the neighbours come and help the patient and you know, if the family is not capable, I mean no family is capable of looking after a person 24 hours, so we try to make shifts to have people come and help the person out. To care for the patients: bathing the patients and giving the medication and stuff like that" (D24).

It was more common that families would struggle to provide the best care they could afford.

Sub-theme 3D: Funding and Resources

The mixed health care system in South Africa provides different levels of services to the population. Government funding varied according to type of institution and resources available. How did this affect palliative care delivery, hospice and palliative care organizations, and ultimately the patients? A spiritual care provider at a large hospice organization responded as follows:

"I don't think we're doing the job to the way we advertise ourselves. I don't think we have the capacity or the resources. Um, I think we're doing the best that we can under the circumstances but the finesse and the finer details of the energetic inter-disciplinary team concept, I think gets lost along the way ... So the necessities of, and the luxury of leisurely consultation around a patient's needs is idealistic, not realistic" (SCP1).

There were two categories that emerged from the data: 1) Palliative Care Resources for Private or State Care, and 2) Hospice Organizations.

1) ***Palliative Care Resources for Private or State Care.*** With the private and public sphere, the patient's resources appeared to define the level of care he or she received. As one doctor described this:

"Financially, you know, if I have a patient who does not have the medical aide, you know, there's no way I can provide them with just proper pain relief for starters. If you want to really give a person who is terminally ill proper pain relief, it costs a lot of money. And obviously there's other things that go with it- to be able to provide nappies, proper nursing care, all of those things, are

costing money. And if a patient is not financially capable of paying it, we just can't provide it" (D17).

Another doctor respondent stated:

"I think there's two worlds. The one world is that you have a medical aide in Africa and then at any good private hospital you can get the best treatment anything, I think, equating in the world. And at the other end there's people with no money and I think we have a poor public health system" (D25).

Participants employed in the private sector would purport to have everything a patient needed. In both hospitals and medical practices there appeared to be no shortages in medications or skilled professionals. However, the health care staff was rarely trained in palliative care:

"Nobody has specific training in palliative care. All training has been in house from myself. And I don't have any specific palliative care training. Just during my general oncology training" (D28).

However, private practitioners rarely perceived this lack of formal training to be a predicament. Many of the participants had been doctors for a long period of time and felt that they had learned sufficient palliative skills on the job.

In the public sector, doctors expressed many concerns with infrastructure, training, a shortage of staff, and the influx of patients. The observation dated March 20, 2007 described how the facilities available in the urban state hospital seemed inadequate for the number of patients present. As well, the condition of the facilities was described as "crumbling"; They frequently shared how patients requiring palliative and end-of-life care were discharged prematurely as the system was unable to handle them. One doctor described his way of explaining medical decisions to the patient's family:

"Because some [family members] might think, 'this is not my responsibility, it is the responsibility of the hospital' but when you tell them the truth of the hospital and say 'you know, as much as we can care for the patient in the ward, if there are shortages of staff, what are we going to do?' or if we have got one nurse, a ratio of one nurse for 50 there's no way the patient can get better care [in comparison to] palliative care if you are at home one on one" (D24).

Public sector doctors wished they were able to do more for their patients but felt they had reached their limits within the present system. Palliative care could not be viewed as a priority, in their opinion, given the larger issues that they faced on a daily basis:

"We don't even have enough nursing staff to cover the patients who are in the hospital. So palliative care is always put on the back burner, you know. In the hospital where I work at the moment, there is no palliative service at all" (D15).

2) ***Hospice Organizations.*** As NGOs, hospice organizations received only a fraction of their funding from SADoH. As a result, hospice organizations had to apply for funds from a variety of sources.

Keeping a Hospice Running: What's on the Table? The majority of hospice organizations were run as NGOs; only those connected to state hospital services received significant levels of government funding. In the hospices that were a part of the study, it appeared that hospice administrators had an excellent grasp of where to apply for funding. It was not unusual for hospices to receive major grants from two or more international agencies (Observation notes: March 14, 2007).

"The inpatient unit is basically funded solely by the Global Fund. They fund the availability of nursing staff and myself as a medical doctor to supervise that. Um, the EU fund, the European Union, funds the home-based care program that we run. And then we have smaller individual funders um, who does support all services. Because none of, not even the Global Fund or the EU, are completely funded, solely funded in terms of the financial, so you, the hospice still has responsibilities to carry costs. ... We've been an NGO, it's always what's on the table tomorrow" (D43).

A significant drawback was that international agencies such as the Global Fund would be very specific as to how the money could be spent (Observation notes: April 10, 2007). Reporting to the granting agency was a time consuming task; a large portion of time was spent both in applying for grants and then preparing the regular reports for these same agencies. Even with major operating grants, hospices were constantly fundraising within their local communities to ensure that they had adequate funds to cover costs. As one social worker stated:

> *"We just, you know, constantly have to [fundraise]...Because you know, we're not the only non-governmental organization in Cape Town. I mean we've got to fight for our funds, you know, to get our little, small slice of the cake at this point in time" (NS9).*

Volunteers were instrumental in all the organizations both to help with simple tasks around the hospice and to carry out fundraising plans (Observation notes: February 14, March 3 & 14, 2007).

Drugs for Hospice Patients. Methods of accessing drugs varied from hospice to hospice. In some organizations, patients had to acquire and pay (if possible) for all their own medications- a process that could be very difficult given the fact that patients were ill and the time it took to complete the transaction was often very tiring. In others, nursing sisters would collect patient medications. In a few, rare situations, the hospice paid for all the drugs and dispensed them directly to patients.

In general, the experience of accessing drugs is different for private and state patients. It is naturally more efficient to get medications if you are on a private plan or can pay for the prescribed drugs. Thus, as participants described their experiences in accessing their drugs for palliative care, they would be similar to their experiences with any medications. However, the added element of participants being in hospice and palliative care programs accentuates the differences and difficulties in the process.

Patients who used the private health care system did not describe their experiences with accessing palliative drugs as particularly difficult. However, the public or state system was fraught with issues. Firstly, the length of time to fill a prescription could be onerous:

"I think the clinics, uh, they're too small, you know. If you want to get your, say your chronic medicine or your palliative medicine, you have to go and sit in a queue. Say in the morning you start at 8:00 and you're lucky if you leave before three or four in the afternoon... So it's really inadequate" (D30).

Secondly, the state pharmacies did not always stock the specific medications or have the correct formulations available (Observation notes: May 16, 2007). Patients often described being able to fill only half (or less) of their prescription, as the clinic did not have enough stock on hand. According to this doctor respondent:

"Sometimes it's difficult to get medicine out of the hospital and to get different types of medicines out of the hospitals is also sometimes difficult. For somebody out there decides this drug is too expensive and then they stop it "(D16).

What was likely the largest issue, however, was that the health care staff was not well educated and did not understand how to administer or prescribe morphine. Therefore, fear of morphine was a barrier in accessing drugs.

"I've had a lot of resistance from the nursing staff to prescribe or to administer morphine. Um, South African nurses in general, I find, are quite resistant to giving people morphine. They feel that it's kind of giving up on the patient or, uh, passive euthanasia... I've tried to do a lot of training with nurses to help them realize that the pain control, including morphine, is part of

good nursing care. So, ja, it's not the supply problem. It's getting people to be given their treatment regularly and correctly" (D18).

Another doctor described how she would regularly be questioned on her prescribing patterns:

> *"Even after I'd done the palliative care course, I'd get often called in that I was far too generous in my prescription of morphine. Even when I had actually documented my assessment of pain and had, you know, given my reasons why, you know, or taken a person through WHO's ladder and come to a point where it was necessary. So people are generally scared of morphine. Even within oncology" (D3).*

Respondents who worked in hospice organizations and were familiar with morphine were supportive of the drug. However, doctors who were interviewed that were not regularly involved with palliative medicine, often were wary of administering morphine. One doctor described how he was able to care for terminal patients without using "*heavy drugs like morphine*" (D37).

Availability of Hospice Staff. An ongoing issue for hospice organizations was human resources (Observation notes: May 22, 2007). Staff shortages were a common problem in hospices for primarily two reasons: 1) hospice salaries were not on par with private or public jobs, and 2) the pool of trained health care professionals in South Africa could not handle the demand. One doctor described the state of human resources at a hospice in the Gauteng province:

> *"At the moment our hospice is in an absolute crisis because the sister in charge has just resigned and least two of the eight sisters that were working have resigned as well. So they're down to six sisters who do the home-based care. And they cover a huge area. Um, so they're just not coping at all. You know if you look at their number of patients a day that they see, I think last time there was a count and they were looking after 40-45 patients each. And to get to each of those patients even once a week is an incredible task. I think the other thing is even from a financial point of view, they get paid very little. Um, and they're not even attracting people, so unless people sort of want to do it for the love of wanting to help others, um, they're not attracting people to that type of health care" (D15).*

In only one hospice, a clear exception, were salaries described as being on-par or higher than those in the public service. This hospice, which raised a relatively large amount of private funds in comparison to other hospices, did not access any international funds (Observation notes: April 18, 2007).

Several of the respondents felt that there was a certain amount of stigma attached to hospice positions, and that jobs in the private or public, for example, would be viewed as the prime jobs to hold. However, others attributed difficulties in finding staff to an overall shortage of trained professionals: According to an inpatient hospice nursing sister:

> *"I think there's just nobody around. Everybody's leaving our pretty country to go and work elsewhere where they think there's more money....We just don't get applications but we're not the only organization. The hospital struggles, the private hospital struggles, everybody around struggles" (NS10).*

This shortage of trained staff meant that hospices relied on volunteers to complement the medical care. An energetic hospice was one with a well organized volunteer group. Hospices relied on a myriad of volunteers for the daily tasks including driving, gardening and cooking. Many hospice organizations ran charity shops to earn money, staffed by volunteers. Without volunteers, the hospice struggled, as can be seen in this quote by the spiritual care provider from an urban hospice:

> *"We tend to be short in the areas of the poorer community. And part of the reason for that also is that people of colour would not necessarily have the same understanding of volunteerism. And because of the distances they travel and their time, would expect payment. And the organization doesn't have the resources to do that" (SCP1).*

4.3.1 Summary of Key Themes

Viewed together, the three themes and their attendant sub-themes identified how palliative and end-of-life care was fragmented and difficult to access within South Africa. In the first theme "Two Solitudes: Participant versus Public Notions of Palliative Care?", individual health care participant's views on palliative care were described differently than those of the collective public Doctors without additional training in palliative care relied on their life experience and held the opinion that palliative care was similar to "tender loving care". Within society at large, palliative care was not well understood. For many, the term hospice equated to death, which meant that hospice care carried some stigma. Due to misconceptions surrounding hospice and palliative care, both the public and the medical community were somewhat fearful. Furthermore, many people did not understand the role of hospice and palliative care across the trajectory of an illness, which further compounded their negative ideas of hospice care.

The second theme, "Accessing Palliative Care", explored both different methods of accessing care as well as barriers to access. Barriers included staff safety, cost of transportation, poor coverage, and racial background, all which negatively affected patients' ability to access palliative care. Many people in need of care, therefore, were not able to receive it. The patients that did receive care were referred to hospices via a number of sources. Most commonly, patients were referred from state hospitals or community clinics, but patients on private medical plans were also referred to hospices as well. Different factors such as the patient's disease profile and the doctors' understanding of palliative care affected the referral process. Lack of a standardized referral process throughout the country created a system that was neither uniform nor transparent.

The theme "The Changing Face of Palliative Care in South Africa" explored how patient care was evolving due to factors such as the introduction of antiretrovirals. A description of hospice workers provided an overview, from the perspective of patients and family care providers, of the people providing palliative care. It was apparent that while the role of the doctor was minimal, patients and family members wished for more patient-doctor interaction while in hospice care. For example, if a doctor did not check up on the patient, participants felt forgotten. The different models of care were also described; the home-based model, while lacking an inpatient unit, was described as being the most efficient and cost-effective method of providing care to the most people. As hospices in South Africa were primarily established by NGOs, funding and resources were critical components to the continuation of adequate palliative care. Successful hospices were those with good funding from a variety of sources. Educating doctors in palliative medicine was described as an add-on within the current medical curricula. Participants suggested that there be a greater focus on palliative medicine within the undergraduate program so that doctors develop a holistic understanding of patient care.

While hospice and palliative care was described as a valuable service to those who received it, societal perceptions, poor education of medical practitioners, and difficulty in accessing care made it unavailable to most.

4.4 Results of Health Care Professional Survey (HCPS)

The purpose of the Health Care Professional Survey (HCPS) was to evaluate the specific educational needs of doctors in the field of palliative care who work in South Africa. Of the 81 health care providers that were interviewed, 75 completed the HCPS (see Appendix 11).

4.4.1 HCPS Participants

The demographic characteristics of the study participants are shown in Table 4.3. Respondents ranged in age from 30 to 64 (mean= 47.48, SD= 8.97), with the majority being female (58.7%).

Table 4.6: Descriptive Statistics for Participants who Completed the Health Care Professional Survey (N=75)

Variable	Count	*Percentage*
Sex		
Male	31	*41.3*
Female	44	*58.7*
Province		
Eastern Cape	5	*6.7*
Free State	5	*6.7*
Gauteng	6	*8.0*
KwaZulu Natal	4	*5.3*
Limpopo	5	*6.7*
Mpumalanga	3	*4.0*
Northern Cape	2	*2.7*
North West	5	*6.7*
Western Cape	40	*53.3*
Role		
Nursing Sister	15	*20.0*
Social Worker	10	*13.3*
Doctor	44	*58.7*
Home-based Carer	6	*8.0*

4.4.2 Results of HCPS

Participants were asked to respond to a survey, consisting of 36 statements relating to specific aspects of palliative care. The survey was divided into 11 sections: 1) Pain, 2) Symptom Control, 3) Bereavement, 4) Psychosocial Aspects of Death, 5) Professional Issues, 6) Ethics, 7) Establishing a Palliative Care Program in the Community, 8) Principles of Palliative Care, 9) Communication with the Patient and Family, 10) Interdisciplinary Communication, and 11) Personal Ability to Cope with a Dying Patient. The survey, developed by Barnabe et al. (3), was used to evaluate the palliative care educational needs of doctors in South Africa. After considering each statement, participants were to rank each as *"very important"*, *"somewhat important"*, or *"not important".* These statements were treated as continuous variables and were coded as 3 (very important), 2 (somewhat important), and 1 (not important).

4.4.2.1 Overall Trends

Participants' responses were consistent; the majority of participants indicated that *all* of the areas should be considered important fields of study for doctors. Respondents selected the ratings "very" or "somewhat" important 94.2% of the time across all 36 survey questions (see Table 4.4). Therefore, an overall trend was that participants placed high importance on all of the different facets of palliative care.

When used in Canada, the Health Care Provider Scale had the ability to discern variations in need by category; the questions associated with bereavement, psychosocial aspects of dying and professional issues were described as significantly more important for participants (3). This ability to note gradations in fields of study, however, was not evident in the South African version. Although it is believed that the scale accurately produced evidence that all areas were considered important, it failed to distinguish small differences. Perhaps if a different scale had been used the results would have shown more variation. For example, if a scale from 1-10 had been used, it may have resulted in greater variety in participant selection.

Table 4.7: Health Care Provider Survey (N=75)

	Very Important		Somewhat Important		Not Important		Missing	
	#	%	#	%	#	%	#	%
Pain								
Assessment	70	93.3	3	4.0	0	0	2	2.7
Management	71	94.7	2	2.7	0	0	2	2.9
Pharmacology	65	86.7	7	9.3	1	2.7	2	2.7
Complementary therapies	34	45.3	34	45.3	4	5.3	3	4.0
Neurophysiology	40	53.3	29	38.7	2	2.7	4	5.3
Symptom Control								
Nausea and Vomiting	67	89.3	4	5.3	0	0	4	6.7
Dysophagia	59	78.7	11	14.7	0	0	5	5.3
Anorexia	52	69.3	18	24.0	1	1.3	4	5.3
Dehydration	65	86.7	6	8.0	0	0	4	5.3
Dypsnea	65	86.7	6	8.0	0	0	4	5.3
Weakness	44	58.7	28	37.3	0	0	3	4.0
Constipation	59	78.7	10	13.3	2	2.7	4	5.3
Diarrhea	61	81.3	8	10.7	1	1.3	5	6.7
Confusion	64	85.3	5	6.7	1	1.3	5	6.7
The last 48 hours	62	82.7	9	12.0	1	1.3	3	4.0
Bereavement								
Theories of grief and loss	48	64.0	36	34.7	1	1.3	0	0
Coping with fears	58	77.3	16	21.3	1	1.3	0	0
The dying child	63	84.0	8	10.7	1	1.3	3	4.0
Child's experiences with grief	55	73.3	15	20.0	0	0	5	6.7
Abnormal grief assessment	54	72.0	20	26.7	0	0	1	1.3
Adjustment after death	49	65.3	26	34.7	0	0	0	0
Psychosocial aspects of death								
Spiritual issues	53	70.7	20	26.7	1	1.3	1	1.3
Religious issues	50	66.7	22	29.3	2	2.7	1	1.3
Cultural issues	56	74.7	18	24.0	0	0	1	1.3
Professional issues								
Resources for the bereaved	48	64.0	23	30.7	2	2.7	2	2.7
Medico-legal concerns	46	61.3	24	32.0	2	2.7	3	4.0
Ethics in palliative care								
Patient competency	53	70.7	15	20.0	1	1.3	6	8.0
Confidentiality	63	84.0	11	14.7	1	1.3	0	0
Research	32	42.7	39	52.0	2	2.7	2	2.7
Resource allocation	43	57.3	24	32.0	3	4.0	5	6.7
Euthanasia	34	45.3	19	25.3	18	24.0	4	5.3
Establishing a palliative care program in the community	62	82.7	6	8.0	1	1.3	6	8.0
Principles of palliative care	67	89.3	4	5.3	0	0	4	5.3
Communication with the patient and family	70	93.3	3	4.0	0	0	2	2.7
Interdisciplinary communication	65	86.7	6	8.0	0	0	4	5.3
Personal ability to cope with a dying patient	69	92.0	5	6.7	0	0	1	1.3
AVERAGE	**56**	***73.8***	**15**	***20.4***	***1.4***	***1.8***	***2.9***	***3.9***

When “not important” was selected, the responses focused on euthanasia more often than in other categories. When analyzed by item, “pain management” was ranked most important (2.97 out of 3, SD=0.16). Other items that were highly ranked included “communication with patient and family” (2.96, SD=0.20), “pain assessment” (2.96, SD=0.20), “control of symptoms nausea and vomiting” (2.94, SD=0.23), and “principles of palliative care” (2.94, SD=0.23). Those that scored the lowest overall were related to “pain and neurophysiology” (2.53, SD=0.56), “pain and comprehensive therapies” (2.42, SD=0.60), “research in palliative care” (2.41, SD=0.55), and “euthanasia” (2.22, SD=0.83).

4.4.2.2 Comparison Testing

As the survey was assessing the educational needs of medical doctors, it was important to test if the participating medical doctors had different impressions of their educational needs than did other health care workers. When the Mann-Whitney statistic was calculated to determine if medical doctors had responded differently on the survey in comparison to the remaining health care workers, significant differences existed in the categories “interdisciplinary communication” (U=518.0, Z=-2.051, p=0.040) and “pain” (U=495.5, Z=-2.079, p=0.039). Cross-tabulations indicated that the scores of other health care workers were significantly higher than medical doctors in both categories.

Table 4.8: Results of Mann-Whitney Test Comparing Scores of Medical Doctors and Other Health Care Workers

Survey Items *(# questions/ category)*	**Medical Doctors (N=44)**		***Other Health Care workers (N=31)***		***Z-score***	***Sig.***
	N	***Mean Rank***	**N**	***Mean Rank***		
Establishing a palliative care program in the community *(1)*	43	*35.34*	26	*34.44*	*-.343*	*.732*
Principles of palliative care *(1)*	44	*35.58*	27	*36.69*	*-.549*	*.583*
Communication with the patient and family *(1)*	44	*36.01*	29	*38.50*	*-1.426*	*.154*
Interdisciplinary communication *(1)*	43	*34.05*	28	*39.0*	*-2.051*	*.040*
Personal ability to cope with a dying patient *(1)*	44	*35.80*	30	*40.0*	*-1.899*	*.058*
Professional Issues *(2)*	44	*39.09*	30	*35.17*	*-.287*	*.774*
Psychosocial aspects of death *(3)*	44	*39.0*	30	*35.30*	*-.846*	*.398*
Bereavement *(6)*	44	*37.45*	31	*38.77*	*-.276*	*.782*
Symptom Control *(10)*	44	*37.59*	31	*37.36*	*-.046*	*.963*
Pain *(5)*	44	*33.76*	31	*44.02*	*-2.079*	*.038*
Ethics *(5)*	44	*35.02*	31	*42.23*	*-1.428*	*.153*
Total Score	**44**	***39.63***	**31**	***35.69***	***-.770***	***.441***

4.5 Summary of Part 1 Results

Part 1 (The *Context of Palliative Care in South Africa*), corresponded to the questions "*How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?*" and "*How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?*". The analysis of structured observations, interviews, and the Health Care Provider Survey produced a comprehensive description of palliative and end-of-life care in South Africa.

Palliative and end-of-life care is not a homogeneous experience in South Africa. Rather, factors like ability to pay and proximity to care determine individual health care experiences. Respondents' experiences in the private and public health care systems were very different. Those reliant on the public system could not be expected to receive the same level of care as those in the private system.

Perhaps in response to the deficiencies in the South African health care system, hospices were developed. In addition to caring for people at end of life, a secondary objective of hospice was to provide excellent palliative care throughout the entire trajectory of illness. Palliative care, a fairly new field in South Africa, was described in other settings, but hospice care was seen to be the primary source for palliative medicine. Stakeholders in the system, be they patients, family care providers, or health care workers, described the merits of hospice care. Even with resource limitations, hospices were described as meeting a critical need within the population. The greatest issue was that hospices were too few and far between; society's need far outweighed their ability to provide meaningful care.

Tied closely to the availability and demand for hospice and palliative care were the educational needs of doctors in the field of palliative medicine. With limited exposure to palliative principles within undergraduate medicine, doctors graduated with a focus on curative as opposed to holistic care. At the systemic level, interview participants highlighted the need for a change in the mindset of health care practitioners; they felt that doctors needed to view the patient in a holistic manner, incorporating the principles of palliative care from birth to death. It was also suggested that with a greater emphasis on holistic care, patients would be more open to the palliative model; the fears of hospice care might be allayed with a greater public understanding of palliative and hospice care.

Specifically relating to medical education, respondents highlighted key areas that doctors needed to focus on: pain management and assessment, communication with patient and family, symptom control, and the principles of palliative care. It was not difficult to see the persistent issues facing patients and family members in those categories.

Due to many factors present in South Africa today, the ever-increasing need for palliative and end-of-life care is the reality. By addressing the needs of society through improved education and strengthened institutional care, it is the hope that patient care will improve. Palliative care should not be considered an elective component of patient management, but rather an essential core service provided to all South Africans.

4.6 Chapter 4 References

(1) Maddocks I. Palliative care education in the developing countries. J.Pain Palliat.Care.Pharmacother. 2003;17(3-4):211-221.

(2) Benatar SR. Health care reform and the crisis of HIV and AIDS in South Africa. N.Engl.J.Med. 2004 Jul 1;351(1):81-92.

(3) Barnabe C, Kirk P. A needs assessment for southern Manitoba physicians for palliative care education. J.Palliat.Care 2002 Fall;18(3):175-184.

CHAPTER FIVE: Results of PART 2: Evaluation of the UCT Distance Education Program

5.1 Introduction

Part 2 consisted of two questions: "*What are/were the positive and negative aspects of the palliative care program as described by current and former students?*" and "*How do former and current students evaluate the influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?*"This component of the research project was based at UCT within the School of Public Health and Family Medicine, thus allowing for greater interaction between the lead researcher, course conveners, administrative staff, and students.

The results of two surveys, the General Survey and the Graduate Survey, will be presented in this chapter. The results of the Pre-Post Workshop Survey are found in Appendix 19. At the outset it was known that the eligible participant sample for the Pre-post Workshop Survey was small (e.g. in 2007 there were 13 eligible participants and in 2006 there were 16) yet it was felt that if there were high response rates (e.g. over 90%) in both the pre and post versions, then the data would be useful. However, the response rates were much lower—8 students from 2007 and 6 from 2006 had matched surveys—which detracted from the usefulness of the results.

5.2 Results of General Survey

5.2.1 Introduction

The General Survey consisted of 31 multiple-choice questions. There were five sections to the survey: 1) Palliative Care Activities, 2) Pain, 3) Assessment, 4) Changes in Treatment, and 5) General Concepts in Palliative Care. The survey was developed from the course objectives (see Appendix 5) and was designed to measure how competent the respondents felt in each of the five areas listed above. The Cronbach alpha of reliability for the six items of the General Survey was 0.81. The inter-item correlation matrix indicated that the correlations between variables ranged from 0.59 to 0.90.

5.2.2 Participants

Of the 125 current or past students eligible to participate in the study, 83 (66.4 %) completed the General Survey. Forty-seven were female (56.6 %). The majority of the participants were older than 30 years (97.5%) (see Table 5.1). The General Survey was completed by both current students (n=44) and graduates of the program (n=39).

Table 5.1: Demographic Overview of General Survey Participants (N=83)

	General Survey*	
Variable	Count	%
Sex		
Male	35	*42.2*
Female	47	*56.6*
Data not provided	1	*1.2*
Age		
18-29	2	*2.4*
30-44	43	*51.8*
45+	37	*44.6*
Data not provided	1	*1.2*

* response rate: 66.4%

5.2.3 Overall Trends

Students could score between 0-93 points on the General Survey (see Table 5.2 for the survey score total and the scores by category). A higher score indicated the perception of greater competence. In the category "Palliative Care Activities", students were asked to determine how well they could perform a specific task. Choices ranged from 0 (needs further basic instruction) to 3 (can perform independently). In the other four categories, students rated their competence level and could select 0 (extremely incompetent) to 3 (extremely competent). The highest average score--indicating that participants perceived themselves to be able to perform a task independently or with extreme competence-- was seen in the category Palliative Care Activities (Table 5.2). In this category, the questions pertained to family conferences, giving bad news, the palliative care treatment approach, home-based hospice referrals, and treatment withdrawal. Participants perceived themselves to have the greatest competence in that field. The lowest average score was seen in the category Changes in Treatment (Table 5.2). Topics ranged from referral of patients with AIDS or cancer to home-based hospice programs, decision-making capacity of patient or family care providers, advanced directives, and the discontinuation of various treatment modalities.

Table 5.2: General Survey Scores by Category and Total Score (N=83)

Category	# of questions	Mean score per question (SD)	Possible Range	Actual Range
Palliative Care Activity	6	2.78 (0.43)	0-18	6-18
Pain	5	2.58 (0.46)	0-15	5-15
Assessment	4	2.48 (0.50)	0-12	6-12
General Concepts in Palliative Care	9	2.17 (0.50)	0-27	5-27
Changes in Treatment	7	2.33 (0.50)	0-21	7-21
Total	**31**	2.42 (0.42)	**0-93**	**34-93**

5.2.4 Results by Category

The five sections of the survey examined different aspects taught in the distance education curriculum. An overview of the survey results can be seen in Table 5.3.

Table 5.3: General Survey Responses (N=83)

	Need further basic instruction		Requires close supervision or teaching		Require minimal supervision		Can perform independently	
	#	%	#	%	#	%	#	%
Palliative Care Activities								
Family Conference	**0**	*0*	**3**	*3.6*	**13**	*15.7*	**67**	*80.7*
Giving Bad News	**0**	*0*	**2**	*2.4*	**6**	*7.2*	**75**	*91.6*
Palliative Care Treatment Approach	**0**	*0*	**3**	*3.6*	**6**	*7.2*	**75**	*91.6*
Home-Based Hospice Referrals	**0**	*0*	**5**	*6.0*	**7**	*8.4*	**70**	*84.3*
Treatment Withdrawal	**0**	*0*	**4**	*4.8*	**13**	*15.7*	**65**	*78.3*
DNR Orders	**2**	*2.4*	**3**	*3.6*	**16**	*19.3*	**63**	*76.0*
Total	**2**	*0.4*	**20**	*4.0*	**61**	*12.2*	**415**	*83.3*
	Extremely Incompetent		Somewhat Incompetent		Somewhat Competent		Extremely Competent	
Pain								
Pain Assessment	**0**	*0*	**1**	*1.2*	**28**	*33.7*	**54**	*65.1*
Oral Opiod Analgesics	**0**	*0*	**2**	*2.4*	**24**	*28.9*	**57**	*68.7*
Parenteral Opioid Analgesics	**2**	*2.4*	**6**	*7.2*	**34**	*41.0*	**41**	*49.4*
Adjuvant Analgesics	**0**	*0*	**3**	*3.6*	**28**	*33.7*	**52**	*62.7*
Pain Specialist	**0**	*0*	**1**	*1.2*	**19**	*22.9*	**60**	*72.3*
Total	**2**	*0.5*	**13**	*3.2*	**133**	*32.3*	**264**	*64.1*
Assessment								
Terminal Delirium	**0**	*0*	**13**	*15.7*	**40**	*48.2*	**30**	*36.1*
Terminal Dyspnea	**0**	*0*	**8**	*9.6*	**36**	*43.4*	**39**	*47.0*
Nausea / Vomiting	**0**	*0*	**1**	*1.2*	**26**	*31.3*	**56**	*67.5*
Constipation	**0**	*0*	**0**	*0*	**28**	*33.7*	**55**	*66.2*
Total	**0**	*0*	**22**	*6.6*	**130**	*39.1*	**180**	*54.2*
Changes in Treatment								
Referral of AIDS patients	**0**	*0*	**5**	*6.0*	**31**	*37.3*	**47**	*56.1*
Referral of Cancer Patient	**0**	*0*	**6**	*7.2*	**25**	*30.1*	**51**	*61.4*
Decision-Making Capacity	**0**	*0*	**8**	*9.6*	**47**	*56.6*	**27**	*32.5*
Advanced Directives	**0**	*0*	**9**	*10.8*	**42**	*50.6*	**31**	*37.3*
Discontinuation of IV Hydration	**0**	*0*	**9**	*10.8*	**30**	*36.1*	**44**	*53.0*
Discontinuation of non-oral feedings	**0**	*0*	**10**	*12.0*	**33**	*39.8*	**40**	*48.2*
Withdrawal from Mechanical Ventilation	**1**	*1.2*	**16**	*19.3*	**41**	*49.4*	**24**	*28.9*
Total	**1**	*0.2*	**63**	*10.9*	**249**	*43.1*	**264**	*45.8*
General Palliative Care Concepts								
Loss in Different Age Groups	**1**	*1.2*	**12**	*14.5*	**51**	*61.4*	**19**	*22.9*
Needs of Children as Relatives	**1**	*1.2*	**17**	*20.5*	**53**	*63.9*	**12**	*14.5*
Palliative Care Management in Children	**3**	*3.6*	**16**	*19.3*	**50**	*60.2*	**14**	*16.9*
Barriers to a Meaningful Death	**0**	*0*	**2**	*2.4*	**41**	*49.4*	**40**	*48.2*
Cultural Variations	**1**	*1.2*	**17**	*20.5*	**36**	*43.4*	**29**	*34.9*
Communication	**0**	*0*	**3**	*3.6*	**39**	*47.0*	**40**	*48.2*
Team Work	**1**	*1.2*	**5**	*6.0*	**33**	*39.8*	**43**	*51.8*
Local Palliative Care Facilities	**2**	*2.4*	**15**	*18.1*	**38**	*45.8*	**27**	*32.5*
Public Policy Debate	**2**	*2.4*	**18**	*21.7*	**36**	*43.4*	**25**	*30.1*
Total	**11**	*1.5*	**105**	*14.1*	**377**	*50.8*	**249**	*33.6*
TOTAL	**16**	*0.6*	**223**	*8.7*	**950**	*37.1*	**1134**	*44.3*

1) Palliative Care Activities. There were six questions in this section that covered the following topics: family conferences, breaking bad news, the palliative care treatment approach, home-based hospice referrals, treatment withdrawal, and DNR orders. The majority of participants (95.5%) felt that they could perform all the activities independently or with little supervision. There was only minor variation between questions. For example, over 80% of the respondents felt "extremely competent" in holding family conferences, giving bad news, home-based hospice referrals, and the palliative care treatment approach. A slightly smaller percentage (ranging from 76.0- 78.3%) stated they were "somewhat competent" in the areas of treatment withdrawal and DNR orders.

2) Pain. Five questions were used to determine student competency in the assessment of pain, use of different forms of analgesics (oral, parenteral and adjuvant), and knowing when to refer the patient to a pain specialist. The general trend was that respondents felt either somewhat or extremely competent in all areas; of the 412 responses corresponding to this category, 264 (64.1%) were in the "extremely competent" category and 133 (32.3%) were in the "somewhat competent" category. Only 15 (3.6%) of responses identified some degree of perceived incompetence, eight of which were in the question pertaining to the use of parenteral opioid analgesics.

It was chiefly the category pertaining to parenteral opioid analgesics that students described themselves as less competent. Here, 41 participants (49.4%) chose "extremely competent", 34 (41.0%) "somewhat competent", 6 (7.2%) "somewhat incompetent", and 2 (2.4%) "extremely incompetent".

3) Assessment. Four questions were used to measure participant competence in assessing terminal delirium, dyspnea, nausea or vomiting, and constipation. In general, the majority of students felt some level of competence in all aspects of assessment. Of the 332 responses in this category, 180 (54.2%) were in the category of "extremely competent", 130 (39.1%) were as "somewhat competent", and 22 (6.6%) as "somewhat incompetent". In all areas except terminal delirium, students reported feeling extremely competent more often than somewhat competent. In the category "Terminal Delirium", however, more students (48.2%) selected "somewhat competent" as compared to the 36.1% responses in the "extremely competent" category.

