



School of Public Health and Family Medicine  
Isikolo Sempilo Yoluntu kunye Namayeza Osapho  
Departement Openbare Gesondheid en Huisartskunde



UNIVERSITY OF CAPE TOWN  
YUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

# How is Palliative Care part of the Right to Health?

## The South African evidence

Thesis presented for the Degree of

DOCTOR OF PHILOSOPHY

in the School of Public Health and Family Medicine

Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

December 2018

PhD candidate:

Elizabeth Gwyther

Supervisors:

Prof Leslie London

Dr Marion Heap

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

## Declaration

I, Elizabeth Margaret Jean Gwyther, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I authorise the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature:... 

Signed by candidate
---------------------

 Date: .....14 December 2018....

## Acknowledgements

To Leslie London and Marion Heap, my PhD supervisors, thank you for persevering with me on my PhD journey, guiding my research and the developing further the philosophy of palliative care as part of the right to health.

Leslie, thank you for lighting the spark for Human Rights and Health and guiding my learning in this discipline.

Marion, thank you for demonstrating practical application of the Right to Health, for cups of coffee and collegial support.

To my research assistants, Linda Ganca, Muriel Stevens for the Accessibility study; and Muriel Stevens, Getrude Mekwa, Trish Gilles, Gavin O'Sullivan, Jacques Stevens, Hilary Grey, Joy Hunter, Zanele Tsotso for the Quality study

To the Mellon PhD group and our skilled mentor, Anna Strebels, thank you Anna for the guidance and encouragement and for your editorial skills. My fellow PhD travellers have supported and encouraged me and the cross-pollination has been valuable.

To Debbie Bradshaw and her team at the Medical research Council Burden of Disease unit for making the South African mortality data available for the needs assessment study.

To Amanda Ganca for her attention to detail as data capturer for the cohort studies (Chapters 5 and 6)

To Rauf Sayed for statistical analysis of APCA POS data and Jordache Ramjith for coaching me in developing skills in the use of Stata.

To my colleagues Callen Hodgskiss and Jolie Nkusi for their assistance and coaching in advanced excel skills; and to Eric Watlington and Shaun Thomas for creating the map of hospice services in Cape Town

To Naomi Fray and Lauren Fray, many thanks for secretarial assistance.

To my family for their support, encouragement and belief in me; thank you, Kate and mom, for your editing skills.

## Acronyms

ACS	American Cancer Society
AIDS	Acquired Immuno-Deficiency Syndrome
APCA	African Palliative Care Association
ASR	Age-Standardized Rate
BoD	Burden of Disease
CHCs	Community Health Centres
CoHSASA	Council for Health Services Accreditation of Southern Africa
CHWs	Community Health Workers
COPD	Chronic Obstructive Pulmonary Disease
CPD	Continuing Professional Development
CVA	Cerebro-Vascular Accident
CVD	Cardio-vascular Disease
CESCR	Committee on Economic, Social and Cultural Rights
DHA	Department of Home Affairs
DoH	Department of Health
DHIS	District Health Information System
DR TB	Drug Resistant Tuberculosis
EAPC	European Association of Palliative Care
EDLs	Essential Drugs Lists
EIU	Economist Intelligence Unit
ESMO	European Society of Medical Oncology
EU	Emergency Unit
FBOs	Faith Based Organisations
GAPRI	Global Access to Pain Relief Initiative
GSF	Gold Standards Framework
HAART	Highly Active Anti-Retroviral Treatment
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association of South Africa
HPCSA	Health Professions Council of South Africa
HRC	Human Rights Council

HREC	Human Research Ethics Committee
HRW	Human Rights Watch
IAHPC	International Association for Hospice and Palliative Care
IASP	International Association for the Study of Pain
ICD-10	International Statistical Classification of Diseases and Related Health Problems–10
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICHC	Integrated Community-based Home Care
ICPCN	International Children’s Palliative Care Network
IHME	Institute of Health Metrics Evaluation
IMCI	Integrated Management of Childhood Illnesses
INCB	International Narcotics Control Board
KCL	Kings College London
KZN	KwaZulu Natal
MND	Motor Neuron Disease
MRC	Medical Research Council
NCDs	Non-Communicable Diseases
NGO	Non-Governmental Organisations
NHA	National Health Act
NHI	National Health Insurance
NEPCAL	Necesidades Paliativas
NPFSPC	National Policy Framework and Strategy for Palliative Care
NSCPC	National Steering Committee for Palliative Care
NSP	National Strategic Plan on HIV/AIDS, TB and STIs
OHSC	Office of Health Standards Compliance
OPD	Outpatient Department
PALY	Palliative Care Yardstick
POS	Palliative Outcome Scale
PROMs	Patient-Reported Outcome Measures
PEPFAR	President’s Emergency Plan for AIDS Relief
PG	Post- graduate
PHC	Primary Health Care

PHS	Public Health Strategy
PIG	Prognostic Indicator Guide
PLHIV	People Living with HIV
PN	Professional nurses
PPCDC	Provincial Palliative Care Development Co-ordinators
QALYs	Quality-Adjusted Life Years
SANC	South African Nursing Council
SALYs	Suffering-intensity Adjusted Life Years
SDGs	Sustainable Development Goals
SHS	Serious Health-related Suffering
SPICT	Supportive and Palliative Care Indicators Tool
SSA	sub-Saharan Africa
StatsSA	Statistics South Africa
STI	Sexually Transmitted Illness
TB	Tuberculosis
UCT	University of Cape Town
UK	United Kingdom
UNDHR	Universal Declaration on Human Rights
UHC	Universal Health Coverage
UICC	International Union for Cancer Control
UN	United Nations
UNICEF	United Nations Children's Fund
USA	United States of America
WHA	World Health Assembly
WHO	World Health Organisation
WHPCA	Worldwide Hospice Palliative Care Alliance
WSP	World Standard Population
XDR TB	Extensively Drug Resistant Tuberculosis

<b>Abstract: How is palliative care part of the Right to health? The South African evidence. ....</b>	<b>1</b>
<b>HOW IS PALLIATIVE CARE PART OF THE RIGHT TO HEALTH? THE SOUTH AFRICAN EVIDENCE ..</b>	<b>4</b>
Foreword.....	4
Rationale for the study .....	6
The Person of the Researcher.....	7
Aim of the research.....	7
Objectives: .....	9
<b>CHAPTER ONE: INTRODUCTION TO THE THESIS .....</b>	<b>10</b>
1.1 Introduction and overview of the thesis .....	10
1.2 Human Rights and the Right to Health .....	11
1.3 The Right to Health in South Africa.....	14
1.4 What is palliative care?.....	14
1.5 Hospice and palliative care development internationally .....	17
1.6 Development of palliative care services in South Africa. ....	18
<b>CHAPTER TWO: LITERATURE REVIEW: PALLIATIVE CARE AS A HUMAN RIGHT .....</b>	<b>20</b>
2.1 Literature search .....	20
2.2 Human rights and public health.....	20
2.3 Equity in healthcare .....	24
2.4 Palliative care as a human right .....	25
2.5 Health care professionals as duty bearers.....	31
2.7 The Right to Health in South Africa.....	32
2.8 Health inequities in South Africa .....	36
2.9 Universal Health Coverage.....	37
2.10 The South African situation with reference to palliative care policies.....	37



2.11 A human rights approach and palliative care .....	40
2.12 Human dignity: a common foundation of Human Rights and Palliative Care .....	42
2.13 Dignity in the context of illness .....	43
2.14 Conclusion.....	45
<b>CHAPTER THREE: THE NEED FOR PALLIATIVE CARE IN SOUTH AFRICA.....</b>	<b>46</b>
<i>Abstract</i> .....	46
3.1 Background .....	47
3.1.1 Palliative care within the healthcare system.....	47
3.1.2 Identifying palliative care need.....	48
3.1.3 Identifying individuals in need of palliative care .....	48
3.1.4 Palliative Care Indicator Tools .....	50
3.1.5 Public health needs.....	52
3.1.6 Background to needs assessment in palliative care .....	53
3.1.7 Epidemiological approaches to needs assessment .....	54
3.1.8 Children's Palliative Care .....	60
3.1.9 Identifying a method of determining palliative care need in South Africa .....	61
3.1.10 Cause of death statistics .....	62
3.1.11 Data quality concerns .....	63
3.1.12 Prevalence of symptoms.....	64
3.1.13 Summary: Determining palliative care need in South Africa .....	65
3.1.14 Problem statement .....	66
3.1.15 Aim and Objectives: .....	66
3.2 Methodology.....	67
3.2.1 Study design.....	67

3.2.2 Study population.....	67
3.2.3 Data source .....	67
3.3.4 Identifying cause of death by ICD-10 codes APNC .....	68
3.3.5 Data abstraction.....	69
3.2.6 Data analysis .....	70
3.3 Results.....	71
3.3.1 Mortality data.....	71
3.3.2 Deaths by age.....	72
3.3.3 Place of death .....	74
3.3.4 Deaths and palliative care need by province.....	75
3.3.5 Disease categories .....	76
3.4 Discussion.....	77
3.4.1 Extent of the need for palliative care in South Africa.....	77
3.4.2 Accuracy of palliative care needs estimates.....	78
3.4.3 Accuracy of the data .....	80
3.4.4 Estimating the need for palliative care in children.....	81
3.4.5 Palliative care needs by province .....	82
3.4.6 Place of death .....	82
3.4.7 Limitations of the study .....	83
3.4.8 A more robust method of assessing palliative care need.....	84
3.5 Conclusion.....	85
<b>CHAPTER FOUR: THE AVAILABILITY OF PALLIATIVE CARE IN SOUTH AFRICA.....</b>	<b>86</b>
<i>Abstract:</i> .....	86
4.1 Introduction .....	87

4.1.1 Availability as described in General Comment 14 .....	87
4.1.2 International support for palliative care.....	88
4.1.3 Human rights and palliative care .....	90
4.1.4 World Health Assembly resolution .....	91
4.1.5 Policy context in South Africa .....	91
4.1.6 The South African Constitution.....	92
4.1.7 Re-engineering of Primary Health Care .....	93
4.1.8 Availability of palliative care services in South Africa .....	95
4.1.9 Growth and decline in South African hospice services.....	97
4.1.10 Funding for hospice services.....	100
4.1.11 Human resources in palliative care.....	100
4.1.12 Availability of palliative care services in the formal health care sector in South Africa .	102
4.1.13 Availability of pain medication (essential drugs).....	103
4.1.14 South African government support for palliative care .....	104
4.1.15 Problem statement .....	105
4.1.16 Aim and Objectives .....	106
4.2 Methodology.....	106
4.2.1 Study design.....	106
4.2.2 Study site.....	106
4.2.3 Study population.....	106
4.2.4 Sampling.....	106
4.2.5 Data collection .....	106
4.2.6 Data collection tools .....	106
4.2.7 Data collection method .....	108

4.2.8 Data storage and management .....	109
4.2.9 Ethical considerations .....	109
4.2.10 Data analysis .....	109
4.3 Results .....	110
4.3.1 Sites providing palliative care .....	110
4.3.2 Elements of palliative care provided by sites .....	112
4.3.3 Human resources .....	112
4.3.4 Organisations with limited staffing.....	114
4.3.5 Staff trained in palliative care .....	1165
4.3.6 Beneficiaries of palliative care .....	1177
4.3.7 Services reporting providing culturally sensitive care .....	1188
4.3.8 Availability of morphine.....	11919
4.3.9 Barriers to patients access to morphine.....	1200
4.3.10 Qualitative analysis of barriers to access to morphine .....	1211
4.3.11 Access to information about the service provided.....	1233
4.4 Discussion.....	1244
4.4.1 Availability of palliative care.....	124
4.4.2 Palliative care services in South Africa .....	1244
4.4.3 Elements of palliative care provided by sites .....	1255
4.4.4 Demographics .....	1266
4.4.5 Human resources for palliative care .....	1266
4.4.6 Level of palliative care training.....	1288
4.4.7 Availability of morphine.....	1300
4.4.8 Comparing the availability of palliative care with estimated palliative care need .....	1322

4.4.9 Realising a right to access to palliative care in the state sector .....	1333
4.4.10 Limitations of the study .....	1344
4.5 Conclusion .....	1355
<b>CHAPTER FIVE: ACCESS TO PALLIATIVE CARE .....</b>	<b>1388</b>
<i>Abstract:</i> .....	1388
5.1.1 Universal Health Coverage .....	13939
5.1.2 Accessibility in terms of Right to Health .....	1411
5.1.3 Recognising patients requiring palliative care .....	1411
5.1.4 Physical accessibility of palliative care services in South Africa .....	1422
5.1.5 Economic accessibility .....	1444
5.1.6 Information accessibility .....	1444
5.1.7 Non-discrimination .....	1455
5.1.8 Referral and integration for improved access to palliative care .....	1466
5.1.9 Problem Statement .....	1477
5.1.10 Aim and Objectives .....	1488
5.2 Methodology .....	1488
5.2.1 Study design .....	1488
5.2.2 Study sites .....	1488
5.2.3 Study population .....	14949
5.2.4 Sampling .....	149
5.2.5 Data collection tools .....	1500
5.2.6 Research assistants .....	151
5.2.7 recruitment of participants .....	152
5.2.8 Data collection procedure .....	1544

5.2.9 Data storage and confidentiality .....	1544
5.2.10 Ethical considerations .....	1544
5.2.11 Data analysis .....	1555
5.3 Results .....	1577
5.3.1 Referral to palliative care.....	1587
5.3.2 Other people or services involved in patients' care .....	15958
5.3.3 Content analysis.....	16059
5.3.4 Loss to follow up .....	1643
5.3.5 Analysis of APCA African POS patient reported outcome measures.....	1665
5.3.6 Analysis of sub-set of patients with high pain scores.....	17170
5.3.7 Summary .....	1732
5.4 Discussion .....	174
5.4.1 Demographics of study participants .....	1744
5.4.2 Access to palliative care.....	1755
5.4.3 Analysis of pain scores .....	17979
5.4.4 Spiritual well-being .....	17979
5.4.5 Additional care providers.....	1800
5.4.6 Accessibility of palliative care .....	1800
5.4.7 Limitations of the study .....	1822
5.5 Conclusion.....	183
<b>CHAPTER SIX: THE QUALITY OF PALLIATIVE CARE - AN ESSENTIAL ELEMENT OF THE RIGHT TO HEALTH.....</b>	<b>185</b>
<i>Abstract:</i> .....	1855
6.1 Introduction .....	1866

6.1.1 Quality as described in Human Rights documents .....	1866
6.1.2 Quality in healthcare.....	1877
6.1.3 Assessing quality .....	1877
6.1.4 Quality of health care in South Africa.....	1888
6.1.5 Quality improvement.....	1888
6.1.6 Office of Health Standards Compliance.....	18989
6.1.7 Measures of quality in hospice sector through PROMs .....	1900
6.1.8 Quality and dignity.....	1911
6.1.9 Home-based care services: palliative care and general care.....	1933
6.1.10 Problem Statement.....	1955
6.1.11 Aim and Objectives: .....	1966
6.2 Methodology.....	1966
6.2.1 Study design.....	1966
6.2.2 Study sites .....	1966
6.2.3 Study population.....	1966
6.2.4 Sampling.....	19797
6.2.5 Sample Size .....	1977
6.2.6 Data collection tools .....	1988
6.2.7 recruitment and training of research staff.....	199
6.2.8 Recruitment of participants .....	200
6.2.9 Data collection process.....	200
6.2.10 Data collection and confidentiality.....	201
6.2.11 Ethical considerations .....	2022
6.2.12 Data analysis .....	2033

6.3 Results.....	2044
6.3.1 Recruitment into study.....	204
6.3.2 Comparison of the two groups: hospice and non-hospice.....	2066
6.3.3 Loss to follow-up.....	2077
6.3.4 Analysis of patient-reported outcomes for patients and identified family members ....	2088
6.3.5 Analysis of Patient Questionnaires .....	21919
6.3.6 Content analysis narrative questions .....	21919
6.4 Discussion.....	225
6.4.1 Quality as element of the Right to Health .....	2255
6.4.2 Patient demographics .....	2255
6.4.3 Patient reported outcomes .....	2266
6.4.4 Patient experience of care: Acceptability.....	2277
6.4.5 Love .....	2288
6.4.6 Respect and dignity.....	2288
6.4.7 Limitations of the study .....	2300
6.5 Conclusion.....	2300
<b>CHAPTER SEVEN: CONCLUSION .....</b>	<b>2322</b>
7.1 Overview .....	2322
7.2 Needs assessment.....	2333
7.3 Assessment of the essential elements of the Right to Health.....	2344
7.4 The use of General Comment 14 as framework for the study .....	2388
7.5 Palliative care as a component of comprehensive care .....	23939
7.6 A Rights-Based Approach.....	2400
7.7 Recommendations .....	2422



REFERENCES.....	2500
APPENDICES.....	273
A Data Collection Tools.....	273
A1 Mortality data abstraction spreadsheet.....	273
A2 Data collection sheet for palliative care sites by province .....	274
A3 Survey document for palliative care sites.....	275
A4 Questionnaire on care needs.....	280
A5 APCA African POS.....	281
A6 Questionnaire on Quality of care.....	283
B Information sheets and Consent forms .....	284
B1 Information sheet and Consent form: Access to care.....	284
B2 Information sheet and consent form: Quality of care.....	287
C Ethical approvals.....	290
C1 UCT FHS HREC approval.....	290
C2 HPCA REC approval .....	291
D Supporting documents.....	292
D1 Letter requesting permission to conduct study at study sites (Access to care).....	292
D2 Letter requesting permission to conduct study at study sites (Quality of care).....	295
D3 ICD-10 codes.....	298
D4 WHO definition of Palliative Care.....	305
D5 Regression analyses comparing hospice and non-hospice PROMS.....	306

## Tables

Table 1.1: Defining Palliative Care (WHO & WHPCA) .....	15
Table 1.2: WHO definition of palliative care for children .....	16
Table 2.1: Timeline of international recognition of palliative care as a human right .....	25
Table 2.2: Summary of WHA resolution 67.19 recommendations to governments .....	30
Table 3.1: Comparison of methods for epidemiological needs assessment for palliative care ...	57
Table 3.2: Comparison of ICD-10 codes selected by Rosenwax and by Mutagh.....	58
Table 3.3: Diseases requiring palliative care identified in Global Atlas of Palliative Care .....	60
Table 3.4: Together for Short Lives Categories of Life Threatening and Life Limiting Diseases...	61
Table 3.5: Key steps for palliative care needs assessment and planning services .....	62
Table 3.6: Minimum and maximum symptom prevalence for five conditions, from Solano.....	64
Table 3.7: ICD-10 codes extracted from 2010 deaths as conditions affecting adults and children that could benefit from palliative care .....	69
Table 3.8: Additional ICD-10 codes extracted from 2010 deaths as conditions affecting children that could benefit from palliative care .....	70
Table 3.9: Deaths ANPC in 2010 by age and gender .....	72
Table 3.10: Population statistics and age-standardised mortality rate causes ANPC per 100,000 population (all ages) by age in 5-yr age bands (2010).....	73
Table 3.11: Population statistics and age-standardised mortality rate for palliative care conditions per 100,000 population (all ages) by province (2010).....	76
Table 3.12: Comparison of three South African estimates on palliative care need .....	78
Table 4.1: Advocacy/lobbying for palliative care as a human right.....	89
Table 4.2: Availability of morphine and presence of doctor.....	119
Table 4.3: Access to morphine compared to profession and training .....	1200
Table 4.4: Access to morphine rural vs urban setting .....	1200
Table 5.1: Sample size calculation .....	1500
Table 5.2: Demographic characteristics for each sub-cohort of patients by diagnosis.....	158
Table 5.3: Proportion of patients referred to hospice by month 6 .....	1588
Table 5.4: Care received other than palliative care services .....	15959

Table 5.5: Themes generated through content analysis .....	1600
Table 5.6: Loss to follow up .....	1655
Table 5.7: Pain reported over the 6-month period .....	1666
Table 5.8: Symptoms other than pain .....	1677
Table 5.9: Worry .....	1688
Table 5.10: Able to share .....	1688
Table 5.11: Life worthwhile .....	16969
Table 5.12: At peace .....	1700
Table 5.13: Help and advice .....	1711
Table 5.14: Oncology patients with pain scores 5/5 at baseline .....	1722
Table 5.15: HIV patients with pain levels 5/5 at baseline.....	1733
Table 6.1: number of organisations and patients per province .....	2055
Table 6.2: Patient demographics by gender and race .....	2055
Table 6.3: Primary diagnoses for participants by hospice and non-hospice .....	2066
Table 6.4: Participants retained in the study.....	2077
Table 6.5: Reasons for loss to study by week.....	2088
Table 6.6: Reasons for loss to study by site .....	2088
Table 6.7: Change over time between week 1 – 4 for group 1: hospice services .....	20909
Table 6.8: Compare change over time between week 1 – 4 for hospices - family outcomes.	2100
Table 6.9: Compare change over time between week 1 – 4 for group 2: non-hospice .....	2111
Table 6.10: Comparison of baseline POS items for hospices and non-hospice services.....	2122
Table 6.11: Change in APCA POS scores over time between weeks 1 – 6 for hospice patients .....	2133
Table 6.12: Compare change over time between weeks 1 – 6 for non-hospice patients.....	2144
Table 6.13: Compare change over time between weeks 1 – 6 hospice family outcomes .....	2155
Table 6.14: Compare change over time between weeks 1 – 6 non-hospice family outcomes	2155
Table 6.15: Regression analysis Symptoms comparing hospice and non-hospice groups.....	219
table 6.16 Patient responses to questionnaire .....	220
Table 6.17: Summary of themes .....	222

Table 7.1: Proposed framework of indicators .....	246
---	-----

## Figures

Figure 3.1: Trajectories of terminal illness in South Africa from the National Policy Framework and Strategy for Palliative Care .....	49
Figure 3.2: Deaths reflecting causes ANPC by age and gender (South Africa, 2010) .....	74
Figure 3.3: Deaths from causes ANPC by age and four main places of death.....	75
Figure 4.1: Distribution of hospice services in South Africa (2010).....	96
Figure 4.2: indicating gaps in palliative care service .....	110
Figure 4.3: Map showing health districts of respondents .....	1111
Figure 4.4: Palliative care services provided as percentage of total number of organisations	1122
Figure 4.5: Cadres of professional staff at site, part-time, full-time and volunteer.....	113
Figure 4.6: Employment of staff providing nursing care .....	1133
Figure 4.7: Employment of counselling staff .....	1144
Figure 4.8: Palliative care training of professional staff .....	1155
Figure 4.9: Training of non-professional staff.....	1166
Figure 4.10: Organisations that cared for children compared to all organisations.....	1188
Figure 5.1: Hospice services in Cape Town in 2010 .....	1433
Figure 5.2: Patients with by gender and diagnosis.....	1577
Figure 6.1: Patient demographics by age .....	2055
Figure 6.2: Diagnoses of all patients in care (both hospice and non-hospice) (n=459) .....	2066
Figure 6.3: Pain .....	2166
Figure 6.4: Symptoms .....	2177
Figure 6.5: Worry .....	2177
Figure 6.6: Family Worry.....	2188

Abstract: How is palliative care part of the Right to health? The South African evidence.