4) Changes in Treatment. Students were asked to respond to seven questions in this category. Topics ranged from referral of patients with AIDS or cancer to home-based hospice programs, decision-making capacity of patient or family care providers, advanced directives, and the discontinuation of various treatment modalities. Regarding referrals of patients, discontinuation of IV treatment, and discontinuation of non-oral feedings students reported being "extremely competent" more often than "somewhat competent". The fields relating to decision-making capacity, advanced directives, and withdrawal from mechanical ventilation, however, showed a greater proportion of students as "somewhat competent".

5) General Palliative Care Concepts. The final nine questions related to pediatric palliative care, cultural issues in dealing with death and dying, patient and staff communication, team work, knowing how to access local palliative care resources, and the broader public policy debate around palliative care in South Africa. The responses to the three questions relating to pediatric palliative care indicated a general trend that participants felt less competent than in any of the other general palliative care concepts.

5.2.5 Comparison Testing

The General Survey was completed by a wide range of participants; to see if different characteristics led to different results, a series of Mann-Whitney statistics were conducted. An analysis comparing scores of graduates to current students determined that in both total score and category scores, the graduates scored higher (current students- mean 71.4, SD 14.2, graduates- mean 79.0, SD 9.9). The Mann-Whitney test (Table 5.4) expanded further on these findings; graduates were found to have significantly higher scores than current students in all categories with the exception of "General Palliative Care Concepts" (U=648.0, Z=-1.927, p=0.054).

Table 5.4: Results of Mann-Whitney Test Comparing General Survey Scores of Graduates and Current Students

Survey Items *(# questions/ category)*	**Current Students (N=44)**	**Graduates (N=39)**	**Z-score**	***Sig.***
	Mean Rank	*Mean Rank*		
Activity	36.88	47.78	-2.420	**.016**
Pain	35.80	49.00	-2.554	**.011**
Assessment & Management	37.23	47.38	-1.959	**.050**
General PC Concepts	37.22	47.40	-1.927	.054
Changes in Treatment	35.58	49.24	-2.590	**.010**
Total Score	35.44	49.40	-2.635	**.008**

A Kruskal-Wallis Test was conducted to examine whether responses varied according to the program level of survey participants (Table 5.5). Four groups were created: 1) first year students, 2) second year students, 3) continuing students, and 4) graduates. The results indicated that significant differences existed: Activity (Kruskal Wallis X^2_3=27.36, p<0.01); Pain (Kruskal Wallis X^2_3= 14.93, p<0.01); Assessment and Management (Kruskal Wallis X^2_3= 13.72, p<0.01); General Palliative Care Concepts (Kruskal Wallis X^2_3= 15.16, p<0.01); Changes in Treatment (Kruskal Wallis X^2_3= 23.85, p<0.01); Overall Score (Kruskal Wallis X^2_3= 21.31, p<0.01). To examine these significant findings, pairwise Mann-Whitney U post hoc comparisons were conducted. In all categories, the scores of first year students were significantly lower than second year students, continuing students and graduates (range p=0.028 to <0.01). In the two categories Changes in treatment and Overall Score, second year students had significantly lower scores in comparison to continuing students and graduates (p values ranged from 0.049 to <0.01).

Table 5.5 Means and standard deviation of General Survey results by program level

	N	Mean Rank	X^2_3
Activity §			27.36
First Year Student	12	15.71	
Second Year Student	17	38.09	
Continuing Student	15	52.43	
Graduate	39	47.78	
Pain §			14.93
First Year Student	12	19.46	
Second Year Student	17	39.35	
Continuing Student	15	44.83	
Graduate	39	49.00	
Assessment & Management §			13.72
First Year Student	12	21.42	
Second Year Student	17	37.00	
Continuing Student	15	50.13	
Graduate	39	47.38	
General PC Concepts §			15.16
First Year Student	12	17.71	
Second Year Student	17	41.50	
Continuing Student	15	47.97	
Graduate	39	47.40	
Changes in Treatment §¶			23.85
First Year Student	12	15.58	
Second Year Student	17	33.59	
Continuing Student	15	53.83	
Graduate	39	49.24	
Overall Score §¶			21.31
First Year Student	12	15.38	
Second Year Student	17	36.15	
Continuing Student	15	50.70	
Graduate	39	49.40	

§first year student significantly lower scores than all other comparison groups

¶ second year students significantly lower scores than continuing students and graduates

Overall, the results of Kruskal Wallis Test may suggest that the students' perception of confidence and competence increases as they move through the program; students develop confidence in the field of palliative care as a result of the distance education palliative care course at the University of Cape Town.

5.3 Results of Graduate Survey

5.3.1 Introduction

The Graduate Survey was designed to assess graduates' perspectives of the distance education palliative care course taught at UCT. It included survey questions (based on the course objectives) as well as open-ended questions in order to solicit information about changes in personal care practice, perceived benefits, limitations, and suggestions for improvement. The survey consisted of 33 questions; 25 in a multiple-choice format and eight open-ended. The Cronbach alpha of reliability for the five items of the Graduate Survey was 0.82. The inter-item correlation matrix indicated that the correlations between variables ranged from 0.21 to 0.73.

5.3.2 Participants

There have been 71 graduates from the distance education program, but accurate contact information was not available for four of them. Of the 67 possible respondents, 41 (or 65.7%) returned a completed Graduate Survey. The demographic overview of participants (Table 5.6) indicates that there were more female respondents (27 or 65.9%) and that the majority of participants were either aged 30-44 years (51.2%) or 45 years and older (46.3%).

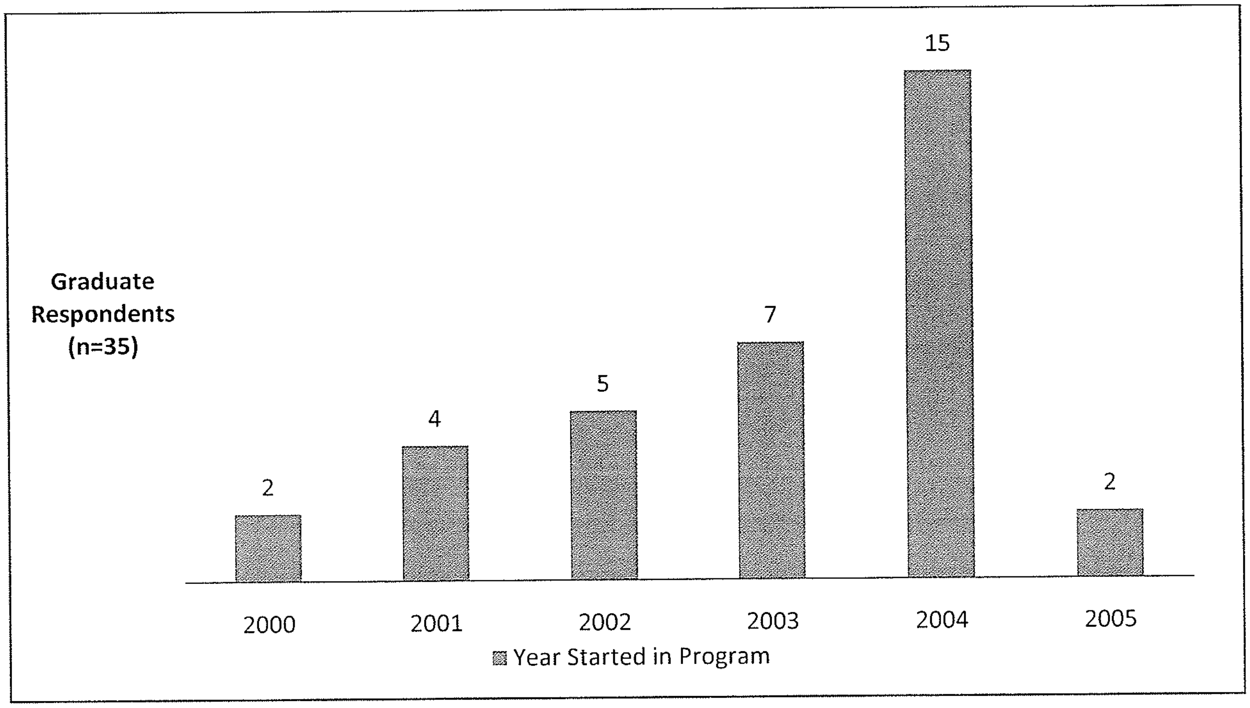
Table 5.6: Demographic Overview of Graduate Survey Participants (N=41)

	Graduate Survey*	
Variable	Count	%
Sex		
Male	14	*34.1*
Female	27	*65.9*
Age Group		
18-29	1	*2.4*
30-44	21	*51.2*
45+	19	*46.3*

* response rate: 65.5%

The graduate survey respondents were asked to provide the year they began and graduated from UCT's distance education course and 35 respondents provided this information. The average length of time it took respondents to complete the course was 1.8 years (range= 1 to 5 years; median= 1 year). As seen in Figure 5.1, the majority (42.9%) of the respondents began the course in 2004.

Figure 5.1 : Year of Graduate Respondents' Entry into Program



5.3.3 Overall Trends

Students could score between 0-100 points on the multiple-choice section of the Graduate Survey (Table 5.7), with higher scores indicating the perception that the program was helpful or useful. Students rated how helpful the course was to them. These statements were considered as continuous variables and were coded as 2 (not helpful), 3 (somewhat helpful), 4 (very helpful), 1 (no opinion), and 0 (not applicable). The highest average scores were seen in the category General Aspects which included topics like management of patients with different conditions, therapeutic principles and practices, knowledge of various treatment choices, and pain management. The lowest average scores were in the category End of Life Care in South Africa which examined topics like the collaboration between public health care structures and NGOs, the public policy debate, and local facilities for palliative care (Table 5.7).

Table 5.7: Graduate Survey Scores by Category and Total Score (N=41)

Category	# of Questions	Mean score per question (SD)	Possible Range	Actual Range
General Aspects	10	3.77 (0.29)	0-40	27-40
Clinical Assessment	6	3.48 (0.38)	0-24	16-24
Team Approach	4	3.50 (0.43)	0-16	10-16
End-of-life Care	5	3.08 (0.70)	0-20	7-20
TOTAL	**25**	3.54 (0.29)	**0-100**	**70-100**

5.3.4 Results by Category

The four sections of the Graduate Survey evaluated the experiences of the distance education course. An overview of the survey results can be seen in Table 5.7.

Table 5.8: Graduate Survey Responses (N=41)

	Not helpful		Somewhat helpful		Very helpful		No opinion		Not applicable	
	#	%	#	%	#	%	#	%	#	%
General Aspects										
quality of palliative care	0	*0*	4	*9.8*	37	*90.2*	0	*0*	0	*0*
management of patients with different conditions	0	*0*	6	*14.6*	35	*85.4*	0	*0*	0	*0*
analyze the literature	2	*4.9*	9	*22.0*	30	*73.2*	0	*0*	0	*0*
support clinical decisions	0	*0*	9	*22.0*	32	*78.0*	0	*0*	0	*0*
knowledge of various treatment choices	0	*0*	12	*29.3*	29	*70.7*	0	*0*	0	*0*
diagnostic principles and practices	1	*2.4*	7	*17.1*	33	*80.5*	0	*0*	0	*0*
therapeutic principles and practices	0	*0*	6	*14.6*	35	*85.4*	0	*0*	0	*0*
pain management	0	*0*	7	*17.1*	34	*83.0*	0	*0*	0	*0*
clinical application*	1	*2.5*	9	*22.5*	29	*72.5*	1	*2.5*	0	*0*
management of other symptoms	0	*0*	9	*22.0*	32	*78.0*	0	*0*	0	*0*
Total	**4**	***0.9***	**78**	***19.1***	**326**	***79.7***	**1**	***0.2***	**0**	***0***
Clinical Assessment										
the range of human behavior associated with loss in different age groups	1	*2.4*	21	*51.2*	19	*46.3*	0	*0*	0	*0*
the particular needs of children as relatives	3	*7.3*	19	*46.3*	19	*46.3*	0	*0*	0	*0*
palliative care management – children	2	*4.9*	24	*58.5*	15	*36.6*	0	*0*	0	*0*
barriers to achieving a dignified death*	0	*0*	9	*22.5*	31	*77.5*	0	*0*	0	*0*
bio-ethical principles in clinical decisions	0	*0*	12	*29.3*	29	*72.5*	0	*0*	0	*0*
cultural variations of belief and behavior	1	*2.4*	20	*48.8*	19	*46.3*	0	*0*	1	*2.4*
Total	**7**	***2.8***	**105**	***42.9***	**132**	***53.9***	**0**	***0***	**1**	***0.4***
Team Approach										
communication	0	*0*	7	*17.1*	34	*83.0*	0	*0*	0	*0*
encounters posing challenging problems	0	*0*	10	*24.4*	31	*75.6*	0	*0*	0	*0*
improving teamwork	1	*2.4*	17	*41.4*	23	*56.1*	0	*0*	0	*0*
problems associated with teamwork, shared care and hospice care	1	*2.4*	17	*41.4*	22	*53.6*	1	*2.4*	0	*0*
Total	**2**	***1.2***	**51**	***31.1***	**110**	***67.1***	**1**	***0.6***	**0**	***0***
End-of Life Care in South Africa										
local facilities for palliative care	6	*14.6*	21	*51.2*	13	*31.7*	1	*2.4*	0	*0*
palliative care facilities	7	*17.1*	22	*53.6*	12	*29.3*	0	*0*	0	*0*
public policy debate	5	*12.2*	19	*46.3*	15	*36.6*	2	*4.9*	0	*0*
development of humane, ethical and equitable public policy	6	*14.6*	15	*36.6*	17	*41.5*	3	*7.3*	0	*0*
collaboration between public health care structures and NGOs *	7	*17.5*	12	*30*	16	*40*	4	*10*	1	*2.5*
Total	**31**	***15.2***	**89**	***43.6***	**73**	***35.8***	**10**	***4.9***	**1**	***0.5***
TOTAL	**44**	***4.3***	**323**	***31.6***	**641**	***62.7***	**12**	***1.2***	**2**	***0.2***

*(n=40)

1) General Aspects. Students were asked to rate how helpful the course was in developing a general understanding of palliative care. For example, students were asked to determine the usefulness of the course in helping them to examine the quality of palliative care in a number of patients with different conditions, to critically analyze the literature concerning the principles of palliative medicine, to evaluate the scientific basis of pain management, and to discuss clinical application of evidence based palliative care. Participants ranked the course using a scale that ranged from "not helpful", "somewhat helpful", "very helpful", "no opinion", to "not applicable". The majority of responses were in the categories "very helpful" (79.7%) or "somewhat helpful" (19.1%) indicating that the course was strong in teaching general concepts of palliative care.

2) Clinical Assessment. Six questions were posed to evaluate how helpful the course was in developing their ability to complete or conduct a range of clinical assessment activities such as assessing human behaviours associated with loss in different age groups; understanding the needs of children; having knowledge pertaining to palliative care management issues specific to children; understanding barriers to achieving a dignified and meaningful death; understanding bio-ethical principles of clinical decisions; and understanding cultural variations of belief and behaviour.

Overall, students responded that the course was "very helpful" (53.9%) or "somewhat helpful' (42.9%) as compared to "not helpful" (2.9%) or "not applicable" (0.3%). There was some variation across questions. For example, in the questions pertaining to barriers to a meaningful death and bio-ethical principles in clinical decision-making, a higher proportion of students reported that the course was very helpful (77.5% and 72.5% respectively). However, in three questions- those pertaining to range of human behaviour associated with loss in different age groups, palliative care management issues specific to children, and cultural variations of belief and behaviour which may influence care- students chose "somewhat helpful" more often than "very helpful". This may indicate a weakness of the course.

3) Team Approach. The third section of the Graduate Survey evaluated how useful the course was in teaching a team approach to providing palliative care. The four areas covered were: communication with staff, patients and relatives who are involved with palliative care; reflection and analysis of challenging encounters; improvement of teamwork within existing facilities; and an approach to the problems associated with teamwork, shared care and hospice care.

Student responses pertaining to communication and challenging encounters were very supportive of the palliative care course; 79.3% (65 out of 82) responses were in the category "very helpful" and the remaining 17 (20.7%) were "somewhat helpful". The responses for the second pair of questions- pertaining to ways to improve teamwork and teamwork issues- indicated less certainty; students chose "somewhat" (42.0%) almost as often as "very" (55.6%).

4) End-of-life Care in South Africa. The fourth section of the Graduate Survey evaluated how helpful the course was in developing the ability to describe local facilities for palliative care, evaluate local palliative care facilities, contribute towards the development of public policy, and promote collaboration between public health care organizations and NGOs involved in palliative care. There were a total of 206 responses in this section; 73 (35.4%) indicated the course was “very helpful”, 91 (44.2%) chose “somewhat helpful”, 31 (15.0%) stated “not helpful”, and 11 (5.4%) selected “no opinion” or “not applicable”. Based on the responses, it appears that respondents do not appear to have great confidence in their ability to locate or evaluate local palliative care service providers. Nor did they find the course particularly helpful in developing a greater understanding of the public policy debate around palliative care. These results may indicate several areas that need further development in the course, or may reflect that those questions are not as relevant to the graduates’ work setting.

5.3.5 Comparison Testing

It was felt that a number of variables may affect a graduate’s survey responses. Three variables in particular: 1) when a student began the palliative care education program, 2) the number of years the participant had been practicing medicine, and 3) the number of palliative patients that the graduate annually treated, were examined further. To examine if the year of enrollment was a factor, two proportional groups were created. Half the trainees enrolled in the program prior to 2004 formed one group (n=19, total score mean rank= 17.03) while those that were enrolled after 2004 were the second group (n=20, total score mean rank= 22.83). The category pertaining to the number of years practicing as a medical doctor was created after examining the median (10 years) and average (29.7 years); The first group consisted of 21 doctors who had practiced medicine for 10 years or less (total score mean rank= 19.95) and the second group more than 10 years (total score mean rank=22.10). The third category looked at the number of patients classified as having a life-threatening illness that the doctor treated annually. The median for this category was 20 patients and the average 19.8 patients. Therefore, the first group included 19 patients or less (n=22, total score mean rank=20.73) and the second had 20 patients or more (n=16, total score mean rank= 17.81)

To evaluate possible differences in the various groupings, a series of Mann-Whitney statistics were conducted. However, the only significant differences between the groups were evident in the Clinical Approach category. Students that had begun the program after 2004 had significantly higher scores pertaining to questions on the ability to: a) clinically assess the range of human behaviour associated with loss in different age groups, b) understand the particular needs of children as relatives, c) have some knowledge of the palliative care management issues specific to children, d) have detailed understanding of barriers to achieving a dignified and meaningful death, e) demonstrate bio-ethical principles underpinning clinical decisions, and f) have knowledge of the cultural variations of belief and behaviour which may influence relevant delivery of care (U=73.5, Z=-3.302, p=0.001). As there was multiple testing, a 1% significance level was chosen to protect against increased Type 1 errors. The significance level of 0.001 seen in this particular analysis appears to be strong evidence of a true difference in scores.

Table 5.9: Results of Mann-Whitney Test Comparing Graduate Survey Scores in Three Groupings

Year Started in Program[xiv] **N=39**	**Began program in 2003 or earlier (n=19)**	**Began program in 2004 or later (n=20)**	**Z-score**	**Significance**
	Mean Rank	***Mean Rank***		
General Aspects	17.76	22.13	-1.252	.211
Clinical Approach	13.87	25.83	-3.302	***.001***
Team Approach	17.95	21.95	-1.150	.250
End-of-life Care in SA	21.18	18.88	-.639	.523
Total Score	17.03	22.83	-1.592	.111

Number of Years Practicing Medicine[xv] **N=38**	**10 or fewer years in practice (n=21)**	**11 or more years in practice (n=20)**	**Z-score**	**Significance**
	Mean Rank	***Mean Rank***		
General Aspects	18.90	23.20	-1.198	.231
Clinical Approach	20.55	21.48	-.250	.803
Team Approach	22.64	19.28	-.940	.347
End-of-life Care in SA	19.52	22.55	-.816	.415
Total Score	18.90	23.20	-1.198	.231

Number of Patients with Life Threatening Illness [xvi] **N=38**	**19 patients or less (n=22)**	**20 patients of more (16)**	**Z score**	**Significance**
	Mean Rank	***Mean Rank***		
General Aspects	19.48	19.53	-.015	.988
Clinical Approach	20.41	18.25	-.596	.551
Team Approach	20.45	18.25	-.650	.515
End-of-life Care in SA	19.86	19.00	-.239	.811
Total Score	20.73	17.81	-.801	.423

[xiv] **Year Started Program**: Group A included students beginning the program earlier than 2003 (n=19) and Group B included students beginning the program in 2004 or later (n=20).

[xv] **Number of Years Practicing Medicine:** median of 10 years; average of 29.7 years. Group A included 10 years or less (n=21); Group B included 11 years or more (n=20)

[xvi] **Number of Patients**: median= 20 patients; average= 19.8 patients. Group A included 19 patients or less (n=22); Group B included 20 patients or more (n=16)

5.3.6 Thematic Results of Open-Ended Questions

There were eight open-ended questions interspersed throughout the Graduate Survey: 1) Can you describe why you enrolled in the palliative care distance education program? 2) Can you explain if and how your care practice has changed for patients requiring palliation? 3) What were three key aspects of your training that you have transferred into your practice? 4) Please identify any weaknesses in the UCT program. 5) How has the palliative care program benefited your patients? 6) How has the palliative care program benefited your co-workers? 7) How would you wish to see the concerns you raise addressed? 8) What are your concerns regarding end-of-life care in South Africa? The questions were designed to examine graduates' perceptions in light of their recent educational experience.

The responses to these questions could be classified into three distinct themes: 1) The Progressive Influence of the Palliative Care Course, 2) Concerns about Palliative Care in South Africa, and 3) Room for Improvement. Each theme will be discussed in turn.

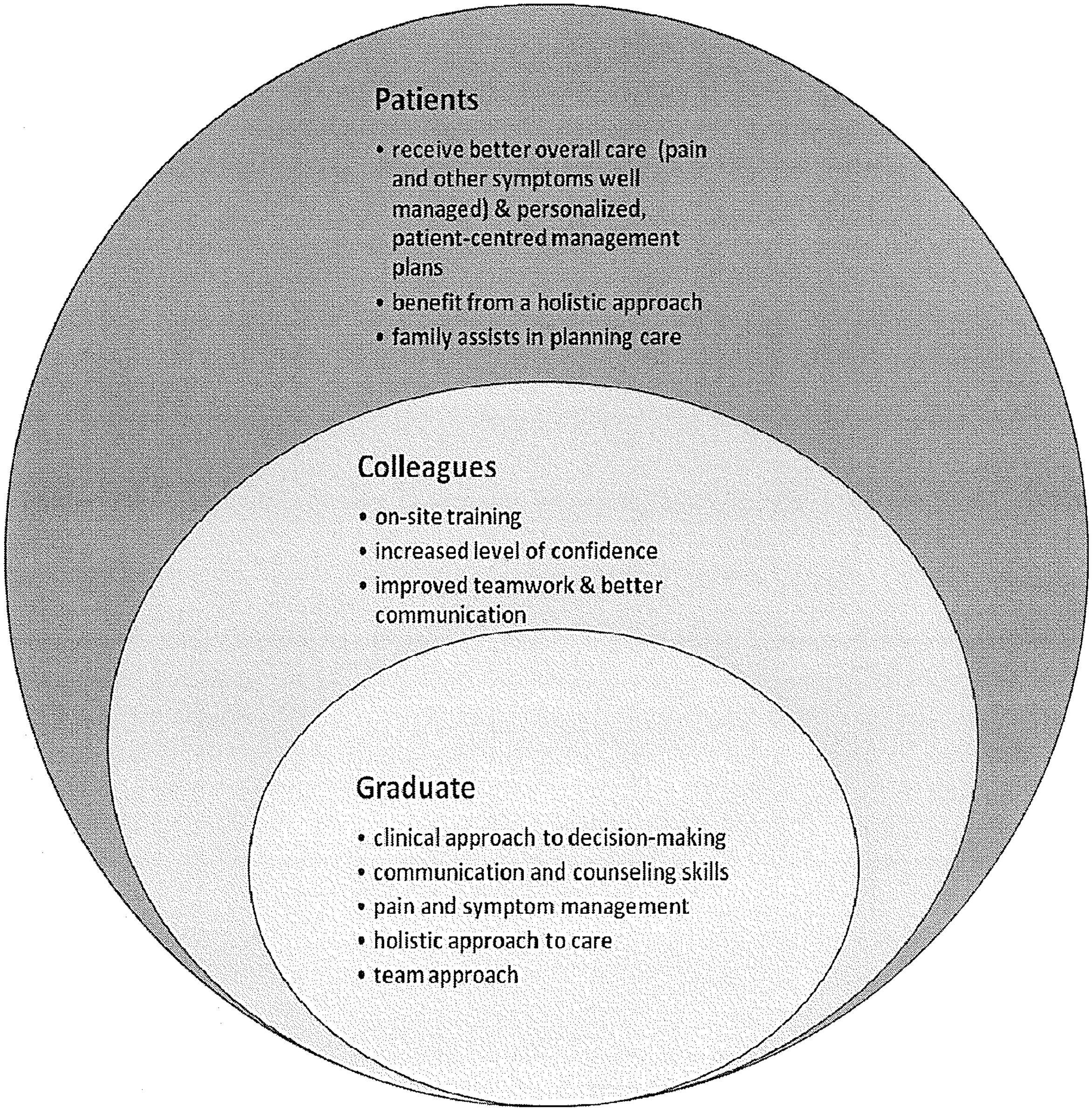
Theme 1: The Progressive Influence of the Palliative Care Course

Participants in the study described how the distance education palliative care course influenced their lives in a progressive way. From changes that occurred on an individual level to the systemic changes in the larger health care environment, respondents emphasized the beneficial nature of the program; the education program had changed their understanding of medical care which spread into different facets of their professional lives. In the words of one participant,

> *"I don't think I even understood what palliative care meant before this course. It certainly was not anything I studied in medical school in my time. But I found that a large number of my younger colleagues did not understand it either, judging by the questions they asked me. It certainly has changed my entire approach to caring for patients with life-threatening illnesses. I now know how to effectively manage pain, nausea, vomiting, constipation, how to recognize delirium, to recognize hallmarks of dying, to break bad news, recognizing conflict in the family and dealing with it, etc." (6242)*

Based on the information provided by participants, it became evident that course material appeared to seep into different levels of the health care system. As seen in Figure 5.2, there appeared to be a ripple effect, where positive elements flowed through different populations and created a better health care environment overall. The following section aims to discuss more specifically the changes that occurred within the students, their colleagues, and the patient population.

Figure 5.2: The Influence of the Palliative Care Program



Sub-theme 1A: Practitioner (Graduate)

Students chose to take the course for a variety of different reasons including but not limited to the reputation of the lecturers, the distance education format, a desire to have an official qualification, and the ideals of the course. A lack of knowledge in palliative care was a prominent theme in the findings, particularly since many perceived palliative medicine to be a new discipline. Respondents shared that, as they had not received any training in palliative medicine in their undergraduate medical degree, they wanted to develop these skills; others described a personal sense of inadequacy in dealing with patients with chronic or life threatening conditions. In the words of one respondent,

"I needed knowledge in palliative care to care for our many terminal HIV/AIDS patients and to educate our undergraduate students. We receive NO training in the undergraduate years (1972-78) and post-graduate years (M.Fam.Med: 1982-83)." (6249)

Doctors also stated that patient need was a reason for selecting the distance education course. Doctors witnessed and delivered inadequate care provision within the workplace and felt a desire to better meet the needs of their patients. Respondents expressed that the HIV/AIDS pandemic had exacerbated the need for palliative care within South Africa and that the increased burden of disease had made them more aware of the discipline. As one respondent wrote,

"I was working in a large provincial hospital and we were seeing a large number of indigent HIV patients. At that stage the government was not providing ARVs. I felt totally ill-equipped to deal with this group of mainly young patients who were staring death in the face". (6242)

The perception that the course was worthy and of great value professionally was clear within participants' responses. From the practitioner (graduate) perspective, skills were developed in five fields: clinical decision-making; communication and counseling skills; pain and symptom management; holistic approach to care; and a team approach. These skills were perceived to be a direct result of the distance education palliative care course and as such, influenced the delivery of health care at end of life. Each sub-theme will be discussed separately.

Clinical decision-making. Respondents felt that their understanding of palliative care had broadened and that this had resulted in a change in their approach to care. In particular, graduates perceived an increase in confidence in clinical decision-making. In the words of one graduate, *"I became more confident with dealing with the problems in the ward. In palliative care it is always difficult to decide when to actively treat the patient and when to accept that the treatment may adversely affect the quality of life of the patient. The course helped me with such decisions" (6280).* Applying the principles of palliative care in daily decision-making was seen as an important lesson gleaned from the distance education course. Doctors felt better able to discuss aspects of care such as advance directives, changing the focus of treatment, and incorporating an ethical approach to care with patients and families.

Communication and counselling skills. As one graduate wrote:

> *"I became more interested in the role of communication and found benefit in the role play [a course technique used to teach communication skills] with regards to breaking bad news. I follow a more structured process to this." (6368)*

The course taught the students to be better communicators; many broad references were made to better or improved communication and counselling skills. Some doctors noted that they had entered the course with no counselling skills and had left with the ability and confidence to meet with patients and families. In day-to-day interactions, pre-bereavement counselling, or in family meetings, counselling skills were seen as critical elements of care. Graduates also specified improvements in listening, training colleagues, and in breaking bad news to both patients and family members.

Pain and symptom management. The bulk of respondents made reference to pain and symptom management. Prior to the course, respondents stated that they had a limited idea of how to treat pain; afterwards, they felt confident to provide excellent pain and symptom management for their patients.

"This course accentuated the importance of good pain relief. I used to be very reluctant to use opioid analgesics, but during the course I learned more about the right way of prescribing these, by anticipating and dealing with side-effects proactively".

Doctors discussed the value in learning about the appropriate use of different medications such as opiates or morphine, and they saw this as a critical component of their training.

Holistic approach to care. Holistic care was described as focusing on the entire patient, including the physical, social, emotional and spiritual needs. Following the course, graduates described a greater consideration for the patient's quality of life. For example, *"Pre-course: I would try to treat patients with breast carcinoma with more toxic chemotherapy to achieve success without consideration for the quality of life. Post course: definitely able to involve families and withdraw treatment to allow the patient a 'more comfortable death'" (6282)*

Some of the respondents stated that a move to holistic care could be seen specifically in the increased involvement by patients and families in the decision-making process. This was manifest in two ways: when making decisions, the doctor would take into consideration the overall needs of both patients and families, or, doctors would invite both patients and families to review different care options before decisions were made. Overall, doctors expressed a greater appreciation of the patient as a person; they had a better understanding of patient autonomy and saw this as a critical aspect to patient care. Several respondents specified how culture, or having a better understanding of the patients' cultural background, shaped care provision. The course had underscored the need to accept and respect cultural and ethnic differences.

Team approach. Managing care with the assistance of a team of health care providers was a novel concept for a portion of the graduates. Learning to apply a team approach also became a highlight of the course; working with an interdisciplinary team and relying on others to provide an aspect of care was an important lesson that they were able to incorporate into their health care practice. Two quotes highlight this:

"I am a better doctor. More skilled, more able to pull a team together that includes patient, family and staff" (3307).

"I'm now able to assess patients who need palliative care and able to establish a palliative team to manage the patient and the family" (6262).

Sub-theme 1B: Colleagues

When graduates incorporated the principles of the education course into their workplace, it was described as benefiting their colleagues. Four areas: on-site training in palliative medicine, increased level of confidence, improved teamwork, and better communication were noted by respondents.

On-site training in palliative medicine. A valuable offshoot of the course was the positive effects training had within the workplace. Many of the graduates noted that a great benefit was having the ability to assist and instruct in palliative care principles. Whether the graduates trained nursing, other doctors, or undergraduate medical students, the value of this education was seen to benefit their colleagues. As one doctor wrote, *"I feel we have all benefited from the knowledge and skills; feel safer. They have learned from me." (3307)*

Increased level of confidence. Earlier it was noted that the course led to a higher level of confidence in the student or graduate. Graduate Survey respondents also noted that their colleagues experienced a related increase in confidence. For example, one graduate said *"I developed confidence in managing our patients, which benefited the inter-disciplinary team"* (6239). Due to an increase in communication and training in the field of palliative medicine, staff was perceived to be more confident in their own decision-making around palliative care. The formal training received in the distance education course bolstered confidence in technique and sound decision making; as the individual practitioners incorporated their training into the workplace, colleagues' confidence also improved.

Improved teamwork. While some survey respondents may have adopted teamwork principles in the workplace prior to the program, this was not a commonplace or well-established practice. In learning of the benefits of teamwork, a greater reliance on a range of health care providers within the palliative care setting emerged. Graduates were able to return to their work settings with a novel approach to care. One respondent (6273) described this as an *"empowering"* experience within the work setting.

Better communication. During the face-to-face workshops held each year for the first and second year students, communication skills are taught. Learning how to communicate with patients, family members and health care staff was seen by graduates as a valuable skill within the work setting. As one graduate stressed *"I became more interested in the role of communication and found benefit in the role play with regards to breaking bad news. I follow a more structured approach to this"* (6368). A range of graduates expressed that they were better communicators as a result of the course

Sub-theme 1C: Patients

Graduates perceived that patient care had improved as a result of the distance education palliative care program. In particular, two sub-themes emerged that highlighted changes in patient care: better overall care and a holistic approach through patient centred management plans

Better overall care. Doctors felt strongly that their patients received better overall care and this was described as a direct result of their training. Graduates felt more competent in providing care; examples of this pertained to changes in overall care, symptom assessment and management, psychosocial care, and communication. The following two quotes express these sentiments:

"My patients are assessed for symptoms better, they receive the best symptom control that I can offer and I pay attention to psychosocial issues. Patients are referred to hospice when necessary." (6234)

"There is greater connectivity, an increased sensitivity and a more profound engagement. I feel more free to discuss and probably advise on matters which I withheld from previously." (6273)

Several respondents felt that taking the course had bolstered their confidence, which transferred directly to better care.