Palliative care is an appropriate and compassionate response to the needs of patients with life-threatening illness. International human rights law establishes palliative care as part of the right to health. But what does this mean in practice? How is palliative care part of the right to health at the country level and in everyday patient experience? This thesis addresses this question with evidence from South Africa. South Africa is important for a number of reasons. The government, despite the country's progressive Constitution (No 108, 1996) which entrenches the right of access to health care has yet to take responsibility for palliative care. Most recently, the South African government co-sponsored the World Health Assembly (2014) resolution on palliative care and thus has a commitment to implementing the resolution.

The thesis employs **General Comment 14 on the Right to Health to frame** the four nested studies that were carried out to address the key research question. General Comment 14 (2000), adopted by the United Nations Committee on Economic, Social and Cultural Rights, describes the normative content of the right to health (Article 12 International Covenant on Economic, Social and Cultural Rights) to include four overlapping elements – availability, accessibility acceptability and quality.

**Aim of the research:** to evaluate current provision of palliative care in South Africa in terms of the Human Rights considerations of availability, accessibility and quality.

Study One commences the thesis by estimating **the need for palliative care** in South Africa. Using mortality data for 2010 for conditions determined a priori to require palliative care, approximately 0.52% of the population were estimated to require palliative care, which translates into an average need of 698.5 persons per 100000 or 1 in 143 people every year. While this is a considerable burden, it is also likely to be a significant under-estimate, given limitations to the methods identified in the study.

Study Two examines **availability** of services to meet the need for palliative care. A survey was completed by 131 palliative care organisations between March 2011 and October 2011. Only 3% of services were located within the public sector. The estimated number of patients who received care during the year was 46,347. This is approximately 18% of the need identified earlier in Study One. Availability of morphine, as a marker for palliative care, was found to be dependent on employment of and level of palliative care training of doctors and was especially poorly supplied in the rural areas. Thus, the availability of Palliative Care appears to be limited by health system factors.

Study Three investigates **access** to palliative care in Cape Town, via two pathways 1) referral of patients requiring palliative care and 2) palliative care in their current care settings. A prospective cohort study over six months followed up 162 participants from three groups: 1) patients with metastatic cancer; 2) patients living with HIV with a CD4 count of  $<200$  cells/mm<sup>3</sup>; and 3) patients diagnosed with motor neuron disease (MND). A questionnaire and a validated patient-reported outcome scale, the African Palliative Care Association (APCA) African Palliative Outcome Scale (POS), was administered at first visit. Thereafter participants were followed up telephonically once a month. Few patients (5%) were referred to palliative care services even though a significant number of patients died during the course of the study, indicating a failure to access palliative care when needed. Patient outcomes for people living with HIV improved significantly whereas the majority of patient outcomes in the cancer and MND groups did not improve. Thus, the accessibility of palliative care to patients already in the health system appears to be poor, except when palliative care is integrated into primary care, as is the case for patients with HIV on ARV treatment.

Study Four evaluated **the quality of care** delivered to patients requiring palliative care in accredited hospice and non-hospice non-governmental services in five of the nine provinces of South Africa. A survey was conducted with 459 patient participants and 253 family members who were followed up over a 4-6 week period. Perceptions of quality care were explored through narrative questions and patient-reported outcomes were assessed using the APCA African POS.

The results show significant improvement in patient reported outcome measures in both hospice and non-hospice groups, with pain and worry showing the most improvement. Content analysis of the narrative questions identified 5 themes: Quality of Care, Place of care, Staff values and attitudes, Information-sharing and Problems experienced by participants

**Conclusion:** The thesis presents evidence that despite nominal commitment by the state, palliative care is not yet implemented as part of the right to health in South Africa. The need is great but availability of palliative care services is insufficient to meet the need. Access is poor even where palliative care is available but is facilitated by integration of palliative care into primary care services. However, when access is achieved, quality of care is generally good and patient outcomes improve over time with evidence that palliative care values patients as individuals. The study considers concepts relating to dignity and human rights in health as core to both human rights and palliative care.

**Implications:** In South Africa, the planned National Health Insurance Policy lists palliative care as a service in the primary health care setting. In addition, a National Palliative Care Policy has been approved with strategies to integrate palliative care into public health facilities. As General Comment 14 has proved useful for the thesis, for the future, it may also provide a framework to monitor state accountability on the basis of Availability, Accessibility, Acceptability, and Quality of palliative care that can be transferred to other countries.

## HOW IS PALLIATIVE CARE PART OF THE RIGHT TO HEALTH? THE SOUTH AFRICAN EVIDENCE

### Foreword

This study explores the question of how palliative care is part of the Right to Health, using General Comment 14 of the Committee on Economic, Social and Cultural Rights (1) to frame the research in terms of the elements of Availability, Accessibility, Acceptability and Quality. This is an interdisciplinary exploration of the subject of palliative care as part of the Right to Health. It draws on human rights theory, epidemiology, biostatistics, principles of palliative care. Mpinga and colleagues identify that the field of human rights and health is not a single discipline and quote Gruskin as identifying that health and human rights encompasses “*legal, advocacy and public health practice*” (2:241). The thesis evaluates the current provision of palliative care in South Africa in respect of elements of Availability, Accessibility, Acceptability and Quality and explores whether a human rights approach could assist in improving access to palliative care in South Africa.

Chapter One describes the rationale for the study, the study aim and objectives and provides an overview of palliative care, of the Right to Health and the consideration of dignity as a common foundation of the two fields.

Chapter Two is the literature review describing the Right to Health and the background to establishing palliative care as a part of the Right to Health. It traces the reference to palliative care in International Human Rights Law and developments at the World Health Assembly meeting in 2014, where South Africa co-sponsored the WHA resolution: ‘*Strengthening of palliative care as a component of comprehensive care throughout the lifecourse*’(3). The chapter describes literature on health inequities in South Africa and the efforts to address these, advocacy efforts to promote integration of palliative care into the South African health system, and the Right to Health in South Africa. It considers dignity as the common foundation to both human rights and palliative care, and the role of palliative care to maintain or enhance dignity in healthcare.



Chapter Three describes a needs assessment for the provision of palliative care in South Africa, as a key prerequisite for later determining whether palliative care services are available or accessible. It discusses international approaches to conducting a needs assessment for palliative care and how symptom prevalence assists in indicating palliative care needs. An analysis of mortality data from the South African Burden of Disease studies follows, with critical commentary on the limitations of these data in providing an accurate needs assessment. The use of a palliative care indicator tool at health facility level is suggested as an alternative method of predicting palliative care needs.

Chapter Four describes the availability of palliative care services, the elements of palliative care provided, and training of staff working in palliative care centres in South Africa. It also looks at availability of morphine as an essential palliative medicine in palliative care facilities, using this as a marker for availability of palliative care services. Finally, the chapter relates the availability of palliative care services in South Africa in comparison with the need identified in Chapter Three.

Chapter Five describes a prospective cohort study of the accessibility of palliative care for patients with chronic illnesses who would benefit from palliative care. The study evaluates demographics of patients receiving care for advanced illness with three diagnoses: patients with advanced cancer, patients living with HIV with CD4 count of  $<200$  cells/mm<sup>3</sup>, and patients diagnosed with motor neuron disease. The study evaluates patient reported outcomes as a measure of palliative care provided in the patients' current care setting, and reports on referral to hospice palliative care services.

Chapter Six describes a prospective cohort study of the quality of palliative care through the measurement of patient reported outcomes in selected non-governmental palliative care services, and the experiences of care described by patients in these services. The study also evaluates the acceptability of the services in terms of sensitivity to cultural, gender and life cycle factors.

Chapter Seven synthesises study findings from the availability study and needs evaluation; the study on access to palliative care for patients with advanced illness; and the study on quality of care. It considers concepts relating to dignity and human rights in health as core to both human rights and palliative care. It comments on the usefulness of General Comment 14 as a framework to assess the South African evidence for availability, accessibility, acceptability and quality of palliative care discusses whether the South African approach could be transferrable to other countries.

### Rationale for the study

It is recognized that palliative care is an appropriate and compassionate response to the needs of patients with life-threatening illness(3). International human rights law, in particular, General Comment 14, establishes palliative care as part of the Right to Health(1). Moreover, recent international statements such as the World Health Assembly Resolution on palliative care (3) and the description of Universal Health Coverage (4) provide guidance to United Nations member states on integrating palliative care into country health systems. In addition, there are normative statements such as those made by both the Special Rapporteur on the Right to Health(5) and the Special Rapporteur on Torture, Cruel, Inhuman and Degrading Treatment(6) (separately and together) recognizing palliative care as an essential element of the Right to Health. This is echoed by the international palliative care community in descriptions of palliative care and pain relief as a human right(7).

However, in spite of this recognition, access to palliative care is woefully inadequate worldwide. The Global Atlas of Palliative Care published in 2014 estimated that over 20 million people worldwide need end-of-life palliative care each year, and that less than 14% of the need is currently met(8). Knaul and colleagues identify an “*access abyss*” and write the emotive comment “*one sees the depth of extreme suffering in the cruel face of poverty and inequity*”(9:1). To date, in South Africa, palliative care has largely been provided to relatively few patients and mostly within the non-governmental (NGO) setting. The thesis explores the accessibility, availability, acceptability and quality of palliative care provided in South Africa, to examine whether and how palliative care is realized as part of the Right to Health in this country. It also

explores the concept that palliative care supports individual dignity and examines whether this is evidenced in the provision of palliative care in South Africa. The South African government co-sponsored the WHA resolution on palliative care and thus has a commitment to implementing the resolution. Thus, this thesis aims to explore how South Africa is performing in ensuring palliative care as part of the Right to Health.

### The Person of the Researcher

The PI on this study is a palliative care clinician, Chief Executive Officer (CEO) of the Hospice Palliative Care Association of South Africa, and a founding trustee of the Worldwide Hospice Palliative Care Alliance. In addition, she has a role in palliative care teaching and research at the University of Cape Town. She has been an active palliative care advocate in South Africa and globally and has served on the World Health Organisation's ad hoc Technical Advisory Group for palliative and long-term care and on the South African National Steering Committee for Palliative Care. She has over twenty years' experience in providing palliative care to hospice patients. She established the palliative care teaching programmes at the University of Cape Town. Thus, there is a bias in approaching this research topic but also an authority in researching the issues. The study has taken some time to come to fruition and in the course of the study the researcher has been a part of international and national developments of palliative care. She has also undertaken study and research into human rights and establishing palliative care as part of the Right to Health and used this experience in undertaking this interdisciplinary study.

### South Africa

There are a number of important considerations that make South Africa a key setting for this study. South Africa has signed and ratified the International Covenant on Economic, Social and Cultural Rights (10). The South African constitution has a human rights focus and includes the Right to Health framed as the right of access to health care in Section 27 of the country's constitution (11). Chapter 1, Section 1 of the South African Constitution also articulates the values that form the foundation of the constitution as including "*Human dignity, the achievement of equality and the advancement of human rights and freedoms*" (para 1). The

Constitution also states the intent *“to redress the results of past racially discriminatory laws and practices”*(11) (para 29 c). Post-apartheid South Africa is a young democracy with a commitment to equity and redress of past (and current inequities). South African people have a strong sense of human rights and social justice which have been used in efforts to address inequities, including in the health sector. There is a quadruple burden of disease in the South African population with the highest burden of HIV of any country in the world and an increasing burden of both communicable and non-communicable diseases(12) which may increase the need for palliative care. South Africa is embarking on the implementation of the National Health Insurance which includes palliative care. Thus, South Africa is a country ideally placed to demonstrate how palliative care might be implemented as a part of the Right to Health. While it is a middle income country, it is located in Africa and lessons learned in South Africa may be applicable to other developing countries. Lastly, the researcher is a South African citizen, living and working in South Africa and has a goal to advance access to palliative care. The insights from this study will be able to find practical application in the advocacy and planning for palliative care for people in need in South Africa.

#### Race and population group

The South African Medical Research Council collects data about population group and this data is used in the analysis of palliative care need.

The inclusion of race in the data collection of the Availability study is not with the intent to perpetuate racist attitudes of the past. The largest provider of palliative care in South Africa, HPCA, states in the organisation’s annual report that HPCA and member hospices do not support racial classification of beneficiaries and have always provided care to anyone in need and free of charge without discrimination. Hospices are required to report on a racial breakdown of beneficiaries for Broad-Based Black Economic Empowerment (BBBEE) rating. This demographic is thus available and allows assessment of provision of care to different races without discrimination on the basis of race.

#### **Research Hypothesis**

If palliative care is part of the Right to Health, how is South Africa performing in realising the right to palliative care?

**Aim of the research:** to evaluate current provision of palliative care in South Africa in terms of the Human Rights considerations of availability, accessibility and quality

**Objectives:**

1. To describe the need for palliative care in South Africa
2. To describe the availability of palliative care services in South Africa
3. To investigate accessibility of palliative care for a cohort of patients with chronic illnesses who would benefit from palliative care
4. To investigate quality of care provided through patient reported outcomes of a cohort of patients cared for in NGO palliative care services

Through the four studies, the thesis will explore whether and how palliative care is realized as part of the Right to Health in South Africa.

### Research Methodology

Each study has a separate description of research methodology and the overall approach to research methodology has used different designs to develop a baseline understanding of the implementation of palliative care as part of the Right to Health in South Africa. This approach allows for exploration of the elements of the Right to Health as described in General Comment 14. The researcher's background is that of a palliative care clinician and advocate for palliative care. The addition of scholarship to advocacy is important in assuring scientific credibility rather than relying only on emotive issues. The value of examining the elements of General Comment 14 in a number of descriptive and analytic sub-studies is that this approach introduces palliative care practitioners to the Right to Health in a practical way demonstrating the application of the Right to Health in the clinical setting. There are different approaches that could have been taken in this study, including the use of indicators developed by the UN to measure progressive realisation of the Right to Health. Although these indicators were not available at the time this study was first designed, some of these have become available after the execution of this study and can be used in future studies.

## CHAPTER ONE: INTRODUCTION TO THE THESIS

This first descriptive chapter explains the Right to Health and the elements of this right as described by international human rights law. It describes how General Comment 14 explores the normative content of the Right to Health. It provides a background description of palliative care and some of the factors that establish palliative care as part of the Right to Health.

### 1.1 Introduction and overview of the thesis

The Right to Health is established through the International Covenant on Economic, Social and Cultural Rights (ICESCR)(10). The ICESCR describes “*the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*” (Article 12) However it was not until the Committee on Economic, Social and Cultural Rights issued General Comment 14 that a substantive understanding of the Right to Health was described(1). A General Comment is an authoritative interpretation of a right contained in International Human Rights Law. Palliative Care is not identified explicitly as a right in the ICESCR. However, in describing “*specific legal obligations*” General Comment 14 states that governments should respect the Right to Health with regard to access to “*preventative, curative and palliative health services*”(1) (para 34); thus identifying palliative care as a component of the Right to Health.

The thesis, investigating how palliative care is part of the Right to Health in South Africa, uses the “*essential elements*” required for the realisation of Right to Health described by General Comment 14(1) from the Committee on Economic, Social and Cultural Rights as its conceptual framework. General Comment 14 describes “*interrelated and essential elements*” that contribute to the Right to Health(1) (para 12). These elements are: Availability, Accessibility Acceptability and Quality, defined as follows:

- (a) “*Availability: Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party*” (para 12 a).
- (b) “*Accessibility: Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party*” (para 12 b). This element has four

overlapping dimensions of non-discrimination and physical, economic and informational accessibility.

*(c) Acceptability: All health facilities, goods and services must be respectful of medical ethics and culturally appropriate (para 12c).*

*(d) Quality: As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality (para 12d).*

As described in the Foreword, there are four studies nested within the thesis which evaluate palliative care as part of the Right to Health, each of the nested studies is introduced by an abstract: 1) The first study (Chapter Three) describes an assessment of the need for palliative care in South Africa; the next three studies examine palliative care within the frame of the essential elements described in General Comment 14: 2) A description of current **availability** of palliative care in South Africa (Chapter 4) with some elements of **acceptability** captured in the assessment; 3) An investigation into **accessibility** of palliative care for a cohort of patients with advanced illness (Chapter 5); and 4) An evaluation of the **quality** of palliative care provided in selected services in South Africa with additional elements of **acceptability** (Chapter 6). Although some elements of Acceptability are included in both Chapters 4 and 6, this thesis did not set out to measure all four elements of the Availability, Accessibility, Acceptability, Quality framework outlined in General Comment 14 independently. The elements of General Comment 14 are overlapping and aspects of Acceptability are included in both Chapters Four and Six reflecting the inter-dependence and indivisibility of human rights and their various elements. However, where existing tools reflected elements of acceptability, these are reported – reflecting the inter-dependence and indivisibility of human rights and their various elements. The final chapter draws the evidence together and identifies how palliative care is part of the Right to Health in South Africa and where there are gaps in realising this right (Chapter 7). This thesis begins by considering the development of the Right to Health at the outset of this study.

## 1.2 Human Rights and the Right to Health

The recent (post-World War 2) concepts and the discipline of Human Rights developed from the Universal Declaration of Human Rights (UDHR)(14). Article one of the UDHR contains the

statement that *“All human beings are born free and equal in dignity and rights”* (14)(para 1). Human rights are expressed as the rights we all have by virtue of being human. There are nine human rights treaties (covenants) agreed at the United Nations. The first two human rights treaties were the International Covenant on Civil and Political Rights (ICCPR)(15) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) (10) which together with the UDHR make up the International Bill of Rights. The ICCPR expresses (amongst other rights) the right to self-determination, the right to life, the right of freedom from torture, cruel, inhuman and degrading treatment, the right to liberty and security of person, and the right to freedom of thought, conscience and religion(15). Rights described in the IECSCR include the right to work, to fair wages and equal remuneration, protection and assistance accorded to the family, with special measures of protection and assistance on behalf of children, the right of everyone to an adequate standard of living for himself and his family, the right of everyone to education, the right of everyone to take part in cultural life and the right of everyone to the enjoyment of the highest attainable standard of physical and mental health(10). Human rights treaties impose obligations on governments to realise rights contained in these treaties. General Comment 14 describes core obligations as the minimum essential levels to recognise the Right to Health; and recognizes that resource constraints may limit full realisation of the obligation with regard to the Right to Health allowing for “progressive realization” of state obligations(1). Each international covenant has a committee of experts to oversee its implementation, and countries that have ratified the treaties are bound by international law to uphold the terms of the covenant.

South Africa is a signatory to the ICECSR and ratified the Covenant in January 2015. As a result, the instrument is legally binding upon South Africa, meaning South Africa is bound to uphold the obligations in the ICESCR, and to align domestic policies and legislation with these obligations. There are 167 state parties (countries that have ratified the ICESCR) as of 13 March 2018(16). State parties are required to submit an initial report to the CESCR within two years of ratification of the Charter and then every five years. The report describes how the state parties are implementing the rights of the Charter. National and international NGOs can send shadow reports to the Committee. Ratification of the ICESCR also commits the state parties to the minimum essential level for each socio-economic right. General Comment 14 describes three



types of obligation with regard to the Right to Health: 1) Respect – the state must not interfere “with the enjoyment of the Right to Health” (1) (para 33); 2) Protect – the state must prevent other parties from interfering with the individual’s Right to Health; 3) Fulfil – the state must “adopt legislative, administrative, judiciary, budgetary measures towards the full realization of the Right to Health” (1) (para 33).

With regard to the Right to Health, the promotion of human rights is an integral part of a health worker’s professional responsibilities. With regard to the Right to Health, the promotion of human rights is an integral part of a health worker’s professional responsibilities, and it is through the health care worker that many health rights are realised or violated. However, violations of the right to health also occur as a result of health systems weaknesses such as restrictive policies and lack of access to medication (17) and as a result of policies impacting on the social determinants of health(17) and as a result of policies impacting on the social determinants of health. This is clearly described in a number of documents from Mann describing the relationship between medicine, public health, ethics and human rights (18) and in the Commonwealth Medical Association’s publication: Medical ethics and human rights: the guiding principles(19). In South Africa, the Truth and Reconciliation Commission identified the need to integrate human rights principles into professional training and practice of health professionals (20-22). Baldwin-Ragaven and London (21) reflect on the human rights abuses of apartheid and the obligations of health professionals. Health care professionals with ethical commitments should firstly ensure that they do not violate human rights and also have a role “to *promote and fulfil human rights*”(21:21). Both by reason of providing the health services on behalf of the state and by reason of medical ethics, health care professionals should be competent to provide palliative care(3). Many health care professionals have undertaken palliative care training in order to provide better care to their patients(24). To date, palliative care has not been a standard part of undergraduate or post-graduate medical and nursing training in South Africa, so health care professionals have had to seek out opportunities to undertake this training(25).