Holistic approach through patient-centred management plans. Doctors described that they now used a holistic approach to patient care. This appeared to be a paradigm shift for many of the graduates in that they moved from a purely curative approach to one that incorporated patient physical, social, and emotional needs.

"They can rely on me and they trust me in dealing with their problems be it clinical or non-clinical." (6244)

This appeared to be a new concept for not only practitioners, but patients as well. Graduates expressed that by incorporating the personalized, patient centred management plans championed in the course, patients had benefited.

Theme 2: Concerns about Palliative Care in South Africa

Two questions of the survey, *"What are your concerns regarding end-of-life care in South Africa?"* and *"How would you wish to see the concerns you raise addressed?"* had the purpose of examining palliative care on a policy level. Based on the responses, the second theme regarding concerns about palliative care in South Africa emerged. As can be seen in Figure 5.3, a list of concerns, based on the responses, were raised by the graduates of the distance education program.

Figure 5.3: Issues Regarding Palliative Care in South Africa

Concerns

- demand for palliative trained staff greater than supply
- lack of awareness or education in palliative care
- stigma related to palliative care and / or patients with HIV/AIDS
- euthanasia debate
- competing claims on scare health care resources: palliative care services suffer
- inacurrate perceptions of palliative medicine and hospice care
- provision of palliative care fragmented
- poor standards in health care
- social conditions draw focus away from palliative care

Methods to Address Concerns

- increase education and funding in palliative medicine
- recognize palliative medicine as a specialty
- raise profile of palliative and hospice care
- insist on better coordination of hospice care
- improve health in general
- increase political awareness of palliative care

Several concerns could be described as systemic health care issues: competing claims on health care resources, demand for trained staff greater than the supply, and poor standards in health care. These issues speak to possible inadequacies within South Africa's public health care system. Resolving these issues will require clear leadership within the public and governmental sector.

The fragmentation of the system of palliative and end-of-life care was also a concern for respondents. Creating a system of care in South Africa where palliative medicine and hospice care was available to the entire population, however, would again require the participation and funding commitments from all levels of government. Graduates also highlighted issues pertaining directly to the general population's ignorance or a lack of education. For example, respondents felt that key concerns included the lack of awareness in the field of palliative care and the lack of palliative care education opportunities for health care providers. Respondents felt that palliative medicine and hospice care was generally misunderstood as was evident through others' inaccurate perceptions of palliative and hospice care.

Closely tied to end-of-life care was the euthanasia debate. The responses indicated that the topic of euthanasia was perhaps contentious or an unresolved medical and societal issue. On a policy level, graduates wanted to have clear leadership that would mandate procedures around end-of-life. Finally, respondents highlighted social deficiencies existing in South Africa: the stigma related to HIV/AIDS, the stigma associated with hospice care, and the overriding social conditions. Different suggestions were given to address the concerns. In particular, by raising the profile of palliative medicine (through education and funding) and creating a coordinated system of health care across the entire trajectory of illness, respondents hoped that health, in general, would improve for all South Africans.

Theme 3: Room for Improvement

The query "*Please identify any weaknesses in the UCT program*" was used in the Graduate Survey to provide feedback for future program planning. Compared to the responses in other questions, a higher proportion of students either left this section blank (n=3) or reported that there were no apparent weaknesses (n=7). The remaining 31 responses were grouped into three sub-themes.

Sub-theme 3A: Poor Communication and Feedback

Several respondents suggested that communication was poor and that feedback from instructors was insufficient. This was apparent both in terms of general communication between student and department and in a variety of specific areas including course expectations, dissertation and ethics procedures. Poor feedback on assignments was described by one student in this way:

"No follow up on assignments- much effort put by student into doing assignments and then only a mark given. No comments or follow up at all. Thus learning from exercise is totally minimal." (6361)

Sub-theme 3B: Administrative Issues

Some items pertaining to the administration of the program were expressed by respondents. Students described space issues during exams, difficulties with email systems, and frustrations due to logistical errors. Some felt that there was not enough staff to run the program efficiently. One student described difficulties in several areas:

"... certain administrative and logistical issues e.g. dates of contact sessions and exams sometimes changed after flights and accommodations arranged. UCT Fee office and bursaries arrangements very muddled." (6234)

Sub-theme 3C: The Wish List

Students frequently identified areas that they wished had been included in the curriculum. The fact that the course did not incorporate a practical component was seen as a missing link in the course. Respondents felt that an evaluated clinical rotation with hands-on experience would be critical; even though the course was understood to be taught through distance education, students felt a practical component was necessary. One graduate wrote that the course needed

"...effective rotation in a hospice for at least one week. For example, I personally do not know what a syringe drive looks like." (6262)

A range of other suggestions for the program were made. For example, one student felt that there should have been more input on how to evaluate and apply scientific research in palliative medicine. Others felt that the literature used in the course was poorly selected, not applicable to South Africa, or redundant. The structure (or lack of structure) was commented on by some; time provided to complete the course was too short; the structure was inadequate and the workshops were too few in number. Finally, students commented that course content was inadequate in the areas of basic sciences, paediatrics, HIV/AIDS, and spirituality.

5.4 Summary of Part 2 Results

Part 2 *(Evaluation of UCT's Palliative Care Distance Education Program)* consisted of two questions; "*What are/were the positive and negative aspects of the palliative care program as described by current and former students?*" and "*How do former and current students evaluate the influence of their educational experience provided through the distance education palliative care program at UCT on their medical practice?*". The straightforward answer to those questions, based on the results of the surveys, is that both former and current students perceived their educational experiences to be extremely positive; the findings from all three surveys provide strong evidence in support of UCT's palliative care distance education course.

Most typically, students perceived the course material and their experiences with the course to be helpful in furthering their knowledge in the field of palliative medicine. The General Survey, in particular, illustrated a change over time; the test scores identified significant differences between the scores of current students versus graduates (graduates scored higher), and was a strong indication that students were able to apply their knowledge and gain confidence and competence in the field.

The results of the Graduate Survey give insight into the strengths and weaknesses of the program which should be helpful in program development. Graduates found that course offerings pertaining to communication and challenging encounters were taught well. A high proportion of graduates also reported that the course was helpful in identifying barriers to a meaningful death and bio-ethical principles in decision-making. However, graduates did not have great confidence in their ability to locate or evaluate local palliative care service providers. Nor did they find the course particularly helpful in developing a greater understanding of the public policy debate around palliative care, or improving teamwork. A substantial proportion of students selected "somewhat helpful" in questions pertaining to cultural variations as well as pediatric palliative care.

The qualitative component of the Graduate Survey allowed for a meaningful discourse on the role that the program took in the careers of students. It was evident that the course influenced graduates in a positive and progressive way. Students were able to identify a "trickle-down effect" where the new skills transferred to their colleagues and ultimately transformed patient care. Graduates were also able to make informed comments relating to the larger palliative care debate in South Africa. When graduates identified concerns relating to the course, they typically related to administrative issues or frustrations with communication. On the whole, UCT's distance education palliative care course was well received by respondents; the flaws and strengths identified by students and graduates should serve to strengthen the course in the future.

CHAPTER SIX: Discussion

6.1 Introduction

The aims of this study were twofold: 1) to provide an analysis of palliative and end-of-life care in South Africa as it is currently provided within hospice and other health care organizations and 2) to assess the palliative care distance education program offered through the University of Cape Town (UCT). The informed evaluation of the distance education program at UCT was best understood within the contextual analysis of palliative and end-of-life care in South Africa. The two parts were linked by common threads such as educational priorities, societal and medical understanding of palliative care, and the role of medical doctors within South Africa.

The qualitative analysis from Part 1 (Palliative and End-of-Life Care in South Africa) yielded three main themes: a) Two Solitudes: Participant versus Public Notions of Palliative Care, b) Accessing Palliative Care, and c) The Changing Face of Palliative Care. Each had a number of sub-themes and categories. The analysis of the Health Care Provider Survey, a component of Part 1, highlighted specific areas to focus on in educational programs of medical doctors. In Part 2 (Evaluation of UCT's Palliative Care Distance Education Program), three surveys were used to assess the distance education palliative care course at UCT. The General Survey was particularly useful in illustrating a change over time; the Mann-Whitney test scores identified that graduates had significantly higher survey scores than did current students. Although the results of the Pre-post Workshop Surveys need to be interpreted with caution due to the small sample sizes, the general trend was that the workshop material was successfully transferred to students. The results of the Graduate Survey gave insight into the strengths and weaknesses of the program. Graduates felt that course offerings pertaining to communication and challenging encounters were taught well. A high proportion of graduates also reported that the course was helpful in identifying barriers to a meaningful death and bio-ethical principles in decision-making.

This study adds to the literature examining palliative care within developing countries. The results of this project highlight who the various stakeholders are within the hospice and palliative care system; patients, family care providers, health care providers, and educators were all shown to play a significant role within the palliative care model. Examining how participants described and understood their various needs and resources was an important aspect of the study. The purpose of this concluding chapter is fourfold: 1) to discuss the study findings within the context of existing empirical literature, 2) to explore the way forward, 3) to consider implications arising from the research project, and 4) to identify the study's biases and limitations.

6.2 The Key Findings

6.2.1 Palliative and hospice in South Africa: A limited understanding

The views expressed in this study by participants highlighted that palliative and hospice care was not well understood by the majority of people (including health care workers) in South Africa. When health care workers were asked to define and describe palliative care, only those with prior training in the field of palliative care were able to fully express the role and purpose of palliative care. Medical doctors frequently equated palliative care with symptom control and focused on reducing pain and other distressing symptoms. Some doctors described palliative care as "tender loving care" which emphasized patient hygiene and nutrition. The results indicated that while it was apparent that most medical providers interviewed for the study had an overall sense of what palliative medicine entailed, those with additional training (e.g. post-graduate distance education program or short courses) were much more familiar with the key concepts of palliative care.

What is Hospice and Palliative Care? Individual responses to the question "What is palliative care?" rarely captured the intended purpose and philosophy of palliative care. The World Health Organization views palliative care as "an approach to care that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain, and other physical, psychosocial and spiritual problems." (1). The philosophy of palliative care espouses: a patient and family focus; active management of distressing symptoms; total, individualized care of the patient; an interdisciplinary team approach; integration of the psychological and spiritual aspects of care; supporting the family throughout the patient's illness and in their own bereavement; and offering support to the patient so they may live as actively as possible until death (2,3). While it was unusual for participants to describe palliative care in the depth ascribed by the WHO, study participants who had received some level of palliative care education or training expressed a greater understanding of palliative care. For example, the responses of medical doctors who had completed the palliative care course at UCT and nursing sisters trained in short palliative care programs clearly indicated that they were knowledgeable in the broader field of palliative medicine and specifically in the roles of each health care worker within the palliative model.

In this study's comparison of responses by various medical practitioners, it was evident that nurses approach and view hospice and palliative care differently than do doctors. Nurses were much more involved in patient care and described palliative care as a "way of life". Doctors, on the other hand, were less involved in patient care and were less effusive in care descriptions. Similar findings have been reported in the literature. For example, a Danish study(4) explored if differences existed when comparing doctors' and nurses' perceptions of palliative and terminal care. In response to the statement "palliative care is a rewarding part of my work", nurses were significantly more likely to agree than doctors. Similarly, doctors in the Danish study were more likely to respond that they would rather leave terminal care to others compared to nurses. At the same time, the majority of doctors and nurses felt that physicians played a key role in reducing patient suffering (4).

In South Africa, the perspectives of doctors on palliative care were described as being affected by the HIV/AIDS epidemic. When doctors did not have the means to care for patients due to the high volume of critically ill patients and the high cost of treatment, it became particularly taxing. For example, doctors reported feeling overwhelmed with the care of patients with HIV/AIDS. In particular, for doctors employed by the state or employed in regions lacking ART programs, there was a particular anxiety expressed about their role in patient care. These types of doctors expressed that public hospitals were not able to handle the patient load due to the high volume of HIV/AIDS patients; doctors described not being able to provide individual and adequate care to their HIV/AIDS patients. Situations like these have also been described in the literature. In a study conducted in the US, Karasz et al. explained how doctors, trained to be healers, experienced role confusion during the pre-ART era. Prior to the introduction of ARTs, patients with HIV/AIDS would progress from health to death in a predictable yet discomforting fashion; as doctors were trained to "cure", they felt unable to provide meaningful care (5). However, this role confusion was described as clearing up in the post-ART era when doctors were described as being healers again; with ARTs extending lives and making HIV/AIDS a chronic illness, end-of-life care was not eliminated but the focus of care was more in line with how doctors had been trained(5). It may be that as ARTs become more available to patients within South Africa, the perspectives of doctors will change and they will describe their involvement in patient care differently. It was certainly the wish expressed by many of the medical doctors who participated in the study that they would like to be able to provide better care to their HIV/AIDS patients.

When health care worker participants were asked to describe how the general public (inclusive of the greater body of health care workers) understood palliative and hospice care, study participants' responses indicated that both health care workers in specific, and society in general were perceived to have a limited understanding. The interviewed health care workers felt that unless members of the public had been involved in some way with hospice, people appeared to have a limited understanding and appreciation of the concept of palliative care. Likewise, study participants perceived the larger body of medical practitioners to view palliative care as having little value; practitioners' focus of medical care was described as being primarily on curing. This viewpoint was expressed in interviews of both the health care practitioners trained in palliative medicine and those without training. Again, the view was that doctors thought of hospice as synonymous with death or dying and that palliative care was not a field of practice known to many. Overall, respondents described how the general public may not have ever heard the phrase "palliative care" and medical practitioners would have received little to no training in the field. As a result, the perception was that hospice and palliative care was not well understood.

Myths and Misconceptions. Participants felt that within society at large, palliative care was not well understood and that misconceptions about hospice and palliative care were evident. Firstly, a number of respondents described how for many people, the term "hospice" equated to death. Participants described how fearful patients or family members would be if their doctors had referred them to hospice as they believed it meant death was imminent. Secondly, participants described the "morphine myth", where people understood morphine to cause death. If a hospice worker would suggest morphine use, for example, then some people- including some of those with medical training- equated it with euthanasia. Thirdly, participants felt that hospice care was perceived by others to be synonymous with AIDS care. Prior to the introduction of ARTs, many patients with HIV/AIDS would have depended on hospice care. While the study did not set out to examine differences in the patient population before and after ARTs, several participants described how hospices were filled with dying HIV/AIDS patients prior to the introduction of ARTs. And although hospices have traditionally cared for a large proportion of cancer patients and patients with other diseases, hospice was perceived as a centre for HIV/AIDS patients.

That hospice and palliative care is not well understood is not unique to South Africa. Different examples from around the world show that the general public often has an inaccurate perception of the meaning of hospice and that the public typically equates it as a place of death (6,7). While some countries have transitioned from an understanding of hospice as a place of death to a place of care at the end stages of illness (6), this transition has not happened in many countries. In South Africa, for example, it appeared that many people still had a limited understanding of the term. These misperceptions have led to a hospice and palliative system that could be described as poorly understood throughout the country.

6.2.2 Accessing Hospice and Palliative Care

Part of the reason that participants described a limited understanding of palliative and hospice care can be attributed to the fact that hospice programming in South Africa is patchy and not accessible to all in need(8,9). The theme, "Accessing Palliative Care", addressed both different methods of accessing care as well as barriers to access. Barriers included staff safety, cost of transportation, poor coverage, and racial background, all which negatively affected patients' ability to access palliative care. Many people in need of care, therefore, were not able to receive it.

Accessing palliative care services offered by hospices was not described by participants as a straightforward process. While there were many channels that led to hospice organizations, the admission protocols were highly variable; each hospice had different admitting forms, sometimes even having a number of different forms to cover different situations. For example, forms for HIV/AIDS patients were different than those for cancer patients. Also, community nurses could refer HIV/AIDS patients but only medical doctors could refer cancer patients. Throughout South Africa, hospice organizations had developed their own referral systems and forms, thus creating bureaucratic difficulties for state hospitals that referred to many different sites.

Current North American literature identified several issues that negatively affect hospice referrals. A lack of knowledge of available end-of-life care programs was the most frequently cited reason that the public or health care sector do not use hospice services(10-16). As well, a general lack of information by those with the ability to refer to hospice (17) was also identified. Other barriers that were commonly discussed included reluctance by patients (18,19), families, and practitioners to deal with the meaning of an impending death (10,13,14), difficulties in communicating (14), and the tendency for specialists to rarely refer directly to hospice (10). A lack of standardization in referral forms was also shown to negatively affect communication within interdisciplinary community palliative care teams (20), thus becoming a barrier in patient care.

As physicians are often the "gatekeepers" in the hospice referral system (19), studies often focus on barriers caused by doctors. In the United States, length of hospice stay has been shown to be particularly affected by a doctor's ability to prognosticate accurately; a doctor's skill in determining the stage of disease often determined how frequently patients get referred (21). In addition, the patients of doctors who refer to hospice more often tended to have longer hospice stays (21), which was seen to be beneficial for patients. So the inability to accurately prognosticate and a doctor's reticence to refer were both seen as barriers. Other physician barriers include discomfort communicating diagnoses and prognosis, a fear of losing control of the patient, and negative perceptions about hospice care (18,19,22). Physicians have also indicated that a key reason for non-referrals was that they believed that hospice was not appropriate for their patient (18).

It was evident from the study participants', and in particular health care providers', descriptions of the referral process, that the hospice referral system was far from ideal.

Based on the available literature, it may appear that referral systems around the world are fragmented and that issues around hospice referral exist world-wide. Yet the data from this study suggest that unique variables exist within South Africa, which have ramifications on care provision and service delivery. The barriers that exist in the South African hospice referral system, namely a lack of transparency in the system, a lack of consistency in processes, and no apparent uniformity amongst the country's hospices, suggest that there are critical factors that need to be addressed. In order to improve on accessibility and to ensure that hospice services are available to all those in need, it will be important to eliminate inefficiencies at the national level and then adopt a national referral standard.

The most able professional body to work on such a task would be the Hospice and Palliative Care Association of South Africa. The organization is well structured and organized (23) and would be well placed to make national recommendations. If an organization of that stature worked together with member hospices to ensure a transparent and consistent referral system, it would be to the benefit of those in need of hospice services.

Around the world, hospices were created, often by individuals or small groups of people, to address the health care needs of terminal patients that were not being met by the medical system in the particular country (24). Hospices were developed and continue to be developed to fill a niche or an unmet need. As the creation of hospices continues to be primarily the result of individual initiatives, however, global hospice services are still often described as patchy with limited access (7,25). Hospices in South Africa were also developed to meet an unmet need, most specifically those of cancer patients (26). And, although the service has changed over time to meet the shifting needs of the country (26), it remains inaccessible to many people.

6.2.3 Perceived Satisfaction with Care

The patients and family care providers interviewed in the study and involved in hospice and palliative care programs were generally satisfied with the care they received; when asked to describe their satisfaction with hospice care, patients and family care providers consistently felt supported by the hospice workers they came into contact with. Patients described feeling satisfied with the care they received from home based carers and nursing sisters. From the patients' perspectives, those two groups of health care workers were instrumental in providing a great deal of support throughout an illness. Family care providers were also grateful for the respite (albeit limited) that hospice care provided. As the primary care providers, family members were often overwhelmed by the caring that was needed and so having hospice involved in care provision was beneficial to them. This appears to be a common sentiment; other studies evaluating satisfaction with end-of-life care report similar findings in caregiver burden (27).

Dissatisfaction with care was very rarely expressed by patients and family care providers. However, some patients and family care provider participants articulated a desire to have more contact with medical doctors. Advice from a doctor was expressed as particularly valuable and thus patients wished to see a doctor from time to time. They were also very clear that interactions between doctor and patient needed to be genuine as opposed to a flippant review of symptoms followed by a new prescription. Patients wanted a doctor to listen to their concerns, to explore ways to manage symptoms, and to engage with them on a meaningful level. Family care provider participants, while not necessarily themselves seeing the need for a doctor visit, were clear that if a doctor visit was meaningful for their loved one, then it was important to include it in the care plan.

It is not unusual that hospice doctors or GPs are typically less involved in the care of their patients with terminal illnesses. The literature shows that even hospice doctors in developed nations are primarily involved in administrative tasks and they rarely perform hands-on patient care (24). It is nurses who assume the majority of the care in providing palliative care (28). Research has shown that family members of deceased people were less satisfied with doctor care than with nursing care (29) which may be related to both the quantity and quality of contact between the different health care providers.

Overall, hospice clients and their family members interviewed for the study were highly satisfied with the care they received. This is a common finding as most people express satisfaction with whatever care they receive (30,31). It may be that the study's results are not necessarily an endorsement of care but a reflection of very low expectations. However, the results do suggest a high level of satisfaction which is a strong point in favour of South Africa's home-based hospice care model, where service is provided for patients in need without the large overhead costs incurred throughout a hospital stay. One recommended change to the current system would be for hospice staff to determine if a patient would like to visit with a medical doctor. If that is the case, it would be appropriate for a face-to-face doctor visit to be scheduled so that the patient has the opportunity to discuss medical and personal issues with a doctor, a person whose opinion and advice they wish to have.

6.2.4 Need for increased awareness and education within the medical community

Tied closely to the availability and demand for hospice and palliative care were the educational needs of doctors in the field of palliative medicine. With limited exposure to palliative principles within undergraduate medicine, participants with a medical background described how doctors graduated from South African medical universities with a focus on curative as opposed to holistic care. At the systemic level, interview participants highlighted the need for a change in the mindset of health care practitioners; they felt that doctors needed to view the patient in a holistic manner, incorporating the principles of palliative care from birth to death. It was also suggested that with a greater emphasis on holistic care, patients would be more open to the palliative model; the fears of hospice care might be allayed with a greater public understanding of palliative and hospice care. Specifically relating to medical education, respondents highlighted key areas that doctors needed to focus on: pain management and assessment, communication with patient and family, symptom control, and the principles of palliative care.

While palliative care has developed as a specialty in some parts of the world (27), it is still very common for the care of terminally ill patients to be handled by general practitioners (32). Thus, participants concerns regarding increased awareness and education in the medical community are warranted. As Pereira stated, "GPs will continue to be key providers of palliative care" (p. 457)(32).

However, a general practitioner's clinical exposure to palliative care patients can be very limited. The general practitioners interviewed for the study not working in hospices or hospitals estimated that the numbers of terminally ill patients that they treated was very small. For example, private doctors interviewed in the study estimated that between zero and ten percent of their patient caseload had a terminal illness. One doctor stated that his estimate of ten percent was that high due to the fact that he opened his private practice to the community. Another identified that he didn't personally treat any patients with life threatening illnesses as he would refer those patients to the state hospital. Although some participants identified that the HIV epidemic was increasing the number of their patients with a life-threatening illnesses that they treated annually, the general practitioners interviewed asserted that the proportion of patients needing end-of-life care was small. Studies have shown that many general practitioners care for very few dying patients from year to year (27,33). One survey of GPs working in London, found that the majority of general practitioners treated less than six terminally ill patients per year (34). An American study estimated that the participating physicians cared for about 15 terminally ill patients over a six month period (18).

Perceived value. In this analysis, the medical doctors who provided some measure of palliative care to their patients perceived their role in this type of care to be important. Even if participating doctors did not treat a large number of patients with life threatening illnesses, they still felt it was an important part of their medical care. However, while doctors felt their role in providing palliative care was important, there were elements of this care (e.g. disclosing bad news) that they preferred to leave for others for reasons such as limited time or lack of training.

This perception that doctors have a valid and important (yet limited) role to take in the provision of palliative care is also seen in the literature. In the early 1990's, a Canadian survey of oncologists was conducted to assess how doctors perceived their roles within supportive and palliative cancer care. One of the survey questions evaluated how often participants were involved in palliative care activities. Overall, the majority of participants perceived themselves to be highly involved in patient palliative care; 61% stated that they "always" assumed a significant role, 33% selected "sometimes", and 6% chose "seldom"(35). The study also found that oncologists felt less comfortable in conveying bad news to patients and that they thought this as a task that should be carried out by the patient's general practitioner(35). These findings raise an interesting question: if doctors perceive themselves to highly involved in palliative and supportive care, why do certain tasks, such as prognostic disclosures, get transferred to other health care practitioners?

Continuity of care. Continuity of care, a concept described by interview respondents, may provide at least part of the answer to the query. When asked to describe the health care providers involved in their care, patients in the study were somewhat confused. They weren't certain about who was providing them care (specialists or hospice doctors) and the type of care they should expect (doctor visits or nursing care). The participants who were private practitioners expressed dissatisfaction with community doctors who had little time for patients who were deemed palliative. The participants who were nursing sisters or hospice doctors described how patients entering hospice care often had little understanding of their medical condition. How do patients receive supportive and continuous care if the practitioners involved in managing their illness have different perspectives on whom should provide care and what that care should consist of?

The literature notes that general practitioners (GPs) are often a patient's first contact in the health care system and are often relied upon to coordinate care for patients as their disease progresses (27,33,36). The logistics of this role, including managing communication amongst the team of practitioners involved in patient care, may not be straightforward. Even so, GPs are described as having a pivotal role to play in the delivery of palliative care (33) and most patients with advanced disease continue with their GP throughout of their illness (36,37).

Patient and family care provider study participants described situations where several medical practitioners were simultaneously involved in patient care but those instances were rare. More commonly, once a patient was referred to hospice, the general practitioner removed him or herself from the patient's care plan. The patient's GP might have been asked to prescribe medications if there was no hospice doctor, but it was rare that the GP would see a patient directly. Similarly, specialist involvement was described as over as soon as curative procedures or medical aide was exhausted; at that point, patients would be transferred back to the GP. It appeared that the existing medical system in South Africa created a scheme whereby patients were transferred along a medical assembly line: the patient entered the system by visiting a GP; the patient might then be transferred to a specialist for further treatment; once treatment options were exhausted, the patient would be transferred back to the general practitioner or directly to the hospice; finally, the GP or hospice doctor would manage the patient. The merits of this model were few as patient care was described as fragmented in this system.

Communication a critical component. Participants recognized that good care was reliant on good communication between the various practitioners, but felt that it was rarely present. Most often, problems with communication were seen when patients had visited several doctors during their illness. For example, if a patient had travelled some distance to receive treatment with an oncologist and then returned to his or her community once treatments were over, it was common that information from the oncologist was not communicated or transferred to the GP. Even when geography was not a factor, it appeared that specialists and GPs did not communicate well. Good communication between patient, medical team, and family members has been described as "central" to a positive end-of-life experience; poor communication can be a source of great dissatisfaction (27). Good palliative care involves both medical and communication skills (33) and it is apparent that communication continues to be a vital issue within South African patient-family-doctor experiences.

In the UK, junior hospital doctors are reported as being highly involved in care of dying people (36), a similar situation as what was described within the South African hospital setting. Study participants, namely nurses or hospice doctors, frequently expressed dissatisfaction with junior doctors' apparent low level of knowledge in the field of palliative medicine. In South Africa, after a two year internship, the junior doctor is required to complete one year of community service (38), most commonly at a state hospital. After the one year period is over, the junior doctor often leaves the hospital setting. In the study, junior doctors were described as inexperienced and lacking knowledge in the field of palliative medicine, thus requiring continuous training and assistance. The literature supports this finding; junior doctors report feeling insufficiently prepared for the task of caring for dying people (36).

In the distance education course, respondents described communication as both a necessary and well taught element. Respondents described how the course taught them to be better communicators; some graduates noted that they had entered the course with no counselling skills and had left with the ability and confidence to meet with patients and families.

6.2.5 Increased Resources Necessary for Hospice and Palliative Care

An issue that was raised across both interviews and surveys was a need for more resources. Several different types of resources were named: human resources (in the form of volunteers or staff), medical resources (in the form of medications or supplies) and infrastructure resources (to enable hospices to provide different services for patients). In general, increased financial resources were seen as the most obvious need. If hospices were to receive secure funding for both short and long-term expenses, then many of the resource stresses would be eliminated. Increased financial resources were described as "necessary" or "desired" as participants felt that an influx of money would greatly benefit hospice organizations in numerous ways. How would hospice services change with increased and stable funding?

First, participants describe how it would mean that less time and effort would be required to manage grants. Participants who were employed in hospice organizations described how personnel needed to spend a great deal of time applying for grants, reporting to funders, and fundraising. In several hospices, one staff member was hired solely for the purpose of grant management. If secure funding was provided to hospice organizations, both the hospice administrators and staff could focus on the care they provide within the community as opposed to tedious administrative tasks revolving around grant management.

Secondly, increased funding would mean that hospice workers could be paid on par with other professional health care workers. In interviews with nursing sisters as well as medical doctors, it was apparent that hiring and maintaining hospice staff was difficult. Although some respondents felt that an overall health care worker shortage in South Africa was to blame, hospices were described as being hit particularly hard. As hospice organizations could not offer comparable wages, they had difficulty hiring staff. Additionally, the turnover in staff was high. Although statistics to compare turnover rates in hospitals and hospices were not available, it seemed particularly high within hospices. At one point during data collection when the interviewer re-contacted many of the health care worker participants, it was not unusual for the participant to have left the organization as he or she was employed elsewhere. With secure funding, hospices would be able to provide salaries on par with other public health care settings. Doing so would likely decrease the high turnover of staff. Furthermore, employees would likely feel more valued in the work setting, which would encourage longevity.

Thirdly, increased and stable funding would allow hospice organizations to hire a part or full-time doctor. Many of the participating hospices relied on volunteer doctors, which, although better than no doctor at all, meant nursing sisters had to prioritize patient need. Additionally, patients would rarely be seen by a doctor unless they chose to visit a community health centre or their general practitioner. Participants described several issues regarding doctor visits: sometimes the patient's illness was too far advanced and it was difficult to transport the patient; waiting for a community doctor could be a day-long event and overwhelming for many palliative patients; patients may not have any type of relationship with their family doctors. As patients and family members were found to desire face to face interactions with medical doctors while in hospice care, employing a doctor would be beneficial.

Fourthly, an increase in base funding would enable hospice organizations to provide different services to patients without medical aide. For example, if hospice organizations had sufficient funds to pay for and dispense palliative medicines, it would mean that all patients would have the same quality, access, and overall experiences regarding medications. It would decrease or eliminate the need for protracted waits to fill prescriptions and issues surrounding pharmacy supply; instead of requiring patients to get medications at the local health care clinics- a time consuming process- hospice patients would receive them directly from the hospices. It would eliminate the bias that medical aide presents within the South African health care system. Secondly, more base funding to hospices would reduce barriers caused by transportation. Transportation was an issue frequently discussed in the interviews; if a patient had limited funds for transportation, he or she would often delay as long as possible a trip to the doctor. Often, this led to a late entry into the health care system when the disease was too advanced for curative treatment. With increased and stable funding, hospices would be able to provide transportation for patients. This would mean patients could be transported to and from hospice without incurring the additional cost burdens which many of them could not afford.

Ensuring a sustainable hospice system within South Africa will require consistent and adequate funding. For this to happen, hospice organizations will need to receive stable government funding. The current funding situation, as described earlier, is dependent on a variety of different international agencies as well as extensive local fundraising. Although many hospices can operate on the funding they receive, the process of applying for grants and monitoring programs utilizes valuable human resources. Therefore, it is critical that a larger and consistent financial base is developed. It will be imperative, as there are a number of competing priorities for limited government funding, that hospice and palliative care organizations present an argument of cost effectiveness; that by investing in palliative care there could or should be an overall reduction in other more costly health care expenses (39).

Currently the South African Department of Health (SADoH) provides limited funding to hospice organizations (23) yet this will need to increase for a sustainable system. Providing a case for hospice care should be straightforward: research has shown that home-based care programs are cost-effective (40). However, convincing SADoH that hospice organizations add value to the health care system appears to be more of a challenge. While SADoH is developing a home-based care program, there is no palliative care service available as part of it(41). The cost-savings piece of home-based care is appealing, but the government has not yet understood the value of incorporating palliative care.

Role of volunteers. In this study, the role of the volunteer was described as instrumental in the various models of palliative and hospice care delivery. In the participating hospices, the volunteer force consisted of retired nursing sisters working several hours a week for the hospice, unemployed home-based carers donating their time and their skills, medical doctors volunteering their time to conduct chart reviews each week, and a wide range of other people. This unpaid force has also been described in the literature regarding South African hospice organizations (42). During the observation periods at hospices in the Western Cape Province, volunteers were seen arranging plants, cleaning, driving mini-buses, preparing snacks, visiting patients, teaching crafts, and leading worship. They were an integral part of hospice programming.

Study participants reflected that without this injection of volunteers, it would be difficult for hospice organizations to be viable. In order to complete all the tasks to run a successful hospice, volunteers were seen to be necessary. A related factor is that the salaries of paid employees are typically less than in comparable health care organizations. The participating health care workers frequently discussed how, in comparison to those of the same professional status working in the public health system, they received less income. Based on these observations and interview data, it appeared that the current system, reliant on the volunteerism of its' citizens, would be crippled without the volunteer sector. The same would be true if hospice workers were paid salaries equal to their contemporaries (e.g. hospice nursing sisters would be paid on par with hospital nursing sisters); the increased personnel costs incurred by hospice organizations with higher pay for staff would affect programming.

The majority of hospices in South Africa are operated as non-governmental organizations (NGOs) and thus are reliant on private funding sources to manage (23,42). The hospices participating in the study were reflective of this fact. Likely as a result of this, South African hospices are typically reliant on the volunteer sector to assist with the care for patients with life threatening illnesses(42,43); volunteers are an indispensable part of the hospice care team (44). In fact, within the home-based models of palliative and end-of-life care, there is an expectation that people will volunteer time (45), an expectation also voiced in the study participants.