### 1.3 The Right to Health in South Africa

The Republic of South Africa is the country situated on the southern tip of Africa. It had a population of 55.91 million people in 2016(26). South Africa is viewed by the World Bank as an upper middle income country(27). It has a multicultural society with different ethnic groups, languages and religions. The country has eleven official languages and an advanced constitution, which is celebrated internationally for its commitment to human rights. However, historical, structural and economic inequalities often prevent realization of the intent of the constitution. Nevertheless, the struggle to overthrow apartheid and build a democratic country has resulted in the population being very aware of human rights and using human rights language to protest unsatisfactory living conditions(28). The awareness has been harnessed in addressing access to healthcare, in particular access to antiretroviral medication for people living with HIV(29). In addressing issues of accessibility and availability of palliative care, this familiarity with health as a human right was used in the South African government's co-sponsoring of the World Health Assembly Resolution 67.19 on palliative care. As there is a risk of South African policies on palliative care not being implemented, the South African familiarity with human rights can be used further to promote the integration of palliative care into the health system through implementation of health care policies.

### 1.4 What is palliative care?

The WHO defines palliative care (30) as *“an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*

The Worldwide Hospice Palliative Care Alliance (WHPCA) endorses the WHO definition as applicable to life-threatening illnesses and in all geopolitical and economic settings (31), and adds explanatory descriptions (written in blue) to the WHO definition (see below, Table 1.1 Page 13). With regard to when palliative care should be provided to patients, the World Health Organization definition of palliative care states that palliative care *“is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life”*, and

the definition of palliative care for children is even more explicit with regard to the value of palliative care early in a life-threatening or life-limiting illness, stating that *“It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.”* (see Table 1.2 below page 13).

Many palliative care clinicians describe palliative care as *“the active total care of patients whose disease is not responsive to curative treatment. .. The goal of palliative care is the best possible quality of life for patients and their families”*(32). With this definition it is not surprising that palliative care is commonly viewed as compassionate care of dying patients. However, the WHO definition is clear that palliative care should be provided in the context of a continuum of care and not only at the end of life.

*Table 1.1: Defining Palliative Care (WHO & WHPCA) (29,30)*

*“Palliative Care:*

- *Provides relief from pain and other distressing symptoms;*
- *Affirms life and regards dying as a normal process when treatment for life-threatening illness is not possible or desired by the patient;*
- *Intends neither to hasten nor to unduly postpone death;*
- *Integrates the social, psychological and spiritual aspects of care as needed and desired by patients and families;*
- *Offers a support system to:*
  - *enable patients to access and adhere to optimal clinical care;*
  - *address social and legal problems and, in particular, to reduce the impact of poverty on patients and their family members including children;*
  - *help patients to live as actively as possible until death;*
  - *help the family cope during the patient’s illnesses and in their bereavement;*
- *Uses a team approach to comprehensively address the needs of patients and their families, including bereavement counselling, if indicated;*
- *Will enhance the quality of life of patients and their families; and will also positively influence the course of illness;*
- *Is applicable early in the course of illness in conjunction with disease-modifying therapies implemented to prolong life such as chemotherapy and radiation therapy for cancer patients and antiretroviral therapy for HIV/AIDS patients; and includes those investigations needed to better understand and treat distressing clinical complications.*

Table 1.2: WHO definition of palliative care for children

*“Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care, appropriate for children and their families, is as follows; (the principles apply to other paediatric chronic disorders)*

- *“Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child’s physical, psychological and social distress.*
- *Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centres, and even in children’s homes.”*

End-of-life care is a key component of palliative care but not the only component. Medical insurance funding for hospice care in the United States of America (USA) was initially limited to the last six months of life, seemingly ignoring the difficulties in identifying the point at which a patient reaches the last six months of life, and this has led to misunderstanding of palliative care, seeing it as only care for the terminally ill patient(33). This fact that many health care professionals and people with advanced illness view palliative care as only care of the dying restricts referral and access to palliative care for many people who could receive significant benefit from this care earlier in the trajectory of the illness(34). In contrast to this misperception, the WHO definition of palliative care(30) emphasises the focus on active living with statements such as: *“quality of life”, “affirms life”, “to help patients live as actively as possible”*, and these goals are implemented by hospice workers and palliative care practitioners in other settings. Palliative care includes rehabilitative care and promotes optimal rehabilitation to improve quality of life and patient dignity, even when cure is no longer possible.

The goal of palliative care is to improve quality of life for patients and family members facing the diagnosis of life-threatening or life-limiting illness. As described above, palliative care is not limited to specific diseases, and the palliative care approach and principles apply to any life-threatening illness. In the WHO definition of palliative care for children, it is stated that the principles apply to paediatric chronic disorders. The UK children’s charity Together for Short Lives

(<https://www.togetherforshortlives.org.uk>) developed a classification of paediatric disorders to explain the reach of children's palliative care. The four categories are: 1) life-threatening conditions for which curative treatment may be feasible but can fail; 2) conditions where premature death is inevitable; 3) progressive conditions without curative treatment options; and 4) irreversible but non-progressive conditions causing severe disability(35).

In addition to early palliative care, the requirement for compassionate care of the dying needs to be recognised and promoted. Modern medical care has a strong bias towards curative medicine so that patients for whom cure is no longer an option are often abandoned by the health system with the words "nothing more can be done"(36). In many health care systems around the world, hospital medicine is focused on acute care, and there has not been an improvement from the times described by Dr. Balfour Mount, pioneer of palliative care, in 1995 when he commented: "*when medical technology doesn't know what to do, the quality and quantity of care falls away*"(36). Hospices and other palliative care services provide early palliative care, as well as active management of symptoms to improve comfort for the dying patient, and support for patient and family members during the end of life period.

Connor and Sepulveda comment that "*assessing palliative care needs is in many ways equivalent to assessing an urgent humanitarian need to reduce unnecessary suffering of patients and their families*"(8:10). As Mount points out in a very powerful statement "*these are the sickest people in the healthcare system; they deserve the best care*"(36).

### 1.5 Hospice and palliative care development internationally

The roots of palliative care are found in care of cancer patients in the UK in the 1960s, when Cecily Saunders researched cancer pain control and established St Christopher's Hospice in London. Saunders identified physical and mental suffering and developed the concept of 'total pain'(37). The UK government End-of Life Care Strategy identifies that palliative care is provided as hospice care (patient admission to a hospice facility), home care, day care, hospital-based palliative care and 'hospice at home'(38). As well as hospices in the voluntary sector, there are two additional charities providing home palliative care, McMillan Cancer Support and Marie Curie Memorial Foundation in the UK (37). HospiceUK, the national organisation supporting hospice

care in the UK, report that 80% of hospice care is provided in the community including hospice at home and day care services(39). Hospice care receives 32% of funding from government and 68% from local communities(39). Palliative care is integrated into the National Health Service, and patients receive palliative care in hospitals and from general practitioners as well as palliative care in the home. Hospital palliative care started in the UK in 1976 and has been implemented in many other countries including South Africa (40,41). Hospital palliative care is provided by multidisciplinary teams comprising nurses, doctors, social workers, spiritual counsellors and other clinical staff(42).

The Economist Intelligence Unit (EIU) reported a Quality of Death Index in 2015 to evaluate palliative care services in 80 countries worldwide(43). The UK is ranked highest in the Quality of Death index due to two factors: 1) integration of palliative care into the National Health System; and 2) a strong hospice movement. The EIU describes that worldwide availability and quality of palliative care depend on the country's income levels and the level of government funding of palliative care services(43). Australia and New Zealand are the next two countries in the EIU ranking(43). South Africa is the highest ranked African country coming in at 34(43). Hospice services in the USA started in 1974, and from the start have been community-based organisations that included non-cancer care and focused on care in the home(44). The Hospice Medicare Benefit was implemented to fund patients with a terminal diagnosis and less than six-months to live who chose not to receive active anti-cancer treatment(44). These conditions resulted in barriers to access of palliative care as it is not possible to accurately predict a prognosis of death within six months. Hospital Palliative Care services were developed in the United States to meet the needs of patients with serious illness and problems with symptom control who were not yet deemed to be terminally ill(44).

#### 1.6 Development of palliative care services in South Africa.

Outside the state sector, South Africa has a network of non-governmental organisations (NGOs) providing palliative care(45). Many of these NGOs have strong working relationships with government facilities, and are well placed to assist and advise in the integration of palliative care into health and welfare facilities. Palliative care services in South Africa started within the non-

governmental sector in the 1980s(45). Hospices were established in communities that could afford to support them, and initially provided end-of-life care to cancer patients. In the public health sector, palliative care services have been established in seven hospitals, and some of these rely on sources of funding outside of government funding to continue their services(45). These are described more fully in Chapter Four. The establishment of hospital palliative care services frequently relies on individual champions within the hospital and not on hospital or government policy, which makes them vulnerable to closure if the champion should leave.

Chapter One has provided a background description of palliative care; a brief overview of the Right to Health and General Comment 14 that explores the intent of the Right to Health and some of the factors that establish palliative care as part of the Right to Health. Chapter Two explores the literature describing the key components of the study: the Right to Health, palliative care as a human right and the common foundation of human rights and palliative care, that is: promoting human dignity. Additional literature supporting the separate studies is discussed at the start of each of Chapters 3-6.

## CHAPTER TWO: LITERATURE REVIEW: PALLIATIVE CARE AS A HUMAN RIGHT

The literature reviewed for this thesis is presented in two ways: 1) Chapter Two addresses the key concepts of the Right to Health, palliative care as a human right and human rights in the South African context; and 2) literature specific to each of the nested studies is described in the introduction to each of the respective chapters.

### 2.1 Literature search

Literature searches were conducted during the time of research proposal development, data collection and write-up of the thesis. The literature search used MEDLINE databases through Pubmed and Ovid and Google Scholar. Key words guided the literature search of databases and Google Scholar. Specific articles identified from references of journal articles found during the literature search were also specifically searched for through Google Scholar. Supervisors and colleagues also sent relevant articles of interest to add to the bibliography. Key words Chapter Two: 'palliative care' 'palliative medicine' AND 'Human Rights'; 'health\*' AND 'Human Rights' 'dignity'; Chapter Three: 'health needs' AND 'assessment'; 'public health' AND 'palliative care'; 'symptom burden' AND 'cardiac failure' OR 'cancer' OR 'HIV' OR 'renal failure'; Chapter Four: 'palliative care' AND 'hospice' OR 'hospital'; 'palliative care' AND 'training'; Chapter Five: 'palliative care' AND 'models of care'; 'palliative care' AND 'funding'; 'palliative care' AND 'cancer' OR 'HIV' OR 'motor neuron/e disease' OR 'ALS'; Chapter Six: 'evaluating quality' AND 'medical care', 'palliative care'; 'quality of life' 'outcome measures' 'patient-centred/centered'.

### 2.2 Human rights and public health

There is a large body of literature describing human rights and health. This chapter provides only a brief overview of the discipline for readers not familiar with this background. It explains the meaning of the Right to Health and how the field of health and human rights has developed. It also discusses how a human rights approach is complementary to a public health approach in establishing palliative care as part of the health system.

The International Covenant on Economic, Social and Cultural Rights (1966) Article 12 states that:

*"The States Parties to the present Covenant recognize the right of everyone to the enjoyment of*



*the highest attainable standard of physical and mental health”* (10) (Article 12). This right is referred to as the Right to Health; this does not mean the right to be equally healthy but the right to the opportunities and services that enable an individual to have as high a standard of health as possible; and to a system of health protection by the state. General Comment 14(1), issued by the Committee that oversees the ICESCR, recognises biological differences between individuals and the impact these have on the attainable standard of health of an individual. However, an individual should still be afforded the opportunity to reach the highest attainable standard of health given biological pre-conditions. Hunt and Backman describe the right to the highest attainable standard of health as a fundamental human right underpinned by *“moral values and reinforced by legal obligations”*(46:90).

The interest in the field of health and human rights grew from the work of Jonathan Mann and colleagues in the early 1990s, considering the rights of people living with HIV(47). Mann suggested that a human rights approach improves the public health response to societal issues impacting on community health and that *“promoting and protecting health .... depends on the promotion and protection of human rights and dignity”*(48:1940). He described how the WHO has moved the concept of health from a biomedical perspective addressing disease to a concept of well-being involving socio-economic factors essential to realise well-being. He proposed that improving well-being becomes possible through linking health and human rights in the following ways - health policies and practices impact on human rights; violations of human rights impact on health; and promotion and protection of human rights are linked with the promotion and protection of health (47). In describing the work of Mann and his colleagues, London states that *“the promotion of human rights and the practice of public health are complementary and indivisible”* in improving health and wellbeing of individuals (49:678). In a review of health and human rights literature over the decade 1999-2008, Mpinga and colleagues identified that the topics most frequently covered were those describing health systems, mental health, HIV/AIDS and reproductive health (50).

Tarantola and Gruskin document the importance of the AIDS pandemic in bringing the disciplines of human rights and public health together under the leadership of Jonathan Mann; firstly with concerns about human rights violations driving people away from health care, and secondly the

need for protection of human rights to develop health policies to benefit people living with HIV(51). The authors give a clear description of the importance of human rights in the development of health policy. They identify that health is important for development and describe governments' obligations to respect, protect and fulfil human rights. They argue that Civil and Political Rights as well as Economic, Social and Cultural Rights impact on the Right to Health and that these rights are inter-related. Poor health and well-being lessen a person's ability to enjoy rights.

General Comment 14 describes the requirements of government to enable the population to achieve optimal health, in terms of availability, accessibility, acceptability and quality. The declaration of Alma Ata states that *"health, which is a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right"* (52)(para 1), and describes the aspiration for all people to achieve this through the Primary Health Care approach(53). This approach includes education and attention to social determinants of health. The Right to Health includes a number of socio-economic factors *"such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment"* (1)(para 4). General Comment 14 explains that *"the Right to Health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health"*(1) (para 9).

In implementing the Right to Health in government policies, it is recognized that governments face constraints in being able to fulfil the Right to Health immediately, and should work towards fulfilling this right through the process of progressive realisation of the Right to Health, reporting on the steps taken towards the realisation of this right. The ICESCR indicates, nonetheless, that there are core obligations related to the Right to Health that should be implemented immediately(1).

A number of authors identify that all rights are inter-related (13,53,54). The inadequate access to health care for poor people in many countries of the world is described as a violation of human rights. Gruskin and colleagues(54) describe that in relation to health, human rights are important

for advocacy, legal standards and development of programmes and services. This has been clearly illustrated in the work of the South African Treatment Action Campaign. Heywood describes how the activist group used a human rights framework, advocacy strategies and the South African legal system to influence government to develop appropriate policies for HIV care; and how civil society was influential in ensuring the affordability of anti-retroviral treatment (ART) engaging also with legal process to improve access to ART in South Africa(29).

London explores concerns that public health policy can unintentionally violate individual human rights in the interests of public good. A human rights framework can advise checks and balances to be considered during policy development to promote both public health and human rights, especially in the context of resource constraints. In the context of global health and global health inequalities, a human rights approach can link local policy challenges to issues of global injustice, calling for intervention at international levels(56). Gostin and Mann proposed a human rights framework to guide officials and policy makers in the development of policies(57). Considering whether the policy enhances “good public health” and whether it does respect, protect and fulfil human rights are the initial steps. Is there a balance between promotion of human rights and protection of public health? Once these issues have been considered, explicit provisions in the policy can be assessed as to whether it is the optimal approach to the problem(57). London identifies this approach as an opportunity to bring synergy between human rights and public health policy making(49). This may be of particular importance in the face of resource constraints. Community agency is important in the realisation of the Right to Health(17,58). London also emphasises that social mobilisation is important to promote community agency in holding governments accountable in the realisation of human rights in health(17). Freidman and Gostin describe the importance of community engagement and understanding the Right to Health to empower communities and individuals to claim health rights(58). In an investigation of using human rights approaches in community settings, London demonstrated that, when coupled with community engagement, human rights strengthen community engagement and agency and promote equity. He describes how an informed, empowered community group can use human rights and the law to improve equity and reduce differences in health outcomes(59). The next section therefore explores in more detail how human rights promote equity in health care.

### 2.3 Equity in healthcare

Equity in health is described by a number of authors as an ethical principle of social justice to eliminate health system disparities that discriminate against poor or marginalised populations (46,57,59). The highest attainable standard of health as evidenced by more advantaged members of society should be the goal to be achieved for the less privileged in our communities. The definition proposed by Braveman and Gruskin is that health equity is *“the absence of disparities in health”* between social groups that are advantaged or disadvantaged(60:256). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) highlight the imperative to provide equitable and accessible services to people with disabilities. There is no mention of palliative care in this convention. (61) Similarly, although the Convention on the Rights of the Child describe *“the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health”*; palliative care is not included in this Convention(62:7).

Hunt and Backman affirm that equality and non-discrimination are fundamental elements of human rights and endorse the definition of equity in health care as *“equal access to health care according to need”*(46:83). They highlight the fact that Hunt, as UN Special Rapporteur on Health, constantly considers the impact of poverty on discrimination in healthcare, and that both medical care and public health are important to the realization of the highest standard of health(46). The WHO report on Poverty Reduction Strategies states that *“States have an obligation to prohibit discrimination and ensure equality to all in relation to access to health care and the underlying determinants of health”*(63:9).

Meier acknowledges that General Comment 14 has done a great deal to explain the Right to Health, but it has not gone far enough in obligating states to protect communities nor to improve determinants of health through public health systems(64). He also criticises General Comment 14, stating that the recommendations in General Comment 14 continue *“to advance individual medical/technological solutions to problems requiring societal reforms”*(64:550). General Comment 14 links individual and public health through access to health services and access to

information. In order to combat worsening health inequities brought about by globalisation, it is necessary to include health promotion and disease prevention as collective rights within the Right to Health. Meier proposes that harmony between individual and collective health rights will improve both, and that in a globalised world the requirement for the collective Right to Health through public health will result in realisation of individuals' rights to health (64).

A number of authors have commented on the importance of using a human rights approach to assess progress in realising the Right to Health, and to hold governments accountable in meeting human rights obligations(13,49,57). Backman and colleagues developed a set of 172 indicators to measure implementation of the Right to Health, and describe that indicators are important to measure progressive realisation of the Right to Health(13). London uses a framework to analyse policy to assess integration of public health and human rights(49). The development of indicators for palliative care would be a useful tool to assess a country's progress towards integration of palliative care into the health system.

#### 2.4 Palliative care as a human right

Brennan explores the legal foundation of the right to palliative care, and while he concludes that there is no "express right to palliative care" in the International Bill of Rights, he proposes that a right to palliative care follows from the Right to Health(65). He identifies that General Comment 14 describes palliative care as part of the Right to Health, and describes efforts to ensure that this right is recognised and enacted. Brennan traces the growing advocacy efforts for palliative care to be recognised as an international human right, citing political voices from Canada(66), Pope Benedict XVI(67), and from the European School of Oncology(68), anaesthetics, the International Association for the Study of Pain (69), as well as the World Health Organisation, for the establishment of minimum standards for pain relief and palliative care. He also describes the calls from the international palliative care community for governments to recognise palliative care as a human right(7,70-72). In establishing World Hospice Palliative Care Day as a day to create awareness around palliative care, Prail wrote to express the view that hospice care is a human right(73).

Table 2.1: Timeline of international recognition of palliative care as a human right

Organisation/body/individual	Year	Document	Nature of document
Somerville (66)	1992	Human Rights & medicine: the relief of suffering	Academic article
EAPC*	1995	The Barcelona Declaration on Palliative Care	Advocacy statement
General Comment 14 (1)	2000	The Right to the Highest Attainable Standard of Health	Soft law document
Senate of Canada (74)	2000	Quality end of life care: the right of every Canadian	Advocacy statement
Mpanga-Sebuyira et al. (70)	2003	The Cape Town Declaration	Academic article
WHO & IASP**	2004	Global Day against Pain	Advocacy statement
Ahmedzai et al. (68)	2004	A new international framework for palliative care	Academic article
Cousins et al. (69)	2004	Pain relief: a universal human right	Academic article
Global Summit of hospice associations	2005	Korea Declaration***	Advocacy statement
Prail (73)	2005	Hospice care is a human right	Advocacy statement
Pope Benedict XVI (67)	2006	Message for the Fifteenth World Day of the Sick	Statement from the Pope
Brennan (75)	2007	Palliative Care as an international human right	Academic article
Radbruch et al. (71)	2007	The Budapest Commitments	Advocacy statement
Gwyther et al. (76)	2009	Advancing Palliative care as a human right	Academic article
Radbruch et al. (72)	2013	The Lisbon Challenge	Advocacy statement
Radbruch et al. (7)	2013	The Prague Charter	Advocacy statement
World Health Assembly (3)	2014	Strengthening of palliative care as a component of comprehensive care throughout the life course	WHA resolution

\*European Association of Palliative care <https://www.eapcnet.eu/events/previous-eapc-events/report-4th-congress-of-the-eapc-barcelona-spain-december-1995>

\*\*International Association for the Study of Pain  
<http://www.iasppain.org/GlobalYear/RighttoPainRelief>

\*\*\* <https://hospicecare.com/newsletter2005/apr05/global.html>

In his publication *“Palliative Care as an International Human Right”*, Brennan explores the international covenants that are the foundation of the Right to Health, and identifies arguments for palliative care within these documents(65). Following this publication, three international organisations, the European Association of Palliative Care (EAPC), the International Association for Hospice and Palliative Care (IAHPC) and the Worldwide Palliative Care Alliance (WPCA), developed papers as advocacy tools to influence governments to include palliative care in state health systems(7,71,72).

Brennan and colleagues describe pain management as a human right, describing the moral, ethical and legal obligations to improve pain management(75). This discussion developed from the International Association for the Study of Pain and WHO 2004 Global Day against Pain. The article explores the reasons behind inadequate pain assessment and management - this in the face of sophisticated knowledge of pain physiology and effective pain management approaches, including national and institutional guidelines for pain management. The authors describe cultural, medical, political and legal barriers to implementing effective pain management, not least of which are over-zealous regulations to prevent diversion of opioids for illegal drug use. They also describe *“medical and lay opiophobia and opioignorance”* (75:page 209), citing inadequate training of medical practitioners and poor understanding of the use of opioids by both doctors and patients as resulting in restricted use of opioids and poor pain control(75). The International Narcotics Control Board has attempted to improve this situation through the publication *“Ensuring balance in national policies on controlled substances”*(76). However, this has not yet achieved acceptable change in opioid use for pain relief as reported by The Lancet Commission on Global Access to Pain Control and Palliative Care (9). Brennan and colleagues also cite Margaret Somerville’s statement that inadequate pain management constitutes medical negligence(75). They explain that General Comment 14, describing core obligations of States to provide access to essential medicines as defined by the World Health Organisation, can be interpreted in consideration of pain management to include access to essential pain medication. Brennan and colleagues claim that there is an ethical duty for doctors to provide pain

management to ensure pain control. They state that failure to do so *“is arguably negligent, a breach of human rights, and professional misconduct”*(75:217).

Gwyther and colleagues review the work done to promote palliative care as a human right, and explore opportunities to advocate nationally and internationally for improved palliative care (77). The authors propose using the human rights discourse in discussion with governments to integrate palliative care into country health systems. They document statements made by the Special Rapporteurs on Health and on Torture that assist in establishing palliative care and pain management as part of the Right to Health that should be recognised by governments and included in health care. They describe how this could be achieved based on the World Health Organisation Public Health Strategy to implement palliative care(77).

The international palliative care community calls (described above and in Table 2.1) on governments to ensure access to palliative care and pain relief, and to recognise their obligation to deliver on the right to palliative care, gained attention and support through key statements by two Special Rapporteurs (5,6). This followed increased advocacy efforts, with the establishment of the Worldwide Hospice Palliative Care Alliance in 2005, and active engagement initially with the Special Rapporteur on the Right to Health.

Special Rapporteurs are independent human rights experts appointed by the UN Human Rights Council (HRC) to promote and protect human rights and to investigate and report on specific areas, investigating complaints or undertaking ‘fact-finding’ visits(54). Both the Special Rapporteur on the Right to Health and the Special Rapporteur on Torture, and other Cruel, Inhuman and Degrading Treatment have issued statements and/or reports that include palliative care in their analyses, and so have solidified palliative care in official Human Rights discourse at the United Nations.

In 2008, Paul Hunt, then the United Nations Special Rapporteur on the Right to Health, advised the Human Rights Council that more attention should be to afforded palliative care to address the global suffering and undertreated pain(5).



In addition, in 2010, the Special Rapporteur on the Right to Health (Paul Hunt) and the Special Rapporteur on Torture, Cruel, Inhuman and Degrading Treatment (Manfred Nowak) made a joint statement identifying the need for access to controlled medicines to relieve pain and suffering to fulfil the right to health and to protect against cruel, inhuman and degrading treatment (78). *Lack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully* (78).

In 2013, the United Nations Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E. Méndez, presented a report to the UN on torture in health care(6). He identified denial of pain relief as being tantamount to torture. He recognised that *“generally, denial of pain treatment involves acts of omission rather than commission, and results from neglect and poor Government policies, rather than from an intention to inflict suffering”* (6) (para 54) He calls upon all States *“to ensure full access to palliative care and overcome current regulatory, educational and attitudinal obstacles that restrict availability to essential palliative care medications, especially oral morphine”* (6) (para 86b); and to *“develop and integrate palliative care into the public health system by including it in all national health plans and policies, curricula and training programmes and developing the necessary standards, guidelines and clinical protocols”*(6) (para 86c).

These statements from the Special Rapporteurs in the modern era of health care and palliative care development are important, as they help to embed palliative care as a human right in discourse at the global level.

The call on governments by the international palliative care community to recognise the right to palliative care led to the adoption in May 2014 by the World Health Assembly of Resolution WHA67.19: *“Strengthening of palliative care as a component of comprehensive care throughout the life course”*(3). The recommendations to governments included in the WHA resolution are summarised in Table 2.2 below (3). The adoption by the World Health Assembly of the resolution, and considerations of how to implement the resolution including considerations of funding palliative care integration, is seen to be an important step in improving access to palliative care for people worldwide, consistent with the international understanding of palliative care as part

of the Right to Health. Notably, a collection of African countries working together supported the WHA resolution(79) on integration of palliative care into country health systems. South Africa, as a member of the WHO Executive Board, was one of a group of 10 countries, including both LMIC and HICs promoting this resolution.

Table 2.2: Summary of WHA resolution 67.19 recommendations to governments (3)

<p>WHA resolution 67.19</p> <p>“Urges member states:</p> <ol style="list-style-type: none"><li>1) <i>to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems,</i></li><li>2) <i>to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives,</i></li><li>3) <i>to provide basic support to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals</i></li><li>4) <i>to aim to include palliative care as an integral component of the on-going education and training offered to care providers in accordance with their roles and responsibilities</i><ol style="list-style-type: none"><li>a) <i>basic training in undergraduate medical and nursing professional education, and in service training at primary health level</i></li><li>b) <i>intermediate training offered to all health care workers who routinely work with patients with life-threatening illnesses</i></li><li>c) <i>specialist palliative care training</i></li></ol></li><li>5) <i>to assess domestic palliative care needs, including pain management medication requirements</i></li><li>6) <i>to review, and, where appropriate, revise national and local legislation and policies for controlled medicines</i></li><li>7) <i>to update, as appropriate, national essential medicines lists</i></li><li>8) <i>to foster partnerships between governments and civil society, including patients’ organizations, to support, as appropriate, the provision of services for patients requiring palliative care</i></li><li>9) <i>to implement and monitor palliative care actions included in WHO’s global action plan for the prevention and control of non-communicable diseases 2013–2020”</i></li></ol>
---

The concept of the highest attainable standard of health described in the ICESCR is echoed in the goal of palliative care as the best possible quality of life for people facing the problems associated

with life-threatening illness. General Comment 14 includes palliative care as part of the Right to Health in Section 34 which describes state obligations as follows: “States are under the obligation to respect the Right to Health by, *inter alia*, refraining from denying or limiting equal access for all persons... to preventive, curative and **palliative** health services”(1) (para 34). In addition, in the section on older persons (Section 25), General Comment 14 includes the obligation for provision of “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity” (1) (para 25). Thus, palliative care is established through General Comment 14 as part of the Right to Health as described earlier(1).

## 2.5 Health care professionals as duty bearers

By framing palliative care as a human right and using human rights language to describe access to palliative care, palliative care is identified as an entitlement and not a privilege; and governments have obligations to ensure access to palliative care(77). Thus, vulnerable patients facing life-threatening illness are rights-holders and the state is the duty bearer and has a duty to ensure the patient has access to quality palliative care, requiring policies and strategies to realise this right, including providing sufficient services of reasonable quality, coupled with access to training in palliative care for health care workers(3). The health care professional is a duty bearer in the context of ensuring that the right is realised (17) and thus, has a duty to ensure the patient has access to quality palliative care. This therefore requires that health care professionals are trained in palliative care, and have the competence to provide quality palliative care and access to palliative care providers for patient referral if necessary.

Furthermore, Gruskin, Mills and Tarantola have provided a powerful argument related to the principles and practice of health and human rights, including the role of the health professional in the promotion of human rights in healthcare(55). They emphasise the importance of training health care workers on human rights and how to incorporate human rights into the work they do.

A human rights approach defines state obligations to respect, protect and fulfil these rights. It is important to explore what the obligation means and who has the duty to implement the rights.

London further describes the role of the health care professional as a duty bearer and describes the responsibilities as a duty bearer not to become an instrument by which states violate these rights; to ensure non-discrimination; and to consider fulfilling these rights as part of professional conduct(17). London also comments on the fact that human rights strengthen health professions' ethical codes, and guide professional bodies in developing regulation for the health professions. This should include a process through which health professions can access support from the professional body if they are concerned about human rights violations(17). Health professionals can provide information on health rights that empower communities in their engagement with development and implementation of health policies(17).

## 2.6 The African Charter on Human and People's Rights

Health is also addressed in the African Charter on Human and People's Rights Article 16 of the African Charter describes the *"right to enjoy the best attainable state of physical and mental health"* (Article 16,1) and binds State Parties to *"take the necessary measures to protect the health of their people and to ensure they receive medical attention when they are sick"* (80) (Article 16.2). Hassim points out that the African Charter does not stipulate progressive realisation or resource constraints, but intimates that the State Parties have an immediate obligation to fulfil the right(81). Motari and Kirigia (80) conducted a survey of the *"Realization of the Right to Health in the WHO African region"*, and report that, while there is commitment to realising the Right to Health by African countries, there remains a great deal that needs to be done to achieve this, including appropriate legislation and policies and adequate budget for healthcare(77). Palliative care was not included as part of the survey document.

## 2.7 The Right to Health in South Africa

South Africa's strong constitution guarantees the Right to Health and mirrors many of the provisions of the ICESCR(11). Section 27 of the Constitution of the Republic of South Africa, Act, No. 108 of 1996 describes access to health care, food, water and social security (Section 27):

*"1. Everyone has the right to have access to*

*a. health care services, including reproductive health care;*

- b. *sufficient food and water; and*
  - c. *social security, including, if they are unable to support themselves and their dependents, appropriate social assistance.*
2. *The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.”*

This raises the question of how to prioritise the South African population’s socio-economic needs in working towards the realisation of the rights articulated in the South African Constitution and the ICESCR, and how to determine the distribution of available resources to realise these rights. In order to realise the right to palliative care as part of the Right to Health, it is important to establish the size of the need for palliative care in South Africa. Chapter Three of this thesis undertakes a needs assessment for palliative care in South Africa.

Both Section 26 (Housing) and Section 27 (Health care, food, water and social security) of the South African Constitution include provisions for progressive realisation of these rights, consistent with the ICESCR(11). However, South African courts, while upholding the concept of progressive realisation, have ruled that health care should be provided according to what is considered “reasonable” in the light of current resource constraints, rather than committing to immediate realisation of core obligations(81). At the national level, South Africa has demonstrated through the Constitution an understanding and recognition of human rights, and the importance of economic, social and cultural rights. The South African government has committed to improving healthcare with regard to both access and quality, to redress the inequities in access to and provision of healthcare of the apartheid era. Ngwena comments on the importance of Section 27 of the Constitution that strives to ensure equality in provision of health care to reduce the impact of social disadvantages with regard to access to health care(83). He describes the challenges of the ‘*disproportionate burden of disease*’ (83:36) and the socio-economic problems with high levels of poverty and unemployment, which impact on ‘*a meaningful realization of the right to health care*’ (83:38).

A number of publications comment on the importance of the Right to Health being recognised in national law(13,46,84,85). Singh and colleagues write with concern that many countries fail to

uphold the Right to Health, but describe that South Africa, with the Right to Health included in the Constitution, has undertaken health reforms in response to both the ICESCR and the constitution(84). The authors describe court cases where the South African Constitutional Court ruled on health matters, citing the government's constitutional obligations as examples of implementing the Right to Health(84). Chinkin explains the international human rights covenants, saying that *"What is important about these instruments is they are international treaties creating legally binding obligations, making clear that the right to the highest attainable standard of physical and mental health is now well entrenched within the canon of international human rights law"*(85:52). She describes how international human rights law sets standards for countries to use in their development of laws and policies requiring them to be non-discriminatory. She expresses concerns, similar to those described by Singh (84) above, that the Right to Health is seen as not justiciable and not enforceable. However, she provides the example of South Africa, where the Right to Health is included in the South African Constitution and has been tested in the South African Constitutional Court(85). Forman also comments that economic, social and cultural rights have previously been perceived as non-justiciable, but she describes that South Africa has led the development of jurisprudence with regard to the ICESCR (86). Among the cases described by Forman are three relating to health care: 1) the Soobramoney case of being denied dialysis on the grounds of limited resources; 2) the ruling that the Minister of Health should ensure access to Nevirapine to prevent transmission of HIV to babies of HIV positive mothers; and 3) the single exit price relating to *"the right to access affordable medicines."* Berger's assessment of the Soobramoney case was that in applying the concept of reasonableness, the state cannot supply everything to everybody at once (81), and that the Constitutional Court accepted the state's claim of limited resources. Thus, the Right to Health is guaranteed in the South African constitution, but there are limits to this right. London writes that *"Jurisprudence on this case remains an important national and global precedent for thinking about how to realize the Right to Health"*(17:78).

Ngwena celebrates that South Africa has an understanding of the holistic nature of human rights, and demonstrates this in the South African Bill of Rights. He notes that section 27 of the South African Constitution affirms the meeting of civil and political rights with socioeconomic rights(83).

He denounces the inequality of health expenditure on the white population during apartheid, and welcomes section 27 and the intent to ensure equality in health expenditure, conferring on the people of South Africa the right to access healthcare. However, he also has some criticism of section 27, calling it a '*paper lion*', in that it is inexact and does not define health care services that should be provided by the state, and allows for progressive realisation of access to healthcare. He does acknowledge section 27 as realistic, requiring the state to meet basic needs and to prioritise primary health care and care to vulnerable people(83).

Ngwena describes that the Constitutional Court has the authority to rule on matters of policy and budget allocations. However, access to healthcare is not only dependent on the Constitutional Court but also on health policies, burden of disease and poverty which are the main constraints affecting universal access to health care services (83). He highlights the importance of addressing issues of poverty to improve general standard of living, in order to ensure realisation of socio-economic rights, including access to health care.

In South Africa, anti-apartheid activists used human rights concepts as part of efforts to challenge and defeat the apartheid system. Thus, the South Africa population is very conscious of human rights, and there are strong community initiatives to protest violations of human rights and to demand realisation of socio-economic rights, such as access to basic services. London warns of the risk of expressing "*health policy decisions as service delivery issues*", as this would negate the power of the Right to Health as expressed in the international human rights instruments(17:71). Himonga debates the cultural legitimacy of Human Rights in respect of individual rights being a western concept, and the importance of community in African culture(85). She describes the concept of Ubuntu as conferring cultural legitimacy on the concept of human rights. The African Charter of Human and People's Rights balances individual rights with individual duties, recognizing an individual's responsibilities towards the community. Himonga considers that the state's protection of individual rights to health care may result in the protection of community rights in respect of access to health care, but that the prime responsibility of the state is to the individual (87).

## 2.8 Health inequities in South Africa

South Africa has a particular and shameful history of health inequities, and these inequities have not been redressed, despite efforts to improve health care in the public sector during the years since the election of a democratic government in 1994. Under apartheid, the unequal allocation of health resources according to race resulted in the majority of South African people being denied access to adequate health care (88). Ngwenya describes that South Africa has the worst income differentials in the world and that reforms to the South African economy and health system are challenged by historical context, poverty and income disparities (83).

In its preamble, the South African National Health Act (2004) recognises *“the socio-economic injustices, imbalances and inequities of health services of the past; the need to heal the divisions of the past and to establish a society based on democratic values, social justice and fundamental human rights; and the need to improve the quality of life of all citizens and to free the potential of each person”*(89). The Objects of the Act include *“to regulate national health and to provide uniformity in respect of health services across the nation by protecting, respecting, promoting and fulfilling the rights of (i) the people of South Africa to the progressive realisation of the constitutional right of access to health care services ...”* (89) (para 2).

Matsoso and colleagues describe the current development of key policies and initiatives, such as the Re-engineering of Primary Health Care(90) and the implementation of a National Health Insurance (91) scheme, as important steps in improving quality of health care, access to health care and equity in health care in South Africa (92).

One of the essential elements to ensure access to health care is adequate financing. Dr. Yogan Pillay of the South African Department of Health makes the point, in his message guide on the South Africa National Health Insurance, that South Africa spends more than the WHO recommended health spend of at least 5% of GDP, but less than the Abuja Declaration of 15% of government spending on health(93). However, the SA health spend is skewed, in that 5% of the 8.5% GDP spend on health (in 2010) was spent on 16% of the population who are on medical aid schemes with 3.5% of GDP spent on 84% of the population the 42 million people without medical



aid cover)(91). Health outcomes in South Africa are still poor. However, efforts to improve primary health care and to implement the NHI have a goal to improve health outcomes(91).

## 2.9 Universal Health Coverage

The Global Goal of Universal Health Coverage (UHC) is based on Human Rights Law, in particular the Right to Health. The WHO defines UHC as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship. Ooms and colleagues evaluate the WHO statement that UHC is “*a practical expression of the concern for health equity and the Right to Health*” (94:2). The authors discuss global health inequalities, and the fact that within countries health equity may be a goal, but that global equity requires international financial assistance from wealthy countries to poorer countries. They agree that UHC is a practical expression of the Right to Health. Sachs describes the disparities in health outcomes between higher and lower socio-economic communities and countries, and the recognition that poor health in one sector of a community affects all sectors; similarly the health outcomes in poor countries also affect richer countries, hence an added stimulus to improve health outcomes globally (95). UHC goes beyond improving physical access to health care. Economic access has an equal weighting with the language of UHC.

Kieny and Evans describe the “*aspiration that all people obtain the health services they need without suffering financial hardship*”, and the importance of a strong health system with all this entails, and adequate health financing (96:305). Authors writing on UHC agree that it covers promotive, preventative, curative, rehabilitative and palliative health services (95,96). In South Africa, UHC is intended to be achieved through the National Health Insurance initiative. The NHI White paper published on 10<sup>th</sup> December, 2015 includes palliative care as an essential service in the primary health care setting (91).

## 2.10 The South African situation with reference to palliative care policies

The SA Patients’ Rights Charter (97) was developed in 1999 as “*a common standard for achieving the realisation of the right*” to access to health care services. The Patients’ Rights Charter includes

access to health care as a Patient Right and includes access to palliative care. It states that: *“Everyone has the right of access to health care services that include: ... iii. provision for special needs in the case of ... patients in pain, persons living with HIV or AIDS patients; ... v. palliative care that is affordable and effective in cases of incurable or terminal illness”*(97)(para 4).

In a critique of the SA Patients’ Rights Charter, London reflects that it is less about rights than about delivery of health services, and makes the recommendation that a Patients’ Rights Charter should be developed by representatives of users and providers, rather than being imposed by the state (98).

There are important health care issues to address in South Africa that overshadow the issue of provision of palliative care. The Re-engineering of Primary Health Care has a strong focus on preventative health and support for people living with chronic illness to maintain stable health, and will be implemented through the deployment of Ward-Based Primary Health Care Outreach Teams. However, there is a gap in the current discussion documents and policies addressing health care in South Africa. The discussions assume that improved primary health care and improved access to health care will ensure that all South Africans will enjoy good health or, at the very least, have stable chronic illness. Originally, the Re-engineering of Primary Health Care documents did not plan care for people who have progressive illness nor for care of people at the end of life. Palliative care advocates were concerned that the result of this silence on progressive illness and end of life care means that patients will be abandoned by the health care system at a time when they most require care. The inclusion of palliative care in the NHI White paper and the approval of a National Policy Framework for Palliative Care addresses these concerns, and are encouraging signs of the intent to include palliative care in the South African health system. The National Health Insurance white paper states that: *“All South Africans will have access to needed promotive, preventive, curative, rehabilitative and palliative health services that are of sufficient quality and are affordable without exposing them to financial hardships”*(91) (para 30a).

In South Africa, there are pressing priorities in health care, including those addressing other sustainable development goals (SGDs) – reducing poverty and improving education and gender

equality are socioeconomic issues that impact on health. The post-2015 Sustainable Development Goals have retained the aim to reduce child mortality, improve maternal health, combat HIV and AIDS, malaria, non-communicable and other diseases, and pursue Universal Health Coverage. Palliative care is a defining component of UHC, and therefore universal access to palliative care is necessary to meet the SDGs (4). Framing palliative care as a human right means that prioritisation, or rationing decisions, must be consistent with protection of the most vulnerable, in a transparent way, based on evidence.

Thus, Palliative Care is described as a part of UHC, and the Worldwide Hospice Palliative Care Alliance Position Paper on Palliative care and UHC affirms that *“palliative care is a needed and essential health care service and a fundamental component of UHC”*, and proposes that *“(c)ountry level action plans on progress towards UHC should include actions towards ensuring palliative care is available, accessible and used by all those that need it. Monitoring of UHC should include a tracer indicator on palliative care, as well as recommending a more comprehensive set of palliative care indicators to be developed, adapted and utilised at the national level”* (99;5).

Stjernswärd and colleagues identified that four pillars are required for the integration of palliative care into a country's health system. These are: 1) a national Policy; 2) education of health care workers, policy makers and the public with regard to palliative care; 3) drug availability; and 4) implementation (100). Concrete steps to develop a National Policy Framework and Strategy for Palliative Care (NPFSPC) in South Africa were implemented in May 2016, when the Minister of Health, Dr Aaron Motsoaledi, established a Steering Committee for Palliative Care to develop and recommend implementation activities for a South African Palliative Care Policy. The Steering Committee has identified seven task teams to conduct the work of the Committee. These are task teams on Policy, Ethics, Education and Training, Medicine Availability, Access for Vulnerable Groups, Support for Families and Careworkers, and Funding.

The South African government has not documented the adequacy of provision of palliative care and of pain management in the country, and thus there is a requirement for an assessment of palliative care provision and palliative care need.

### 2.11 A human rights approach and palliative care

London writes of three principles underpinning a human rights approach to health (17). These are: 1) taking into consideration that civil and political rights and socio-economic rights are inter-dependent, and that governments should develop policies to realise the Right to Health; 2) the importance of an active civil society; and 3) state accountability.

Tarantola and Gruskin also use three aspects to explain the interaction between human rights and public health: 1) the national and international context of health policy and policies affecting health; 2) assessing the outcome and impact of health policies and human rights; and 3) the process of policy-making including community participation in policy-making (51). In describing the importance of an active civil society to ensure the realisation of socio-economic rights, London makes it clear that governments are responsible for these obligations and should not rely on NGOs or community action to fulfil the obligation (17).

A human rights approach provides standards to measure implementation of the Right to Health, and assists in identifying the rights holder and the duty bearer, as well as the state obligation to respect, protect and fulfil the Right to Health.