Literature from the US describes the role of volunteers as “absolutely essential” (46,47) within the palliative care team. However, it appears that a definition of “essential” is different for a resource-rich country than one considered middle income. For example, in their studies on volunteers, Claxton-Oldfield et al. describe the intrinsic value of having volunteers spend time interacting with patients and family members. Indeed, they have posited that volunteers have been shown to spend the most time interacting with patients and family members in comparison to other team members such as nurses and doctors (47). Their studies go on to explore the palliative care team’s perception of volunteers and find that volunteers were ranked significantly lower than nurses, family members, pharmacists, doctors and spiritual advisors (47). So while volunteers were described as "essential" to the system, they were not seen to be highly valued.

Based on the interviews and observations in participating hospices, it cannot be said that hospice volunteers in South Africa were perceived in the same way. There is such a great need for volunteers within the system that volunteers are an integral and highly appreciated part of the organization. While many volunteers were observed to be completing menial tasks, short conversations with them would indicate that they felt appreciated for the work they did. Like in the American literature, volunteers in South Africa can be described as "essential". However, in South Africa, a volunteer base is not optional as it appears to be in resource-rich countries; volunteers provide critical services and make a vital contribution to hospice organizations in South Africa.

6.2.6 Perceived Educational Needs of Doctors

The study participants who were health care workers perceived medical doctors to be poorly educated in the field of palliative medicine on the whole. Furthermore, participants perceived palliative care to be of low priority within current undergraduate programs within South Africa. While several South African universities were described as incorporating palliative medicine within the undergraduate curricula, the perception was that it was regarded as an "add-on" and lacked importance within the program. Respondents agreed that palliative medicine needed to be integrated to a greater degree within the undergraduate curriculum in order for it to be perceived as an important element of medical education. The Health Care Provider Survey respondents highlighted key areas that they felt doctors should focus their education on: pain management and assessment, communication with patient and family, symptom control, and the principles of palliative care.

Distance Education Program at UCT. The positive effects of the post-graduate course were evident within the study: the study participants who had completed the post-graduate palliative care course at UCT spoke highly of the program. Additionally, many of the patients and family care providers interviewed for the study had been treated by doctors trained in the program and all expressed satisfaction with their care. Most typically, students perceived the course material and their experiences with the course to be helpful in furthering their knowledge in the field of palliative medicine. The General Survey, in particular, illustrated a change over time; the Mann-Whitney test scores identified significant differences between the scores of current students versus graduates (graduates scored higher), and was a strong indication that students were able to apply their knowledge and gain confidence and competence in the field. Although the results of the Pre-post Workshop Surveys need to be interpreted with caution due to the small sample sizes, the general trend was that the workshop material was successfully transferred to students.

The results of the Graduate Survey gave insight into the strengths and weaknesses of the program, which should be helpful in program development. Graduates found that course offerings pertaining to communication and challenging encounters were taught well. A high proportion of graduates also reported that the course was helpful in identifying barriers to a meaningful death and bio-ethical principles in decision-making. However, graduates did not have great confidence in their ability to locate or evaluate local palliative care service providers. Nor did they find the course particularly helpful in developing a greater understanding of the public policy debate around palliative care, or improving teamwork. A substantial proportion of students selected “somewhat helpful” in questions pertaining to cultural variations as well as pediatric palliative care.

The qualitative component of the Graduate Survey allowed for a meaningful discourse on the role that the program took in the careers of students. It was evident that the course influenced graduates in a positive and progressive way. Students were able to identify a “trickle-down effect” where the new skills transferred to their colleagues and ultimately transformed patient care. Graduates were also able to make informed comments relating to the larger palliative care debate in South Africa.

However, graduates identified that a hospice rotation, at minimum, should be a required component of the post-graduate program. The felt they would have benefited from hands-on experience. In a distance education format it is difficult to incorporate elements such as experiential learning or interdisciplinary teams within the program design. In the distance education palliative care program at UCT, students attend two 3-day workshops in both their first and second years. During these workshops, students learn through a variety of teaching methods including case histories and role plays. However, at no point in the course does the program include any patient contact. It appears that this would be deemed a vital adaptation of the program, which would allow students to apply their coursework in a practical setting(48). In addition, if distance education students were given the opportunity to work as a part of an interdisciplinary team within a palliative care setting and directly with patients and family members, it would provide the opportunity for active learning (49).

Post-graduate vs. Undergraduate. Although students and graduates of UCT's distance education course were complimentary when describing their post-graduate program, it remained an elective post-graduate offering as opposed to a required component of the undergraduate medical curriculum. This meant that only the doctors that selected the program on the basis of interest would be receiving specialized training in palliative care as opposed to training all undergraduates. In order to reach a greater proportion of doctors, it is imperative that a greater focus be placed on undergraduate education. This is not to negate the value of the post-graduate program as it was proven to be effective, but the importance of undergraduate training needs to be highlighted.

Health care worker participants suggested that a foundational change in the undergraduate curriculum was necessary in order for would-be practitioners to learn holistic care principles; instead of focusing only on the curative educational model (as is the current situation (50), it was suggested that a holistic model of care should be introduced. In a cure-oriented curriculum, the primary foci of instruction would be curative treatment options; a curriculum like this would not emphasize the value of palliative medicine within the treatment model. Research concurs with this description of medical education and several authors have described it to be the focus of education, either literal or implied, within many medical universities. For example, Brasel and Weissman discussed the "informal curriculum" taught in medical schools, one which reinforces that death is a medical or therapeutic failure(15,51,52). On the other hand, a holistic model focuses on care for the entire patient, including his or her social and spiritual needs and is one that suits the principles of palliative medicine very well. Within the curative model, for example, there is less focus on the alleviation of distress and suffering from early on in the disease trajectory whereas within the holistic palliative care model, this is a central tenet.

Participants outlined that both the undergraduate and post-graduate palliative care curricula needed to cover an extensive range of subject areas. As seen in the results of the Health Care Provider Survey, a survey to evaluate the educational needs for medical doctors, each of the 36 items on the survey was consistently deemed essential within a palliative care curriculum. Respondents rated each possible area as "very" or "somewhat" important 94.2% of the time. Although respondents consistently ranked pain assessment, pain management, communication, symptom control, and the principles of palliative care as most important, the overall trend was that health care workers placed a high value on all of the different facets of palliative care.

Other empirical research highlights similar findings or outcomes. For example, in 2000, the American Academy of Pain Medicine Undergraduate Committee recommended that pain medicine, end-of-life care, and palliative care should be required elements of the core medical school curriculum, citing that "one of the main impediments to skillful end-of-life care is the lack of quality undergraduate education" (p. 224)(53).

Communication skills. Communication was also a recurring theme within the education data. Many medical doctors interviewed for the study expressed a lack of communication skills; they did not know how to break bad news to patients nor did they feel comfortable discussing elements of death and dying with patients. When asked how patients were told of a life-threatening illness, doctors' responses were typically vague. Unless the individual had been trained, there seemed to be no clear process for delivering news to patients. Sometimes doctors admitted feeling that they did not have enough time to communicate news appropriately with patients and so left it for nurses or other colleagues. Graduates of the post-graduate program at UCT described how one of the major benefits of the course was that it taught communication skills. Their training was reflected in how they cared for patients. For example, trained hospice doctors were aware that patients often received little information from other health care workers regarding their disease and so when a patient entered hospice, educating and communicating with the patient became a priority. The interview data also revealed that doctors trained in palliative care principles spent time with patients and families, preparing them for the journey of dying and death.

The literature also highlights the importance of good communication within palliative care (14) but explains that it is not always present. Good communication is a critical element of high quality palliative care, yet "many family caregivers report limited and delayed communication about the incurable illness, life expectancy, and hospice as a treatment alternative" (p. 8)(54).

During the study, the medical doctors without palliative training expressed interest (but were not fully committed) in learning more about palliative care. While they felt that it would be beneficial in their medical practice, they weren't convinced it was a priority. This is consistent with the literature. In a study of medical doctors by Wakefield et al, it was found that almost 80% of their Australian sample felt they could benefit from additional training in pain control(34). In a study set in KwaZulu Natal, South Africa, doctors indicated that they were also open to training in palliative medicine (55). On the other hand, as doctors see palliative patients infrequently, they may not see the value in staying abreast of current knowledge or even learning best practices (27). In South Africa, it will be critical to find a balance between need and interest in order to develop appropriate community-based educational programs.

6.3 The Way Forward

In his description of palliative care in the developing world, Maddocks writes the following:

> *"Those relatively few health workers, who, either through religious commitment, innate sensitivity or exposure to a persuasive example of good palliative care turn to this discipline, deserve strong encouragement and much practical support from the more established programs of the affluent world" (p. 220)* (56)

If the primary aim, as Maddock proposes, is for developed countries to support those less developed, what would this look like? Would the way forward for developing countries be to mirror programs in developed nations? Ideally, moving the palliative care agenda ahead will necessitate a co-operative approach, where practitioners and educators from all resource levels learn from each other, benefiting from best-practices.

This project has highlighted two integrated components: context of care and palliative care education (Table 6.1); those two concepts will be central to further development in the field of hospice and palliative care. With the foundation of education and context of care, two key recommendations arise from this study: to increase accessibility and to make palliative care education a priority. These priorities also mirror those stressed by the World Health Organization: health services priority, public awareness, and professional education (6) as well as Kellehear's paradigm of health promoting palliative care (57). Two priority areas are subsumed in the recommendation to increase accessibility: a) to improve referral process for existing hospice and palliative care services, and b) to lobby the South African government to raise the profile of palliative care within the health care system. To address the education agenda, it is recommended that palliative care education be made a priority in three particular groups: a) undergraduate medical students, b) general public, and c) practicing medical doctors (Table 6.1).

This project has highlighted two integrated components: context of care and palliative care education (Table 6.1); those two concepts will be central to further development in the field of hospice and palliative care. Embedded within the foundation of education and context of care, two broad recommendations arise from this study: 1) improve accessibility to palliative care and hospice services by addressing barriers to care present in HPCA hospice programming and 2) increase the palliative care content in undergraduate, post-graduate, and professional medical training, aiming for uniform inclusion of palliative care curricula and a compulsory component of medical education. These priorities also mirror those stressed by the World Health Organization: health services priority, public awareness, and professional education (6). (Table 6.1).

Table 6.1: Overview of Recommendations, Target Areas, and Outcomes / Necessary Actions

Recommendation #1: ***Improve accessibility to palliative care and hospice services by addressing barriers to care present in HPCA hospice programming.***		
Target Area	**Outcomes or Necessary Actions**	**Connection to the Data**
A) HPCA		
Improve HPCA referral process in existing hospice and palliative care services.	To increase the standardization in the HPCA referral process, the same referral form needs to be used by all HPCA hospice organizations.	Part 1: Theme 2 (Sub-themes 1 & 2)

Recommendation #2:
Increase the palliative care content in undergraduate, post-graduate, and professional medical training, aiming for uniform inclusion of palliative care curricula and a compulsory component of medical education.

Target Area	**Outcomes or Necessary Actions**	**Connection to the Data**
A) *Undergraduate*		
Review palliative care content of undergraduate medical curricula in all South African universities.	To determine: a) if and how palliative care content is incorporated, b) instructional techniques used to teach palliative care, c) student perceptions of palliative care and palliative care curriculum, and d) if curriculum is addressing the range of educational needs as outlined in both the Health Care Provider Survey and the sub-theme pertaining to educational needs of doctors.	Part 1: Theme 3 Part 1: HCPS
B) *UCT's Post-graduate Palliative Care Program*		
Strengthen content of the distance education palliative care program by incorporating feedback of graduates and current students.	Introduce the following changes into the post-graduate program: a) a practical component such as a hospice rotation to ensure students receive a blend of theoretical and hands-on learning, b) strengthen areas of curriculum pertaining to pediatrics and cultural variations in care, and c) wherever possible, be certain that learning modules are sensitive to South African cultures and norms.	Part 1: Theme 3 Part 2: Graduate Survey Part 2: General Survey
C) *UCT's Post-graduate Palliative Care Program*		
Strengthen the evaluation of students' work in the palliative care distance education program.	Improve feedback on assignments by using rubrics (made available to students with assignment instructions) and detailed comments to indicate strengths and areas for improvement.	Part 2: Graduate Survey
D) *UCT's Post-graduate Palliative Care Program*		
Evaluate the distance education program's workshop for first and second year students.	To determine: a) if workshop objectives are adequately addressed, and b) to determine if changes in patient outcomes occurred as a result of the workshop. Possible methods could include a pre-post design, using matched controls and a range of tools such as surveys and chart audits.	Part 2: Pre-Post Workshop Survey
E) *Professional Development*		
Educate practicing medical doctors in the field of palliative care using a variety of professional development opportunities.	To ensure that all medical doctors practicing medicine in South Africa have a minimum level of palliative care training. Professional development opportunities could range from hospital rounds to short courses geared towards teaching key elements of palliative care.	Part 1: Theme 1, sub-theme 2 Part 1: Theme 2: sub-theme 2

6.3.1 Context of Care

Part 1 (The *Context of Palliative Care in South Africa*), corresponded to the questions "*How do various stakeholders describe, understand and experience palliative and end-of-life care in South Africa?*" and "*How do health care providers articulate the palliative and end-of-life care educational needs of medical doctors?*". The analysis of structured observations, interviews, field notes, and the Health Care Provider Survey produced a comprehensive description of palliative and end-of-life care in South Africa from the perspective of patients, family care providers and health care workers.

In general, it was apparent that an individual's financial resources played a large role in the type of health care that could be expected. With the majority of South African residents using public health care, the system was unable to cope with the burden of illness within the resources available. Participants described how public health care was substantially different in comparison to private care; those reliant on the public system could not be expected to receive the same level of care as those in the private system.

Perhaps in response to the deficiencies in the South African health care system, hospices were developed. In addition to caring for people at end of life, a secondary objective of hospice was to provide excellent palliative care throughout the entire trajectory of illness. Palliative care, a fairly new field in South Africa, was described in other settings, but hospice care was seen to be the primary source for palliative medicine. Stakeholders in the system, be they patients, family care providers, or health care workers, described the merits of hospice care. Even with resource limitations, hospices were described as meeting a critical need within the population. The greatest issue was that hospices were too few and far between; society's need far outweighed their ability to provide meaningful care.

Due to many factors present in South Africa today, the ever-increasing need for palliative and end-of-life care is the reality. The context of care has shaped palliative and hospice care programming within the country and continues to determine accessibility. The primary recommendation, therefore, would be to improve accessibility to palliative care and hospice services by addressing barriers to care present in HPCA hospice programming to ensure a wider range of care is available and provided to all those in need.

6.3.1.1 Improve Accessibility

What are methods for increasing accessibility to hospice and palliative care services within South Africa? Of utmost importance is the improvement to the existing hospice referral process. It will be critical to change existing protocol and streamline the referral process within Hospice and Palliative Care Association of South Africa (HPCA) hospices. If a transparent and consistent hospice referral system was implemented, the benefits would be numerous.

Referral process. What constitutes an ideal referral system for South Africa? To increase accessibility, several changes need to be made in order that more people can gain access in a timely fashion. Participants described elements of the ideal referral system as consisting of a strong education component, repeated exposure to the same concept, and solid relationships with outside health care workers. A three-stage process has been developed based on the responses of participants, highlighting key components of an ideal referral system.

Table 6.2: Framework for the Ideal Referral System in South Africa

Stage	*Activity*	*Examples*
Pre-Referral		
	Generate positive public awareness of hospice and palliative care	Community newsletters
		Public hospice events(58)
		Educational advertisements- radio or newspaper
	Educate doctors, nursing sisters, and other health care providers in palliative medicine	Short courses on palliative medicine and hospice care (11)
		Pamphlets or electronic media containing critical information on palliative care(12)
	Educate general public to reduce stigma of hospice care	Information days or sessions(58)
Diagnosis & Treatment		
	Educate practitioners on palliative care principles	Short information sessions on hospice care (59)
	Provide patients with information on hospice care	Pamphlets available in clinics and doctor's offices
Referral Process		
(Timing)	Encourage early referral	Doctors to work in partnership with hospice care providers
(Process)	Standardize form	Develop and pilot a standardized form with stakeholder input

In many ways, if the *Pre-Referral Stage* is successful, then the rest of the framework will fall into place. The objectives of the Pre-Referral are threefold: 1) to generate positive public awareness of hospice and palliative care, 2) to educate doctors, nursing sisters, and other health care providers in palliative medicine and 3) to educate general public to reduce stigma of hospice care. Examples or program ideas can be seen in Table 6.1. By implementing programs to meet the stated objectives, the overall level of knowledge relating to hospice and palliative care should improve. This is especially important as reducing the stigma related to hospice care among the general population should create a more positive perception of hospice services. Altering awareness is also critical for health care practitioners, as they were described by respondents as not understanding hospice and / or palliative care sufficiently. As seen in other studies, it is critical to promote palliative care educate within the general public and health care community (58).

The *Diagnosis and Treatment Stage* would ideally extend the general information provided in the Pre-Referral Stage. Information would be geared to the needs of patients (relating to the role of palliative care throughout the trajectory of disease) and the educational needs of doctors, so that they can determine how to incorporate palliative care within the treatment plan. Patient information would need to be presented in the official languages spoken in South Africa; while Afrikaans and English are spoken by many throughout the country, it would be important to provide information in all of the tribal languages such as Zulu and Xhosa. Furthermore, the information would need to be presented at a level that would be understandable by those with less education. Doctor information would contain prompts for hospice follow-up. As well, hospice organizations could offer their skills as pain specialists to develop a partnership with local practitioners.

The final stage, the *Referral Process*, would culminate in earlier hospice referrals and a smoother referral process. As respondents remarked, a solid system is based on good relationships and community education. With a formal program geared to addressing concerns regarding the purpose of hospice care (thus negating the notion that entry into a hospice meant death) and to educate both health care providers and the general public on the purpose of palliative care (thus eliminating the notion that palliative care is only provided to patients who are actively dying), the ideal hospice referral program will be created. In addition, the creation of a consistent intake form would benefit the overall process.

6.3.2 Increase profile of palliative care

Tied closely to the availability of hospice and palliative care was the education of doctors in the field of palliative medicine. Palliative care training is occurring within South Africa in a variety of different settings. For example, UCT includes palliative care in its undergraduate program and offers the distance education palliative care post-graduate program. The HPCA provides training in the form of short courses for home-based carers and nursing sisters. However, palliative care education is limited and still in its infancy. The general public and many health care practitioners harbour many misconceptions about hospice and palliative care.

The results of both Parts 1 and 2 of this study pointed to the second recommendation and focused on a necessary change in South Africa's education and health system: the need to enhance a broad range of resources with implications for palliative care increase the profile of palliative care. This recommendation focused on three areas: 1) undergraduate medical education, 2) post-graduate medical education, and 3) professional development for trained doctors. With limited exposure to palliative principles within undergraduate medicine, doctors graduated with a focus on curative as opposed to holistic care. Participants highlighted the need for a systemic change in the medical educational programs and they expressed that palliative care education need be given priority.

6.3.2.1 Medical Education

Due to the need for palliative care within South Africa, palliative care content cannot be viewed as optional within medical curricula. Therefore, it is recommended that a review of the palliative care content in South Africa's undergraduate medical programs be undertaken. This would be useful in determining if and how palliative care content is taught within the medical curricula, instructional techniques used to teach palliative care, student perceptions of palliative care and palliative care curricula, and if curricula is addressing the range of educational needs as outlined in both the Health Care Provider Survey and the sub-theme pertaining to educational needs of doctors. Currently, most undergraduate medical programs in South Africa do offer students some form of programming in palliative medicine but it is limited in scope and often viewed as less significant by students. Palliative care education needs to be an important element within undergraduate medical education programs shown through an increased number of hours in the curriculum and given the same academic value as other fields. In addition, the general public needs to be educated on hospice and palliative care. Finally, those medical practitioners with no palliative care education need to be involved in palliative care training programs.

Palliative care education in South Africa remains a fringe topic within the undergraduate and post-graduate settings. Although several South African universities are including palliative care within undergraduate curriculums and UCT has developed a fine post-graduate course, the field is generally regarded as a fringe topic; in comparison to other medical fields, there is much less time in the curriculum spent on palliative medicine and students regard the subject area as less important than others. Palliative care needs to become an integral part of South Africa's medical curriculum and part of the medical certification exam. This would promote it as an important and necessary component of medicine and give it the status it deserves.

Around the world there is evidence of palliative care being incorporated into medical schools in a more deliberate fashion (60,61); many countries are developing curricula, sometimes at a national level, which is an indication of how people are perceiving its value to be increasing. In some parts of the world, palliative care education is no longer seen as a fringe topic (62)and this is what universities in South Africa need to strive towards. A commitment to palliative care education needs to be made in order to improve quality of life in patients (7).

Palliative care education for medical students has been shown to promote valuable skills and attitudes critical in the care of patients with life-threatening illnesses

(63) . Even if one does not consider the great burden of illness in the country and the role that palliative care could play in response to this, it must be recognized that each person who is born will eventually die. As medical schools routinely teach obstetrics, they should have equal focus on palliative care. As Charlton and Currie state, "knowledge and skills are required to safely enable both the birth of a human being and his or her eventual terminal decline and exit from the world with a minimum of suffering " (p. 64) (36).

To develop a program of study, initial steps would be to consider a range of other models and possibly build on the UCT program. There are a range of palliative care programs described within the literature which could shape an undergraduate program. For example, the palliative care curriculum for the Stanford Faculty Development Centre consists of eight 2-hour modules (15). The Harvard Medical School's course "Practical Aspects of Palliative Medicine" is a 3-day course for physicians and other health care workers (15). At the University of California, a palliative care interdisciplinary program, consisting of four training sessions over four weeks, was found to be effective (64). A range of programs offered in Canadian universities (63) are also described in the literature. One American study described an effective short course in palliative care (65), consisting of a seven day rotation in end-of-life care for undergraduate medical students. The course was mandatory for all second year internal medicine residents at the university where the course was developed. The course consisted of an orientation day, six days of hospice visits. Feedback was solicited at the end of the rotation. The primary role of students was to observe patient-practitioner interactions, but they were also encouraged to interact with patients and contribute to the health care plans. The program evaluation showed significant improvements in attitudes and perceived knowledge of end-of-life care. It was suggested that the course would be feasible in a range of health care settings (65).

In the UK, palliative care was recognized as a specialty in 1987, which paved the way towards specialty training (36). If palliative care was regarded as a specialty, and with that designation there was increased status or financial gain, there would be increased motivation for medical students to see palliative medicine both as a viable element of the curriculum and as a future career path(56). Currently in South Africa, palliative care is not recognized as a specialty. Thus, there is no career path or additional remuneration that would result from the completion of the post-graduate course (50).

Post-graduate medical education. Examples of educational assessment in postgraduate medical education are scarce. In general, there is very little evidence describing effective educational assessment and even less with respect to how palliative care education influences practice (66). However, the task of evaluation is important to the constant development and success of a palliative care educational program; feedback from evaluation assists in keeping an intervention current, applicable to the needs present in the community, and appropriate for the participants. The feedback of students and graduates of UCT post-graduate distance education program should be carefully considered by course convenors. Three specific recommendations regarding UCT's post-graduate medical education were made: 1) strengthen content of the distance education palliative care program by incorporating feedback of graduates and current students, 2) strengthen the evaluation of students' work in the palliative care distance education program, and 3) evaluate the distance education program's workshop for first and second year students.

The common elements of student and graduate responses provided the type of guidance useful in the continued development of a program. For example, as the suggestion to incorporate a practical component to the course (e.g. a hospice rotation) was spoken of regularly, it was obviously something that course conveners needed to consider; students clearly felt that while the theoretical aspects of palliative care were covered adequately, the practical element was lacking. Another theme useful in program development was that curriculum pertaining to pediatrics and cultural variations in care should be strengthened. Finally, students felt the course literature should be based on research conducted in an African context wherever possible. As such, the program planners can alter the readings accordingly.

Students and graduates of the distance education program also felt that the evaluation of students' work by instructors needed to be improved. They felt the current use of a grade and comments did not provide sufficient detail or feedback. Hence, methods that would ensure uniformity and consistency of feedback for all student should be implemented. More specifically, the recommendation was to incorporate rubrics or marking guides for each assignment. If made available when the assignment is given, these should provide clear guidelines in the completion of an assignment; with a rubric, students have the expectations and the mark break-down for each element of the assignment guiding their preparation. Without a rubric, students have to rely heavily on written comments (in the case of distance education programs), which may not be sufficient in providing enough detail and can be more subjective. A rubric can be more objective, while still providing valuable written commentary.

One of the objectives of the study's evaluation was to understand the impact of the workshops provided to both first and second year students. However, the small samples that completed the pre-post surveys did not provide sufficient data. Thus, another attempt at the evaluation of the workshops would be worth considering. In a future evaluation, it would be important to determine: a) if workshop objectives are adequately addressed, and b) to determine if, beyond written evaluation, outcomes may also determine if behavioural changes, in terms of actual palliative care practices, have taken place.

Professional Development. As South African universities begin teaching palliative care in undergraduate curricula and as University of Cape Town continues on with the post-graduate course in palliative care, more and more medical doctors will gain an awareness of palliative care in their medical practice. However, the majority of doctors would still not have been trained in palliative care, which means it is critical to focus on professional development opportunities for medical doctors in the field of palliative care.

This study points to the need for further education in the field of palliative care for practicing medical doctors. Palliative care education does not need to be based solely at universities. To reach a range of practitioners, it will be critical that a variety of opportunities are available. Professional development opportunities could range from hospital rounds to short courses geared towards teaching key elements of palliative care. For example, "half-day demonstration workshops... workshops extending over several days of weeks, certificate courses" (p. 219) (56) would each provide an opportunity for health care practitioners to gain mastery in the field of palliative care.

Public Education. The findings of this study accentuate that the South African public is generally ignorant about hospice and palliative care. In order for palliative care to gain acceptance within the country, it will be vital to educate the general public. As Kellehar proposes, a health promoting palliative care model- one that marries the ideals in public health promotion with the core concepts in palliative care-- could be utilized (57). Goals of this model could include the provision of education and information for health, dying, and death or social supports aimed at the needs of people with life threatening illnesses (57).

Educational and health promotional interventions, however, should not be seen as synonymous with fundraising campaigns. As hospice organizations in South Africa need to raise funds in order to operate, public fundraising drives are necessary. But asking for money is not the same as providing education about the program or using the tenets of health promotion to expand palliative care. So while fundraising is an important component of hospice administration, a separate targeted program needs to focus on education.

There are examples in the literature that are useful when developing an education program. In Japan, for example, a unique population-based intervention to improve public perception and understanding of palliative care was conducted. The intervention was designed to address numerous misconceptions regarding pain and opioids, communication with health care professionals, hydration, nutrition, and legal issues about end of life options (67). The educational intervention consisted of a one-hour lecture. The lectures were delivered at community halls prior to public community meetings. Although the long-term effects of the study were not known, the short-term results indicated that the intervention was effective in reducing misconceptions around palliative care and home deaths (67).

The way forward requires substantial but not unattainable change on a local, provincial and national scale. Based on the contextual and educational elements of the students, two recommendations were made: to increase accessibility and to make palliative care education a priority. Moving these recommendations forward will involve improving the hospice referral process and lobbying government. As well, it will require a greater commitment to medical education and education of the general public. Implementing those recommendations should see palliative and hospice care evolving into a mainstream service within South Africa's health care system.

6.4 Biases and Limitations

A systematic approach to data collection, interpretation and communication was used to address the influence of bias upon the researcher and research findings. That said, a number of biases and limitations do need to be discussed.

Part 1 (Palliative and End-of-Life Care in South Africa). To ensure credibility and in the attempt to sustain objectivity through reflexivity, the reflective process of field notes were incorporated into the design(68,69). This allowed for a detailed documentation of the research process and provided the researcher with the ability to review and reflect upon the history of the study. The researcher used field notes to reflect upon the broader assumptions made in the course of the research(68,69); exploring the researcher's role as a foreign, English speaking female was particularly important within this process.

***Researcher/Participant Bias*.** It is difficult to know for certain what affect one individual has on another. It is especially difficult to know if one's characteristics have affected the behaviours of others within a research study. That said, some participants, and in particular Xhosa speaking participants, may not have been fully open to disclose information to the researcher; issues of trust or fear of foreigners may have affected the interview process. Having a Xhosa speaking translator mediated this process to a great degree; to guide the interpretation of interviews with Xhosa speaking individuals, the translator would assist with cultural interpretations in addition to language interpretations. While this was critical in both the broader understanding of the racial issues within South Africa and the specific understanding of certain behaviours during interviews, it may be that some participants felt hindered during interviews.

To address concerns related to objectivity within the research process, several procedures were followed. Firstly, Nvivo 7 was used throughout the project as computer-assisted coding and analysis as this is seen by some to enhance credibility (68). Additionally, a co-researcher- Dr. Genevieve Thompson- based in Winnipeg, Manitoba, assisted with the analysis by reviewing the data and addressing inconsistencies found in the early analyses of the data. In this way, the co-researcher would examine the influence of bias upon the research findings as much as possible (70) and could address her concerns with the researcher as the study progressed. Discrepancies or negative cases (portions of interviews that seemed inconsistent with findings) were examined by both co-researchers throughout the analysis to explore the additional meaning they offered (68,69). Thirdly, other people were also asked for advice throughout the process. Namely the doctoral advisor (HC), the doctoral committee members (SM & RH), and the field advisor (LG) were approached on various issues relating to appropriate procedures and methodologies within the study population.

For example, it was during one of the committee meetings that a consensus was reached about the study population; it was felt that, even though the patient sample size had already been exceeded, it was not representative of the province's population, thus reducing the study's generalizability. The three most commonly spoken languages in the Western Cape province of South Africa were Afrikaans, English, and Xhosa; the majority of South Africans can speak English with some fluency. Therefore, interviews with participants were conducted in English by the primary investigator. However, the process resulted in the overwhelming majority of patient participants being white or Afrikaans; the Xhosa speaking population was not well represented. To ensure a more accurate representation of the South African population, a Xhosa-speaking translator was hired to assist with interviews of Xhosa speaking people. The researcher conducted the interviews and translation was provided when participants spoke in Xhosa. Thus the overall sample was more accurately reflective of the ethno-cultural variation found within South Africa's diverse population.

Interview Structure. Due to distance and cost factors, phone interviews were conducted with doctors not living in the Western Cape; face to face interviews were conducted with those living in Western Cape. The reality of the project was that there were fewer face to face interviews with doctors (n=8) compared to phone interviews (n=40). The face to face experience may have provided data that was more complex and rich due to the added depth an in-person interview affords, although that did not become obvious in the analysis. What the phone interviews lacked was the ability to contextualize the information. Although the researcher asked specific questions about the community and nature of the doctor's practice, it was not equivalent to being able to walk around a doctor's premise and conduct a structured observation.

Convenience Sample. A number of factors contributed to the need to use a convenience or purposive method to determine interview participants for Part 1. Namely, the convenience sample was able to be fielded within the time period available. Secondly, the purposive sample was inexpensive in comparison to probability sample selection methods such as random sampling or national surveys. And finally, the convenience samples was useful when collecting data in small or rare populations (71), a definition that would apply to this study. As Shapiro et al. suggest, "they are an invaluable means of developing hypotheses about phenomena that can later be studied in experiments, more generalizable to populations, or both" (p. 955)(71).

Due to the nature of a convenience sample, however, the study may contain specific biases. Most notably, the high proportion of respondents selected directly from Hospice and Palliative Care Association of South Africa (HPCA) organizations (63 or 54.3%) meant that this study examined a particular organization in greater detail than others. Within South Africa, home-based care and end-of-life care is provided by other organizations including NGOs and the government, or without any formal assistance. While the study did include non-HPCA hospices (n=2) and government hospitals (n=2), there was an imbalance in the sample. The results, therefore, may imply that palliative and end-of-life care is better resourced than is the actual case. Or, it may be the case that HPCA hospices have an overrepresentation of patients in comparison to other organizations. This data was not known. Thus, although the data and results of this study were valuable, it would be important to investigate other models of care in greater detail.

The recruitment of medical doctors also contained limitations. Eighteen (45%) of the 40 non-Western Cape doctor respondents were current students or graduates of the distance education course and six of the 40 (15%) were recommended by interview participants. As described in the results, the UCT program participants had a greater understanding of palliative care on many levels. This could skew the results as 45% of the general population does not have training in palliative care; the results might therefore overly inflate the level of knowledge in the medical community. Secondly, having participants recommend people may provide a more homogeneous sample; participants typically recommend people who they feel would be “good” for the interview, who may understand and be interested in the topic, and who would likely agree to participate. All of the recommended people agreed to be interviewed which may mean the interview data implied greater satisfaction or higher baseline knowledge with regards to palliative care. It is therefore important to keep these facts in mind when reviewing the results.

As seen in Chapter 4, the demographics for the sample of participating medical doctors was similar to the overall population of doctors that practice medicine in South Africa which may improve the generalizability of the study’s data. However, a disadvantage of a convenience sample is that the representativeness is unknown, even if the sample is selected to reflect the national demographics (71).

Length of Interviews. As reported in Sections 4.2.1 – 4.2.5, the length of interviews varied. Several of the interviews with patients and family care providers were quite short. This may be a reflection of burden of illness (e.g. several participants were bed ridden and/or very ill), language issues (e.g. where the interviewer was not always able to fully understand the participant responses and thus less able to probe for greater detail), or informant discomfort with the interview process. The concern with a short interview is that enough time is not given to the interviewee to adequately address the issues. Two points of clarification need to be made: a) the reported interview length is not reflective of the amount of time that was spent with each participant, and b) questions were constructed in such a way that would allow them to elaborate on their responses.

The time that the interviewer (and translator) spent with a participant was not reflected in the length of the interview. Prior to recording the interview, time would be given to review the consent form, make friendly conversation, and respond to questions or comment. Similarly, time would be spent after the interview in general conversation. Field notes were used to capture this material. Thus, the interview data was not the only source of material and the length of the recorded interview does not adequately reflect the depth of the conversation.