London argues that agency is critical to a human rights approach to influencing health policy development (17), and that rights *“need to be coupled with community engagement”* to be effective (98:55). The challenge for palliative care advocacy is that the community requiring palliative care often does not have the capacity – physical or emotional capacity – to advocate for better care. Unlike the case for other conditions, patients requiring palliative care are often too sick or frail, and family members emotionally exhausted as carers to have a strong voice to demand better care.

Two powerful advocates for better end of life care articulate this problem: Hinton, 1967: *“We emerge deserving of little credit; we who are capable of ignoring the conditions that make mute people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced”* (101:159); and Chochinov, addressing the Canadian Senate in 2000: *“Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak”* (74).

A further consideration is that people avoid considering their own mortality and choices of end-of-life care, especially while they are enjoying good health, so there have been few advocacy efforts by people outside palliative care workers.

There are, nonetheless, some strong patient and family member advocates for palliative care who are helping to grow awareness of the need and benefits of this care. The advocacy efforts to expand access to palliative care by health care practitioners and palliative care supporters have been key to successes in the development of palliative care to date. The Hospice Palliative Care Association of South Africa (HPCA) is an umbrella body established in 1987 to share best practice amongst hospices in South Africa, to provide guidance and support to member organisations to improve accessibility and availability of palliative care, and to monitor quality of care (102). HPCA has played a strong role in promoting access to palliative care in South Africa and provide a voice at the national level for hospice organisations, to ensure that they have the resources to provide palliative care to people requiring this care (103).

There is a particular challenge in addressing the advocacy of an unpopular or ignored topic, when the agency of the vulnerable group has been diminished by their illness. The National Strategic Plan on HIV (NSP), for example, refers frequently to the importance of comprehensive care and support, but there are no indicators to report on care and support, nor on pain management. Without a requirement to report on these interventions they are likely to be neglected (104).

The question “Is access to palliative care a Human Right?” may therefore seem to demand a positive response, but without a ‘vocal constituency’ or community engagement, can patients with advanced illness realise this right? Do we lose the Right to Health when illness progresses and becomes incurable?

Hunt explores the development of the rights-based approach to health, and recommends that the Right to Health is held as the central consideration to this approach, drawing on international human rights law to uphold state accountability in realising the Right to Health (105). General Comment 14 describes health as “*a fundamental human right indispensable for the exercise of other human rights*” (1) (para 1). The preamble to the UDHR recognises “*the inherent dignity and of the equal and inalienable rights of all members of the human family*”(14). The next section

explores the consideration that human dignity has been identified as a foundation principle for both palliative care and human rights.

## 2.12 Human dignity: a common foundation of Human Rights and Palliative Care

General Comment 14 describes the Right to Health as a fundamental Human Right and affirms that *“Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity”*(1). Mann speaks of the discipline of human rights and of public health as approaches to ‘ameliorate suffering’(106). This resonates with the goal of palliative care – an approach to relieve suffering and to improve quality of life in the face of life-threatening illness (30).

Brennan describes that both palliative care and human rights are based on principles of the dignity of the individual, and the principles of universality and non-discrimination, which inform a common goal of both medicine and human rights to relieve suffering (107). Earlier in this chapter, Mann’s comment that *“promoting and protecting health ....depends on the promotion and protection of human rights and dignity”* was cited (48:113).

Dignity is identified as a key concept in International Human Rights Law documents. For example, the first clause of the preamble to the UNDHR states that the: *“... recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world”* (12) (preamble). This statement illustrates an understanding that universal human rights are derived from the inherent dignity of all persons and that, because everyone has inherent dignity, they have the right to be respected and have their dignity protected. In her article examining the concept of dignity, Jacobson argued that Mann described dignity as a link that explains the relationship between the promotion and protection of human rights and health status(108). Human rights law has been described as *“the law of human dignity”*, and Jacobson reports that during the drafting of the UDHR, dignity was a theme running throughout the discussions and debates (108).

Somerville argues that there is a “common thread linking respect for persons” with “respect for their human rights, medicine, ethics and law”, and she speaks about respect for the dignity of the individual: *“to leave patients in avoidable pain and suffering should be regarded as a serious*

*breach of fundamental human rights... and a grave affront to respect for persons and their dignity ...” (66:205)*

In considering claims that human rights are a western concept and thus not applicable to Africa, Himonga explores individual and community ways to use Ubuntu for the realisation of Right to Health, describing the concept of Ubuntu as conferring cultural legitimacy on human rights from an African perspective (87). In explaining Ubuntu as an open, flexible concept, Himonga quotes Justice Mkgoro who describes Ubuntu as “group solidarity” with “*key values of group solidarity, compassion, respect, human dignity, conformity to basic norms and collective unity. Its spirit emphasizes respect for human dignity*” (87:177). Justice Mkgoro elaborates further that “*the basic constitutional value of human dignity relates closely to Ubuntu, an idea based on deep respect for the humanity of another*” (87:181). Ubuntu identifies that people are part of a collective or community and this concept supports the inherent dignity of the person. Himonga writes that the Ubuntu attribute of dignity supports the requirement of health care professionals to treat all patients equally without discrimination (87).

### 2.13 Dignity in the context of illness

In the discourse surrounding the concept of dignity (107,108,109,110), the concepts of intrinsic and extrinsic dignity have emerged. Human dignity is seen as intrinsic dignity, an inherent and inalienable attribute belonging to every human being by virtue of being human(107). As such, all humans are equal and all humans should be treated with respect. Intrinsic dignity relates to concepts of equity and justice in which human worth is not contingent upon issues of autonomy, physical or intellectual ability, health or illness.

Extrinsic dignity is a term to describe social or individual dignity, dignity that can be enhanced or diminished. Extrinsic dignity is subjective. Social or individual dignity is the dignity of self and relates to concepts of self-worth, self-esteem and self-respect(107). It is important in relation to our view of ourselves as intact, autonomous persons; a dignity in relation to others, being treated with respect, whether interactions are affirmation and valuing of individuals(108). We need to be aware that how we treat others impacts on their view of themselves.

The dichotomies between human dignity and social or individual dignity are evident. Human dignity is described as dignity that is inalienable; nothing can remove it, whereas social and individual dignity can be enhanced or can be lost. Lack of respect for a person or a group impacts on social dignity; social power differentials impacts on social dignity; serious illness impacts on social and individual dignity(108,109).

Illness impacts a person's physical integrity, and the resulting loss of independence and control can also threaten a person's sense of dignity (109). Chochinov maintains that if the health care professional affirms the patient's value, seeing them as a person and not just an expression of their illness, this upholds a person's sense of dignity. Thus, patient-centred care and valuing the patient, according them respect, and seeking to understand their experience enhances their sense of extrinsic dignity (109). Chochinov describes that patients who see themselves as a burden on others have a *"fractured sense of dignity"*, and question whether their continued existence has any value or meaning (110) (page 440). The goals of palliative care include control of distressing symptoms and restoring psychological and spiritual health in a respectful, person-centred way, restoring dignity in the face of serious illness (107). Thus, palliative care attempts to restore a person's dignity by control of distressing symptoms, and exploring emotional, psychosocial and spiritual issues to assist a person to regain a sense of balance or wholeness in spite of the illness. Chochinov and colleagues at the Manitoba Palliative Care Research Unit have identified a model of dignity in dying patients (111) that comprises three main domains: illness-related concerns; a dignity conserving repertoire; and a social dignity inventory. The group have worked to develop Dignity Therapy, encouraging patients to record their life narrative to describe what was meaningful to them and what 'legacy' they would like to leave for their families. The group report on a study conducted in Canada and Australia found that dignity therapy assists people to find *'a sense of meaning and purpose while reinforcing a continued sense of worth'* within a care framework(112:5524). In recognizing dignity as innate, human rights provides a framework for bringing extrinsic dignity, as described by Mann, Brennan, Jacobson and Chochinov into line with intrinsic dignity (106,107,108,109).

One of the founding statements of palliative care comes from Dame Cecily Saunders: *"You matter because you are you, and you matter until the last moment of your life"* (113:12). This statement



expresses the palliative care philosophy that loss of extrinsic dignity does not affect intrinsic dignity, and the efforts of palliative care can be described as attempting to restore or improve a person's extrinsic dignity so that it reflects innate internal dignity.

#### 2.14 Conclusion

In considering the human rights covenants, it is important to recognise that the obligation for the realisation of human rights is the responsibility of governments, and not specifically the obligation of health professionals. This is why the international palliative care community called on governments to ensure that palliative care policies are in place; that palliative care drugs are available; and that health care workers are trained in palliative care. In addition to government responsibility, Hunt and Backman emphasise the importance of community participation in contributing to policy development, implementation and accountability(5), and London emphasises this same point of community agency (17). The provision of palliative care is part of the continuum of care for patients and family members to be provided by health care professionals. Brennan contends that this responsibility for care "*rests on a broad humanitarian and professional impulse of compassion*"(107:94), and that compassion is a recognition of and response to the inherent dignity of the individual patient.

This study considers the Right to Health in South Africa for people whose biological condition is such that they have been diagnosed with serious illness that is considered life-threatening, and who require the interventions provided by palliative care services, to ensure the highest attainable standard of health and best possible quality of life in the circumstances facing them. It focuses on the human Right to Health, and how to use human rights to advance the right to palliative care through access to quality palliative care services.

This chapter has provided a brief overview of the literature describing health and human rights, palliative care as a human right, and considered dignity as the common foundation of the two fields.

Building on the ICESCR and General Comment 14 which sets out how access to healthcare is defined, the following chapter will identify the need for palliative care in South Africa; before the availability, accessibility and quality of palliative care in South Africa can be assessed.

## CHAPTER THREE: THE NEED FOR PALLIATIVE CARE IN SOUTH AFRICA

### *Abstract*

**Background:** A needs assessment is a recognized planning tool to inform a state's obligation to fulfil the Right to Health and would assist in planning the necessary palliative care services so as to realize patients' Right to Health. Different needs assessment methodologies have been based on mortality rates for anticipated deaths and hospital admissions for ICD-10 codes associated with conditions requiring palliative care. **Aim:** to describe the need for palliative care in South Africa. **Objectives:** 1) To identify causes of death by ICD-10 code in SA associated with the need for palliative care (ANPC); 2) To describe the number of reported deaths in SA in the year 2010 ANPC. **Methodology:** South African mortality data for 2010 was obtained from the Burden of Disease (BoD) Research Unit at the Medical Research Council. The ICD-10 codes were reviewed by the PI and South African palliative care doctors to identify diagnoses appropriate for palliative care in the local setting. Data relating to these ICD-10 codes were extracted from the full BoD data set for analysis. Data were analysed according to age, gender, underlying cause of death by ICD-10 diagnosis, and place of death. In addition, an age-standardized mortality rate (SMR) was calculated by province. **Results:** at least 258,268 people who died in 2010 would have benefitted from palliative care. From a total population of 49,991,300, this equates to 0.52% of the population. The average need for palliative care for the South African population is 698.5 persons per 100,000; close to 1 out of every 143 people every year. The top six disease categories were: 1) TB; 2) CVD (including CVA); 3) HIV; 4) malignant neoplasms; 5) metabolic causes; and 6) respiratory disease. **Discussion:** Mortality data has demonstrated a large burden of illness needing palliative care in South Africa. However, mortality data may underestimate need and give an incomplete picture, pointing to limitations in using this approach to identify palliative care need. A more robust method of assessing palliative care need is proposed; derived from identifying individuals in need of palliative care and extrapolating this to population need. **Conclusion:** A needs assessment for palliative care in South Africa provides motivation to include palliative care in national health policies, and information for the state to plan appropriate services at the appropriate level of health care to ensure the government responds to the obligations to respect, protect and fulfil the Right to Health.

### 3.1 Background

#### 3.1.1 Palliative care within the healthcare system

Palliative care is recognised as an important component of modern healthcare(8). As discussed in Chapter Two, the World Health Assembly (WHA) adopted a Resolution in May 2014 urging member states to integrate palliative care services across all levels of care; to ensure adequate funding and human resources for palliative care; and to train all care providers in palliative care according to their roles and responsibilities(3). There is recognition of the role of palliative care in strengthening health systems and ensuring quality, person-centred care for people with advanced progressive illness. As in any health system planning and implementation process, there needs to be collaboration between health policy makers, health care managers and health care workers to integrate palliative care into the health system. The starting point is a health needs assessment.

Considering state obligations, a National Health Plan is part of a Human Rights approach to health as described in General Comment 14, and one of the “obligations of immediate effect” described by Backman and colleagues(13) (page 2048). In describing the legal obligations of member states, General Comment 14 identifies 1) the obligation to respect, protect and fulfil the Right to Health. Respectively, this implies refraining from denying access to palliative care (respect); ensuring equal access to health services and ensuring health professionals “*meet appropriate standards of education, skill and ethical codes of conduct*”(1) (para35); and adopting a national health policy with a detailed plan that includes provision of palliative care. A needs assessment for palliative care in South Africa would help to inform the national health plan that prioritises vulnerable groups. This would become a benchmark against which to measure realisation of health rights for people needing palliative care.

A needs assessment in health care can identify gaps in healthcare provision and is useful in planning appropriate health services. Healthcare need is defined as “*the population’s ability to benefit from healthcare*”(114:502). The WHO Health Systems Glossary defines health needs as “*objectively determined deficiencies in health that require health care, from promotion to palliation*”(115). A further definition, described by Higginson and colleagues as an epidemiological approach to health needs assessment, includes three aspects – “*the size of the*

*need..., the services available...and the effectiveness and cost effectiveness of the services”(116:502).*

This chapter undertakes a needs assessment for palliative care in South Africa. The healthcare needs of people living with advanced illness are often ignored in the face of urgent priorities to address conditions with possibility of cure, and to enhance preventative and promotive healthcare measures(9). Traditionally, public health services have been planned around promotive, preventative, curative and rehabilitative services. At the time of the Declaration of Alma Ata(52), although hospices had been established for some time, palliative care was not yet a part of the formal health care services. The impression is that formal healthcare abandons patients whose illness is no longer curable(36), and this violates both the moral imperative of providing care to the end of life and the person’s human rights to access this care. More recently, palliative care has been included within the definition of Universal Health Coverage(95). This, in addition to the WHA Resolution to integrate palliative care into health systems, has resulted in palliative care gaining acceptance in public health alongside promotive, preventative, curative and rehabilitative care. The growth of palliative care services in the NGO sector (described earlier) reflects unmet need by the public sector.

### 3.1.2 Identifying palliative care need

Need is used to describe both individual need and public health need, and both aspects will be considered in this chapter. Palliative care is a discipline that focuses particularly on the individual, assessing holistic care needs of the patient and of the family. If individual needs are appropriately identified this can be extrapolated into population need.

### 3.1.3 Identifying individuals in need of palliative care

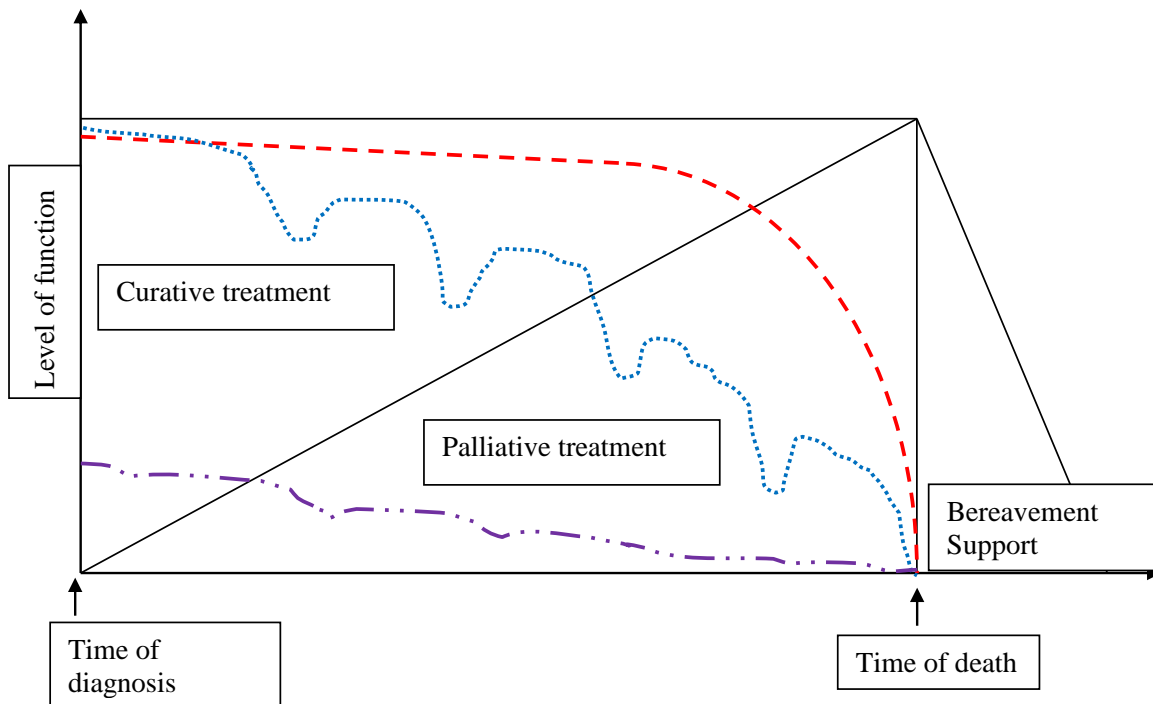
The World Health Organisation (WHO) recommends providing palliative care *“in conjunction with other therapies that are implemented to prolong life”(30)*. However, without knowledge of palliative care and guidance as to when to implement palliative care, many doctors do not consider providing palliative care or referring to palliative care, and may not have the communication skills necessary to discuss referral(119). Lynn identified three illnesses trajectories for adult patients (adapted in Figure 1) that complicate the decision on when to

implement palliative care (120). She described an illness trajectory that pertains to patients with advanced cancer – a predictable course with patients retaining functional ability until late in the illness and then a rapid decline. This trajectory is relatively easy to recognise, and therefore referral of patients with late stage cancer to a palliative care service such as hospice is recognised and accepted by practitioners and patients. A second trajectory epitomized by organ system failure follows a trajectory of longer illness, gradual decline and acute exacerbations of illness before death which can seem sudden and ‘unexpected’. Medical prognosis may be inaccurate in predicting the course of illness and likelihood of death for these patients. The third trajectory typified by frail elderly patients, patients with stroke or dementia is that of a gradual prolonged decline. All three groups of patients would all benefit from palliative care.

In developing the concept of the illness trajectories, Lynn drew on a detailed guidance document compiled by the National Hospice Palliative Care Organisation in the USA, intended to assist in prognosis for patients with non-cancer diagnoses. It uses a combination of use of medical services, functional ability, clinical and laboratory markers to suggest guidelines for enrolment in a hospice service (120). This was at a time when US health insurance (Medicare) payments for hospice care were limited to patients whose life expectancy was six months or less. Lynn comments that this restriction resulted in most cancer patients using hospice having a median length of care in the hospice service of less than three weeks(120). Thus, even in a situation with a recognised illness trajectory, patients did not receive palliative care until much later than WHO recommendations. Moreover, while illness trajectory describes the intensity of palliative care required by different disease groups, it does not quantify the need for palliative care.

These illness trajectories are described in the South African Policy Framework and Strategy for Palliative Care and Figure 3.1 (see below) adapted from Lynn takes into consideration the quadruple burden of disease experienced in South Africa (120,36).

Figure 3.1: Trajectories of terminal illness in South Africa from the National Policy Framework and Strategy for Palliative Care (121) adapted from Lynn.



**Diagram from NPFSPC: The relationship of curative and palliative treatment with illness trajectories.**  
 (red) Cancer trajectory  
 (blue) End stage chronic illness trajectory (e.g. heart failure, renal failure, HIV)  
 (purple) Dementia/ Frailty trajectory  
 "Palliative care should be offered from the time of diagnosis. As function declines over time and cure is no longer possible, curative care becomes less significant and palliative care becomes more important until the time of death. The family is supported through the bereavement process."

### 3.1.4 Palliative Care Indicator Tools

The Gold Standards Framework (GSF) (122) developed in the UK has a Prognostic Indicator Guide (PIG) to assist clinicians in primary care to identify patients who would benefit from palliative care. GSF has three criteria to identify palliative care patients: 1) the surprise question – Would you be surprised if this patient were to die within the next 6-12 months? 2) patient choice or need, such as the patient who chooses not to continue chemotherapy or the patient who chooses to stop or who is not eligible for renal dialysis: and 3) clinical indicators described in more detail for different conditions. These conditions include cancer, organ failure, in particular COPD, heart disease, renal disease, liver disease, general neurological diseases such as motor neuron disease,

Parkinson's disease, multiple sclerosis, dementia, frailty and stroke. The GSF aims to identify people who need more pro-active supportive care as their illness progresses.

The University of Edinburgh and National Health Service in Scotland developed the Supportive and Palliative Care Indicators Tool (SPICT) which is described as a "guide to identifying people at risk of deteriorating health and dying" (123). SPICT advises that patients should be offered supportive and palliative care if they have one or two of the following general indicators of deteriorating health such : i) poor performance status; ii) dependency on others for care; iii) two or more unplanned admissions to hospital; iv) weight loss of >5% over the past 3 months; and v) persistent symptoms. SPICT also describes further criteria depending on the patient's diagnosis of cancer, dementia or frailty, neurological disease, heart/vascular disease, respiratory, kidney or liver disease.

Both the GSF Prognostic Indicator Guide and the SPICT are practical documents that are easy for practitioners to use. Both tools identify patients close to the end of their lives, rather than identifying patients with serious illness at the time of diagnosis. However, if these patients are identified and receive appropriate palliative care, the consideration of palliative care may become a routine part of care planning for patients with serious illness. Early palliative care can be provided by the physician and care team, providing disease specific treatment with a smooth transition to end-of-life care and to a palliative care team if the illness progresses.