Additionally, the interviewer consistently used prompts to encourage participants to expand on their answers. The interviews with patients and family care providers focused on the health care that was provided as well as their satisfaction with care. In brief, participants were asked to list the health care providers that they saw, describe the care that was provided by each, and discuss their satisfaction with this care. It was most common that patients and family care providers were seen primarily/only by hospice nurses. The longest interviews were those where the patient or family care provider was involved with a number of different health care practitioners, yet this was not common. Participants were given opportunity to discuss and expand their responses throughout the interview.

Part 2: Evaluation of the UCT Distance Education Program. The three limitations within Part 2 of the study were seen in: 1) the usage of self-report to assess learning and skills, 2) the survey's response rates, and 3) the sample size generated in each survey. Each will be discussed in turn.

Self-Report. Using the survey methodology, current students and graduates were asked to both express the positive and negative aspects of the palliative care distance education program as well as evaluate the influence of the program on their medical practice. The General Survey examined perceived competence in the areas covered by the course. The Graduate Survey focused on how well the graduates were able to incorporate course material into their medical care practices. This survey also incorporated open-ended questions in order to get more qualitative and more textured information. The third survey, the Pre-Post Workshop Survey, aimed to evaluate the usefulness of the workshops held for first and second year students. The "post" portion of the survey was completed four months after the workshop in order measure a perceived change in practice.

As shown in Section 2.7.1 (Methods to Review Palliative Care Education), a range of methodologies are available for an evaluation of palliative care education programs. In the review of the literature that was conducted for this study, it was found that the majority of studies in fact, do utilize self-report methods such as pre-post surveys or questionnaires. However, the strongest designs were described as including observational methods such as chart reviews or prescribing audits; methods that allowed a comparison between perception and reality increased the validity of the results. The strongest designs were described as evaluating a program from a few angles and times; combinations of quantitative and qualitative methods were found to be the strongest and most revealing research designs as the confluence of data collected at different times or in different ways produced the most complete evaluation.

In this study, it was believed that using a complex evaluation strategy employing several different methods would reach beyond simple learner satisfaction (72) and move towards a true evaluation. The overall aim of utilizing three different surveys, therefore, was to provide layers of data in order to triangulate the various experiences of the students and graduates. With the low response rate in the pre-post analysis, the Graduate and General Surveys needed to be weighted more heavily. However, all the surveys relied on measuring the perception of change; the use of self-report to gain access to elements of behavioural change was a limitation.

Asking medical doctors to report on their own care has limitations and could have skewed the results. Firstly, the desire to report a positive effect or satisfaction might have created data that favours a positive and perhaps inaccurate evaluation. Secondly, the inability to recall details accurately when asked to reflect on past experiences may have led to a misrepresentation of the experience. As there was no other measurement administered (e.g. chart audit) to determine if the reported changes in care practice were observed in daily routine or if inconsistencies existed (73) the results of the study need to be understood as containing an unquantifiable element of subjective variability.

Although different methods were considered when determining the study design, it was felt that survey methodology was the best fit given the study parameters pertaining to time, size of classes, and funding. Two particular elements, a control group and a prescription audit, were considered but ultimately not included in the final design.

A control group was not utilized in this study even though the inclusion of controls may have had benefits. Specifically, a control group could have been used to complete the General Survey, thus providing baseline data. Additionally, having a control group would have allowed the researcher to determine if the study population was uniquely different (e.g. having prior interest or education in the field being examined) (66). Given the constraints due to small class sizes, selecting a control group from the course participants would have further narrowed the sample sizes, resulting in less data for comparison. Matched controls, using a sample of post-graduate students in a comparable program, would likely have been the only route to proceed but it was felt that a close match would not have been possible (and thus ineffective) given the uniqueness of the palliative care program. It is interesting to note that in the review of the literature pertaining to palliative care education, control groups were not used in any of the studies (N=18).

The second element that was considered was a pre-post prescription audit. In this study, incorporating a pre-post prescription audit would have meant a sample of students would have their prescription practices audited at the start of the program (upon acceptance) and then a second audit could occur several years post-program. In this way, there would be data providing both baseline evidence as well as data that could support or negate a change in behaviour. However, with limits on the length of the study (11 months), using a prescription audit was not feasible. In addition, the funding for the study would not have covered the additional time and travel expenses to gather prescription data. While it was recognized that a stronger design could have been created, the strongest design possible was implemented, given the number of constraints.

Survey Response Rates. As this study's sampling frame was not large (e.g. a total of 133 students have been involved in the program from 2001-2007) and as this group was seen to have a unique educational experience, it was anticipated that the survey response rates would be around 80%. The results of all three surveys were somewhat lower: General Survey (66.4%), Graduate Survey (65.5%), and the Pre-Post Surveys (2006-37.5%; 2007- 61.5%).

A review of health studies research studies indicated that a "low" or "high" survey response rate is defined somewhat arbitrarily by the study authors. Some perceive success to range in the 80-100% rate of return (74,75) yet others see a 50% response rate as fine (76). Studies dealing specifically with postal surveys for medical doctors report a wide range of response rates; response rates ranging from 25-50% were most common (76-79) and only small studies (n=12) of specialists produced extremely high response rates (100%) (75).

Based on the review of the literature, it is evident that a range of response rates are described as acceptable and that lower response rates are not unusual when surveying medical doctors. Although the response rates for this study were lower than anticipated, they were within reported acceptable limits. Without having the opportunity to discuss with non-participating doctors their reasons for opting out, several possibilities are likely: participating in research studies is not a high priority (76), it is easy to throw away a survey, and the time commitment was perceived to be too great. It is believed that if a more compact package was mailed (e.g. with a shortened consent form) or a telephone survey was conducted, then the response rates would have been higher.

Sample Size. The final sample sizes for the General Survey (N=83) and the Graduate Survey (N=41) might be viewed as insufficient. A priori sample size calculations were not conducted beforehand as recruitment was fixed by the size of the sampling frame. For example, the sample could only consist of current students or graduates of UCT's distance education palliative care course thus limiting the people available for the study. In addition, factors such as the time available for data collection could have adversely affected response rates. While small sample sizes do not invalidate the significant findings reported, they increase the likelihood that real differences or associations were not detectable.

6.5 Implications and Recommendations for Further Research

This study provides useful data on palliative and hospice care for South Africa. Specifically, the results of the study provide excellent detail relating to both hospice care and palliative medical education within the country; the two distinct parts of the study provide unique and informative data. In Part One, palliative and hospice care is analyzed from the perspective of patients, family care providers, and health care providers. A thematic description of palliative care in South Africa included the three themes of "Two Solitudes: Participant versus Public Notions of Palliative Care", "Accessing Palliative Care", and "The Changing Face of Palliative Care". In the first theme "Two Solitudes: Participant versus Public Notions of Palliative Care", it was apparent that while medical providers had an overall sense of what palliative medicine entailed, those with post-graduate education in palliative medicine were much more familiar with the key concepts of palliative care. The second theme, "Accessing Palliative Care", explored both different methods of accessing care as well as barriers to access. The theme "The Changing Face of Palliative Care in South Africa" examined how palliative care was evolving and adapting to the changing needs of patients. The introduction of ARTs, for example, was shown to have a great effect on the care of patients with HIV/AIDS. In addition, respondents identified educational needs of medical doctors in the field of palliative care. In Part Two, the evaluation of UCT's post-graduate palliative care program, current students and graduates described the usefulness and applicability of the program within their health care practice.

The general findings of the study are consistent with the limited empirical literature describing both palliative care in developing countries and palliative care education. However, the combination of needs, resources and perceptions as reported by study participants ensures that the results are meaningful and unique within the context of South Africa. For example, the data on referral systems resulted in recommendations that were applicable specifically to South Africa. In addition, the educational needs of doctors are closely related to the current issues in South Africa such as burden of illness, the health care system, and race.

A variety of future research needs became apparent during the course of the study. For example, as the study focused on palliative care within an adult population and as the needs of children are different (80), it is imperative to explore how the needs of children are defined in South Africa. A research project involving children could evaluate existing pediatric hospices or investigate the needs of children as care providers. Secondly, it would be important to explore the role of home-based care providers not specifically trained in palliative care. As the South African government has recently been funding general home-based care programs as a response to the HIV/AIDS epidemic, it will be important to examine the benefits and drawbacks of such a system. Within that investigation, it would be critical to determine the role of palliative care within the general home-based care program. Thirdly, the results indicated that a significant focus needs to be *undergraduate* education, it is necessary to evaluate the current progress of undergraduate palliative care education within South African medical schools. Having baseline data on what is currently offered will be important for program development within a national system. Fourthly, while the project successfully described care for people within a hospice setting, many respondents were clear that a great proportion of individuals do not have medical care at end of life. To truly understand end-of-life care in South Africa, research needs to be conducted to investigate the care for those without the resources to seek out or access additional health care services. An investigation of that kind will determine the level of stigma relating to HIV/AIDS, death and dying within those particularly vulnerable communities. Finally, the proposed methodology did not intend or permit an examination of provincial variation. Interviewing five doctors per province was not sufficient to document variation between different regions or provinces within South Africa yet it was apparent that differences do exist. A study focused on the provincial differences in palliative care provision would be a natural extension of this work. Only data with that degree of breath and depth will reveal South Africa's true needs pertaining to care for the dying.

6.6 Conclusion

The aims of this study were twofold: 1) to provide an analysis of palliative and end-of-life care in South Africa as it is currently provided within hospice and other health care organizations and 2) to assess the palliative care distance education program offered through the University of Cape Town (UCT). This study has highlighted two integrated areas--context of care and palliative care education—which will be central to further development in the field of hospice and palliative care. Two recommendations arose from this study: to increase accessibility and to make palliative care education a priority. To increase accessibility, two priority areas will be: a) to improve referral process for existing hospice and palliative care services, and b) to lobby the South African government for greater prominence of palliative care within the health care system. To address the education agenda, it is recommended that palliative care education be given priority in three particular populations: a) undergraduate medical students, b) general public, and c) practicing medical doctors. The benefits of the post-graduate distance education palliative care program are limited to a small group of practitioners and it is important the principles of palliative care gain prominence.

As Fainsinger has noted, palliative care research has been gaining momentum over the past decade; evidence of increasing grant support in both developing and developed nations has highlighted changing perspectives on the importance of palliative care (81). As the momentum continues to grow, it will be critical to focus research in communities with the greatest need. Noteworthy developments have occurred in South Africa within the field of palliative medicine. However, assisting and promoting further development, informed by sound and thoughtful palliative care research, is vital to achieving the best possible care for people with life threatening and limiting illnesses living in South Africa.

6.7 Chapter 6 References

(1) World Health Organization. World Health Organization definition of palliative care. Available at: http://www.who.int/cancer/palliative/definition/en/. Accessed May/ 05, 2006.

(2) Meghani SH. A concept analysis of palliative care in the United States. J.Adv.Nurs. 2004 Apr;46(2):152-161.

(3) Benatar SR. Reflections and recommendations on research ethics in developing countries. Soc.Sci.Med. 2002 Apr;54(7):1131-1141.

(4) Vejlgaard T, Addington-Hall JM. Attitudes of Danish doctors and nurses to palliative and terminal care. Palliat.Med. 2005 Mar;19(2):119-127.

(5) Karasz A, Dyche L, Selwyn P. Physicians' experiences of caring for late-stage HIV patients in the post-HAART era: challenges and adaptations. Soc.Sci.Med. 2003 Nov;57(9):1609-1620.

(6) Twycross R. Patient care: past, present, and future. Omega (Westport) 2007 - 2008;56(1):7-19.

(7) Webster J, Kristjanson LJ. "But isn't it depressing?" The vitality of palliative care. J.Palliat.Care 2002 Spring;18(1):15-24.

(8) Noah BA. AIDS and antiretroviral drugs in South Africa: public health, politics, and individual suffering: a review of Brian Tilley's It's my life. J.Law Med.Ethics 2003 Spring;31(1):144-148.

(9) Tshibangu KC, Worku ZB, de Jongh MA, van Wyk AE, Mokwena SO, Peranovic V. Assessment of effectiveness of traditional herbal medicine in managing HIV/AIDS patients in South Africa. East Afr.Med.J. 2004 Oct;81(10):499-504.

(10) Sanders BS, Burkett TL, Dickinson GE, Tournier RE. Hospice referral decisions: the role of physicians. Am.J.Hosp.Palliat.Care 2004 May-Jun;21(3):196-202.

(11) Taylor CL. Improving referral of patients to hospice through community physician outreach. J.Pain Symptom Manage. 2004 Sep;28(3):294-295.

(12) Bomba PA. Enabling the transition to hospice through effective palliative care. Case Manager 2005 Jan-Feb;16(1):48-52; quiz 53.

(13) Friedman BT, Harwood MK, Shields M. Barriers and enablers to hospice referrals: an expert overview. J.Palliat.Med. 2002 Feb;5(1):73-84.

(14) Van Vorst RF, Crane LA, Barton PL, Kutner JS, Kallail KJ, Westfall JM. Barriers to quality care for dying patients in rural communities. J.Rural Health 2006 Summer;22(3):248-253.

(15) Brasel KJ, Weissman DE. Palliative care education for surgeons. J.Am.Coll.Surg. 2004 Sep;199(3):495-499.

(16) von Gunten CF, Von Roenn JH, Johnson-Neely K, Martinez J, Weitzman S. Hospice and palliative care: attitudes and practices of the physician faculty of an academic hospital. Am.J.Hosp.Palliat.Care 1995 Jul-Aug;12(4):38-42.

(17) Bebko CP. A comparison of hospice gatekeepers: do they have the necessary information to refer? Health Mark.Q. 1995;13(2):79-86.

(18) Bradley EH, Fried TR, Kasl SV, Cicchetti DV, Johnson-Hurzeler R, Horwitz SM. Referral of terminally ill patients for hospice: frequency and correlates. J.Palliat.Care 2000 Winter;16(4):20-26.

(19) McGorty EK, Bornstein BH. Barriers to physicians' decisions to discuss hospice: insights gained from the United States hospice model. J.Eval.Clin.Pract. 2003 Aug;9(3):363-372.

(20) Street A, Blackford J. Communication issues for the interdisciplinary community palliative care team. J.Clin.Nurs. 2001 Sep;10(5):643-650.

(21) Lamont EB, Christakis NA. Physician factors in the timing of cancer patient referral to hospice palliative care. Cancer 2002 May 15;94(10):2733-2737.

(22) Weckmann MT. The role of the family physician in the referral and management of hospice patients. Am.Fam.Physician 2008 Mar 15;77(6):807-812.

(23) Clark D, Wright M, Hunt J, Lynch T. Hospice and palliative care development in Africa: a multi-method review of services and experiences. J.Pain Symptom Manage. 2007 Jun;33(6):698-710.

(24) Carlson MD, Morrison RS, Holford TR, Bradley EH. Hospice care: what services do patients and their families receive? Health Serv.Res. 2007 Aug;42(4):1672-1690.

(25) Shiozaki M, Morita T, Hirai K, Sakaguchi Y, Tsuneto S, Shima Y. Why are bereaved family members dissatisfied with specialised inpatient palliative care service? A nationwide qualitative study. Palliat.Med. 2005 Jun;19(4):319-327.

(26) Gwyther L. Palliative care response to HIV/AIDS in South Africa. Int.J.Palliat.Nurs. 2005 Mar;11(3):112-113.

(27) Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. Palliat.Med. 2002 Nov;16(6):457-464.

(28) McIlfatrick S, Curran CI. District nurses' perceptions of palliative care services: part 2. Int.J.Palliat.Nurs. 2000 Jan;6(1):32-38.

(29) Marco CA, Buderer N, Thum SD. End-of-life care: perspectives of family members of deceased patients. Am.J.Hosp.Palliat.Care 2005 Jan-Feb;22(1):26-31.

(30) Connor SR, Teno J, Spence C, Smith N. Family evaluation of hospice care: results from voluntary submission of data via website. J.Pain Symptom Manage. 2005 Jul;30(1):9-17.

(31) Gelfman LP, Meier DE, Morrison RS. Does palliative care improve quality? A survey of bereaved family members. J.Pain Symptom Manage. 2008 Jul;36(1):22-28.

(32) Pereira GJ. Palliative care in the hinterlands: a description of existing services and doctors' attitudes. Aust.J.Rural Health 2005 Dec;13(6):343-347.

(33) Groot MM, Vernooij-Dassen MJ, Crul BJ, Grol RP. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. Palliat.Med. 2005 Mar;19(2):111-118.

(34) Wakefield MA, Beilby J, Ashby MA. General practitioners and palliative care. Palliat.Med. 1993;7(2):117-126.

(35) Gilbert R, Willan AR, Richardson S, Sellick S. Survey of family physicians: what is their role in cancer patient care? Can.J.Oncol. 1994 Jul;4(3):285-290.

(36) Charlton R, Currie A. A UK perspective on worldwide inadequacies in palliative care training: a short postgraduate course is proposed. Am.J.Hosp.Palliat.Care 2008 Feb-Mar;25(1):63-71.

(37) Farquhar M, Grande G, Todd C, Barclay S. Defining patients as palliative: hospital doctors' versus general practitioners' perceptions. Palliat.Med. 2002 May;16(3):247-250.

(38) University of Cape Town, Faculty of Health Sciences. Student Handbook. 2008.

(39) Scott JF, MacDonald N, Mount BM. Palliative medicine education. In: Doyle D, Hanks WC, MacDonald N, editors. . 2nd ed. Oxford: Oxford Medical Publications; 1998. p. 1169-1200.

(40) Uys L, Hensher M. The cost of home-based terminal care for people with AIDS in South Africa. S.Afr.Med.J. 2002;92(8 I):624-628.

(41) Department of Health: Republic of South Africa. Republic of South Africa: Progress Report on Declaration of Commitment on HIV and AIDS. 2005;March 2006.

(42) Clark D. South Africa. Available at: http://www.eolc-observatory.net/global_analysis/southafrica.htm. Accessed May 03, 2006.

(43) Demmer C. AIDS and palliative care in South Africa. Am.J.Hosp.Palliat.Care 2007 Feb-Mar;24(1):7-12.

(44) Guirguis-Younger M, Grafanaki S. Narrative accounts of volunteers in palliative care settings. Am.J.Hosp.Palliat.Care 2008 Feb-Mar;25(1):16-23.

(45) Crowe S. Home truths. Nurs.Times 2001 Sep 27-Oct 3;97(39):26-27.

(46) Claxton-Oldfield S, Claxton-Oldfield J. Some common problems faced by hospice palliative care volunteers. Am.J.Hosp.Palliat.Care 2008 Apr-May;25(2):121-126.

(47) Claxton-Oldfield S, Hastings E, Claxton-Oldfield J. Nurses' perceptions of hospice palliative care volunteers. Am.J.Hosp.Palliat.Care 2008 Jun-Jul;25(3):169-178.

(48) Low J, Cloherty M, Wilkinson S, Barclay S, Hibble A. A UK-wide postal survey to evaluate palliative care education amongst General Practice Registrars. Palliat.Med. 2006 Jun;20(4):463-469.

(49) Hall P, Hupe D, Scott J. Palliative care education for community-based family physicians: the development of a program, the evaluation, and its consequences. J.Palliat.Care 1998 Autumn;14(3):69-74.

(50) Gwyther L, Rawlinson F. Palliative medicine teaching program at the University of Cape Town: integrating palliative care principles into practice. J.Pain Symptom Manage. 2007 May;33(5):558-562.

(51) Kinzbrunner BM. The role of the physician in hospice. Hosp.J. 1997;12(2):49-55.

(52) Melvin TA. The primary care physician and palliative care. Prim.Care 2001 Jun;28(2):239-249.

(53) Chang HM, Gallagher R, Vaillancourt PD, Balter K, Cohen M, Garvin B, et al. Undergraduate medical education in pain medicine, end-of-life care, and palliative care. Pain Med. 2000 Sep;1(3):224.

(54) Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? J.Palliat.Med. 2005 Dec;8(6):1176-1185.

(55) Larsen JV. Palliation of recurrent carcinoma of the cervix in a district hospital. S.Afr.Med.J. 2001 Mar;91(3):182, 184.

(56) Maddocks I. Palliative care education in the developing countries. J.Pain Palliat.Care.Pharmacother. 2003;17(3-4):211-221.

(57) Kellehear A. Health promoting palliative care. Melbourne ; New York: Oxford University Press; 1999.

(58) Claxton-Oldfield S, Claxton-Oldfield J, Rishchynski G. Understanding of the term "palliative care": a Canadian survey. Am.J.Hosp.Palliat.Care 2004 Mar-Apr;21(2):105-110.

(59) Casarett D, Karlawish J, Morales K, Crowley R, Mirsch T, Asch DA. Improving the use of hospice services in nursing homes: a randomized controlled trial. JAMA 2005 Jul 13;294(2):211-217.

(60) Lloyd-Williams M, Carter YH. Can medical education extend palliative care? Palliat.Med. 2003 Oct;17(7):640-642.

(61) Kelly D, Gould D, White I, Berridge EJ. Modernising cancer and palliative care education in the UK: insights from one Cancer Network. Eur.J.Oncol.Nurs. 2006 Jul;10(3):187-197.

(62) Weissman DE, Blust L. Education in palliative care. Clin.Geriatr.Med. 2005 Feb;21(1):165-75, ix.

(63) Oneschuk D, Hanson J, Bruera E. An international survey of undergraduate medical education in palliative medicine. J.Pain Symptom Manage. 2000 Sep;20(3):174-179.

(64) Fineberg IC, Wenger NS, Forrow L. Interdisciplinary education: evaluation of a palliative care training intervention for pre-professionals. Acad.Med. 2004 Aug;79(8):769-776.

(65) Yacht AC, Suglia SF, Orlander JD. Evaluating an end-of-life curriculum in a medical residency program. Am.J.Hosp.Palliat.Care 2006 Dec-2007 Jan;23(6):439-446.

(66) Macleod RD, Nash A, Charny M. Evaluating palliative care education. Eur.J.Cancer.Care.(Engl) 1994 Dec;3(4):163-168.

(67) Miyashita M, Sato K, Morita T, Suzuki M. Effect of a population-based educational intervention focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care. Palliat.Med. 2008 Jun;22(4):376-382.

(68) Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ 2000 Jan 8;320(7227):114-116.

(69) Mays N, Pope C. Qualitative research in health care. Assessing quality in qualitative research. BMJ 2000 Jan 1;320(7226):50-52.

(70) Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. Res.Nurs.Health 1997 Apr;20(2):169-177.

(71) Shapiro MF, Berk ML, Berry SH, Emmons CA, Athey LA, Hsia DC, et al. National probability samples in studies of low-prevalence diseases. Part I: Perspectives and

lessons from the HIV cost and services utilization study. Health Serv.Res. 1999 Dec;34(5 Pt 1):951-968.

(72) Hall P, Weaver L, Hupe D, Seely JF. Community-based palliative care education: can it improve care of the terminally ill? Acad.Med. 1999 Oct;74(10 Suppl):S105-7.

(73) Gharoro ET, Igberase GO, Okubor PO, Onakewhor JU. Caring for the terminally ill: what do the doctors think? Afr.J.Med.Med.Sci. 2003 Dec;32(4):377-380.

(74) Claudio L, Stingone JA. Improving sampling and response rates in children's health research through participatory methods. J.Sch.Health 2008 Aug;78(8):445-451.

(75) Mickelson JJ, Macneily AE, Samarasekera D, Beiko D, Afshar K. Competence in pediatric urology upon graduation from residency: perceptions of residents, program directors and pediatric urologists. Can.Urol.Assoc.J. 2008 Jun;2(3):205-210.

(76) Drummond FJ, Sharp L, Carsin AE, Kelleher T, Comber H. Questionnaire order significantly increased response to a postal survey sent to primary care physicians. J.Clin.Epidemiol. 2008 Feb;61(2):177-185.

(77) Sices L, Feudtner C, McLaughlin J, Drotar D, Williams M. How do primary care physicians identify young children with developmental delays? A national survey. J.Dev.Behav.Pediatr. 2003 Dec;24(6):409-417.

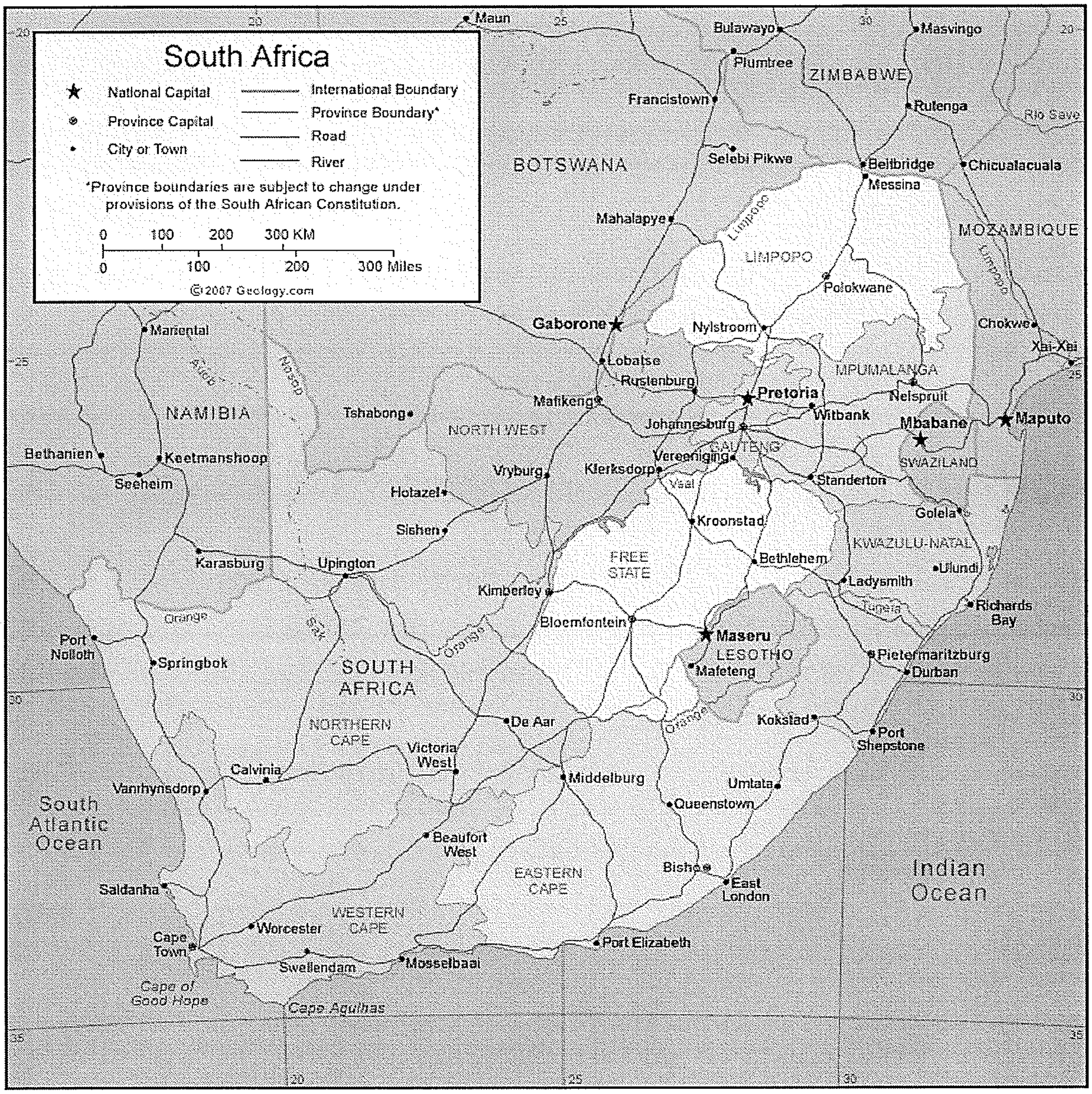
(78) Kaner EF, Haighton CA, McAvoy BR. 'So much post, so busy with practice--so, no time!': a telephone survey of general practitioners' reasons for not participating in postal questionnaire surveys. Br.J.Gen.Pract. 1998 Mar;48(428):1067-1069.

(79) Thompson DB, Ahrens MJ, LeRoy BS, Brown D, Berry SA. Newborn blood spot screening and genetic services: a survey of Minnesota primary care physicians. Genet.Med. 2005 Oct;7(8):564-570.

(80) Liben S,. Pediatric palliative medicine: obstacles to overcome. Journal of palliative care 1996;12(3):24.

(81) Fainsinger R. Global warming in the palliative care research environment - adapting to change. Palliat.Med. 2008 Jun;22(4):328-335.

Appendix 1: Map of South Africa



Appendix 2: Provincial mortality rates in South Africa, 2000 (based on table page 499)

	Eastern Cape	Free State	Gauteng	Kwa-Zulu Natal	Limpopo	Mpumalanga	Northern Cape	North West	Western Cape	South Africa
Population Total	6 897 865	2 862 088	8 765 922	9 211 922	5 277 432	3 054 973	955 010	3 753 128	4 399 414	45 081 010
										Deaths
Total	80 362	36 860	104 971	129 858	53 815	40 008	15 305	45 177	41 555	556 585
Male	41 289	20 619	60 336	66 385	27 410	21 717	9 810	25 246	23 377	303 081
Female	39 074	16 240	44 635	63 473	26 404	18 291	5 495	19 931	18 178	253 504
Child mortality (per 1,000 live births)										
Infant mortality rate	70.9	61.8	44.4	68.4	51.6	58.9	46.4	55.2	31.7	59.1
Under 5 mortality rate	105.0	99.0	74.6	116.4	80.7	99.8	68.1	88.5	46.3	94.7
Adult mortality (%)										
Adult mortality	38.6	42.6	39.3	48.7	39.9	47.5	34.2	42.0	30.8	42.9
Adult male mortality	45.0	49.3	46.0	54.6	46.7	53.8	40.9	48.8	37.5	49.4
Adult female mortality	32.2	35.9	32.7	42.8	33.1	41.3	27.5	35.2	24.1	35.7
Life expectancy (years)										
Life expectancy	56.2	55.1	58.0	***51.6***	57.1	***53.1***	60.5	55.9	***63.4***	55.2
Male life expectancy	53.3	52.4	55.1	***49.4***	54.3	***50.7***	57.2	53.1	***59.8***	52.4
Female life expectancy	59.0	57.9	61.0	***53.8***	60.1	***55.5***	63.9	58.8	***67.0***	58.5
Age-standardized death rate per 100 000										
Total	1 494	1 583	1 435	1 762	1 478	1 724	1 314	1 556	1 174	1 542
Male	1 790	1 856	1 703	2 051	1 784	2 002	1 584	1 828	1 445	1 831
Female	1 283	1 334	1 194	1 549	1 268	1 476	1 082	1 308	946	1 303
YLL per 100 000										
Total	24 919	27 253	23 725	32 209	23 678	30 262	19 863	25 963	16 764	26 735
Male	28 482	30 441	26 843	35 145	27 390	33 194	23 314	29 227	20 293	30 462
Female	22 179	23 985	20 593	29 880	20 937	27 420	16 618	22 174	13 465	23 352

* estimate of the number of deaths refer to the 12- month period that started in mid-2000 and are referred to as 2000

Appendix 3: HIV/AIDS episodes in an evolving epidemic

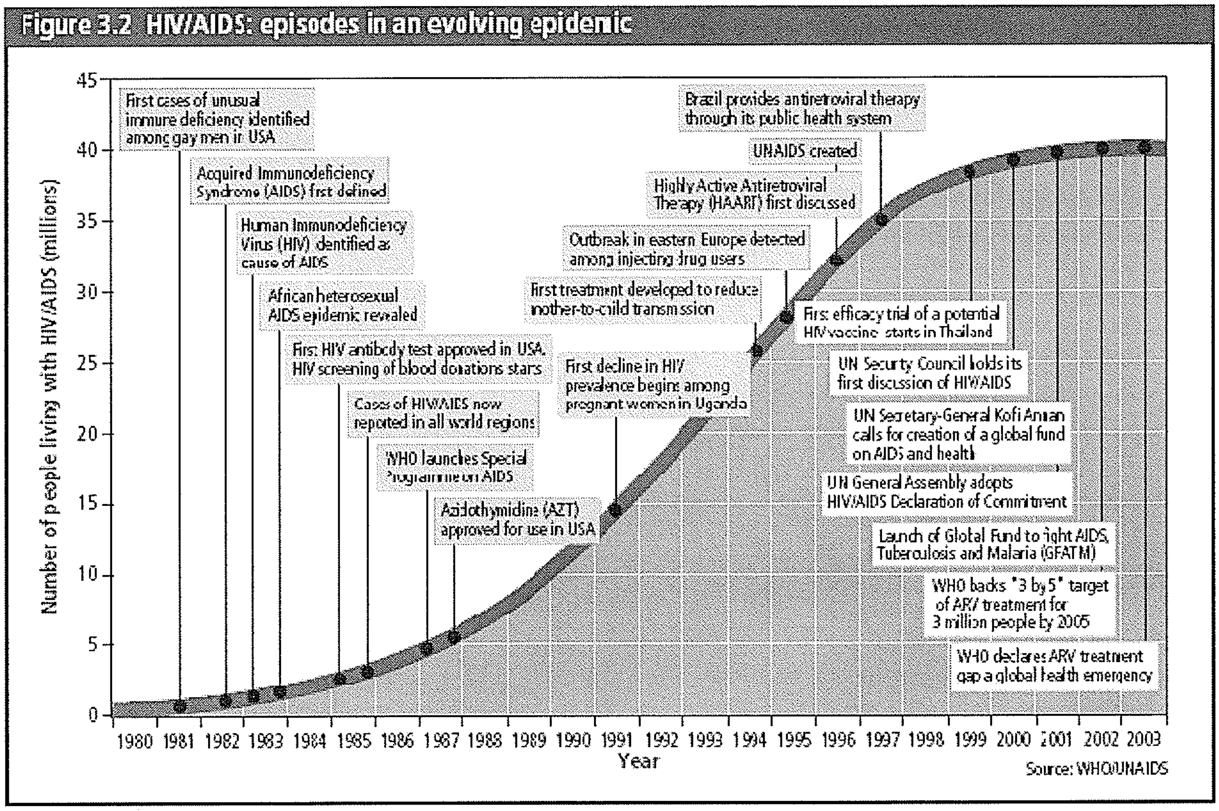


Figure 3.2 HIV/AIDS: episodes in an evolving epidemic

Source: WHO/UNAIDS

Appendix 4: Literature Review of Palliative Care in Africa

Search of PubMed, Google Scholar, and CINAHL databases on 04/02/06 and updated on 03/03/08; MeSH terms used were "palliative care" "palliate*" "South Africa" "Southern Africa" "Africa South of the Sahara" and "Africa"; completed a search of references in research articles.

Type of Article	**South Africa**	**Sub-Saharan Africa or African countries**	**Global**
Research	Jameson (2007) Lerato (2006) Uys (2003) Uys (2002) Uys (2002) Uys (2001) Uys (2001)	Collins (2007) Fainsinger (1998) Gharoro (2003) Harding (2005) Harding (2003) Kikule (2003) Lavy (2007) Mwaba (2001) Olweny (2003) Olweny (2005) Shawn (2005) Soyannwo (2001) Sukati (2005) Zimba (2001)	
Editorial / Correspondence	Gwyther (2004) Van Niekerk (2003) Larsen (2001)	Molyneux (2003) Merriman (2005) Senyimba (2005) Singer (2000) Tawfik (1993) Tectonidis (1998) Williams (2000)	
Descriptive / Report	Clark (2005) Crowe (2001) Defilippi (2007) Gwyther (2002) Gwyther (2005) Gwyther (2007)	Clark (2007) Coughlan (2003) De Baets (2007) Demmer (2007) Freeman (2007) Gray (2007) Jagwe (2007) Livingstone (2003) Merriman (1996) Mpanga (2003) Mwangi-Powell (2007) Palliative Care Trainers… (2003) Sepulveda (2003) Singer (2006) Solanke (1997) Soyannwo (2007) Spence (2004) Wright (2008)	Aranda (1999) Higginson (2007) Krasuka (2002) Webster (2007)

Appendix 5: Course Objectives of UCT distance-education training program

1 to critically examine the quality of palliative care in a number of patients with different conditions in the light of current knowledge and skills and to be able to reflect on personal practice in the management of these patients
2 to be able to critically analyze the literature concerning the principles of palliative medicine
3 to be able to support clinical decisions with objective evidence
4 to know about ways in which advanced disease can be modified by oncological, surgical and medical treatments
5 to be skilled in the diagnostic principles and practices of clinical palliative medicine
6 to be skilled in the therapeutic principles and practices of clinical palliative medicine
7 to be able to evaluate the scientific basis of pain management and discuss clinical application to palliative care
8 to be able to evaluate the scientific basis of the management of other common symptoms in palliative medicine and discuss practical application of this knowledge
9 to be able to describe and clinically assess the range of human behaviour associated with loss in different age groups
10 to understand the particular needs of children as relatives
11 to have some knowledge of the palliative care management issues specific to children
12 to have detailed understanding of barriers to achieving a dignified and meaningful death
13 to be able to demonstrate bio-ethical principles underpinning clinical decisions
14 to have knowledge of the cultural variations of belief and behaviour which may influence relevant delivery of care
15 to be skilled in communication with staff, patients and relatives who are involved with palliative care and be able to reflect on and analyze encounters posing challenging problems
16 to understand ways of improving teamwork within existing facilities
17 to have a systematic yet sensitive approach to the problems associated with teamwork, shared care and hospice care
18 to be able to describe in detail local facilities for palliative care and to evaluate these facilities
19 to understand the public policy debate around care of terminally ill patients and to contribute towards the development of humane, ethical and equitable public policy.
20 to promote and facilitate collaboration between public health care structures and NGOs involved in home-based, residential and inpatient palliative care.

Appendix 6: Workshop Objectives

Principles of palliative care

- To understand the principles of palliative care as expressed in the WHO definition of palliative care
- To recognize the continuum of care in palliative medicine
- To recognize the active nature of palliative care
- To recognize the patient and family as an integral part of the palliative care team
- To understand the holistic nature of palliative care

End of Life care

- To recognize the changing symptoms and signs as death approaches
- To be able to actively manage changing symptoms at end of life
- To be able to advise and support family members of the dying patient

Ethical decision making

- To consider the ethical principles guiding end-of-life care
- To review and recognize the ethical concepts underlying medical decision-making
- To consider the ethical decision-making in end-of-life care

Communication skills

- Further develop knowledge of communication skills
- Understand the importance of the Health Care Provider's attitudes
- Practice communication skills in safe learning environment
- To develop skills to assist in Breaking Bad News

Grief, loss & bereavement

- To understand the concepts of attachment, change, loss and mourning
- To recognise the stages of the normal grief reaction
- To be able to provide appropriate care and support in bereavement.
- To understand cultural diversity in terms of death, loss and bereavement

Complicated grief

- To identify risks for unresolved grief
- To consider the role of the bereavement counsellor
- To know when to refer for professional assessment and treatment

Principles of pain control

- To understand the different types and causes of pain
- To perform a thorough pain assessment

- To gain knowledge of the general principles of pain management as described by the WHO
- To manage neuropathic pain in a palliative care setting
- To identify and apply non-pharmacological methods in the management of chronic pain

Management of Symptoms in advanced disease

- To understand the causes of common symptoms in advanced disease
- To develop an approach to management of commons symptoms in advanced disease
- To understand the impact of symptom control on quality of life
- To recognise the occasions when palliative surgery, chemotherapy and radiotherapy are appropriate interventions

Palliative Care in HIV/AIDS

- To understand the distinctive features of palliative care in AIDS
- To understand the overlap between the management of treatable Opportunistic Infections and palliative care
- To understand the causes and appropriate management of the conditions which present in terminally ill AIDS patients
- To understand the integration between palliative care and disease-oriented care
- To understand broadly the psycho-social issues affecting AIDS patients and their families
- To have an understanding of the difficult issues (clinical, social and ethical) raised by the national HAART roll-out programme
- To understand some of the ethical dilemmas around medico-legal issues relating to AIDS deaths

Cultural and spiritual care

- To understand the elements of culturally sensitive care
- To explore the philosophy of Ubuntu
- To understand the close link between culture and spirituality
- To identify the barriers to culturally sensitive care
- To understand how to overcome these barriers
- To understand the difference between spirituality and religion
- To identify how health care practitioners can deliver spiritual care as part of holistic palliative care.

The MPT & care for the caregiver

- To understand the working of a multi-professional team in palliative care.
- To recognize the skills brought to the team by individual members
- To recognize the problems of stress and burnout in yourself and in staff members
- To recognize and be able to implement personal and organizational coping mechanisms
- To promote and develop positive resilience

Appendix 7: Letter of Invitation

UNIVERSITY OF CAPE TOWN

UNIVERSITY OF MANITOBA

Date

Re: Participation in End-of-Life Palliative Care Research Project

Dear:

My name is Carla Ens and I am writing this letter to introduce you and your staff to a research project that I hope you deem worthy of participation. I am a PhD student from the University of Manitoba (Canada) and am working on this project alongside Dr. Liz Gwyther of the University of Cape Town. The project has been approved by the research ethics boards at both universities.

This research project will document the role and educational needs of doctors in South Africa within the domain of palliative end-of-life care. Key informants for this evaluation will include patients with life-threatening illness, family care providers, and health care providers.

We are in the process of identifying people who would be interested in participating in the project. The criteria for a ***patient*** to be a participant will be: a) receiving hospice services, b) able to complete a one half hour interview, c) 18 years of age and older, d) willing and able to provide informed consent, and e) able to communicate in either Xhosa, Afrikaans, or English. For a ***family member***, he or she will a) need to be currently caring for an ill relative in hospice care (not need to be the primary caregiver, but does need to be involved in care-giving tasks on a daily basis), b) must be 18 years of age or older, c) must be competent to provide valid informed consent, and d) able to speak English, Afrikaans, or Xhosa. ***Doctors and nurses*** will need to meet the following criteria: a) provide care to terminally ill patients, b) able to complete a one hour interview, and c) can communicate in English.

We would like to arrange face-to-face interviews with 5 physicians, 5 nurses, 10 patients, and 10 family care providers. Your assistance would be helpful and necessary in order to determine possible participants. If you feel that you have enough information to introduce the project to your staff, patients, or family carers, I would appreciate you doing so. If you would prefer me to introduce the project, please let me know and I will arrange to visit.

I would like to begin interviews as soon as possible. If you have identified potential participants, please forward their contact information to me. Conversely, you could forward them my contact information and they could then reach me directly. Thank you for your time and I look forward to hearing from you shortly.

Sincerely,

Carla Ens
PhD Candidate University of Manitoba
Research Fellow University of Cape Town

Appendix 8: Interview Guides

Health Care Providers

Hello, my name is Carla Ens and I am a doctoral student at the University of Manitoba in Canada. My research assistant, Kate Jackson from the University of Cape Town, is here as well to help with the interview. Thank you for participating in this interview. Your participation will help ensure that we have empirical data needed to inform palliative care education and improve end-of-life care in South Africa. It should take approximately half an hour to complete. If at any time you would like to stop the interview, please let me know.

We will start the interview by gathering some **basic demographic information** to determine the characteristics of our participants.
Could you tell me your name and age?
From where did you receive your training? In which year?
Have you taken any additional training (e.g. courses or conferences) in palliative care?

The next part of the interview relates to your work setting.

Please describe for me your position at ____________________________.
How long have you worked here?
Could you briefly describe your duties?

Approximately how many patients (with life threatening illnesses) would you offer care to per month?

This section of the interview deals with **access to care within health care systems and organization of care**.

What is the referral process for patients with life threatening illness to be admitted into hospice care?
Prompts: Who gets referred and who does not meet referral standards?

Do you feel that this is an adequate referral system?
What do you feel are the barriers and challenges to accessing palliative care?
Prompts: For example, do you feel there are racial barriers that affect access? Transport issues? Ethnic Issues? Political Issues? Financial Issues?

Does your organization have sufficient resources to offer palliative care to all patients with life-threatening illnesses?

Prompts: For example, is there sufficient health care staff? Is there adequate and sufficient medications?

Has staff received training in palliative care? Please explain what type of training staff has received? Is there adequate equipment?

Let us now take some time to discuss **information provided to patients and families**.
How are patients told of a life threatening diagnosis and what to expect?
How is the topic of death and dying dealt with in patients and families?
Prompts: Is it something that can be discussed openly? Forbidden?

Are patient's families instructed on how to care for patients with life-threatening illnesses?
Prompts: physical care? emotional care?

The final section of the interview deals with **palliative care education and educational needs of doctors**.
Could you describe for me the role of a doctor within hospice care?

In your opinion, would you consider the doctor's role to be integral or unnecessary within the palliative care team?

Do you feel that there could be changes in the education of doctors to enhance their role within palliative medicine? Please explain.

Do you consider palliative care to be an important part of your practice? Please explain.
How would you describe the palliative care to someone who is unfamiliar with the phrase?

That marks the end of the interview. Do you have any additional comments or questions?

Thank you for taking the time to complete this interview. The data will be compiled and a brief summary will be made available to you if you so wish.

Patients

Hello, my name is Carla Ens and I am a doctoral student at the University of Manitoba in Canada. My research assistant, Kate Jackson from the University of Cape Town, is here as well to help with the interview. Thank you for participating in this interview today. The information you provide is helpful in improving care. There are four parts of the interview and it should take less than twenty minutes to complete. If at any time you would like to stop the interview, please let me know.

I will start the interview by getting some **personal details**.
Could you please tell me your name and age?

The second part of the interview aims to get an **overall picture of your satisfaction** with the hospice system and specifically the professionals you have been in contact with. The information that you provide is confidential and will not be shared with any of your care providers.

While in hospice care, how often do you see:

A) a doctor?
   Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
   Would you like to see that health care provider more often? Less often? Please explain.
   Do you see the same doctor or do you have more than one?

B) a nurse?
   Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
   Would you like to see that health care provider more often? Less often? Please explain.
   Do you see the same nurse or do you have more than one?

C) a social worker?
   Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
   Would you like to see that health care provider more often? Less often? Please explain.
   Do you see the same social worker or do you have more than one?

D) Any other health care professionals?
   Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
   Would you like to see that health care provider more often? Less often? Please explain.
   Do you see the same person each time?

The third part of the interview will help me understand better the **type of care that you receive** from a range of people.

What type of care do you receive from a **doctor**? physical care? emotional care? Would you say that you are satisfied with the care that you receive from the doctor(s)? Please explain why or why not.

What type of care do you receive from a **nurse**? physical care? emotional care? Would you say that you are satisfied with the care that you receive from the nurse(s)? Please explain why or why not.

What type of care do you receive from a **social worker**? physical care? emotional care? Would you say that you are satisfied with the care that you receive from the social worker(s)? Please explain why or why not.

Are there other health care professionals that provide you with care?
What type of care do you receive from a ___________________? physical care? emotional care? Would you say that you are satisfied with the care that you receive from the _________________? Please explain why or why not.

Who, outside of the health care professionals, looks after you?
How is this care provided?
Prompts: Is care provided every day? Once a week, etc.?

The final part of the interview deals with your **illness**.
Can you tell me about your illness?
Prompts: For example, does it have a name? When were you given this diagnosis? By whom were you given this diagnosis?

Can you describe symptoms that have caused you discomfort in the last 2 weeks?
For example, do you have pain? Shortness of breath? Nausea and vomiting? Other symptoms (explain)?

Are you able to control these symptoms?
For example, do you use medication? therapies? Or other methods (explain)

Thank you for taking the time to complete this interview. After I am finished this study, would you like a short summary of the results? If yes, then please provide me with your mailing address.

Family Members

Hello, my name is Carla Ens and I am a doctoral student at the University of Manitoba in Canada. My research assistant, Kate Jackson from the University of Cape Town, is here as well to help with the interview. Thank you for participating in this interview today. The information you provide is helpful in improving care. There interview should take about thirty minutes to complete. If at any time you would like to stop the interview, please let me know.

I will start the interview by getting some **personal details**.
Could you please tell me your name and age?
In which region of the Western Cape do you live?

The first part of the interview relates to care provision
What is your relationship to the patient you provide care to?
Can you provide me with a short description of the person that you are caring for?
Prompts: What is his / her age? gender? diagnosis?

Can you describe for me the type of care that you provide?
Prompts: Do you provide physical care? Emotional care?

How often do you provide care?
Prompts: Is this care provided on a daily basis? Weekly? Other?

For how long each day do you provide care?

The second part of the interview aims to get an **overall picture of your satisfaction** with the hospice system and specifically the professionals your family member has been in contact with. The information that you provide is confidential and will not be shared with any of the care providers.

While in hospice care, how often does your family member see:

A) a doctor?
   Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
   Do you feel that is adequate? Too often? Please explain.
   Does he or she see the same doctor each time?
B) a nurse?
   Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
   Do you feel that is adequate? Too often? Please explain.
   Does he or she see the same nurse each time?

C) a social worker?
Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
Do you feel that is adequate? Too often? Please explain.
Does he or she see the same social worker each time?

D) Any other health care professionals?
Prompts: daily, once a week, more than once a week, once a month, 2-4 times per month
Do you feel that is adequate? Too often? Please explain.
Does he or she see the same ____________ each time?

The third part of the interview will help me understand better the **type of care that your family member receives** from a range of people.

What type of care does he or she receive from a **doctor**? physical care? emotional care? Would you say that you are satisfied with the care that he or she receives from the doctor(s)? Please explain why or why not.

What type of care does he or she receive from a **nurse**? physical care? emotional care? Would you say that you are satisfied with the care that he or she receives from the nurse(s)? Please explain why or why not.

What type of care he or she receive from a **social worker**? physical care? emotional care? Would you say that you are satisfied with the care that he or she receives from the social worker(s)? Please explain why or why not.

Are there other health care professionals that provide your family member with care? What type of care does he or she receive from a __________________? physical care? emotional care? Would you say that he or she satisfied with the care that you receive from the ________________? Please explain why or why not.

Who, outside of the health care professionals, looks after your family member?
How is this care provided?
Prompts: Is care provided every day? Once a week, etc.?

Additional Comments….

Thank you for taking the time to complete this interview. After I am finished this study, would you like a short summary of the results? If yes, then please provide me with your mailing address.

Thank you again for participating in this interview.

Appendix 9: Observation Checklist

Date:

Time of Observation:

Length of Observation:

Assistance by:

☐ **Hospice** ☐ **Hospital**

☐ **Home** ☐ **Other:**

Address:

Checklist	*Response*	*Comment*
Environmental Characteristics		
Ability to have visitors?	Yes No	
Noise level High (constant noise)		
Medium (intermittent noise)		
Low (infrequent noise)		
Privacy		

Comments:

Availability of health care professionals		
How many workers on staff?		
Physicians		
Nurses		
Social Workers		
Other		
Number of patients under care (approximately)		

Other (general impressions of environment, and the extent to which it can deliver the services it purports to offer):

Appendix 10: Stewart's Framework

Personal &Social Environment

Patient and Family Situation
Spirituality
Culture, religion
Financial resources
Socioeconomic status
Recognition of imminence of death
Preferences, needs
Expectations of care
Concurrent life events

Clinical status, case mix
Diagnosis, severity, complexity
History, trajectory
Care needs, prior care
Current physical and cognitive health

Social support for patient
Family, close friends available
Spiritual counselling available
Tangible support
Emotional support

Social support for family
Tangible support
Emotional support
Night and day support
Support during bereavement

Structure of Care

Access to Care within System
Availability of hospice and palliative services
Financial access to hospice and palliative services
Referral Restraints

Organization of Care
Management, leadership values
Provider mix: race / ethnicity, skills in end-of-life care, cultural sensitivity
Time allowed for care
Service comprehensiveness
Services able to meet needs
Costs to system

Formal support services available
Home care for patient
Respite care for caregiver
Family counselling
Spiritual counselling

Physical environment(s) of care
Location of death
Opportunities for social
Interaction or privacy
Transfers

Process of Care with Physicians, Nurses, Social Workers

Technical Process- Patient
Appropriate use of medications and treatment
Accurate prognosis
Appropriate, timely referral for support services, counselling, specialty care
Knowledge and attentiveness to managing dying patients
Continuity, coordination of care

Decision Making Process- Patient and Family
Information provided about options, risks/ benefits of each
Preferences for care elicited
Patient, family involved in decisions
Advance care planning

Information, Counselling- Patient and Family
Patient's condition, what to expect
Pre-grief and bereavement process
Community and health care resources
What to expect at time of death, what to do next
How to care for patient

Interpersonal and Communication Style- Patient and Family
Respectfulness
Attention to existential spiritual needs
Quick response when patient or family needs to talk
Compassion, cultural sensitivity
Facilitate patient / family communication

Satisfaction with Health Care

Patient Satisfaction with Health Care
Preferences honoured regarding way of dying
Satisfaction with:
- Technical process
- Decision-making process
- Timeliness and usefulness of information, counselling
- Interpersonal and communication style

Family Satisfaction with Health Care
Satisfaction with:
- Technical process
- Decision-making process
- Timeliness and usefulness of information, education, counselling
- Interpersonal and communication style
- Extent to which patient family preferences honoured
- Extent to which opportunities provided to patient to complete life meaningfully

Quality and Length of Life

Quality of Life- Patient
Physical comfort
Psychological well-being
Social functioning and well-being
Spiritual well-being, meaningfulness of life
Physical functioning
Cognitive functioning
Overall perceived quality of life

Quality of Life of Family and Loved Ones
Caregiver burden
Physical comfort
Psychological well being
Social functioning and well-being
Spiritual well-being, meaningfulness of life
Economic resources left
Present at death of patient
Bereavement
Grief resolution, closure

Quality of Dying of Patient
Perceptions by patient, family, loved ones of quality of dying of patient

Length of Life

Appendix 11: Health Care Professional Survey

Name: ______________________________ Date: ____________________
Email: ______________________ Age: _______ Sex: ☐male ☐female
Location(s) of employment: ____
Province: ____________________ Phone: _____________ Fax: ____________
Where and when did you receive medical training? ______________________________
Have you taken any additional training in palliative care? If yes, please briefly describe.

Consider the educational needs of physicians within the field of palliative medicine. Rank each issue as *very important*, *somewhat important*, or *not important*, according to your personal opinion.

Issue	Very Important	Somewhat Important	Not important
Pain			
Assessment			
Management			
Pharmacology			
Complementary therapies			
Neurophysiology			
Symptom Control			
Nauseau and Vomiting			
Dysophagia			
Anorexia			
Dehydration			
Dypsnea			
Weakness			
Constipation			
Diarrhea			
Confusion			
The last 48 hours			
Bereavement			
Theories of grief and loss			
Coping with fears			
The dying child			
Child's experiences with grief			
Abnormal grief assessment			
Adjustment after death			
Psychosocial aspects of death			
Spiritual issues			
Religious issues			
Cultural issues			
Professional issues			
Resources for the bereaved			
Medico-legal concerns			
Ethics in palliative care			
Patient competency			
Confidentiality			
Research			
Resource allocation			
Euthanasia			
Establishing a palliative care program in the community			
Principles of palliative care			
Communication with the patient and family			
Interdisciplinary communication			
Personal ability to cope with a dying patient			

Appendix 12: Consent Forms

UNIVERSITY OF CAPE TOWN

UNIVERSITY OF MANITOBA

INTERVIEWS of Patients and Family Care Providers

Title of Study: **South African Physicians and the Provision of Palliative End-of-Life Care: An Evaluation of Perceived Roles, Competencies and the Influence of Distance Education in Addressing these Needs**

Principal Investigator: Carla Ens, School of Public Health and Family Medicine, Faculty of Health Sciences, Anzio Road, Observatory 7925;

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of the Study

The purpose of the study is to document the role of South African doctors during end-of-life care. The study is being conducted by Carla Ens, a PhD student in Community Health Sciences from the University of Manitoba, Canada. The study has been approved by the Research Ethics Boards of the University of Manitoba and the University of Cape Town.

A total of 70 participants will participate in this study.

Study Procedures

If you take part in this study, you will complete **one interview** with Carla Ens. The interview will last between 15-25 minutes. During the interview, you will be asked to describe your experiences as a patient or family care provider. Interviews will be tape recorded and transcribed. You may decline to answer any questions and may withdraw from the study at any time.

Risks or Discomforts

If you take part in this study, there are no known risks to participating and there are no costs associated with your participation in this investigation. The possibility does exist that the recounting of some of your experiences may be emotionally upsetting. In that event, you are free to end the interview and make the researcher aware of your feelings. At that time you will be able to discuss these feelings with a support person of your choosing. If you would prefer, you could be referred to the social work service at the nearest health care centre.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information from this study will contribute toward improving the education of physicians.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feels that it is in your best interest to withdraw you from the study, they will remove you without your consent.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. No one will be personally identified in the research. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law

The results of the study will be published as a PhD dissertation and may be published in the form of a journal article. This project is being supervised by Dr. Liz Gwyther, University of Cape Town and Dr. Harvey Chochinov, University of Manitoba.

During the course of the study, the data collected will be stored in a locked cabinet and will only be reviewed by the researcher and her thesis committee Chairperson. Names and identifying information will not appear on the transcripts. The consent forms will be store in the same manner, in a separate location. At the completion of the study, the interview data will be retained for a period of seven years and then they will be destroyed.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

I understand that I may contact the researcher, Carla Ens or the Field Research Advisor, Dr. Liz Gwyther, at 021 406 6174. For questions about your rights as a research participant, you may contact The University of Cape Town Research Ethics Board Office at Room ES2-24 Groote Schuur Hospital, Old Main Building, Observatory 7925.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Carla Ens or her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba or University of Cape Town Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

________________________________ __________________
Participant's signature Date (day/month/year)

____
Participant Printed Name

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: ____________________________ **Date** ________________
(day/month/year)
Signature: ______________________________________
Role in the study: __________________________________

UNIVERSITY OF CAPE TOWN

UNIVERSITY OF MANITOBA

INTERVIEWS of Health Care Providers

Title of Study: **South African Physicians and the Provision of Palliative End-of-Life Care: An Evaluation of Perceived Roles, Competencies and the Influence of Distance Education in Addressing these Needs**

Principal Investigator: Carla Ens, School of Public Health and Family Medicine, Faculty of Health Sciences, Anzio Road, Observatory 7925 ,
email:

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of the Study

The purpose of the study is to document the role of South African doctors during end-of-life care. The study is being conducted by Carla Ens, a PhD student in Community Health Sciences from the University of Manitoba, Canada. The study has been approved by the Research Ethics Boards of the University of Manitoba and the University of Cape Town.

A total of 70 participants will participate in this study.

Study Procedures

If you take part in this study, you will complete **one interview** with Carla Ens. The interview will last between 15-25 minutes. During the interview, you will be asked to describe your experiences as a health care provider as they relate to providing care at end-of-life. Interviews will be tape recorded and transcribed. You may decline to answer any questions and may withdraw from the study at any time.

Risks or Discomforts

If you take part in this study, there are no known risks to participating and there are no costs associated with your participation in this investigation. The possibility does exist that the recounting of some of your experiences may be emotionally upsetting. In that event, you are free to end the interview and make the researcher aware of your feelings. At that time you will be able to discuss these feelings with a support person of your choosing. If you would prefer, you could be referred to the social work service at the nearest health care centre.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information from this study will contribute toward improving the education of physicians.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feels that it is in your best interest to withdraw you from the study, they will remove you without your consent.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. No one will be personally identified in the research. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law

The results of the study will be published as a PhD dissertation and may be published in the form of a journal article. This project is being supervised by Dr. Liz Gwyther, University of Cape Town and Dr. Harvey Chochinov, University of Manitoba.

During the course of the study, the data collected will be stored in a locked cabinet and will only be reviewed by the researcher and her thesis committee Chairperson. Names and identifying information will not appear on the transcripts. The consent forms will be store in the same manner, in a separate location. At the completion of the study, the interview data will be retained for a period of seven years and then they will be destroyed.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

I understand that I may contact the researcher, Carla Ens or the Field Research Advisor, Dr. Liz Gwyther, at 021 406 6174. For questions about your rights as a research participant, you may contact The University of Cape Town Research Ethics Board Office at 021 406 6338 or Room ES2-24 Groote Schuur Hospital, Old Main Building, Observatory 7925.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Carla Ens or her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba or University of Cape Town Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

______________________________ ______________________

Participant's signature Date (day/month/year)

____

Participant Printed Name

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: ___________________________ Date ________________
(day/month/year)

Signature: ____________________________________

Role in the study: ________________________________

UNIVERSITY OF CAPE TOWN

UNIVERSITY OF MANITOBA

SURVEYS

Title of Study: **South African Physicians and the Provision of Palliative End-of-Life Care: An Evaluation of Perceived Roles, Competencies and the Influence of Distance Education in Addressing these Needs**

Principal Investigator: Carla Ens, School of Public Health and Family Medicine, Faculty of Health Sciences, Anzio Road, Observatory 7925;

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

Purpose of the Study

The purpose of the study is to evaluate the Palliative Care Distance Education Program, offered by the University of Cape Town. The study is being conducted by Carla Ens, a PhD student in Community Health Sciences from the University of Manitoba, Canada. The study has been approved by the Research Ethics Boards of the University of Manitoba and the University of Cape Town.

A total of 125 participants will participate in this study.

Study Procedures

If I agree I will complete two out of three surveys designed to evaluate different aspects of the course.

☐ **General Course Evaluation**

All former and current students to complete a questionnaire based on the objectives of the course. It is anticipated that this will take approximately 15 minutes to complete. This survey will be measuring confidence in palliative and end-of-life procedures.

☐ **Workshop Evaluation**

First and second year students attending seminars to complete a pre-post survey. The purpose of the pre-post survey is to evaluate the seminar and whether the objectives are being met. The pre survey will be completed prior to the first sessions and the post survey will be sent 3 months following the completion of the seminar.

- **Graduates' Evaluation**

Graduates of MPhil and Diploma program will be asked to complete a survey regarding general aspects of the course. It will take approximately 30 minutes to complete the survey. Each question will have you rate, on a numerical scale your impressions of various aspects of the course, and provide you the opportunity to explain your rating.

Risks or Discomforts

If you take part in this study, there are no known risks to participating and there are no costs associated with your participation in this investigation. The possibility does exist that the recounting of some of your experiences may be emotionally upsetting. In that event, you are free to end the interview and make the researcher aware of your feelings. At that time you will be able to discuss these feelings with a support person of your choosing. If you would prefer, you could be referred to the social work service at the nearest health care centre.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information from this study will contribute toward improving the education of physicians.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feels that it is in your best interest to withdraw you from the study, they will remove you without your consent.

Confidentiality

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. No one will be personally identified in the research. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law

The results of the study will be published as a PhD dissertation and may be published in the form of a journal article. This project is being supervised by Dr. Liz Gwyther, University of Cape Town and Dr. Harvey Chochinov, University of Manitoba.

During the course of the study, the data collected will be stored in a locked cabinet and will only be reviewed by the researcher and her thesis committee Chairperson. Names and identifying information will not appear on the transcripts. The consent forms will be store in the same manner, in a separate location. At the completion of the study, the interview data will be retained for a period of seven years and then they will be destroyed.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

I understand that I may contact the researcher, Carla Ens or the Field Research Advisor, Dr. Liz Gwyther, at 021 406 6174. For questions about your rights as a research participant, you may contact The University of Cape Town Research Ethics Board Office at 021 406 6338 or Room ES2-24 Groote Schuur Hospital, Old Main Building, Observatory 7925.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Carla Ens or her study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba or University of Cape Town Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

________________________________ ________________

Participant's signature Date (day/month/year)

____

Participant Printed Name

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: ______________________________ **Date** ________________
(day/month/year)

Signature: ____

Role in the study: ____________________________________

Appendix 13: Consent Script

Hello, my name is Carla Ens and I am a doctoral student at the University of Manitoba in Canada. Your contact information was provided to me as you have indicated interest in participating in my research study. The study has been approved by the Research Ethics Boards of the University of Manitoba and the University of Cape Town. I would like to describe the study for you and respond to any of your questions or comments before you decide if you would like to participate.

The purpose of the study is to document the role of South African doctors during palliative and end-of-life care. There will be a total of 70 participants in this study.

If you take part in this study, you will complete **one interview** with me.

Script will alter depending on participant:
Health Care Provider: The interview will last between45-60 minutes. During the interview, you will be asked to describe your experiences as a health care provider as they relate to providing care at end-of-life.

Patient or Family Member: The interview will last between 20-30 minutes. During the interview, you will be asked to describe your experiences as a patient or family member as they relate to receiving or providing care during a serious illness.

Interviews will be tape recorded and transcribed. You may decline to answer any questions and may withdraw from the study at any time.

If you take part in this study, there are no known risks to participating and there are no costs associated with your participation. The possibility does exist that talking about your experiences may be emotionally upsetting. In that event, you are free to end the interview and make me aware of your feelings. At that time you will be able to discuss these feelings with a support person of your choosing. If you would prefer, you could be referred to the social work service at the nearest health care centre.

There may or may not be direct benefit to you from participating in this study. We hope the information from this study will contribute toward improving the education of physicians.

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feels that it is in your best interest to withdraw you from the study, they will remove you without your consent.

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. No one will be personally identified in the research. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law

During the course of the study, the data collected will be stored in a locked cabinet and will only be reviewed by the researcher and her thesis committee Chairperson. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

Do you have any questions about the project or about the process of consent?

If you would like to proceed with this interview, I will document that you have provided me with verbal consent on ____________________ (insert date). I would like to have a copy for my files that has your signature on it. Could you provide me with a fax number or address so that I can send you a hard copy of the form?

Thank you.

Appendix 14: Xhosa Consent Form

UNIVERSITY OF CAPE TOWN

UNIVERSITY OF MANITOBA

Isihloko Sophando: Ogqirha BoMzantsi Afrika kunye nendlela abanika inyameko ngayo ekupheleni kobomi bomntu:
Uvavanyo lwembono zendima edlalwa, ubuchwepheshe negalelo lwemfundo yamgama ekusombululeni ezimfuno.

Umphandi Oyintloko: Carla Ens, wesikolo se Public Health ne Family Medicine, kwicandelo le Health Sciences;

Uyacelwa ukuba uthabathe inxaxheba kuphando esilwenzayo. Nceda thabatha ixesha lakho ukujonga uphonononge lefomu yesivumelwano ukuze ubuze nayiphina imibuzo onganayo kubasebenzi abenza uphando, ungathabatha ixesha lakho ukwenza isigqibo sokuthabatha inxaxheba koluphando, unganakho nokuyincokola nezihlobo zakho , usapho lwakho okanye ugqirha wakho phambi kokuba wenze isigqibo. Le fomu yesisivumelwano inganamagama ongawaqondiyo. Nceda ubuze abasebenzi abenza uphando bakucacisele onke amagama okanye nayiphina into ongayiqondiyo.

Injongo zophando

Injongo zophando kukufumanisa indima edlalwa ngogqirha bomZantsi Afrika ekunakekeleni abantu xa befikelela ekupheleni kobomi babo.
Oluphando lwenziwa nguCarla Ens, ongumfundi weqondo lePhD kwizifundo zeNzululwazi Zempilo yoLuntu nosuka kwiYunivesithi yaseManitoba, eCanada. Oluphando luvunyelwe yiBodi yemigaqo yophando yeYunivesithi yaseManitoba neYunivesithi yaseKapa.
Abantu abangamashumi asixhenxe (70 bakube bethabatha inxaxheba koluphando.

Inkqubo yophando

Ukuba uthabatha inxaxheba koluphando, uCarla uzakudlana nawe indlebe kube kanye.
Oludliwano- ndlebe lothabatha nje imizuzu elishumi (10). Ngexesha lodliwano-ndlebe uyakucelwa uchaze izimvo zakho njengesigulane okanye omnye wosapho ngexesha ubugula okanye unyamekela ogula kakhulu.
Oludliwano- ndlebe lwakwenziwa kwiteyiphu rekhodi ukuze luphindwe lubhalwe phantsi selusuka kwiteyiphu leyo. Unakho ukwala ukuphendula lemibuzo okanye ungarhoxa koluphando nangaliphina ixesha.