Gomez-Batiste and colleagues in Catalonia used the GSF and SPICT in developing the "*Necesidades Paliativas*" (NEPCAL) in the Palliative Care Needs programme in Catalonia (124), and described that the frail elderly also require palliative care. Moreover, the authors identified that particular attention needs to be paid to problems of pressure ulcers, infections, dysphagia, delirium, falls and psychological adjustment difficulties in older people. The NEPCAL tool adds the consideration of demand (from the family) to the patient choice option of GSF and SPICT. In addition, the health care practitioners' assessment of the need to limit therapies was included, as well as additional clinical parameters of emotional distress and common geriatric problems. Evaluation of the NEPCAL tool demonstrated that it was effective in identifying patients with advanced chronic conditions needing palliative care in any care setting and in activating a palliative care approach(124). A study of palliative care indicator tools conducted by Maas and

colleagues recommended validation of a tool adapted to local conditions, in order to improve access to palliative care(125). The authors found that in most European countries referral to palliative care still depended on the palliative care knowledge and experience of individual doctors(125). Using these tools assists in identifying individual patients who would benefit from palliative care. However, in planning health care services, a population needs assessment is required rather than a clinical tool.

### 3.1.5 Public health needs

Based on the WHO definition of palliative care, it is clear that describing palliative care needs for a population is a complex exercise. Palliative care is not only the care of patients who are dying or close to the end of their lives; patients with chronic illnesses may also have palliative care needs. In addition, palliative care can be provided in many settings; in hospices, at home, in frail care (care homes), children's homes, hospitals, in doctors' rooms, in clinics. The need for dedicated palliative care services is influenced by the knowledge and skills of health care professionals in other settings, and the availability and prescribing of palliative care medications at health care facilities. For example, in countries where pain control is taught to doctors and nurses, and analgesic medication is stocked in all pharmacies, the need for referral to a pain specialist, palliative care or hospice team is not required, if the primary clinician is equipped to manage pain problems experienced by patients. The United Nations Children's Fund (UNICEF) and the International Children's Palliative Care Network (ICPCN) published a three country report (South Africa, Kenya and Zimbabwe) (126) assessing the need for palliative care in children, in which the authors argued that it is important to distinguish between generalist and specialist palliative care, that primary health care providers can adequately manage children's needs through a palliative care approach, but that children with more complex symptoms require more specialist palliative care. There may also be emotional, social and spiritual needs that require specialist palliative care. The authors of the paediatric needs assessment used prevalence data from the Institute of Health Metrics Evaluation at Washington University, and mortality data from the WHO Global Health Estimates Study, to quantify children's need for palliative care(126).



Thus, factors to consider when assessing the need for palliative care include: the conditions that would benefit from palliative care for adults and children; and the prevalence of symptoms for these conditions; as well as the intensity of care that would be required, which relates to the severity of patient symptoms whether these are physical, psychosocial or spiritual problems.

When to start palliative care, where to provide palliative care and who would provide palliative care are also important elements in planning palliative care services. Population statistics required to quantify the need for palliative care go beyond death registration statistics. However, disease prevalence statistics and hospital admission statistics are not readily available in many countries, including South Africa. Thus, an initial baseline assessment of need may have to rely on estimates using mortality data which is likely to underestimate need.

### 3.1.6 Background to needs assessment in palliative care

Higginson (127) discusses Maslow's hierarchy of needs (128) and Bradshaw's taxonomy of need (129) as foundation approaches in defining need. Bradshaw's taxonomy of needs describes the following:

- Felt need – what individuals feel they need
- Expressed need – demand for services
- Normative need – need as defined by professionals
- Comparative need – comparing service provision for similar groups of people in different areas.

For palliative care, there are a number of problems with this taxonomy. Felt need: people requiring palliative care are usually experiencing serious illness and are looking for cure or a return to a previous level of health. One of the functions of palliative care is to assist people in recognising the progressive nature of their illness, and the reality that they are unlikely to regain a particular level of health. Patients are not able to describe felt need until they recognise this. Expressed need: it is uncomfortable for people to talk about death and even to consider their wishes for end of life care, although this may be changing as more people write an advance directive or advanced healthcare plan. With this 'death-denying' approach, there may be a lack of awareness of the option of palliative care and of local palliative care services, resulting in a

lower demand for services. Normative need: health care professionals are taught that their role is to cure and there is inadequate training in palliative care. Doyle and Woodruff (130) describe doctors' reluctance to refer to palliative care if they do not have an understanding of or a belief in the discipline. Comparative need: in South Africa, there are still vast inequalities in access and quality of care (131,132), and palliative care is provided by a relatively small non-governmental sector. Even in the major cities of South Africa there is inadequate provision of palliative care. In a survey of palliative care needs in public hospitals in Cape Town, van Niekerk and Raubenheimer(133) found that 54.8% of patients admitted to general medical wards had palliative care requirements, and used this research to motivate for a palliative care service to be established in Groote Schuur Hospital. Thus, there is not yet a gold standard for palliative care provision that can be used in determining palliative care needs in South Africa. This illustrates that in underserved communities comparative need does not give a good measure of need for palliative care. Even in the UK, where palliative care services are well developed, both specialist and generalist palliative care is delivered in different ways and different settings, so that it is difficult to use services to describe comparative need and to recommend regional or national provision of palliative care (134).

Stevens and Gillam describe health care need as the capacity to benefit from health care(135). They make the point that health care includes "*not only treatment but also prevention, diagnosis, continuing care, rehabilitation, and palliative care*" (135:1149). Recent publications from the Lancet Commission on Palliative Care suggest measuring serious health related suffering (SHS), and propose a measure of suffering-intensity-adjusted life-years (SALYs) as a public health measure of palliative care need. These concepts require additional study and research to develop valid and reliable tools to establish these measures (9).

### 3.1.7 Epidemiological approaches to needs assessment

Higginson proposed an epidemiologically-based needs assessment for palliative care in the United Kingdom (UK) in 1997 (127). This was the earliest published population-based palliative care needs assessment and influenced future needs assessments globally. Higginson reviewed prevalence of symptoms experienced by cancer and non-cancer patients published by Addington-

Hall(136), and drew on a number of studies to estimate that 25-65% of cancer deaths in one year required care from a support team and 15-25% required in patient hospice care(127). Murtagh, Higginson and colleagues reviewed this original needs assessment and estimated that 60.28% of deaths (cancer and non-cancer) required palliative care. Higginson also describes cost-effectiveness of palliative care service and models of care(127). Franks, Higginson and colleagues elaborate the epidemiological approach by pointing out that mortality data of conditions in which death is a predictable outcome, and the prevalence of symptoms associated with advanced illness in these conditions, could serve to estimate Palliative Care need(137). As an alternative method, they note that need could be derived from assessment of health service use by patients receiving palliative care. However, because the use of palliative care services does not identify unmet need, and in countries with few palliative care services and limited access to these services, unmet need may far exceed need described by palliative care service providers, Franks and colleagues opt for the epidemiological approach, using cause-specific mortality related to frequency and type of symptoms, maintaining that this method identifies palliative care needs more accurately(137).

Rosenwax and colleagues used population-based data, mortality data and hospital morbidity data to determine palliative care needs in Australia(138). The authors considered minimal estimate, mid-range estimate and maximal estimate for palliative care need(138). They described the minimal estimate as being an estimate of death from any one of ten causes as defined by the International Statistical Classification of Diseases and Related Health Problems–10th Revision (ICD-10): cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, motor neuron disease, Parkinson's disease, Huntington's disease, Alzheimer's disease and HIV/AIDS. The mid-range estimate is more inclusive, describing death from a condition for which the person had been admitted to hospital within the 12 months preceding death, not limited to specific conditions. The maximal estimate covers deaths from all causes other than maternal, perinatal, injury, poisoning and other external causes. Rosenwax and colleagues describe this as close to an ideal situation, where all health care workers are competent in providing palliative care and can offer this care to anyone close to death(138).

Gomez-Batiste and colleagues addressed the issue that palliative care should be provided early in the course of a life-threatening or life-limiting illness and not just at the end of life. The researchers evaluated the prevalence of palliative care needs in Catalonia(139) through a study in three primary health care centres, a district hospital, a social health centre and four nursing homes. Patients with eight pre-specified conditions were assessed by their clinicians, doctors and nurses. Of the 51,595 people using the facilities surveyed, 1064 patients with chronic conditions were identified as needing palliative care. Using the NEPCAL tool the researchers identified individuals who would benefit from palliative care, and used this to measure the population-based prevalence of people in need of palliative care. Although this study limited eligibility of participants surveyed to eight conditions, it is the first study to directly link assessment of individual care needs to the public health need.

The hospital survey conducted by Van Niekerk and Raubenheimer was a survey of case notes of patients in twelve Cape Town hospitals, adapting the Gold Standards Framework Prognostic Indicator Guide to identify patients with active life-limiting disease who would benefit from palliative care(133). It is not clear who provided the answer to the “surprise question” in this survey of case notes, but it was found that 54.8% of patients in the general medical wards met the requirements for palliative care(133). Although this was a broad survey, it provides important information regarding the extent of the need for palliative care particularly in medical wards where clinicians have not previously considered referral of patients to palliative care.

Murtagh, Higginson and colleagues(134) used a population-based approach to determine the size of the need for palliative care in England. The authors used mortality data, underlying cause of death and contributory cause of death, and hospital admission date for a three-year period, and concluded that data on symptom prevalence and hospital data did not add to the accuracy of estimates for palliative care need. There is lack of precision in using symptom prevalence, as most patients experience a number of symptoms, so that patients with different symptoms would be identified more than once. Considering that many patients receive palliative care at home, data on hospitalisation is likely to underestimate palliative care need. However, the number of unplanned hospital admissions is a criterion for identifying individual need for palliative care in

indicator tools described above (Supportive and Palliative Care Indicator Tool and the Gold Standards Framework Prognostic Indicator Guide); and this metric could be adapted for use in population needs assessment.

Murtagh and colleagues reviewed previous palliative care needs assessment approaches, and proposed using ICD-10 codes with an analysis of underlying and contributory causes of death in estimating palliative care need(134). The ICD-10 diagnoses were reviewed and expanded, guided by an expert group. The authors commented on the evolution of palliative care practice beyond traditional cancer and specified non-cancer diagnoses, which extend the provision of palliative care; and the fact that patients experience palliative care needs before the end-of-life period. Murtagh and colleagues(134) evaluated the needs assessment methods used by Higginson(127), Rosenwax(138) and Gomez-Batiste(139). Table 3.1 summarises Murtagh’s (134) overview of the four studies (all from the developed world) assessing palliative care need.

*Table 3.1: Comparison of methods for epidemiological needs assessment for palliative care(134)*

Author	Method	Estimated need
Higginson (127)	Mortality data; symptom prevalence	60.28% of deaths due to cancer & 6 specified non-cancer conditions (UK)
Rosenwax (137)	Mortality data (causes according to specified ICD-10) codes – see below; hospital usage	Min 50% deaths Midrange estimate 55.5% Max 89.4% deaths (W Australia)
Gomez-Batiste (139)	Percentage of deaths from chronic disease needing PC using indicator tool (NEPCAL)	75% deaths from advanced chronic disease (Spain)
Murtagh (134)	Mortality data (ICD-10 refined to include additional conditions requiring palliative care) see below	69-82% deaths in high income countries require palliative care (England and Wales)

Murtagh and colleagues identified limitations due to the evolution of palliative care to include more non-cancer conditions and lack of epidemiological data particularly from care homes(134).

In fact, the needs assessment by all four authors emphasise the importance of providing palliative care to people with non-cancer diagnoses.

Table 3.2 describes the ICD-10 codes used in the Murtagh(134) and Rosenwax(137) methods.

*Table 3:2 Comparison of ICD-10 codes selected by Rosenwax and by Mutagh (134)*

Cause of death	ICD-10 codes
<i>Rosenwax et al.</i>	
Neoplasm	C00-D48
Heart failure	I500, I501, I509, I111, I130, I132
Renal failure	N180, N188, N189, N102, N112, N120, N131, N132, I132
Liver failure	K704, K711, K721, K729
Chronic obstructive pulmonary disease	J40, J410, J411, J418, J42, J430, J431, J432, J438, J439, J440, J441, J448, J449
Neurodegenerative disease	
Motor neuron disease	G122
Parkinson's disease	G20
Huntington's disease	G10
Alzheimer's	G300, G301, G308, G309
HIV/AIDS	B20-B24
<i>(Murtagh) refined method</i>	
Malignant neoplasm	C00-C97
Heart disease, including CVD	I00-I52, I60-I69
Renal disease	N17, N18, N28, I12, I13
Liver disease	K70-K77
Respiratory disease	J06-J18, J20-J22, J40-J47 & J96
Neurodegenerative disease	G10, G20, G35, G122, G903, G231
Alzheimer's, dementia and senility	F01, F03, G30, R54
HIV/AIDS	B20-B24

There have been a number of assessments of the need for palliative care in different countries. Higginson and colleagues conducted a systematic review of the approaches used in describing needs assessments, and found that the epidemiological approach was the mostly commonly used approach, assessing the size of the need from mortality data, the availability of services, and the effectiveness and cost-effectiveness of services, to identify gaps in service provision(116). One Australian study used bereaved family members as a proxy for identifying need for palliative

care(140). However, this was a limited method as participants were family members not patients. Higginson and colleagues further comment on the challenges of conducting a needs assessment in developing countries, where there are many additional needs arising from poverty, and questions about accuracy of data(116). The authors comment on the imperative of acting on the results of a needs assessment to include palliative care in health care planning and implementation of services(116).

It is of interest to note that of the 77 palliative care needs assessment reports that met the inclusion criteria for the Higginson study, 37 were from Africa. There are two possible reasons for the number of needs assessment studies in Africa. Firstly, it may reflect a response to the overall poor level of palliative care development in Africa, and thus a requirement to document the need so as to influence policy makers to implement palliative care development. The other reason for the number of needs assessment reports may be the active involvement of the African Palliative Care Association established in 2004 in addressing the development of palliative care in Africa, with support from funders such as United States Aid for International Development, the Open Society Foundations and Diana Princess of Wales Memorial Fund(142).

In 2014, the World Health Organisation and Worldwide Palliative Care Alliance published the Global Atlas of Palliative Care, reporting that over 29 million people worldwide died of diseases requiring palliative care in 2011(8). The authors derived this estimate from the WHO mortality data reported as part of the WHO Global Health Estimates for 2011. They conducted Delphi studies to identify diseases to include in the analysis, and in addition, conducted an internal review to finalise the list of diseases by ICD-10 code. Further to the mortality data, the authors used estimates of pain prevalence for cancer (80% pain prevalence)(126), progressive non-malignant diseases (67% pain prevalence (143)) and HIV(55% pain prevalence(144)) to adjust the numbers of deaths, and reported that the “*estimated number of people in need of palliative care at the end of life is 20.4 million*”(8:12). The authors comment that this is an under-estimate of need, as it does not include people requiring palliative care prior to the last year of their life, nor care of family members and the bereaved. A limitation of this study is the fact that most people with advanced chronic illness requiring palliative care have multiple symptoms, so even if they

do not suffer pain they are likely to experience other distressing symptoms. This is discussed in more depth below.

*Table 3.3: Diseases requiring palliative care identified in Global Atlas of Palliative Care (8)*

*Diseases requiring palliative care for adults:*

Alzheimer's and other dementias, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, drug-resistant tuberculosis (TB).

*Diseases requiring palliative care for children:* cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, kidney diseases, neurological disorders and neonatal conditions.

### 3.1.8 Children's Palliative Care

As described above, Connor and Sisimayi conducted a needs assessment of palliative care for children in three African countries, commissioned by United Nations Children's Fund (UNICEF) and the International Children's Palliative Care Network (ICPCN) (145). The data sources included prevalence data from the Institute of Health Metrics and Evaluation (IHME) at the University of Washington and mortality data from WHO Office of Health Statistics and Informatics. They note that over 360 conditions have been identified as eligible for palliative care for children(145). These conditions can be classified in categories developed by the UK group Together for Short Lives (35). See Table 3.4 below.



*Table 3.4: Together for Short Lives Categories of Life Threatening and Life Limiting (35)*

Category 1: Life-threatening conditions for which curative treatment may be feasible but can fail. Examples: cancer, irreversible organ failures of heart, liver, kidney.

Category 2: Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.

Category 3: Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.

Category 4: Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy.

In the study conducted by Connor and Sisimayi, the statement was made that not all children with a prevalent condition would need palliative care, and an adjustment factor for the expected presence of pain was used as an indicator for palliative care(145). This adjustment factor for pain was taken from adult studies, with only Henley's study on HIV-infected children being relevant to children(144). It did not account for the fact that pain is only one of the symptoms experienced by children with life-threatening illness. Nonetheless, the study reported that 56,485 children died (due to all causes) in South Africa in 2010. Taking into account chronic paediatric conditions that require palliative care, the analysis of prevalence data with adjustment for pain prevalence resulted in an estimate of 801,155 children needing generalised palliative care, 304,441 of whom would require specialised palliative care. The authors compared the estimated need with reports of provision of palliative care in South Africa, and concluded that only 4.76% of current need is being met(145).

### 3.1.9 Identifying a method of determining palliative care need in South Africa

Higginson's health care needs assessment(127) describes the epidemiological approach to palliative care needs assessment as comprising six key steps, steps 2 and 3 being the core of a needs assessment (See Table 3.5 below).

In deciding a methodology to determine the size of the need for palliative care in South Africa, limitations in the use of mortality data and of symptom prevalence were considered.

*Table 3.5: Key steps for palliative care needs assessment and planning services (127)*

1. Statement of the problem
2. Division into relevant subcategories - different services, different diseases/groups of people
3. Determining the size of the need – incidence and prevalence of each sub-category using mortality rates and symptom prevalence
4. Determining the current level of services
5. Determining effectiveness & cost-effectiveness
6. Make recommendations – models of care.

### 3.1.10 Cause of death statistics

All authors describing use of mortality data to estimate palliative care describe the evolution of palliative care practice beyond traditional cancer and specified non-cancer diagnoses, thus including more patients in palliative care services; and the fact that there are palliative care needs earlier in the illness than just prior to death (127,134,138,139).

As described earlier, the WHO definition of palliative care states that palliative care is “*applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life*”(30). Thus, mortality data do not describe the whole of the need for palliative care. Patients with advanced chronic illness and those with progressive disease have many palliative care needs that include control of distressing symptoms, psychological, social and spiritual support. The period of time prior to death that patients require palliative care is highly variable, and depends on patient and family resources, the debility resulting from the illness and the intensity of nursing

requirements. These complex needs may result in the conclusion that anyone with advanced illness requires palliative care, and more accurate data to determine need would be prevalence data rather than mortality data.

### 3.1.11 Data quality concerns

Both Higginson in her early publication(127) and Murtagh and colleagues(134) comment on the inaccuracies of death registrations in recording actual cause of death. This reflects the South African experience described by Bradshaw and the Burden of Disease Research unit(146). StatsSA comment that *“the quality of the reported information is determined largely by the diligence and integrity of the certifying official – physician, forensic pathologist, professional nurse or in some rural areas traditional headman”*(147:2). Bradshaw and colleagues report that a review of the quality of cause of death data found poor quality data in South Africa, with 20% ill-defined deaths and less than 70% deaths registered in year 2005(147). Subsequently, there was an effort to improve reporting on cause of death. In 2007, registration of deaths in South Africa had improved to 82% of deaths, although cause of death information had not improved. Assessment of cause of death information for the 2007 mortality data from StatsSA revealed that 13.8% of reported deaths were ill-defined and 9.0% were categorized as ‘Garbage’ codes – the term used in the Global Burden of Disease study to describe codes that do not provide cause of death(147).

A study of the quality of death certification at an academic hospital in Cape Town in 2004 identified that a third of all death certificates had errors that would affect classification of underlying cause of death(148). A further study of City of Cape Town death notification forms over a one year period in two Cape Town suburbs, found major errors in over 40% of forms(149). In response to concerns raised by these inaccuracies, a guide to completion of death certificates was developed by the Divisions of Forensic Medicine at the Universities of Stellenbosch and Cape Town and the Medical Research Council Burden of Disease unit(150). The impact of the intervention was evaluated with reduction of errors in completing death certificates by the group undertaking the training. This training has the potential to improve the quality of death certification(149).

### 3.1.12 Prevalence of symptoms

Palliative care “provides relief from pain and other distressing symptoms”(30). This clinical imperative of palliative care is often the focus of palliative care interventions by palliative care doctors and nurses, while also recognising the importance of psychosocial and spiritual care.

*Table 3.6: Minimum and maximum symptom prevalence for five conditions, from Solano et al. (143)*

Diagnosis \ Symptom	Cancer	AIDS	Heart disease	COPD	Renal disease
Pain	35-96%	63-80%	44-77%	34-77%	47-50%
Depression	3-77%	10-82%	9-36%	37-71%	5-60%
Anxiety	13-79%	8-34%	49%	51-75%	39-79%
Confusion	6-93%	30-65%	18-32%	18-33%	No data
Fatigue	32-90%	54-85%	69-82%	68-80%	73-87%
Breathlessness	10-70%	11-62%	60-88%	90-95%	11-62%
Insomnia	9-69%	74%	36-48%	55-65%	31-71%
Nausea	6-68%	43-49%	17-48%	No data	30-43%
Constipation	23-65%	34-35%	38-42%	27-44%	29-78%
Diarrhoea	3-29%	30-90%	12%	No data	21%
Anorexia	30-92%	51%	21-41%	35-67%	25-64%

International literature on palliative care needs assessment also utilizes the symptom burden of different illnesses to motivate for palliative care services, and to persuade policy makers of the extent of the need for clinical palliative care services. For example, Solano and colleagues compared symptom prevalence for five major conditions: cancer, HIV, heart disease, chronic obstructive airways disease (COPD) and renal disease(143). Their findings are displayed in the Table 3.6 above.