Iingozi nenkxalabo

Ukuba uthabatha inxaxheba koluphando akukho zingozi zaziwayo ekuthabatheni inxaxheba kungekho naxabiso layanyaniswa nokuthabatha inxaxheba koluphando. Kuyinyaniso kona ukuba ukuthetha ngezi zinto kungavuselela iinkumbulo ezingakonakalisa emoyeni. Ukuba kunjalo uvumelekile ukuba uluyekise udliwano-ndlebe ukuze umazise umphandi ngendlela ovakalelwa ngayo. Ngelixesha ungathetha ngendlela ova ngayo nomntu okhethwe nguwe. Xa uthanda ungadityaniswa nomntu wezentlalo-ntle okanye wezempilo.

Xa usisigulane esithabatha inxaxheba koluphando oko akuyikuphazamisana nonyango lwakho nangayiphina indlela.

Inzuzo

Inokubakhona okanye ingabikho inzuzo engqamene nawe ngokuthabatha inxaxheba koluphando. Siyathemba ukuba ulwazi esilufumeneyo koluphando luyakuphucula izifundo zogqirha.

Uthabatho nxaxheba ngokuzithandela / ukurhoxa koluphando

Isigqibo sokuthabatha inxaxheba koluphando usithabatha ngokuzithanndela. Ungala ukuthabatha inxaxheba okanye urhoxe koluphando nangaliphina ixesha. Isigqibo sokungathabathi inxaxheba koluphando asiyikuphazamisana nonyango lwakho olufumanayo kweliziko lezempilo. Ukuba abaphandi babona kuyimfuneko ukuba urhoxe bokurhoxisa bengafunanga mvume kuwe.

Imfihlelo

Ulwazi oluqokelelwe koluphando lungathi lupapashwe ezindaweni zasesidlangalaleni, kodwa igama lakho nayo nayiphina into enokwenza waziwe ayikuvezwa. Akukho namnye oyakwaziwa kuphando. Phantsi kwayo nayiphina inzame esiyenzayo ukugcina ulwazi ngawe lusemfihlakalweni asingekhe siqiniseke ngokupheleleyo ngemfihlakalo, kungenzeka olulwazi ludizwe xa umthetho ufuna njalo

Ingxelo zoluphando zopapashwa njengo mqulu wePhD ukuze zipapashwe kwincwadi zophando (journal). Oluphando longanyelwe nguGqirha Liz Gwyther weYunivesithi yase Kapa kunye no Gqirha Harvey Chochinov we Yunivesithi yase Manitoba.

Ulwazi oluqokelelweyo logcinwa kwikhabhathi ezitshixwayo, ngabaphandi kuphela abayakukwazi ukufikelela kulo. Igama lakho nayo nayiphina into enokwenza waziwe aliyikuvela kulenkcazelo. Ifomu yesivumelwano iyakugcinwa kwangoluhlobo kwindawo eyahlukileyo. Lwakuphela uphando lenkcazelo iyakugcinwa kangangeminyaka esi xhenxe (7) ukuze itshatyalaliswe.

Icandelo lebhodi yemigaqo yezophando lwezempilo laseManitoba lungawajonga lamaxwebhu ophando ukuqinisekisa ukusulungeka kwenkqubo yophando.

Ndiyaqonda ukuba ndinakho ukuqhakamshelana nomphandi u Carla Ens kwinombolo…………… okanye umcebisi wophando uGqirha Liz Gwyther kwinombolo………………

Imibuzo engamalungelo akho mjengomthathi – nxaxheba zingabhekiswa kwikomiti yemigaqo yezophando ye Yunivesithi yaseKapa.
Musa ukutyikitya esisivumelwano ngaphandle kokubuza imibuzo onayo naphambi kokufumana impendulo eyanelisayo kuyo yonke imibuzo onayo

Isivumelwano

Ndiyifundile lefomu yesivumelwano. Ndibenalo nexesha lokuthetha ngoluphando noCarla Ens okanye abasebenzi abenza uphando. Ndizifumene impendulo zemibuzo yam kubo ngolwimi lwam. Ingozi zophando nenzuzo zichaziwe . Ndiqinisekile ukuba andinyanzelwanga ngabaphandi ukuthabatha inxaxheba koluphando nangayiphina indlela.
Nabuphina ubuhlobo endinabo nabaphandi (njengo mphathi wam, umqeshi, okanye oisizalwane sam) abuchaphazelanga ukuthabatha kwam isigqibo sokuba yinxalenye yoluphando
Ndiyaqonda ukuba ukuthabatha kwam inxaxheba koluphando asilonyanzelo ndingarhoxa nangaliphina ixesha.
Ndiyavuma ngokupheleleyo ukuthabatha inxaxheba koluphando.

Ndiyaqonda ukuba naluphina ulwazi olunokwenza ndaziwe luyakugcinwa emfihlakalweni, kodwa lomfihlakalo ayiqinisekiswa kananjalo . Ndiyagunyazisa ukuhlolwa kwawo nawaphina amaxwebhu am anxulumene nophando olu yibhodi yemigaqo yezophando ye Yunivesithi yaseManitoba neYunivesithi yaseKapa ukuqinisekisa ukusulungeka kwekqubo yophando

Ngokutyikitya lefomu yesisivumelwano andiwatyeshelanga nawaphina amalungelo omthetho endinawo ekuthabatheni inxaxheba kuphando.

________________________________ ________________

Utyikityo lomthathi – nxaxheba Umhla/ inyanga/nonyaka

____

Igama lomthathi –nxaxheba

Mna otyikityileyo ndiyaqinisekisa ukuba zonke inkcukacha zoluphando zichaziwe kumthathi – nxaxheba obhalwe ngasentla ndaye ndiqinisekile ukuba umthathi – nxaxheba uziqondile kwaye unika isivumelwano esiqinisekileyo

Igama elibhaliweyo_________________________Umhla________________

Tyikitya___________________________

Appendix 15: General Survey

Demographic Information

Gender	☐ Male ☐ Female
Age	☐ 18-29 ☐ 30-44 ☐ 45+
Years working in palliative care	
Number of medical partners	

Survey

Please indicate your degree of competence by placing an (X) in the appropriate box.

Activity	Can perform independently	Require minimal supervision	Requires close supervision or teaching	Need further basic instruction
1. conducting a family conference to discuss important end-of-life decisions				
2. giving bad news to a patient or family member				
3. discussing the palliative care treatment approach with patient and family				
4. discussing home-based hospice referral with patient and family				
5. discussing treatment withdrawal (e.g. antibiotics, hydration, non-oral feeding) with patient and family				
6. discussing do not resuscitate (DNR) orders with patient and family				

Pain	Extremely Competent	Somewhat Competent	Somewhat incompetent	Extremely Incompetent
1. assessment of pain				
2. use of oral opioid analgesics				
3. use of parenteral opioid analgesics				
4. use of adjuvant analgesics (e.g. antidepressants, anticonvulsants)				
5. knowing when to ask for help from a pain specialist				

Assessment	Extremely Competent	Somewhat Competent	Somewhat incompetent	Extremely Incompetent
1. assessment and management of terminal delirium				
2. assessment and management of terminal dyspnea				
3. assessment and management of nausea / vomiting				
4. assessment and management of constipation				

Changes in Treatment	Extremely Competent	Somewhat Competent	Somewhat incompetent	Extremely Incompetent
1. knowing when it is time to refer an AIDS patient for home-based hospice care				
2. knowing when it is time to refer a cancer patient for home-based hospice care				
3. knowing how to determine decision-making capacity				
4. knowing when to discuss advanced directives with patients and family members				
5. knowing when it is appropriate to discuss withdrawal from mechanical ventilation				
6. knowing when it is appropriate to discuss discontinuation of IV hydration				
7. knowing when it is appropriate to discuss discontinuation of non-oral feedings				

General Palliative Care Concepts	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
1. ability to describe and clinically assess the range of human behaviour associated with loss in different age groups				
2. understanding of the particular needs of children as relatives				
3. knowledge of the palliative care management issues specific to children				
4. understanding of barriers to achieving a dignified and meaningful death				
5. knowledge of the cultural variations of belief and behaviour which may influence relevant delivery of care				
6. communication with staff, patients and relatives who are involved with palliative care and be able to reflect on and analyze encounters posing challenging problems				
7. understanding of ways to improve teamwork within existing facilities				
8. detailed knowledge and evaluation of local facilities for palliative care				
9. understanding of the public policy debate around care of terminally ill patients				

Thank you for participating in this survey. Please provide your email address if you would like to:
a) Like to receive a copy of the final report ______yes ______no

b) Be open to further contact for additional research of this kind ______yes ______no

Your email address: ____

You can contact the Lead Investigator by email: carla.ens@gmail.com
or by phone: 076 715 8076

Appendix 16: Graduate Survey

Gender	☐ Male ☐ Female
Age	☐ 18-29 ☐ 30-44 ☐ 45+
Year Entered Distance Education Course	
Year Graduated	
How many years have you practiced medicine?	
How many patients (approximately) would you typically care for at end-of-life per month?	
How many medical partners do you have?	

Survey

How helpful was the course in developing your ability to:	Not helpful	Somewhat helpful	Very helpful	No opinion	Not applicable
1. critically examine the quality of palliative care in a number of patients with different conditions in the light of current knowledge and skills?					
2. critically reflect on personal practice in the management of patients with different conditions?					
3. critically analyze the literature concerning the principles of palliative medicine?					
4. support clinical decisions with objective evidence?					
5. know about ways in which advanced disease can be modified by oncological, surgical and medical treatments?					
6. be skilled in the diagnostic principles and practices of clinical palliative medicine?					
7. be skilled in the therapeutic principles and practices of clinical palliative medicine?					
8. be able to evaluate the scientific basis of pain management?					
9. be able to discuss clinical application of evidence based palliative care?					
10. be able to evaluate the scientific basis of the management of other common symptoms in palliative medicine and discuss practical application of this knowledge?					

1. Can you describe why you enrolled in the palliative care distance education program?

2. Can you explain if and how your care practice has changed for patients requiring palliation? Examples from pre-post course would be helpful.

3. What were three key aspects of your training that you have transferred into your practice?

   a.

   b.

   c.

4. Please identify any weaknesses in the UCT program.

Clinical Assessment

How helpful was the course in developing your ability to:	Not helpful	Somewhat helpful	Very helpful	No opinion	Not applicable
1. be able to describe and clinically assess the range of human behaviour associated with loss in different age groups?					
2. understand the particular needs of children as relatives?					
3. have some knowledge of the palliative care management issues specific to children?					
4. have detailed understanding of barriers to achieving a dignified and meaningful death?					
5. be able to demonstrate bio-ethical principles underpinning clinical decisions?					
6. have knowledge of the cultural variations of belief and behaviour which may influence relevant delivery of care?					

Team Approach

How helpful was the course in developing your ability to:	Not helpful	Somewhat helpful	Very helpful	No opinion	Not applicable
1. be skilled in communication with staff, patients and relatives who are involved with palliative care?					
2. be able to reflect on and analyze encounters posing challenging problems?					
3. understand ways of improving teamwork within existing facilities?					
4. have a systematic yet sensitive approach to the problems associated with teamwork, shared care and hospice care?					

5. How has the palliative care program benefited your patients?

6. How has the palliative care program benefited your co-workers?

End-of Life Care in South Africa

How helpful was the course in developing your ability to:	Not helpful	Somewhat helpful	Very helpful	No opinion	Not applicable
1. be able to describe in detail local facilities for palliative care?					
2. To evaluate local palliative care facilities?					
3. understand the public policy debate around care of terminally ill patients?					
4. contribute towards the development of humane, ethical and equitable public policy?					
5. promote and facilitate collaboration between public health care structures and NGOs involved in home-based, residential and in- patient palliative care?					

7. What are your concerns regarding end-of-life care in South Africa?

8. How would you wish to see the concerns you raise addressed?

Thank you for participating in this survey.

Please provide your email address if you would like to (please check yes or no):
a) Like to receive a copy of the final report _____yes _____no
b) Be open to further contact for additional research of this kind
_____yes _____no
Your email address: ____
You can contact the Lead Investigator by email [redacted]

Appendix 17: Pre-post Workshop Survey

Demographic Information

Gender	☐ **Male** ☐ **Female**
Age	☐ **18-29** ☐ **30-44** ☐ **45+**
Years in Practice?	**Number of Medical Partners?**

Survey

Please indicate your ability level or degree of competence by placing an (X) in the appropriate box.

1. Principles of Palliative Care	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Understanding the principles of palliative care as expressed in the WHO definition of palliative care				
Recognizing the continuum of care in palliative medicine				
Recognizing the active nature of palliative care				
Recognizing the patient and family as an integral part of the palliative care team				
To understand the holistic nature of palliative care				

2. End-of-Life Care	Extremely Competent	Somewhat Competent	Somewhat incompetent	Extremely Incompetent
Able to recognize the changing symptoms and signs as death approaches				
Able to actively manage changing symptoms at end of life				
Able to advise and support family members of the dying patient				

3. Ethical Decision Making	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Able to consider the ethical principles guiding end-of-life care				
Able to review and recognize the ethical concepts underlying medical decision-making				
Able to consider the ethical decision-making in end-of-life care				

4. Communication Skills	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Further develop knowledge of communication skills				
Understanding the importance of the Health Care Provider's attitudes				
Able to practice communication skills in safe learning environment				
Developing skills to assist in Breaking Bad News				

5. Grief, Loss & Bereavement	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Understanding the concepts of attachment, change, loss and mourning				
Recognizing the stages of the normal grief reaction				
Providing appropriate care and support in bereavement.				
Understanding cultural diversity in terms of death, loss and bereavement				

6. Complicated Grief	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Identifying risks for unresolved grief				
Considering the role of the bereavement counsellor				
Knowing when to refer for professional assessment and treatment				

7. Principles of Pain Control	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Understanding the different types and causes of pain				
Performing a thorough pain assessment				
Gaining knowledge of the general principles of pain management as described by the WHO				
Managing neuropathic pain in a palliative care setting				
Identifying and applying non-pharmacological methods in the management of chronic pain				

8. The MPT and Care for the Caregiver	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Understanding the working of a multi-professional team in palliative care.				
Recognizing the skills brought to the team by individual members				
Recognizing the problems of stress and burnout in yourself and in staff members				
Recognizing and be able to implement personal and organizational coping mechanisms				
Promoting and developing positive resilience				

9. Management of Symptoms in advanced Disease	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Understanding the causes of common symptoms in advanced disease				
Developing an approach to management of commons symptoms in advanced disease				
Understanding the impact of symptom control on quality of life				
Recognizing the occasions when palliative surgery, chemotherapy and radiotherapy are appropriate interventions				

10. Palliative Care in HIV/AIDS	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Understanding the distinctive features of palliative care in AIDS				
Understanding the overlap between the management of treatable Opportunistic Infections and palliative care				
Understanding the causes and appropriate management of the conditions which present in terminally ill AIDS patients				
Understanding the integration between palliative care and disease-oriented care				
Understanding broadly the psycho-social issues affecting AIDS patients and their families				
Have an understanding of the difficult issues (clinical, social and ethical) raised by the national HAART roll-out program				
Understanding some of the ethical dilemmas around medico-legal issues relating to AIDS deaths				

11. Cultural and Spiritual Care	Extremely competent	Somewhat competent	Somewhat incompetent	Extremely incompetent
Understanding the elements of culturally sensitive care				
Exploring the philosophy of Ubuntu				
Understanding the close link between culture and spirituality				
Identifying the barriers to culturally sensitive care				
Understanding how to overcome these barriers				
Understanding the difference between spirituality and religion				
Identifying how health care practitioners can deliver spiritual care as part of holistic palliative care				

Thank you for participating in this survey. Please provide your email address if you would like to:
a) Like to receive a copy of the final report ______yes ______no

b) Be open to further contact for additional research of this kind ______yes ______no

Your email address: ____

You can contact the Lead Investigator by email:

Appendix 18: Statistics from Health Professionals Council of South Africa (updated November, 2007)

Western Cape Province																		
	Asian			Black (& African)			Colored			White (& European)			Other / Unknown / Blank			Total		
	Male	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***
Fam Docs & GPs	195	120	**315**	71	52	**123**	110	65	**175**	1515	962	**2477**	774	400	**1174**	2665	1599	**4264**
Specs. & SubSpecs	45	22	**67**	16	10	**26**	14	7	**21**	1090	303	**1393**	637	152	**789**	1802	494	**2296**
Other	14	1	**15**	4	0	**4**	3	0	**3**	130	37	**167**	66	19	**85**	217	57	**274**
TOTAL	254	143	**397**	91	62	**153**	127	72	**199**	2735	1302	**4037**	1477	571	**2048**	4684	2150	**6834**
Limpopo / Northern Province																		
Fam Docs & GPs	35	8	**43**	315	137	**452**	0	0	**0**	184	56	**240**	129	39	**168**	663	240	**903**
Specs. & SubSpecs	8	2	**10**	28	3	**31**	0	0	**0**	40	2	**42**	34	6	**40**	110	13	**123**
Other	0	1	**1**	0	0	**0**	0	0	**0**	1	0	**1**	1	0	**1**	3	0	**3**
TOTAL	43	11	**54**	343	140	**484**	0	0	**0**	225	58	**283**	164	45	**209**	776	253	**1029**
Mpumalanga Province																		
Fam Doc & GPs	55	11	**66**	222	73	**295**	0	2	**2**	279	95	**374**	122	29	**151**	678	210	**888**
Specs. & SubSpecs	4	1	**5**	5	0	**5**	0	0	**0**	87	10	**97**	39	6	**45**	135	17	**152**
Other	0	0	**0**	0	0	**0**	0	0	**0**	1	0	**1**	0	0	**0**	1	0	**1**
TOTAL	59	12	**71**	227	73	**300**	0	2	**2**	367	105	**472**	161	35	**196**	814	227	**1041**
Free State Province																		
Fam Doc & GPs	21	6	**27**	152	47	**199**	7	2	**9**	410	221	**631**	189	71	**260**	779	347	**1126**
Specs. & SubSpec	4	1	**5**	16	3	**19**	3	0	**3**	219	46	**265**	107	30	**137**	349	80	**429**
Other	0	0	**0**	0	1	**1**	0	0	**0**	21	2	**23**	13	2	**15**	34	5	**39**
TOTAL	25	7	**32**	168	51	**219**	10	2	**12**	650	269	**919**	309	103	**412**	1162	432	**1594**
Gauteng Province																		
Fam Doc & GPs	556	310	**866**	1088	599	**1687**	27	26	**53**	1880	1352	**3232**	1085	565	**1650**	4636	2852	**7488**
Spec. &	151	61	**212**	220	97	**317**	7	3	**10**	1518	433	**1951**	796	268	**1064**	2692	862	**3554**
Sub-specs	43	3	**46**	16	7	**23**	2	2	**4**	179	52	**231**	106	33	**139**	346	97	**443**
TOTAL	750	374	**1124**	1324	703	**2027**	36	31	**67**	3577	1837	**5414**	1987	866	**2853**	7674	3811	**11,485**

Kwa Zulu Natal Province																		
	Asian			Black (& African)			Colored			White (& European)			Other / Unknown / Blank			Total		
	Male	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***
Fam Doc & GPs	953	490	**1443**	372	175	**547**	22	12	**34**	689	310	**999**	645	209	**854**	2681	1196	**3877**
Specs. & SubSpecs	277	96	**373**	46	20	**66**	6	4	**10**	396	63	**459**	350	83	**433**	1075	266	**1341**
Other	45	18	**22**	7	0	**7**	1	0	**1**	27	0	**27**	31	6	**37**	111	24	**135**
TOTAL	1275	604	**1879**	425	195	**620**	29	16	**45**	1112	373	**1485**	1026	298	**1324**	3867	1486	**5353**
Northwest Province																		
Fam Doc & GPs	55	17	**72**	112	54	**166**	3	2	**5**	246	83	**329**	113	33	**246**	529	189	**718**
Specs. & SubSpecs	3	2	**5**	13	1	**14**	2	0	**2**	96	10	**106**	42	4	**46**	156	17	**173**
Other	1	0	**1**	2	0	**2**	0	0	**0**	0	0	**0**	0	0	**0**	3	0	**3**
TOTAL	59	19	**78**	127	55	**182**	5	2	**7**	342	93	**435**	155	37	**292**	688	206	**894**
Northern Cape Province																		
Fam Doc & GPs	22	6	**28**	33	9	**42**	9	1	**10**	125	50	**175**	68	24	**92**	257	90	**347**
Specs. & SubSpecs	2	0	**2**	1	0	**1**	0	0	**0**	30	5	**35**	10	3	**13**	43	8	**51**
Other	0	0	**0**	0	0	**0**	0	0	**0**	4	0	**4**	0	0	**0**	4	0	**4**
TOTAL	24	6	**30**	34	9	**43**	9	1	**10**	159	55	**214**	78	27	**105**	304	98	**402**
Eastern Cape Province																		
Fam Doc & GPs	121	37	**158**	235	126	**361**	25	9	**34**	376	154	**530**	305	88	**393**	1062	414	**1476**
Specs	31	0	**31**	29	5	**34**	3	0	**3**	223	33	**256**	132	15	**147**	418	53	**471**
Sub-specs	2	0	**2**	3	1	**4**	0	0	**0**	10	1	**11**	10	2	**12**	25	4	**29**
	154	37	**191**	267	132	**399**	28	9	**37**	609	188	**797**	444	105	**549**	1505	471	**1976**

Foreigners

Fam Doc & GPs	41	18	**59**	28	9	**37**	3	3	**6**	309	135	**444**	212	63	**275**	593	228	**821**
Specs	16	2	**18**	11	3	**14**	0	1	**1**	229	37	**266**	156	29	**184**	412	72	**484**
Sub-specis	3	0	**3**	1	0	**1**	0	0	**0**	22	4	**26**	8	3	**11**	34	7	**41**
TOTAL	60	20	**80**	40	12	**52**	3	4	**7**	560	176	**736**	378	95	**470**	1039	307	**1346**

Province Totals

	Asian			Black (& African)			Colored			White (& European)			Other			Total		
	Male	*emale*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***	*Male*	*Female*	***Total***
Western Cape	254	143	**397**	91	62	**153**	127	72	**199**	2735	1302	**4037**	1477	571	**2048**	4684	2150	**6834**
Limpopo	43	11	**54**	343	140	**484**	0	0	**0**	225	58	**283**	164	45	**209**	776	253	**1029**
Mpumalanga	59	12	**71**	227	73	**300**	0	2	**2**	367	105	**472**	161	35	**196**	814	227	**1041**
Free State	25	7	**32**	169	50	**219**	10	2	**12**	650	269	**919**	309	103	**412**	1162	432	**1594**
Gauteng	750	374	**1124**	1324	703	**2027**	36	31	**67**	3577	1837	**5414**	1987	866	**2853**	7674	3811	**11,485**
KZN	1275	604	**1879**	425	195	**620**	29	16	**45**	1112	373	**1485**	1026	298	**1324**	3867	1486	**5353**
Northwest	59	19	**78**	127	55	**182**	5	2	**7**	342	93	**435**	155	37	**292**	688	206	**894**
Northern Cape	24	6	**30**	34	9	**43**	9	1	**10**	159	55	**214**	78	27	**105**	304	98	**402**
Eastern Cape	154	37	**191**	267	132	**399**	28	9	**37**	609	188	**797**	444	105	**549**	1505	471	**1976**
Foreign	60	20	**80**	40	12	**52**	3	4	**7**	560	176	**736**	378	95	**470**	1039	307	**1346**
GRAND TOTAL	2703	1233	3936	3047	1431	4479	247	139	386	10336	4456	14792	6179	2182	8458	22513	9441	31954
	8.4%	3.8%	**12.3%**	9.5%	4.5%	**14.0%**	0.8%	0.4%	**1.2%**	32.3%	13.9%	**46.3%**	19.4%	6.8%	**26.5%**	70.5	29.5%	

Appendix 19: Results of the Pre-Post Workshop Surveys

All first and second year students attend a three-day workshop each year at the University of Cape Town. While the workshop objectives are the same for year one and year two, different lectures and activities are presented in each year. The aims of the workshops were to provide instruction in the following 11 areas: 1) principles of palliative care, 2) end-of-life care, 3) ethical decision making, 4) communication skills, 5) grief, loss & bereavement, 6) complicated grief, 7) principles of pain control, 8) multi-professional team & caring for the caregiver, 9) management of symptoms in advanced disease, 10) palliative care in HIV/AIDS, and 11) cultural and spiritual care. A 50-question Pre-post Workshop Survey was designed to measure student competency in those 11 areas. The same survey was given to the 2006 and 2007 groups; as they receive different instruction, the surveys were analyzed separately.

The Pre-workshop Survey was completed on the first day and the post-workshop survey was completed between four and five months after the workshop. Scores could range from 0-150 points. Students could respond to each question by selecting one of four options: 3 (extremely competent), 2 (somewhat competent), 1 (somewhat incompetent), or 0 (extremely incompetent). A higher score was an indication of a greater perception in competence.

Participants

Of the 20 students that began the course in 2006, there were 16 workshop participants. Fifteen of these students completed the Pre-workshop Survey and six completed the Post-workshop Survey. Of the students who began the course in 2007, there were 13 workshop participants. Nine of these students completed the Pre-workshop Survey and the Post-workshop Survey was completed by eight of these students. Therefore, there were six matched surveys for 2006 students and eight matched surveys for students who began the course in 2007. Due to the small number of matched surveys, the results must be interpreted with caution. It is only appropriate to look at overall trends as opposed to statistical comparisons.

Pre-Post Survey Workshop Response Rates

Workshop	Total Participants	Pre-Survey (count)	Response Rate (%)	Post-Survey (count)	Response Rate (%)
2006	16	15	93.4%	6	40.0%
2007	13	9	69.2%	8	88.9%

Results by Category- Pre-Post Workshop Survey (2006)

Six matched surveys were used in the analysis of the pre-post workshop surveys completed by students that the distance education course in 2006. To provide a comparison between pre-workshop and post-workshop scores, the average score from each survey category was compared. Scores could range from 0-3; a higher score would indicate the perception of greater competence. The table below displays the pre-workshop and post-workshop scores for the students who began the course in 2006.

Pre-Post Workshop Matched Survey Results- 2006 (N=6)

Survey Category	Pre-Workshop Average	Post-Workshop Average	Mean Difference
Principles of Palliative Care	2.83	2.83	0
End-of-life Care	2.44	2.61	+0.17
Ethical Decision Making	2.39	2.61	+0.22
Communication Skills	2.38	2.67	+0.29
Grief, Loss & Bereavement	2.21	2.38	+0.17
Complicated Grief	2.00	2.48	+0.48
Principles of Pain Control	2.60	2.56	-0.04
The Multi-Professional Team and Care for the Caregiver	2.37	2.73	+0.36
Management of Symptoms in Advanced Disease	2.54	2.33	-0.21
Palliative Care in HIV/AIDS	2.48	2.79	+0.31
Cultural and Spiritual Care	2.07	2.29	+0.22

To see if the pre workshop and post workshop scores differed significantly, nonparametric tests were conducted. Significant differences were noted in five categories: end-of-life care (U= 21.0, Z=-2.90, p<0.01), ethical decision making (U= 23.5, Z= -2.54, p=0.01), grief, loss and bereavement (U=22.5,Z=-2.69, p<0.01), complicated grief (U=27.0 , Z=-1.97, p=0.05), and principles of pain control (U= 26.0, -2.13, p=0.03).

Results of Mann-Whitney Test Comparing Pre and Post Workshop Survey Scores (N=6)

Survey Items *(# questions/ category)*	**Pre Workshop Scores**	**Post Workshop Scores**	**Z-score**	***Sig.***
	Mean Rank	*Mean Rank*		
Principles of Palliative Care	6.83	6.17	-0.33	0.738
End-of-life Care	3.50	9.50	-2.90	0.004**
Ethical Decision Making	3.92	9.08	-2.54	0.011*
Communication Skills	4.67	8.33	-1.79	0.074
Grief, Loss & Bereavement	3.75	9.25	-2.69	0.007**
Complicated Grief	4.50	8.50	-1.97	0.049*
Principles of Pain Control	8.67	4.33	-2.13	0.033*
The Multi-Professional Team and Care for the Caregiver	7.33	5.67	-0.82	0.411
Management of Symptoms in Advanced Disease	8.25	4.75	-1.70	0.088
Palliative Care in HIV/AIDS	9.50	3.50	-2.90	0.004**
Cultural and Spiritual Care	6.08	6.92	-0.42	0.675
Total Score	5.83	7.17	-0.64	0.521

*p=0.05
**p=0.01

Results by Category- Pre-Post Workshop Survey (2007)

Eight matched surveys were available for the analysis of the pre-post workshop surveys completed by students that began the distance education course in 2007. To provide a comparison between pre-workshop and post-workshop scores, mean scores from each category were determined. In every question, scores could range from 0-3; a higher score indicated greater perceived competence.

Pre-Post Workshop Matched Survey Results- 2007 (N=8)

Survey Category	Pre-Workshop Average	Post-Workshop Average	Mean Difference
Principles of Palliative Care	2.02	2.45	+0.43
End-of-life Care	1.58	2.17	+0.59
Ethical Decision Making	1.50	2.00	+0.50
Communication Skills	1.81	2.09	+0.28
Grief, Loss & Bereavement	2.08	1.84	-0.24
Complicated Grief	1.38	1.92	+0.54
Principles of Pain Control	1.60	2.08	+0.48
The Multi-Professional Team and Care for the Caregiver	1.85	2.18	+0.33
Management of Symptoms in Advanced Disease	1.78	2.13	+0.35
Palliative Care in HIV/AIDS	1.70	2.14	+0.44
Cultural and Spiritual Care	1.46	1.86	+0.40

To see if the pre workshop and post workshop scores differed significantly, nonparametric tests were conducted. Significant differences were noted in nine categories: Principles of Palliative Care (U=48.5, Z= -2.09, p=0.04), End-of-life Care (U=49.5, Z= -2.03, p=0.04), Ethical Decision Making (U= 43.0, Z= -2.90, p<0.01), Palliative Care in HIV/AIDS (U=46.0, Z=-2.41, p=0.02), Principles of Pain Control (U=45.5, Z=-2.39, p=0.02), Management of Symptoms in Advanced Disease (U=46.5, Z=-2.29, p=0.02), Cultural and Spiritual Care (U=46.0 , Z= -2.35, p=0.02), Complicated Grief (U= 47.0, Z= -2.24, p=0.025), and Total Score (U=43.5, Z=-2.58 , p=0.01).

Results of Mann-Whitney Test Comparing Pre and Post Workshop Survey Scores (N=8)

Survey Items *(# questions/ category)*	Pre Workshop Scores	Post Workshop Scores	Z-score	*Sig.*
	Mean Rank	*Mean Rank*		
Principles of Palliative Care	6.06	10.94	-2.09	0.037*
End-of-life Care	6.19	10.81	-2.03	0.042*
Ethical Decision Making	5.38	11.63	-2.90	0.004**
Communication Skills	6.81	10.19	-1.49	0.137
Grief, Loss & Bereavement	6.75	10.25	-1.51	0.132
Complicated Grief	5.88	11.13	-2.24	0.025*
Principles of Pain Control	5.69	11.31	-2.39	0.017*
The Multi-Professional Team and Care for the Caregiver	6.94	10.06	-1.34	0.182
Management of Symptoms in Advanced Disease	5.81	11.19	-2.29	0.022*
Palliative Care in HIV/AIDS	5.75	11.25	-2.41	0.016*
Cultural and Spiritual Care	5.75	11.25	-2.35	0.019*
Total Score	5.44	11.56	-2.58	0.010**

*p=0.05
**p=0.01

General Trends in the Pre-Post Workshop Surveys

Within the 11 survey categories, a range of areas were covered. For example, the survey evaluated general concepts such as how well students understood the principles of palliative care as defined by the World Health Organization, the active and holistic nature of palliative care, and the continuum of care in palliative medicine. In the section measuring concepts related to end-of-life care, students were asked to evaluate perceived competence in their ability to recognize the changing symptoms and signs as death approaches, to actively manage changing symptoms at end of life, and to advise and support family members of the dying patient. Questions pertaining to ethical decision making were concerned with the ethical principles guiding end-of-life care and the ethical concepts underlying medical decision-making. Communication skills, the principles of pain and symptom control, and the management of advanced diseased were also evaluated. Students were also assessed in their knowledge of grief, loss and bereavement; questions pertaining to concepts of attachment, the stages of the normal grief reaction, unresolved grief and cultural diversity were designed to measure their understanding. The category "multi-professional team & caring for the caregiver" examined students' understanding the working of a multi-professional team in palliative care, problems of stress and burnout, and personal and organizational coping mechanisms. The survey also looked specifically at the palliative care needs of patients with HIV/AIDS and pertinent cultural care issues. A number of questions were included to measure students' ability to understand the following: elements of culturally sensitive care, the philosophy of Ubuntu, the link between culture and spirituality, barriers to culturally sensitive care, and how health care practitioners can deliver spiritual care as part of holistic palliative care.

In general, the post-workshop scores were higher than pre-workshop scores. For the students that began the course in 2006, significantly higher post scores were seen in five categories and for those in 2007, significant differences were noted in nine categories. These results can be interpreted in two ways. Firstly, it may be a reflection of the positive value of the workshop itself; students perceived themselves to have an increased understanding in a number of different categories. The workshop, as an educational intervention, may indeed have been very effective in teaching particular workshop objectives to students. However, a second interpretation needs to be considered. It is not entirely accurate to attribute all observed changes to the workshop itself, as other factors might have produced those changes {{1486 Bureau of Justice Assistance; }}. Essentially, the pre-post method is not able to determine anything other than *perceptions* of change in practice. Without additional documentation supporting the results, the measurement of competence levels is an extremely subjective process{{1103 Hinkka,H. 2002; }}. Finally, self-report has limitations related to social desirability, interviewer effects and self-selection {{1150 Schulman-Green,D. 2003; }}.

Appendix 20: Qualitative Theme Dictionary

Palliative and End-of-Life Care in South Africa

Theme 1: Two Solitudes: Participant versus Public Notions of Palliative Care

- Sub-theme 1A: Through the health care providers' lens
- Sub-theme 1B: The larger picture

Theme 2: Accessing Palliative Care

- Sub-theme 2A: I can't get in!
    - a) (Lack of) Resources: Getting there costs money
    - b) Staff Access & Safety
    - c) Stigma: Hospice Care and HIV/AIDS
    - d) Too Few… Too Small
    - e) Doctors: Blissfully Ignorant
    - f) Public: Fearfully Ignorant
    - g) Colour Matters
- Sub-theme 2B: Access routes
    - a) (Lack of) Standardization
    - b) (Lack of) Knowledge

Theme 3: The Changing Face of Palliative Care

- Sub-theme 3A: Patient Care
    - a) Patient and Family Care Providers' Description of Hospice Care
    - b) Role of Health Care Providers
    - c) Role of Medical Doctors
    - d) Satisfaction with Hospice Care
    - e) Patients in the General Population
- Sub-theme 3B: Educational Needs of Medical Doctors
    - a) Current status of educational programs:
    - b) Suggested Changes
- Sub-theme 3C: Models of Palliative and End-of-Life Care
    - a) Hospice Organizations
        - *a. inpatient care*
        - *b. home-based services*
    - b) Hospital based Palliative Care Ward
    - c) Hospital Care
    - d) Care by Family or Community
- Sub-theme 3D: Funding and Resources
    - a) Palliative Care Resources for private or state care
    - b) Hospice Organizations
        - *a. Keeping a Hospice Running: What's on the Table?*
        - *b. Drugs for Hospice Patients*
        - *c. Availability of Hospice Staff*

Responses by:

NS: Nursing Sisters	D: Medical Doctors	FCP: Family Care Providers
SW: Social Workers	SCP: Spiritual Care Providers	C: Home-based Carers

Palliative and End-of-Life Care in South Africa

Theme 1: Two Solitudes: Participant versus Public Notions of Palliative Care

Palliative care is understood differently- by people receiving palliative care, by those in the health care sector, and by other people involved in care provision

Sub-theme 1A: Through the health care providers' lens

Health care workers' perceptions of palliative care

D40: ***Well, we explain it to them in nice terms***

D17: ***I would say the treatment to make the changeover from life to death as easy as possible.***

D34: ***Palliative care, you know, uh, and I can only speak for that, that's in the form of tender loving care—TLC.***

D1: ***it's a form of medicine that's driven by the requirements of the patient …focusing much more on what the patient thinks is important and a lot less on what the doctor thinks is important. I mean I think it's important for the science of medicine to control diseases, but I mean we used to have patients in our hospitals dying of cancer who haven't been given morphine. You know, so we're seriously missing the point when deciding the patient feels is important.***

NS10: ***I would say this is a time of caring. Caring for, uh, the patient and family. And especially for the patient who needs to be comforted. Especially with the pain and other symptoms that might upset them. Just to walk along with them. And care.***

SW7: ***I always try to stress to the patients that the doctor has done as much as he or she can to try to remove all the growing disease. And now we're at a stage where we can't remove it anymore but we can care for them, make them free of symptoms, help them with pain, and make the quality of living excellent. So we'd rather focus on the quality of life than the quantity of life.***

Sub-theme 1B: The larger picture

Societal perceptions of hospice and palliative care

D15: ***Because now when you start discussing palliative medicine with interns and doctors, they sort of feel as though you're moving into a realm of medicine that is far less important than cardio-thoracic surgery or neurosurgery, say for instance. It just seems like, oh you know, "do we have to do that?! Why can't we discuss something interesting?", do you know what I'm saying? There's not much interest in it.***

D18: ***At the hospital I worked at where we tried to get a palliative team going and my colleagues thought it was a waste of time because these people are dying anyway so don't waste your energy.***

D3: *Palliative medicine as such, first of all, hasn't been acknowledged first by our government as a field or specialization.*

D41: *the formal public health system is just not geared up for palliative care at all. And is almost totally not interested in our side.*

NS12: *one GP actually admitted to me that he cannot cope with a patient that is dying. He doesn't know what to do. They were trained to cure not to have to tell family. He even said he would like to have help knowing what to say to the family when somebody has passed away*

NS4: *they [doctors] don't want to take nurses' views on board and take into consideration you're your experience because you've worked longer than they have. I mean there are doctors who've just finished training who've never done any HIV/AIDS um... have no HIV/AIDS experience and you could actually tell them a thing or two but they just won't, they just won't receive it.*

SW7: *I believe in private practice there's quite a bit of resistance by the doctors to refer to hospice.*

Theme 2: Accessing Palliative Care

How do people access palliative care? Is it accessible for everyone who needs it? What are typical methods of getting palliative care services?

Sub-theme 2A: I can't get in!

Barriers to Access include: Patient Resources, Safety of Staff, Stigma, GP's Ignorance, Hospice Coverage, Patient Ignorance, and Race

a) (Lack of) Resources: Getting there costs money

D18: *I think the great divide in South Africa is between the people with medical aide and those who don't. And people with medical aide are usually, or are better off than the middle class and the HIV rate is much lower. So the poor, the vast majority of the population, don't have medical aide and so, you know, your average private practitioner would only see them for minor inter-current illnesses. But they certain wouldn't be able to go to them regularly.*

SW1-3: *We don't have a good public transport system and it's very expensive for the unemployed, the really poor people, it's really very expensive.*

SW6: *cost of transport is a significant barrier for patients. It is expensive to go to a doctor and so some of the people will be very in their disease before they get diagnosed.*

b) Staff Access and Safety

SW9: *There are a few geographical areas that are unsafe to send our staff members in. But if those patients are prepared to come to areas, say for instance move to relatives that are falling within our catchment area, we are prepared to look after them. It's not always working. Because when they reach the stage of being bed-ridden, then they would prefer to be in their own areas. But we don't exclude them as a person, it's just the geographical area that a problem. Because we also have to be, cognizant of the safety of our staff: we can't send them into areas which is dangerous for them.*

c) Stigma: Hospice Care and HIV/AIDS

D43: *Most of our male patients wouldn't want us to come with a hospice car at all. We'd have to park a block away and the nursing staff has to come without uniform to go there.... I can understand* *it...there's many reasons for stigma and discrimination in the community, within homes, but also the attitude of the hospitals hasn't helped to break that stigma. And I think hospice is not an isolated um group that has the problems with stigma....I wish I could say to you its improving. I think it's slowly, slowly stepping on but it's not really, we haven't overcome that barrier yet, it's still very much there.*

D47: *a lot of people don't admit they've got HIV and they would rather die at home than admit they've HIV... If we know about all our cancer patients and all our HIV patients, the HIVs would be much much more. But in reality you won't see that because 90% of people HIV positive aren't going to admit it.*

NS17: *Ja, well, the, the, the stigma with HIV will be there. But, uh, we're trying our best. Like here we're running support groups- there's my social worker, (states name), who's running a support group on Tuesday and Wednesday, you know. And I see people coming in... the first day they are in denial, they won't be really keen to come but by the end of the month, you'll see that they wish they could be there. And they call the others, you know. So they're getting used to it now. I mean the stigma thing is also going down. Ja, they're learning to adapt to the situation. It's not like when this started really. Because they can see themselves being happy, and it's not that much, no...*

d) Too Few... Too Small

D28: *I think there are, like I said, a couple of organizations that do offer some kind of support. But I think it's fragmented*

D7: *I would say it seems like they [name of hospice] have something going and it seems like other people are benefiting from it. But it's not the people coming from this hospital. Meaning they say they've got 50 beds and the 50 beds are full. Obviously they're doing something for somebody, but it's not for me. I am unable to really access that service.*

NS12: *But my main problem and concern is the people that are outside our boundaries. And our boundaries we won't have telephonic correspondence within our area that ends at Veldriff. But further on there's a big area that is not covered by hospice at all. And, I mean, it's people that can be, because of where they're living, they're not able to get the quality of care as somebody that may be* living in our area.

e) Doctors: Blissfully Ignorant

D41: *It may sound a bit of a paradox in this day and age but there are still doctors who don't know what palliative care is and there are doctors that don't know the difference between a hospice and a hospital...And it's not the old doctors entirely, the modern generation is also blissfully ignorant. Well some of them, that is, I'm not saying all of them.*

NS7: *I would say 9 out of 10 doctors don't know what's going on.*

NS3*: I think a lot of sometimes we feels that the doctors rather keep the patients back in the hospital to do their thing instead of referring them to palliative care*

SCP1*: I think that this is a bit of a minefield, this area, because we don't necessarily have cooperating GPs who should maybe consider referral of their patients earlier. So they're not necessarily positive minded in the way that direct people to us.*

SW9: *From the GP perspective I think we, um, we still have a long way to go. I think there's a lot of ignorance still uh, from GPs perspective*

f)Public: Fearfully Ignorant

D2*: I think the main barrier to accessing palliative care would be ignorance on the part of the patients. I mean they don't know that there's a service available.*

D13: *I think that the patient's themselves are barriers, at times. They see the name "hospice" and they, and then they worry, they think "well that's the end".*

D21: *one of the barriers I've battled with over the many, many years that I've worked is the cultural beliefs that basically nobody wants you ever to talk about someone dying (I: OK). It's almost like if you do that, you are putting a curse on the patient and they are going to die.*

NS2*: If people have really been involved first hand, they know and then they tell someone and they get the message. In the more affluent type of society, they see hospice as a welfare organization so they tend to think "no, it's for poor people". And um then you also get people who think they are not dying yet so I can't go to hospice. So there's, I think there's a bit of education needed in clinics and people who supposedly refer.*

SCP1: *I think that patient's themselves are very reluctant to self-refer because their placement here is a recognition that they're going to die.*

SW7: *Um, the doctors invariably offer the patients this care, there is great resistance from patient point of view in South Africa to receiving hospice care. There's the belief that if you're referred to hospice, it will make you die....more quickly. So a tremendous number of patients refuse to be referred. This creates a problem all along. Because the hospices ask of us that we refer as early as possible. The patients resist till as late as possible. So there's a big gap.*

g) Colour Matters

D16: *It depends on race, I would say, here. The problem being with black patients, if somebody dies at hospice they don't want to bring a patient to hospice again. If one of their family dies in hospital, they don't want to take another family member there again. Um, white people don't like hospice anymore because there's so many Black people with AIDS in hospice so, I think that's part of the problem. Even with our fundraising it is sometimes now difficult to get the more influent White people to donate money because they say "that place now is just full of AIDS", you know. And which is not really the case because at any given time we've got maybe equal amounts of AIDS and cancer there so... We are working on the problem*

NS18: *I want to be honest with you. There is the race issue...You cannot run away from it. There is. Even if you could see the structure of St. Luke's Hospice in central, that alone without any explanation, there is ... that is an issue. But- aaahhh—whatever it is man, I don't want to go deeply into it, uh huh, but the race issue is there.*

Sub-theme 2B: Access routes

The hospice referral system as described by stakeholders.

a) (Lack of) Standardization

D46: *we have mainly two kinds of patients that we admit. One group would be patients with cancer, with terminal cancer disease. The other group is patients with ARV with uh retroviral disease with HIV/AIDS. Ja. Um. And I think it works a little bit differently with the two kinds of patients.*

NS10: *if there's something on our form that we think is now outdated, or this is a new thing that we need to bring in, then we make a new form and add it.*

D3: *we don't have such a good system of support and referrals between home-based care organizations and our normal main stream health care system. And so, um, ja, I wouldn't really be absolutely sure that they have, that most people have the support of the home-based care service. But there are several in existence. But difficult to gauge what exactly those home based services actually provide. That they would be able to provide the whole package of the palliative care service or whether they are just there when someone is ill and to help you wash, dress and that kind of thing.*

D32: *Yes, there are a number of hospices but we don't ever refer.*

b) (Lack of) Knowledge

D3: *And I think that a lot of people don't know about the referral process...There still is a misconception about what hospice provides them, you know the difficulty in what hospice traditionally was perceived to be and what we actually do do, what actually gets done by hospice. And uh, so there is that problem of referrals.*

NS10: *All these doctors know about our referral system because we provide them with the forms. And our doctor goes and have meetings like once a month, on a Tuesday, with the hospital doctors and she has a separate time with the private doctors. It's a good relationship with them.*

Theme 3: The Changing Face of Palliative Care

Aspects pertaining to the burden of illness, the role of medical providers, and South Africa's health care system have all affected palliative care delivery models.

D26: *I think of course regarding AIDS because it's changing. I mean people were much more aware are starting to become aware of HIV and are a little bit more open about the diagnosis and the meaning of it. But of course the meaning has changed now with ARVs again. I mean now many, there are people, or several people who are basically terminal, dying, and they still get better with ARVs.*

D43: *Initially we thought we may discharge the patients [responding well to ARVs] but we know that at some stage they'll need our support and care again.*

D45: *Especially now with the advent of ARVs because I mean we knew before. Because when I started working in '96 in HIV clinics, I was full of patients and I'd see them here because they'd die. There were no ARVs, you know? So that was different. But now, we know different...it's not the end of the road.*

D47: *Well, strictly speaking, HIV patients are not considered terminal anymore. They are treated more as a chronic illness.*

Sub-theme 3A: Patient Care

A description of both the patients of the medical doctors who were interviewed and the patients who receive hospice and palliative care.

D18: *there are hundreds of people around here who are on ARVs who have experienced being very ill and are now well. But the gap between the number of people on treatment and the number needed are still huge. And the majority of people only find out that they are HIV positive when they are very ill with pneumonia, or meningitis or severe TB. So the need for palliative care, in my experience, has actually not decreased at all. And I don't think it will. Not for the next decade, I'm sure, you.*

D20: *At our hospice also it's completely free. Inpatient and outpatient. So you're looking at at least 1% of the population that are admitted to the hospice who have medical aide. So 99%, no.*

D21: *And the patients are generally rural and poor and with a lot of unemployment.*

D23: *Are you finding that because of your proximity to Zimbabwe, that you also have people coming down from Zimbabwe as well?*

Of course, quite a large number of them. Quite a large number of them. And it is causing a big problem, you know. We are treating people who we don't know their identity...We don't know where they stay, they don't reveal. Some of them actually stay in the bushes here.... Of course now we treat them even then, but ...they have no permit to be here. So half of them are found and arrested, they are deported and then they would go through and they would be back again through [by the end of the week]. And then some of them actually come across the veld as criminals. The rest are clean. Lions devoured one of them- probably- they just left a few bones and a skull, finished. And there, it's not very far from here...these types of casualties are not uncommon. Sometimes they get the ideas to cross the Limpopo River.... But then of course there is the problem of crocodiles.

b) Role of Health Care Providers

From the perspective of both patients, family care givers and health care providers, a description of care received and provided.

C1: *So there we are doing home visits where we were caring for people in the community that are sick. And the others we just refer to the hospitals.... If I'm here in the ward, I must check all the bottles of urine. I must make sure, I must check that everything is clean. I must take all the bottles near the beds and go to the sluice room. To empty the urine and clean the bottles.... I must make sure I clean the beds. ... And sometimes, someone can call you and talk to you, and you have to advise her and encourage her spiritually.*

D18: *most of the practical caring is done by nurses and the caregivers and family members.*

D39: *Anybody who would be at home would be under the guidance of the home-based carers which are then under the supervision of a professional nurse.*

D42: *The whole idea behind our hospice here is to have a multi-disciplinary team where you have a doctor, nurse, social worker and somebody from the religious part, the luminary or the pastor or whatever it is. And any other person that might come in, a family member or whatever. If we have a problem, we get the whole together and we solve it. But you also um, sort out the problem before hand so that you do not have the pastor sitting in on a medical problem or the social worker sitting in on the, well she could sit in on the pastoral problem (laughs), but you follow what I mean.*

FCP1: *Because normally I have to phone the doctor and wait for him on the phone and so with her [hospice nursing sister], she speaks to him straight away and she phones me back. So that's nice.*

FCP10: *because when we [the family care provider and the hospice nursing sister] talk we understand each other and there at day hospital we don't understand each other. And yet when she comes here, we talk together and we understand. We see the way forward.*

SCP1: *So my work function has shifted from being trainer, motivator, developer of local hospices with a fair PR function and HR function, I've build quite an HR function because of my calling as a priest, and so people sometimes have needed confidential things to talk about.*

SW5: *Most of the time we [social workers] only see patients. We go out on home visits. I go with the sisters. Most of the time people they refer the patients when there's social problems or social needs uh for the bereavers and stuff when people have lost their loved ones then we will see them afterwards as well to support them.*

SW8: *When the doctor says "[SW8], this patient is going to discharge we must have a plan. Contact the family." And the family is sometimes playing hide and seek (laughs) so you know... (laughs). That's all.*

c) Role of Medical Doctors

From the perspective of both patients, family care givers and health care providers, a description of care provided by doctors. The value of the role was also expanded on.

D1: *I'm available to all the nurses at anytime. To phone or SMS or discuss what we should do. We have, they, the hospice has monthly meetings where they discuss these sort of issues with the staff and on a couple of occasions they've called me in and said, you know, can you give a discussion in this area?*

D11: *I provide pain control, nausea and vomiting control, but maybe, maybe I do that because it is part and parcel of the oncology procedures. But I do strongly believe that palliative care or symptom, a person that is more into it, will be able to help more.*

D22*: I think I would be lying if I said that I think the doctors should be the front line worker in palliative care at the district level of medicine. What I see is that the doctor, being very clear and factual in disclosing the disease to the patient, and then getting our people on board to help with the continuity of care. And to be [available] from time to time but not necessarily being the lead health worker*

D43: *I sometimes feel it's a jack-of-all trades. You do everything and I wonder (laughs). I'm quite happy to do that because I like variety but it's quite tricky. Um, because you have to really be everything. From a psychologist to a social worker, medical doctor well experienced in HIV medicine*

D44: *I just volunteer to work on their ward rounds. Or their folder rounds. We don't see patients.*

NS10: *they are there to support us and the patient. And we are like telling them this is where the stage of the patient is and what they needs are and the doctor will prescribe pain medication.*

NS2: *once a month I sort of highjack my [hospice] doctor to go with me because it's nice for her to see the patients too. And it's nice to have a backer up, and then she checks if we're doing the right thing.*

FCP10: *But the [clinic] doctor didn't check him. He just asked "what do you feel" and he says "no, this one is painful" and they say "OK, we're going to give you morphine, we've got nothing to do". You see? They always just give the medicine, it's only to give the medicine.*

Perceived Value

D16: *I don't think you can go without physicians.*

D18: *I think doctors have an important role, especially in South Africa, in prescribing medicines and accessing medicines.*

D38: *I think the role of the doctor is very important. As far as the care of the patient is concerned, there the doctor isn't always necessary. But the moment you involve palliative care, I think the doctor is absolutely necessary and I think one should play a very important role there.*

D40: *Everybody looks up to a doctor. Not to say they don't look up to a social worker and so on. But if they see a doctor they say "yes", you know, "the doctor says so, we must do it".*

NS11: *I think it is very important to have a doctor on the team. We don't know everything and we, sometimes we need a doctor to ask something and he can write down the medicines and so on.*

Sub-theme 3B: Educational Needs of Medical Doctors

The areas to focus an educational program in palliative care for medical doctors

Note: these were also identified in the Health Care Provider Survey

a) Current status of educational programs

D10: *Current oncology students will be assigned some reading but palliative care is not a significant part of the oncology curriculum.*

D18: *I think palliative care is still taught very badly for doctors, and nurses actually, and your average medical student doesn't get too much exposure. They still, on the ward rounds, concentrate on the curative issues and symptom control is kind of viewed as a bit of TLC and it's trivialized by family doctors in the hospitals*

D6: *Because caring for dying patients is the one thing that we don't get educated on. I cannot even once remember during my training having a session or education or training on caring for the dying patient*

D8: *I actually find the same problem with the, with the students, the medical students. They think it's not really worth it. They actually concentrate on healing patients and not caring for patients.*

D9: *What we try to do now is train our medical students and the pre-graduates in their final year, their fifth year, we train them. We take them to the hospices, we lecture them, we show them how we do it in the hospital. And then post-graduate doctors we do have a course in palliative care as well.*

b) Suggested Changes

D15: *the principles of palliative medicine aren't sort of restricted to just palliative care. It should be across the board. This is how we should be treating all our patients.... I say we need to build an interest and one can do that if we introduce it early on in the medical program. I think by leaving it out, it's almost as if it's not important.*

D18: *I think we need a fundamental, you know, change in the medical student curriculum for them to realize that if you're going to be a doctor in South Africa for the next two decades, you're still going to be dealing with large numbers of terminally ill people.*

D30: *I think that the palliative treatment is very often a thing that develops with the character of the doctor. Not necessarily an academic thing.*

D5: *It must start with the counseling aspect. I think we are not trained on counseling. We don't know what counseling is until you get to the practical situation.*

NS16: *I think that they must do it in their student years from the beginning. Palliative care must be included all the time, you see. And there you can learn... You know what happens with our patients is they complain a lot about the way the doctor bring the message over to the patients. Do you understand? And you know that that is the most important, important message for the patient. The way the doctor bring it over to the patient. And the thing is, and I think palliative care must be from the beginning in the student years. They must learn palliative care is important.*

SCP1: *I think that physicians really need to understand about pain management.*

Sub-theme 3C: Models of Palliative and End-of-Life Care

What are the informal and formal organizational structures for palliative and end-of-life care delivery?

a) Hospice Organizations

a. inpatient services

D13: *we have a 10 bedded adult inpatient unit and a 5 bedded pediatric unit. ... And, um, we have 8 sisters that work in the home-care division that run, actually, a huge area. A sister carries anything from 15-30 patients at any given time. Not usually much less than that. And, um, we see the patients at home. If necessary they come into the unit. Otherwise they nurse at home. Um, we have a very good psychosocial department so if there are emotional, psychological issues with the patients then we refer them. They're not automatically seen. Only if they need counseling or we feel that there's a need for counseling then we'll address that. But they're not routinely seen, um, by the psycho-social staff. OK. Um, ja, we have a daycare department where once a week patients, it used to be a bit more than that but we've had a few problems with the actual running of the daycare. At the moment is happening twice a week where patients can come and get together. Those that are well enough. Um, we have a pharmacy where we can prescribe medications and a lot of our meds are made up here. Especially the morphine. I feel very safe using the morphine here since I know exactly how it's made up and that's very handy for us to have our own pharmacy.*

NS11: *the need for me, personally, is an inpatient. You see we've got our carers at home, we've got the family, but sometimes its people, family don't want their people to die at home. You see. It's not everybody that can take it, that their people must die at home. You see. I think it will be nice to have an inpatient. That's my personal feeling.*

D43: *Initially that was going to be what the department of health looked at um, to do partnerships, instead of isolated palliative care units run by hospices. And I think that's the only viable cost effective way for the future, in any event. It costs, it's very expensive. I know that the hospice in Port Elizabeth, St. Francis Hospice, they were looking at costs about a year ago and they were quoting two million at least, at that time, to run an independent care facility....*

b. home-based care

NS10: *We are a community-based organization. We see the patients at their homes. The ones that come here [for daycare] are the ones that are able to be mobile. We go to most of them at home that are bedridden and we care to them.*

NS11: *I see my chronic patients once a month... the patients with the hypertension, diabetes, and so on, arthritis, um, I see them once a month. Where I do their blood pressure, and the diabetics I do the sugar test, the blood sugar level. And uh, the HIV and cancer patients I see once a week. But if there's problems, like we sometimes I see two times a week, a day.*

NS7: *I work mostly in Faerie Land which is an informal settlement and the communities mostly Black. And uh my worst is that I don't understand the language. So I have two Black nurses which are like my children and then I have two Colored nurses. They somehow placed me where I'm staying so it's easy for me to go the one day with one lot and the other day with the other lot and they work all around. And if something goes wrong, especially living in a Black community for the nurses, they um they're never left alone. Because the nurses that I work with live in homes and their informal settlement is right next door. And they know that they're nurses so they literally never sleep. Because then they go to their homes, and then the baby's born and then they need a doctor and then the nurses of course just phone and say "help, help". And it's mostly ones or its half of it I would say are not our patients and the other half is the community. So they're really involved with what they do. And it's not just the Black nurses but the colored ones too. So their privacy, they didn't realize it, but their privacy also went with that, becoming a nurse at hospice. And ja I love it.*

b) Hospital based Palliative Care Ward

D1: *The palliative care ward is in a separate part of the hospital which has been refurbished by private money, uh, as part of a grant. And what we have, we have 10 individual wards that accommodate one patient each and one of those we've actually converted into a chemotherapy ward so we can give IV chemotherapy*

D8: *except for our wards, we have a so-called step-down facility where I'm actually in charge, looking after about 20 patients on average.*

D43: *It's a public-private partnership. Um. We, six beds is really too small to run as an independent IPU, it's just not cost effective. So we're doing it in combination with the department of health. Ward A is the chronic care ward and we're just linking with them. They haven't really had palliative care experience or palliative care type interventions there so that's we're providing. And that link is its strengthening year by year. It was a very loose link initially but, ja, gradually that's growing. It takes a lot of effort though.*

c) Hospital Care

D26: *We have some wards in the backside of the hospital and they get terminal care there.*

D25: *They normally go to the provincial hospital but there they are so over-crowded, most of them eventually just get some medicine and go home.*

D16: *Because I mean you think about a provincial hospital there's 10,000 patients to see and 20 doctors to do it.*

D18: *the hospital where I work does not offer formal hospice care although many of the patients are terminally ill*

D26: *the problem with general wards is that their medical condition is looked after. And, uh, and in general wards people get a fair amount of neglect if they've got something that nothing can be done for, from a medical point of view. In other words, there's not a lot of... there's some palliative care that is given, and they are busy trying, um, there's a project in place to develop a sub-acute ward but we don't have space at the moment.*

D43: *looking after a very sick HIV patient is expensive. So um, in terms of that patient, they weren't really admitted. They weren't the first ones. Your cardiac failures and your cardiac myocardial infarction patients and trauma would be preferenced for getting a bed if there was a choice. And our patients would be seen overnight and discharged the next morning. Well not our patients, the HIV patients*

d) Care by Family or Community

D17: *If there is an end of life situation, it would be handled by the family only. Sort of at home in the person's home, and the surrounding community people might go out and help these people.*

D25: *I'm talking now about the people living in the shack houses and informal areas. Ja, they rely mostly on their family members to look after feeding them, cleaning them, giving them their medicines, etc.*

D6: *But in our community where we live, course it's a very rural area, people are very compassionate. So all the neighbours come and help the patient and you know, if the family is not capable, I mean no family is capable of looking after a person 24 hours, so we try to make shifts to have people come and help the person out. To care for the patients: bathing the patients and giving the medication and stuff like that.*

D40: *Many of these people don't even have the people to care for them. They only have the neighbour, or a caregiver that just comes in once and a while to see them. So this person is very ill and cannot care for all those things.*

Sub-theme 3D: Funding and Resources

The mixed health care system in South Africa provides different levels of funding and resources to the population. How does this affect palliative care delivery, hospice and palliative care organizations, and ultimately the patients?

SCP1: *I don't think we're doing the job to the way we advertise ourselves. I don't think we have the capacity or the resources. Um, I think we're doing the best that we can under the circumstances but the finesse and the finer details of the energetic inter-disciplinary team concept, I think gets lost along the way ... So the necessities of, and the luxury of leisurely consultation around a patient's needs is idealistic, not realistic.*

a) Palliative Care Resources for private or state care

NS17: *financially, you know, if I have a patient who does not have the medical aide, you know, there's no way I can provide them with just proper pain relief for starters. If you want to really give a person who is terminally ill proper pain relief, it costs a lot of money. And obviously there's other things that go with it- to be able to provide nappies, proper nursing care, all of those things, are costing money. And if a patient is not financially capable of paying it, we just can't provide it.*

D24: *medication is always available. We don't, we never have shortages. The issue is advocating.*

D25: *I think there's two worlds. The one world is that you have a medical aide in Africa and then at any good private hospital you can get the best treatment anything, I think, equating in the world. And at the other end there's people with no money and I think we have a poor public health system So those two worlds are a big problem.*

D28: *Nobody has specific training in palliative care. All training has been in house from myself. And I don't have any specific palliative care training. Just during my general oncology training.*

D37: *We've got a pharmacy here and I've got, uh... I'm very well trained in that sort of thing. Without having to use heavy drugs like morphine drips and such. We don't need that actually much.*

D4: *Um, there's a lack of skills amongst many of our nurses, even the relatively long-standing and even some of the senior nurses are quite weak in terms of their nursing knowledge and skill.*

D6: *At our private hospital in Frankfurt, we have the most wonderful staff. And one of the sisters there she is an excellent nurse and she has got extensive training and also experience in terminally ill patients. So that is the one place that they're really care for...But that is only for the part of my practice that is financially in, that can use that facility.*

D24: *Because some might think, "this is not my responsibility, it is the responsibility of the hospital" but when you tell them the truth of the hospital and say "you know, as much as we can care for the patient in the ward, if there are shortages of staff, what are we going to do?" or if we have got one nurse, a ratio of 1 nurse for 50 there's no way the patient can get better care, palliative care if you are at home one on one.*

D19: *I mean the people are resigning in droves, heading for the private sector or overseas. We've lost 3 excellent sisters in the last, uh, couple of months or so, 5 months. And they're irreplaceable*

D15: *we don't even have enough nursing staff to cover the patients who are in the hospital. So palliative care is always put on the back burner, you know. In the hospital where I work at the moment, there is no palliative service at all.*

b) Hospice Organizations

a. Keeping a Hospice Running: What's on the Table?

D43: *The IPU is basically funded solely by the Global Fund. They fund the availability of nursing staff and myself as a medical doctor to supervise that. Um, the EU fund, the European Union, funds the home-based care program that we run. And then we have smaller individual funders um, who does support all services. Because none of, not even the global fund or the EU, are completely funded, solely funded in terms of the financial, so you, the hospice still has responsibilities to carry costs. ... We've been an NGO, it's always what's on the table tomorrow.*

NS13: *All donated good and volunteers work voluntary obviously to just sell the goods. So all of that money, which is quite nice, go to admin costs or whatever...*

SW9: *We just, you know, constantly have to [fundraise]...Because you know, we're not the only non-governmental organization in Cape Town. I mean we've got to fight for our funds, you know, to get our little, small slice of the cake at this point in time.*

b. Drugs for Hospice Patients

D21: *We obviously buy in all our own medicines, um, so we have to raise funds for that. Um, but generally speaking, I mean the medicines are usually on the EDL, they're not very expensive*

D30: *I think the clinics, uh, they're too small, you know. If you want to get your, say your chronic medicine or your palliative medicine, you have to go and sit in a queue. Say in the morning you start at 8:00 and you're lucky if you leave before three or four in the afternoon... So it's really inadequate.*

D37: *we've got, we supply from the clinic all the pain control they need.*

NS3: *Medications- we've got enough we get it from the hospital so we don't have any problems with that.*

NS6: *we don't buy medicine. We don't buy medicine at all. I mean um what what I do with my patients, 'cause they they're all out of the um village areas I persuade my patients to go to the clinic.*

SW5: *When its patients of ours that's admitted to us then uh they fill in charts for them that they take that the carers get all our patients' medications so they don't need to go there to fetch their stuff. The sisters will take it to them.*

C5: *The Hospice I can see for the moment they have enough staff and the medication. Because uh if you come here to the clinic, they tell you they have no pain tablets, they've got no vitamin B for the people you know. Hospice is giving more care with their patients.*

D13: *So we do charge patients who can pay. Obviously if they are on a medical aide they do pay or if they can afford it, they pay. Otherwise we don't charge. But we're very careful about what we prescribe if we're not charging. And we try to still get the patients to get medications from hospital and wherever which clinic they're going.*

D16: *a few years ago the government paid you per patient. Now you get nothing. Now everything is fundraising. Sometimes it's different to get medicine out of the hospital and to get different types of medicines out of the hospitals is also sometimes different. For somebody out there decides this drug is too expensive and then they stop it.*

D18: *I've had a lot of resistance from the nursing staff to prescribe or to administer morphine. Um, South African nurses in general, I find, are quite resistant to giving people morphine. They feel that it's kind of giving up on the patient or, uh, passive euthanasia, people are worried about. So, um, I've tried to do a lot of training with nurses to help them realize that the pain control, including morphine, is part of good nursing care. So, ja, it's not the supply problem. It's getting people to be given their treatment regularly and correctly.*

c. Availability of Hospice Staff

D15: *At the moment our hospice is in an absolute crisis because the sister in charge has just resigned and least 2 of the 8 sisters that were working have resigned as well. So they're down to 6 sisters who do the home-based care. And they cover a huge area. Um, so they're just not coping at all. You know if you look at their number of patients a day that they see, I think last time there was a count and they were looking after 40-45 patients each. And to get to each of those patients even once a week is an incredible task. I think the other thing is even from a financial point of view, they get paid very little.*

Um, and they're not even attracting people, so unless people sort of want to do it for the love of wanting to help others, um, they're not attracting people to that type of health care.

D41: *We can't find people who want to work here.*

NS10: *I think there's just nobody around. Everybody's leaving our pretty country to go and work elsewhere where they think there's more money. .... We just don't get applications but we're not the only organization. The hospital struggles, the private hospital struggles, everybody around struggles.*

NS14: *I think in the community when there's a load of 40 patients and when you've got 5 patients dying and they need more and more care, I would say that the community sister's very stretched. In the unit, I think we're alright with our volunteer staff. If we didn't have our volunteer staff we would be very hard-pressed.*

SCP1: *we tend to be short in the areas of the poorer community. And part of the reason for that also is that people of colour would not necessarily have the same understanding of volunteerism. And because of the distances they travel and their time, would expect payment. And the organization doesn't have the resources to do that.*