Studies show that patients at this stage of their lives and illness experience multiple symptoms. In a survey of patients living with HIV in Uganda and South Africa, Harding and colleagues

reported on 7-day prevalence of symptoms(152). The mean number of symptoms experienced by 224 HIV-positive patients was 18 symptoms, identified using the Memorial Symptom Assessment Schedule Short Form (MSAS-SF) as survey tool to identify symptom prevalence(152). In a study of patients attending three HIV clinics in South Africa also using MSAS-SF, Farrant and colleagues reported the mean number of symptoms as 10.24(153). Lokker and colleagues found that heart failure patients at a tertiary hospital in Cape Town reported a mean of 19 symptoms with over 90% of patients reporting on shortness of breath, tiredness and pain as physical symptoms and worry, feeling irritable and feeling sad as psychological symptoms(154). Because of the multiplicity of symptoms, pain is often used as a proxy to describe need for palliative care(8). However, the table above shows the wide range of pain prevalence, so estimates become less useful if adjusted for a pain prevalence that was originally determined in the UK for cancer and six non-cancer diagnoses. However, in their assessment of methods of conducting population palliative care needs assessment, Murtagh and colleagues concluded that data on symptom prevalence and hospital data did not add to the accuracy of estimates for palliative care need(134).

### 3.1.13 Summary: Determining palliative care need in South Africa

The majority of needs assessments described above have used an epidemiological approach, based on mortality data reported as ICD-10 codes, to estimate palliative care need. Some studies have also used hospital usage statistics and symptom prevalence statistics. However, hospital usage is not a good measure of palliative care need in South Africa which lacks readily available data on hospital admissions in a central database. Moreover, the significant provision of home-based care in South Africa is likely to result in fewer hospital admissions leading to under-estimation of need based on hospital admission alone. Further, given the view that additional data on symptom prevalence do not add accuracy, as described by Murtagh and colleagues(134), it was decided that in spite of limitations, mortality data would be used in this baseline study of palliative care need in South Africa, as mortality data are available and will provide a first baseline estimate of palliative care need to inform healthcare planning.

#### 3.1.14 Problem statement

Palliative care is recognized as an essential element of Universal Health Coverage and is included in the South African white paper describing the National Health Insurance planned for the country. A health needs assessment is a state obligation fulfilling the Right to Health and is important for planning of health services, and this includes needs assessment for palliative care. The published literature describes different approaches to needs assessments in the developed world. It is important to estimate palliative care need for South Africa, in order to inform health care planning and to realise the right of access to palliative care for people needing this care in South Africa. Despite limitations described above, this study follows the epidemiological approach to estimating palliative care need using mortality data. This will provide a baseline needs assessment comparable with international studies, and refinements on the approach will be discussed.

#### 3.1.15 Aim and objectives

The aim of this chapter of the thesis: to describe the need for palliative care in South Africa.

Objectives:

1. To identify causes of death by ICD-10 code in SA associated with the need for palliative care
2. To describe:
  - i. the number of reported deaths in SA in the year 2010 associated with the need for palliative care
  - ii. age adjusted rates of death from causes associated with the need for palliative care
  - iii. the number of reported deaths reflecting palliative care need by age, gender, province, place of death and disease groups from mortality data reported for the year 2010

## 3.2 Methodology

### 3.2.1 Study design

A retrospective descriptive study of mortality data from the South African Medical Research Council (MRC) Burden of Disease Research Unit was conducted through secondary analysis of the mortality data for the year 2010. The methodology is based on Murtagh's approach of identifying ICD-10 codes for conditions where palliative care can provide benefit, as described in the literature and through discussion with an expert group(134).

### 3.2.2 Study population

The study population was people who died in South Africa from 1<sup>st</sup> Jan to 31<sup>st</sup> Dec 2010, using the Medical Research Council mortality database.

### 3.2.3 Data source

Mortality data is derived from the deaths registered with the South African Department of Home Affairs (DHA). The DHA sends copies of death notification data to Statistics South Africa (Stats SA). Cause of death statistics are recorded in accordance with the World Health Organisation's regulations that require member nations to code deaths according to the International Classification of Diseases (ICD-10). Stats-SA make the data available to the Burden of Disease (BoD) Research Unit at MRC. The BoD researchers review the data and remove or amend coding errors, adjusting for misclassified deaths and garbage codes, and note recodes. The Burden of Disease Research unit reports on age-standardized mortality rates (ASMR) and trends for the nine provinces of South Africa. The subset of data made available by the MRC for this study included data on year of death (2010), month of death, age, sex, population group(race), province, and institution where death occurred, up to five possible causes of death, one category for underlying cause, whether death was due to natural or unnatural cause, underlying cause re-code, and age in 5-year age bands (age 5) with a category 0, then 1-4, 5-9, 10-14). Most death notifications had only a single cause. Underlying cause of death is defined by the National Centre for Health Statistics ICD-10 Mortality Manual as *"the disease or injury which initiated the train of morbid*

*events leading directly to death or the circumstances of the accident or violence which produced the fatal injury”(155:9)*

### 3.2.4 Identifying cause of death by ICD-10 codes associated with the need for palliative care (ANPC)

In order to identify deaths from conditions associated with the need for palliative care (ANPC) an advisory group was constituted. This group comprised South African palliative care doctors involved in both clinical care and academic teaching and research from the University of Cape Town, University of KwaZulu Natal, University of Pretoria and University of the Witwatersrand. Three documents were circulated to the group: 1) a complete ICD-10 list (Appendix D3, page 299); 2) the list from the study by Murtagh and colleagues(134); and 3) the ICD-10 codes based on the UK report for the children’s palliative care organization, Together for Short Lives (156). Discussion amongst the advisory group was by email and telephone over a 3-month period and the group was asked to draw on their experience in providing care to patients to develop consensus with regard to diagnoses that would benefit from palliative care in the South African setting. Drafts of the evolving South African ICD-10 list of causes associated with the need for palliative care were created and sent to the advisory group until consensus was reached. Causes of death that may lead to sudden and unexpected death and cause of death in pregnancy and childbirth were excluded. The final study tool included ICD-10 codes for tuberculosis, infections related to HIV co-infections, diabetic disorders recoded by BoD study as death from cardiovascular causes. See Table 3.7 below.



*Table 3.7: ICD-10 codes extracted from 2010 deaths as conditions affecting adults and children that could benefit from palliative care*

Cause of death	ICD-10 codes
Tuberculosis (TB) & Drug Resistant TB	A16, A17, A18, U51, U52
Human Immuno-deficiency Virus (HIV) infections and co-infections (not TB)	B20, B21, B22, B23, B24, B33, B34, B45, B58, B59
Malignant neoplasms	C00-C97
Deaths recorded as benign neoplasms	D2-5, D9, D10 D12-16, D18, D19, D21-48
Diabetic disorders reclassified as Cardiovascular disease	E10, E11, E14 (recoded as I11, I12, I25 or I64)
Dementia & senility	F01, F03, G30, R54
Neurological disorders not cerebro-vascular accidents (CVA)	G10,12,20-25, G31, G35
Cardiovascular disease (including CVA)	I01, I11-13, I25, I35, I42, I50, I61-64, I85
Chronic respiratory disease	J40, 42-44,84,96,98
Liver disease	K72-74
Renal disease	N17-19
Paediatric	P10, P11, P21, P27, P28, P29, P35, P37, P52 P83, P91, P96
Genetic disorders	Q00, Q01, Q03, Q04, Q07, Q20-23, Q25, Q26, Q28, Q32, Q33, Q39, Q41, Q43, Q44, Q60, Q61, Q64, Q74, Q75, Q77-82, Q85-87, Q91-93
Deaths recorded due to symptoms	R5-7, R9-11, R17, R18, R40, R51, R52, R60, R64

### 3.2.5 Data abstraction

The researcher edited the dataset to include only causes of death associated with the need for palliative care (see appendix A1, page 274). It is recognised that family members may benefit from bereavement care provided by palliative care services for any cause of death, but this study focused on the need for palliative care prior to death.

The final lists of ICD-10 codes for cause of death used in the analysis of Mortality statistics are included in Table 3.7 and Table 3.8. Table 3.7 includes diagnoses that apply to both adults and children and Table 3.8 includes additional codes included for children only.

*Table 3.8: Additional ICD-10 codes extracted from 2010 deaths as conditions affecting children that could benefit from palliative care*

Cause of death	ICD-10 codes
Infections (slow virus infections of NS)	A81
Benign neoplasms and immunodeficiencies	D33, D43, D44, D48, D56, D61, D70, D76, D81, D82, D83, D84, D89
Metabolic disorders	E 31, E 34, E70-72, E 73-77, E79, E 83, E84, E88
Neurological disorders	G11, G40, G60, G70, G71, G80, G82, G93
Cardiovascular disease	I27,
Liver disease	K55, K76, K86
Disorders of bone & connective tissue	M31, M32, M89
Renal disease	N25
Neonatal conditions	P10, P11, P21, P27, P28, P29, P35, P37, P52 P83, P91, P96
Congenital disorders	Q00, Q01, Q03, Q04, Q07, Q20-26, Q28, Q32, Q33, Q41, Q43, Q44, Q 60, Q61, Q64, Q74, Q75, Q77-82, Q85-87, Q91-93

### 3.2.6 Data analysis

The data set of deaths recorded in South Africa in 2010 was supplied by the South African Burden of Disease study in an Excel spreadsheet. This dataset was reduced to deaths from conditions that benefit from palliative care (as in Tables 3.7 and 3.8), through the consensus exercise described above, and saved in a new Excel spreadsheet. This excel sheet was identified as ‘all palliative care deaths’ for purposes of analysis. Additional Excel sheets were created from all

palliative care deaths, to reflect deaths from specific disease categories and by province. For each death there were data on age, by sex, population group(race), province, institution (place of death), cause of death, age grouped in 5-year age bands.

The data was analysed in Excel, using pivot tables to generate tables and graphs indicating the total number of deaths from underlying causes associated with the need for palliative care by age and gender. Deaths are also reported by age group and place of death. The total number of deaths for the top six diseases requiring palliative care are reported.

Age-standardised mortality rates were calculated according to methodology used by the office of National Statistics referencing World Standard Population (157). The total number of deaths by age group were compared to the 2010 South African population figures, to calculate age specific mortality per 100,000 and age standardized mortality rate calculated against World Standard Population.

### 3.3 Results

#### 3.3.1 Mortality data

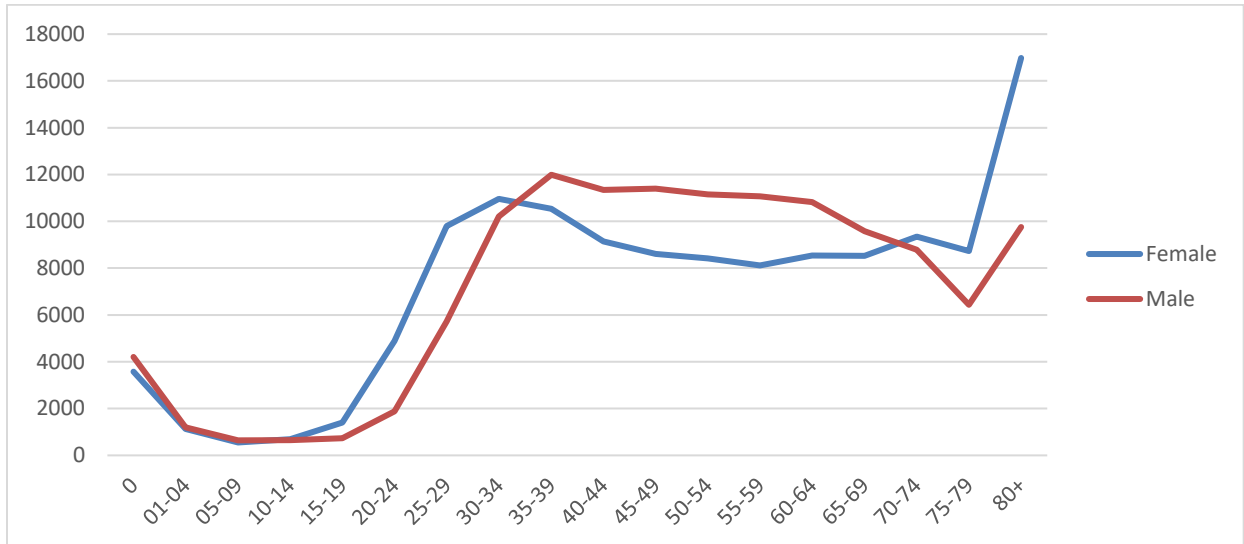
There were 543,856 deaths recorded in South Africa in 2010. The number of deaths in South Africa from causes associated with the need for palliative care (ANPC) is estimated as 258,268 people (adults and children) for 2010. This is 0.52% of the population in 2010 and 47.48% of all deaths

The estimates are recorded below in Table 3.8 and Figure 3.1.

Table 3.9: Deaths ANPC in 2010 by age and gender

Deaths	Gender				Grand Total
	Female	Male	Unknown	Unspecified	
0	3570	4206	9	93	7878
01-04	1128	1197		3	2328
05-09	552	643			1195
10-14	693	657		1	1351
15-19	1407	734		3	2144
20-24	4893	1883	2	8	6786
25-29	9804	5717	1	20	15542
30-34	10964	10211	2	22	21199
35-39	10535	11990		18	22543
40-44	9148	11337		19	20504
45-49	8608	11404	1	22	20035
50-54	8411	11157		15	19583
55-59	8114	11072		18	19204
60-64	8543	10818		14	19375
65-69	8527	9579		10	18116
70-74	9346	8792		7	18145
75-79	8725	6428			15153
80+	16980	9753		7	26740
Unspecified	138	253	2	54	447
<b>Grand Total</b>	<b>130086</b>	<b>127831</b>	<b>17</b>	<b>334</b>	<b>258268</b>

Figure 3.2 Deaths reflecting causes ANPC by age and gender (South Africa, 2010); excluding 0.17% of deaths where age or gender was not specified



### 3.3.2 Deaths by age

Paediatric deaths (0-19) are 5.67% of total deaths from causes associated with the need for palliative care by age and gender. Paediatric palliative care deaths under the age of 1 year comprise 53.94% of all palliative care deaths of children and adolescents under the age of 19 years.

#### 3.3.2.1 Age-standardised mortality rates

Age-standardised mortality rates (see Table 3.10 below) reflect the high mortality rate for children in the first year of life and a relatively high mortality rate for young adults – a relatively consistent mortality rate between the ages of 40-79.

Table 3.10: Population statistics and age-standardised mortality rate causes ANPC per 100,000 population (all ages) by age in 5-yr age bands (2010)

Age bands	PC Deaths	Population	ASR*	WSP#	Age Stdised mortality rate/100,000
0	7878	1024100	769.26	17,917	137.83
01-04	2328	4096600	56.83	70,652	40.14
05-09	1195	5181200	23.06	86,870	20.04
10-14	1351	5202300	25.97	85,970	22.33
15-19	2144	5226200	41.02	84,670	34.74
20-24	6786	5018500	135.22	82,171	111.11
25-29	15542	4518800	343.94	79,272	272.67
30-34	21199	4035700	525.29	76,073	399.60
35-39	22543	3465200	650.55	71,475	464.98
40-44	20504	2524200	812.30	65,877	535.12
45-49	20035	2230600	898.19	60,379	542.32
50-54	19583	2019100	969.89	53,681	520.65
55-59	19204	1653700	1161.27	45,484	528.19
60-64	19375	1319700	1468.14	37,187	545.96
65-69	18116	985200	1838.81	29,590	544.11
70-74	18145	694900	2611.17	22,092	576.86
75-79	15153	441400	3432.94	15,195	521.64
80+	26740	353900	7555.81	15,445	1.166.99
<b>Unspecified</b>	447				
<b>Grand Total</b>	258268	49991300	23319.66	1,000,000	698.52
The age-standardised mortality rate per 100,000 population (all ages) is:					<b>Rate per 100,000</b> <b>698.52</b>

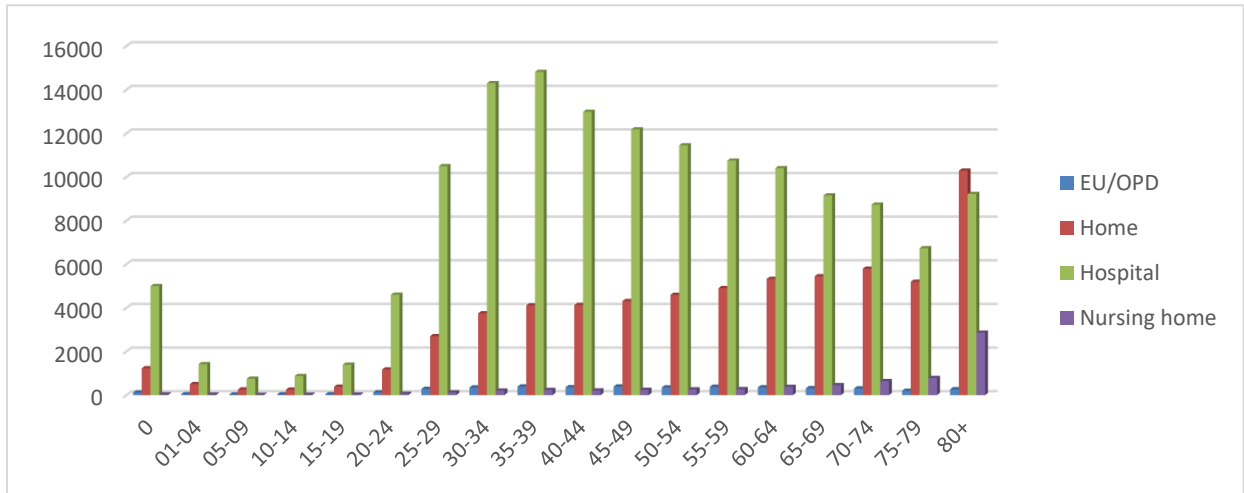
\*Age-Standardized Rate

#World Standard Population

### 3.3.3 Place of death

Most deaths occur in hospital except in the elderly where more deaths occur at home (See Figure 3.2 below). There are few deaths in the Emergency Unit/Out Patient Department, which are grouped together as a category in the dataset received from BoD Research Unit.

Figure 3.3: Deaths from causes ANPC by age and four main places of death



### 3.3.4 Deaths and palliative care need by province

In analysing the deaths and palliative care need by province, the numbers of deaths reflecting palliative care need was highest in Kwazulu-Natal, Gauteng and Eastern Cape (See Table 3.11 below), which are provinces with larger populations. However, age-standardised mortality shows that Free State province had the highest palliative care need and Gauteng province had the lowest palliative care need. The Free State had a 56% higher mortality rate for people requiring palliative care than Gauteng. The average need for palliative care for the South African population is 698.5 persons per 100,000; that is close to 1 out of every 143 people every year.

*Table 3.11: Population statistics and age-standardised mortality rate for palliative care conditions per 100,000 population (all ages) by province (2010)(56)*

Province	Population	% population by province	Deaths reflecting PC need (2010)	% PC need by province	Age-stdised mortality rate reflecting PC need/100,000
Free State	2824500	6%	19241	7%	887.38
Eastern Cape	6743800	14%	39967	16%	801.09
Northern Cape	1103900	2%	7207	3%	791.83
North-West	3200900	6%	18914	7%	788.64
Mpumalanga	3617600	7%	19180	7%	782.42
KwaZulu Natal	10645400	21%	58323	23%	778.10
Western Cape	5223900	11%	26851	10%	660.47
Limpopo	5439600	11%	20603	8%	568.71
Gauteng	11191700	22%	47982	19%	568.30
South Africa	49991300	100%	258268	100%	698.52

### 3.3.5 Disease categories

The top six disease categories identified as predictable causes of death reflecting palliative care need in 2010 were: 1) TB 62,611; 2) CVD (including CVA) 54,295; 3) HIV 46,490; 4) malignant neoplasms 34,964; 5) metabolic causes 21,705; and 6) respiratory disease 12,833.



### 3.4 Discussion

One of the obligations imposed on the state by the Right to Health is the obligation to ensure appropriate legislative, administrative and budgetary measures to fulfil the Right to Health. A needs assessment is an important step in the process. An assessment of palliative care needs in South Africa is useful to inform healthcare planning, at a time when the South African government is implementing Universal Health Coverage through National Health Insurance and the National Policy Framework and Strategy for Palliative Care. The NHI White paper includes palliative care as a component of comprehensive health care for South Africa(91). The first feature of the NHI is identified as universal access and describes that *“All South Africans will have access to needed promotive, preventive, curative, rehabilitative and palliative health services that are of sufficient quality and are affordable without exposing them to financial hardships.”*(91)(p viii, para 38) The NHI White paper describes the comprehensive health services and continuum of care from community outreach through primary health services to specialised care, including palliative care in the continuum of care(91).

#### 3.4.1 Extent of the need for palliative care in South Africa

Analysis of the mortality statistics from the MRC Burden of Disease unit indicates that there were 258,268 people in South Africa in 2010 who could have benefited from palliative care (See Table 3.9). It is important to note that this is likely to be an under-estimate of palliative care need, describing only those patients who died in 2010 and not those requiring early palliative care; so, this should be seen as a baseline estimate for planning health care services until more accurate estimates can be achieved. Since this study was conducted, the National Policy Framework and Strategy for Palliative Care (NPFSPC) has been developed and estimates that in 2014 between 45-50% of all deaths in South Africa required palliative care (225 835 people, see Table 3.12)(121). This compares to the 47.48% estimate derived from this study. The NPFSPC estimate was based on the Murtagh method, which identified fewer conditions than those identified by the advisory group in this study(134). This contrasts with the study conducted by Murtagh and colleagues in England which identified that 60.28% of all deaths need palliative care(134). In considering the difference between England, a high-income country, and South Africa, a middle income country, reasons for the difference may relate to the quadruple burden of disease in South Africa resulting

in a higher proportion of infant and maternal mortality, a higher number of deaths from communicable diseases and a higher proportion of sudden deaths from injuries (intentional and non-intentional)(12).

A recent publication from the Medical Research Council (158) used an estimate of 0.75% of the population requiring palliative care and estimated the need for palliative care in 2016 to be 348,033 people(158). This estimate was based on the WHO report “A community health approach to palliative care for HIV/AIDS and cancer patients in Sub-Saharan Africa” identifying that between 0.5-1% of a country’s population would require palliative care (159).

*Table 3.12: Comparison of three South African estimates on palliative care need*

	Current study (Murtagh method adapted)		National Policy (Murtagh method)		MRC report (WHO report)	
	#	%pop	#	%pop	#	%pop
2010	258,268	0.70%				
2014			225,835	0.42%		
2016					348,033	0.75%
Extrapolated to 2017	<b>347,668</b>		<b>237,384</b>		<b>423,900</b>	

### 3.4.2 Accuracy of palliative care needs estimates

Using mortality data provides a consistent result in estimating palliative care need. However, including estimates of palliative care need for non-fatal chronic conditions provides a higher figure. Table 3.12, which summarises three studies of palliative care need in South Africa, generates three widely different estimates indicating the importance of an accurate methodology for this estimation.

Using ICD-10 data may result in inclusion of some deaths not consistent with requiring palliative care, as it cannot be certain that 100% of deaths from a particular ICD-10 category required palliative care. This would over-estimate need for palliative care. However, the symptom burden and psychosocial problems associated with these diagnoses make it likely that patients and families would have experienced benefit from palliative care.

Palliative care is a complex discipline and has developed to respond to the needs of patients presenting with any life-threatening or life-limiting illness, and it is recognized that these needs develop early in the course of an illness (8,124,127,137,138). Thus, mortality data does not describe the entire need for palliative care. Patients with advanced chronic illness and those with progressive disease have many palliative care needs that include control of distressing symptoms, psychological, social and spiritual support. The periods of time prior to death that patients require palliative care is highly variable and depends on patient and family resources, the debility resulting from the illness and the intensity of nursing requirements.

In addition to care of patients, family members also benefit from the assistance of palliative care services to support them in providing the daily care required by the patient, and in managing the impact of the illness on their own lives. These complex needs may result in the conclusion that anyone with advanced illness requires palliative care, and more accurate data to determine need is prevalence data rather than mortality data. Gomez-Batiste and colleagues identified that *“1.45% of the total population and 7.71% of the population aged over 65 are ‘surprise question’ positive”* (124:1). The ‘surprise question’ refers to one of the criteria used to identify people who would benefit from palliative care in the NEPCAL palliative care indicator tool. The accuracy of the ‘surprise question’ has been assessed in a systematic review and meta-analysis conducted by White and colleagues and the pooled accuracy was found to be 74.8%(160).

The palliative care need derived in this thesis is estimated as 0.52% of the population. This lower proportion may be explained by the higher infant mortality rate and a higher rate of death from accidents and injuries; and possibly because of the younger population in South Africa.

The World Health Organisation definition of palliative care described in Chapter One explains that palliative care *“is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life”* (30). Symptoms may start well before death and before the year of death, and the need for palliative care before the year of death indicates an error that results in under-estimating need when using only mortality data. The WHO definition of palliative care for children states that *“It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease”* (30). In considering the palliative care

needs for children, the definition describes that the principles apply to paediatric chronic disorders, life-limiting as well as life-threatening illness. Thus, the use of prevalence data, if available, would be more accurate in assessing palliative care need.

### 3.4.3 Accuracy of the data

It is important to recognise that the epidemiological approach to assessment of palliative care need relies on accuracy and availability of up-to-date statistics. The World Health Organisation report on estimates of deaths for member states relies on country information on cause of death. The level of evidence for causes of death is categorized into three groups. The first group provides reasonably complete death registration data coded by ICD-10 code. The second group, including South Africa, has incomplete death registration data, and the WHO uses cause of deaths models to adjust for incomplete data. The third group is where there is no country information on cause of death. Bradshaw comments in the Cause of Death Report of 2010 that, although there have been improvements in death registrations, there is still concern about accuracy of death notifications and errors made on the death notification forms(147). The StatsSA report on mortality data and causes of death published in 2014 states that the collaboration between Statistics South Africa, Department of Home Affairs and Department of Health ensures collection of data from the civil registration system and aims to improve the quality of the data(161). These statistics have been important in providing accurate data to report on the Millennium Development Goals as well as to plan health care services in South Africa.

The mortality data used in this study were from 2010 mortality statistics. The 2014 StatsSA report on Mortality and causes of death in South Africa, 2011 (161) acknowledged problems of the accuracy of the data but reported improvement in the completeness of notification comparing years 1996-2001 (estimated completeness of 89%) with completeness of 94% for the period 2007-2011(161). However, quality of the data was still a concern with a relatively high level of ill-defined cause of death, 23.9% for the 2010 death registrations, reflecting a low level of quality(161). Some of the factors contributing to inaccuracy are content errors and omissions on death certificates and misreporting of causes of death. In an effort to improve errors, researchers working on the SA Burden of Disease study recode Underlying Causes of Death from data

included on the death certificate as immediate cause of death and contributing causes of death. The current study used the Burden of Disease unit's Underlying Cause of Death to estimate need. Recognising the under-estimate of need when relying only on mortality data to estimate need, international researchers(134,145) suggest that ideally, information on disease prevalence as well as mortality should be used to identify palliative care need in healthcare planning, including district level data. However, accurate prevalence data are not currently available in South Africa. The researcher explored the possibility of using prevalence data for South Africa from the Institute of Health Metrics Evaluation (IHME) at the University of Washington for the year 2010(162). However, the IHME prevalence data are limited to a few diagnoses, and are themselves estimates rather than directly calculated statistics. In correspondence relating to missing data, such as prevalence of MDR TB and XDR TB (multi-drug resistant tuberculosis and Extensively drug resistant tuberculosis), which are very important causes of death in South Africa, IHME personnel reported that the ICD-10 codes describing DR TB are considered junk codes by IHME and not include in the database (162) thereby excluding one of leading causes of death in South Africa (147). Thus, this dataset was not useful for the study. At the time of this study, there was thus no reliable source of prevalence data for South Africa, although databases such as the District Health Information System (DHIS) may provide these data in the future.

#### 3.4.4 Estimating the need for palliative care in children

The difference in estimating palliative care from mortality data compared to prevalence data can be seen in the estimate derived in the current study using MRC Burden of Disease mortality data of 14,640 children under the age of 19 who died from causes that could have benefitted from palliative care; and comparing this to the estimate from the 2013 UNICEF/ICPCN study (125) on the need for palliative care in three African countries (South Africa, Kenya and Zimbabwe), which derived estimates from two sources. The UNICEF/ICPCN study used mortality data from WHO Global Health Estimates (Causes of Death 2000-2011) and from the Institute of Health Metrics and Evaluation at the University of Washington country level prevalence data for the identified conditions requiring palliative care to assess palliative care need for children. These conditions used in the Connor study (125) were fewer than those used in the current study. Connor's

estimate of palliative care need, once prevalence data were included, is 304,441 children requiring specialist palliative care, which is equivalent to 152/10,000 children under the age of 19 years(125). This study suggests that there is a significant underestimate of palliative care need for children if only mortality data are used. In addition to conditions that result in death over a short period that can be measured by assessing mortality statistics, there are many chronic life-limiting conditions requiring palliative care in childhood, such as cerebral palsy, muscular dystrophy and cystic fibrosis.

#### 3.4.5 Palliative care needs by province

The analysis of palliative care need by age-standardised death shows that the greatest need for palliative care is in the Free State Province 0.9/100; followed by five provinces of similar need – Eastern Cape, Northern Cape, North-West Province, Mpumalanga and KwaZulu Natal; followed by Western Cape; and then Limpopo and Gauteng having the lowest population need 0.6/100. It is not clear as to what might contribute to the inter-provincial differences. The StatsSA reports do not comment on accuracy and quality of death registration by province. Provincial differences in service provision for HIV and TB may account for the higher palliative care need in some provinces. Effective HAART and TB adherence programmes may contribute to survival of patients with these conditions in Western Cape and Gauteng; thus, the appearance of lower palliative care need if only mortality statistics are considered. However, research studies show that there are significant palliative care needs for patients with HIV infection and patients with TB infection (153,163,164). Problems relating to equity of access to palliative care are flagged in reviewing these results, and require consideration in the next phase of the research that assesses availability of services described in Chapter Four and accessibility of palliative care in Chapter Five. The rural provinces have the higher need for palliative care, and the thesis will examine whether services are available to meet this need.

#### 3.4.6 Place of death

As described in the literature (165,166), the majority of people in both the developed world setting and in the developing world express a preference to die at home, with hospital being the least desired place of death. A survey conducted in England indicated home as first choice, then

hospice, then a low percentage of people choosing hospital or care home or home of a friend or elsewhere (167). The analysis of place of death in this study revealed that in South Africa in 2010, the majority of deaths occurred in hospital (see Figure 3.2), the next most common place of death being people's own homes. Together hospital and home were the place of death for more than 95% of deaths. There are few hospice inpatient units in South Africa, with most hospice care being provided in the patient's own home, so the option of hospice as a place to die is not generally available to South Africans. The results of this study show that death at home is more common for older people, so than over the age of 80 more people die at home than in hospital. It is important that appropriate palliative care is provided in the home to ensure comfort and quality of life even at the end of life. In the context of the implementation of NHI, this means that it will be important to ensure the availability of palliative care in the home for people at the end of life. This will most likely be more cost-effective than the current situation of the majority of people dying in hospital (41,168), and, provided good care is available in the home, will meet people's preferences, as described in the literature, of being at home when they die. The Medical Research Council has recently developed an investment case evaluating ward-based outreach team costs and within this study identified the cost-saving of palliative care to the health system of R3.3billion/year(169).

#### 3.4.7 Limitations of the study

A limitation of this study was the method of developing consensus with regard to the conditions included in the assessment of need. An expert advisory group was constituted and contributed to the development of the list through discussion but did not do so through a formalised methodology. A more robust method would have been to follow a Delphi consensus exercise to reach consensus on conditions to include as signalling the need for palliative care.

The study used only mortality data, as prevalence data and data on hospital usage are not readily available in South Africa, so the palliative care needs may have been under-estimated.

An additional concern is that of accuracy of reporting through death certification. Although efforts have been made to improve this accuracy(150), quality of death registration data is a concern. This study was conducted using 2010 burden of disease data and, with the impact of

scale-up of antiretroviral treatment and change in policy to test and treat rather than starting ARVs contingent on CD4 count, there is likely to be a lower mortality rate from HIV. TB is the most common cause of death and has been since 2010, so deaths from TB are increasing.

#### 3.4.8 A more robust method of assessing palliative care need

This study has highlighted the need for a more robust method of assessing palliative care need. Although it is recognized that palliative care is applicable to chronic diseases in both adult and paediatric populations, it is uncertain as to what the gap is in the need for palliative care for patients identified by mortality data, and the need that is not identified because of uncertainty of prognosis of many diseases. Using annual mortality statistics, it is not possible to identify the total number of people requiring palliative care. This is a significant limitation in being able to develop an accurate needs assessment for health planning purposes. It is recommended that a palliative care indicator tool, possibly based on SPICT or GSF PIG, that identifies palliative care needs for individual patients and adapted to the South African setting would overcome these limitations. One of the SPICT measures is the number of unplanned hospital admissions for the diagnosis that requires palliative care(123). Hospital admission data is available in South Africa in routine health information systems. Thus, the SPICT, adapted and validated for the South African setting, could provide the population needs assessment for South Africa. This approach presumes appropriate primary health care for the patient's life-limiting condition. In a recent study of palliative care needs of patients with heart failure in a tertiary cardiology service, Lokker and colleagues found that only 58% of patients had been prescribed an ACE inhibitor, although this medication is included in the standard treatment guidelines and on the essential medicines list for primary health care facilities(154). Additional advantages of using a palliative care indicator tool would be sensitising doctors to identify people with palliative care needs, and the development of a register of people with palliative care needs at health facilities, to alert staff to provide this care and implement referral to specialist palliative care services if necessary. Disadvantages include the introduction of a new procedure and possible resistance to use of an indicator tool by clinicians. There may also be an over-estimate of people requiring palliative care based on unplanned hospital admissions, if they were not receiving optimal treatment for their



condition. However, they may then receive the benefit of review of treatment to ensure adherence to treatment guidelines.

### 3.5 Conclusion

Calculating need from age-standardised mortality rates, this study identified that 0.52% of the population required end-of-life palliative care in 2010, or close to 1 out of every 143 people every year. Even though this is likely to be an underestimate of true need, this still represents a high burden of suffering and distress, which can be effectively managed through compassionate care by health care workers skilled in the management of pain and other distressing symptoms, in addition providing emotional and spiritual support to patients and family members.

This information generated on palliative care need should be used in planning palliative care services in the provinces of South Africa. The state should plan palliative care services according to need to ensure equity in the provision of palliative care. Thus, consideration should be given to provinces with greater need, care of children especially those in the first year of life, care for the elderly, and palliative care services in hospitals. With improved recognition of palliative care, provision of effective home-based palliative care will be an important area for health planning. A recommendation from this study includes development and validation of a practical palliative care indicator tool for use in South Africa for more accurate planning of palliative care services. Comparing availability to need will inform health care planning as the government implements the WHO resolution 67.19. and help the state to meet its obligations to fulfil the Right to Health, as framed in General Comment 14.

The next chapter will examine current availability of palliative care in South Africa and successful models of palliative care in different healthcare settings. It will also discuss the gaps in current availability, and initiatives that may successfully address these gaps in the light of the South African government's Re-Engineering of Primary Health Care and the commitment to universal health coverage(169). The estimate of palliative care need in South Africa described in this chapter will enable comparison to identify the gap between need and provision of services in order to realise accessibility and availability of palliative care as part of the Right to Health in South Africa.

## CHAPTER FOUR THE AVAILABILITY OF PALLIATIVE CARE IN SOUTH AFRICA

### *Abstract:*

**Background:** Availability is a key element within the Right to Health. General Comment 14 describes availability as “Functioning public health and health-care facilities, goods and services, programmes, ... available in sufficient quantity within the State party.” The previous chapter identified high levels of need for Palliative Care in South Africa. This study examines the availability of palliative care services in South Africa, particularly in relation to the need for such services. **Aim:** to describe the availability of palliative care services within South Africa. **Objectives:** 1 ) to identify palliative care services in South Africa; 2) to describe palliative care services in South Africa; 3) to describe human resources within palliative care services and levels of palliative care training; 4) to describe demographics of palliative care beneficiaries in South Africa; 5) to describe perceptions of palliative care providers regarding availability of morphine; and 6) to compare availability of palliative care with need identified in Chapter Three. **Methodology:** A list of organisations funded for the provision of palliative care and the Hospice Palliative Care Association database were used to identify services providing palliative care. A predominantly quantitative questionnaire using an on-line Survey Monkey<sup>(R)</sup> site was distributed to 131 services identified as providing palliative care between March 2011 and October 2011, exploring the elements of palliative care provided by these services, staffing and staff training for palliative care, and availability of morphine for pain management. Data were captured in Excel and pivot tables were used to analyse the data. Data on availability of morphine, employment of doctors and training of doctors was imported into Stata for Chi squared testing, and estimation of Odds ratios (with 95% Confidence Intervals) to assess whether there was a statistically significant association between availability of morphine and 1) employment of doctors; and 2) training levels of doctors. Content analysis was conducted on the narrative question regarding availability of morphine to identify themes emerging from the data. **Results:** Of 104 palliative care services that responded (79% of those surveyed) only 3% of services were located within the public sector. Palliative care services most commonly employed nurses as clinical staff, and the majority of staff trained in palliative care were professional nurses. NGO services rely on volunteers. Availability of morphine in the NGOs was dependent on employment of and level of palliative care

training of doctors. It was estimated that the organisations surveyed provided care to between 9.5% and 18.3% of people needing palliative care in 2010. **Conclusion:** The majority of NGOs (hospices) provide comprehensive palliative care services in South Africa but availability of palliative care services in South Africa are insufficient to meet the need for palliative care identified in Chapter Three.

#### 4.1 Introduction

This chapter focuses on the availability of Palliative Care services in South Africa. It examines Availability under the framework of a Right to Health described by General Comment 14 (1). It builds on the discussion in Chapter Three of palliative care need in South Africa and the needs assessment using an epidemiological model described by Higginson and Murtagh(127,134). In Higginson’s model, a health needs assessment describes the level of need and the nature and level of current service provision of palliative care. The description of the current level of provision of palliative care forms the focus of this chapter, through a survey of identified palliative care services.

##### 4.1.1 Availability as described in General Comment 14

General Comment 14 describes Availability as: *“Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the State party’s developmental level. They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs”*(1) (para 12a). These elements are also described in the WHO Public Health Strategy (PHS) for Palliative Care(95). In addition to appropriate policies for palliative care, the PHS describes the need for training for palliative care, availability of essential palliative care medicines and availability of palliative care services. With the strong WHO support for palliative care over the past 30 years, it is relevant to consider WHO measures and other sources of international support for palliative care.

#### 4.1.2 International support for palliative care

The first edition of WHO Cancer Pain Relief was published by the WHO in 1986 and translated into 22 languages. A WHO Expert Committee on Cancer Pain Relief and Active Supportive Care revised and updated the publication in 1996, adding a section on opioid availability(170).

The WHO definition (2002) of palliative care guides the development of palliative care services in different contexts. The WHO published the Essential Medicines List for Children, Palliative Care in 2008 (171) and in 2013 the WHO Essential Medicines in Palliative Care was prepared by the International Association for Hospice and Palliative Care and published by the WHO(172).

A number of organisations have been influential in lobbying for greater attention to improving availability of palliative care over a period of time (See Table 4.1). The International Association of Hospice and Palliative Care (IAHPC) developed from the International Hospice Institute and College established in 1996, with the objective to support development of palliative care in each country according to the context and resources(173). In 2005, a further two international organisations, the International Children's Palliative Care Network (ICPCN) and the Worldwide Hospice Palliative Care Alliance (WHPCA) were established, following two years of discussion with regard to sharing best practice for children's and adult hospice and palliative care at international meetings.

The WHPCA created a number of working groups, including an advocacy work group to provide support to national associations to build their own advocacy skills and to engage with governments to persuade them to make palliative care a priority(174). The International Union for Cancer Control (UICC) and the American Cancer Society (ACS) established the Global Access to Pain Relief Initiative (GAPRI) in 2009 and, in the same year, launched the Treat the Pain Initiative. The Treat the Pain campaign produced a series of videos with interviews of patients and palliative care clinicians and activists, to highlight the need for better control worldwide.

Table 4.1: A summary of advocacy/lobbying for palliative care as a human right (1992-2011)

Date	Topic	Type of publication	Author & Organisation
1992	Human Rights and medicine: the relief of suffering(66)	Conference paper	Margaret Somerville, Canadian Human Rights Foundation
1999	Relief of acute pain: a basic Human Right? (175)	Journal article	Michael Cousins, International Association for the Study of Pain
2004	Pain relief: a Universal Human Right(69)	Journal article	Michael Cousins, IASP
2005	Hospice care a Human Right(73)	Journal article	David Prail Help the Hospices, UK
2007	Palliative care as an international Human Right (65)	Journal article	Frank Brennan, Calvary hospital, Sydney Australia
2007	Pain Management: a fundamental Human Right (75)	Journal article	Frank Brennan, Calvary hospital, Sydney Australia
2009	"Please, do not make us suffer any more..." Access to Pain Treatment as a Human Right (176)	Human Rights Watch report	Diederik Lohman, Human Rights Watch
2009	Treat the Pain Program* (UICC & ACA program)	Advocacy videos	Meg O'Brien Global Access to Pain Relief Initiative
2009	Statement on Palliative Care and Human Rights (177)	Position paper	Worldwide Hospice Palliative Care Alliance
2010	Needless Pain Government Failure to Provide Palliative Care for Children in Kenya (178)	Human Rights Watch report	Human Rights Watch
2011	Uncontrolled Pain Ukraine's Obligation to Ensure Evidence-Based Palliative Care (179)	Human Rights Watch report	Human Rights Watch

\*<http://treatthepain.org/about.html>

Human Rights Watch (HRW) also focused on the problem of pain and access to opioid medication in their efforts to influence governments to improve access to palliative care and pain relief (176,

178,179). The HRW reports developed from research and interviews with patients, doctors, nurses and policy makers were powerful, emotive advocacy tools. The involvement of HRW in efforts to improve access to palliative care has been significant, and this organisation has strong credibility in the human rights arena. Both GAPRI and HRW joined the WHPCA advocacy group, which included members from Hospice Palliative Care Organisations, IAHPC, ICPCN and donors funding palliative care development. In 2009, the WHPCA adopted a position paper on palliative care and human rights stating, *“there is a universal recognition that the provision of Palliative Care falls within the international Right to Health and that this recognition places a series of obligations on national governments for its provision”*(177:2). Persistent lobbying from national palliative care associations, from WHPCA and partner organisations prepared the WHO executive committee to adopt a proposal to integrate palliative care into country health systems. This advocacy group crafted the palliative care resolution, and HRW worked closely with the government of Panama to draft the proposed resolution and present it to the WHO executive committee in January 2014.

#### 4.1.3 Human rights and palliative care

The entry of human rights language into the world of palliative care advocacy and lobbying can be traced back to Margaret Somerville’s paper on “Human Rights and medicine: the relief of suffering” in 1992(66). Adequacy of pain management and availability of pain medication are often used as proxies to measure availability of palliative care; focusing on a single factor, such as pain management makes efforts to integrate palliative care more manageable(8).

The International Association for the Study of Pain (IASP) focused on the right to pain relief, as did Human Rights Watch when they joined the call for better access to pain relief and palliative care(75). Lohman describes obstacles to pain relief and palliative care, including failure to enact policies, restrictive legislation affecting the availability of opioids, failure to ensure effective supply of essential medicines and lack of training of healthcare professionals in pain management and palliative care. He describes these obstacles as resulting in violation of the Right to Health(180).

#### 4.1.4 World Health Assembly resolution

In May 2014, palliative care was discussed for the first time at a World Health Assembly meeting. A resolution that had been debated at the WHO executive board meeting in January 2014 was presented to the Assembly as resolution A67.19 Strengthening of palliative care as a component of comprehensive care throughout the life course(3). The WHA recognised *“the limited availability of palliative care services in much of the world”* (preamble) and recommended that member states: *“develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels”* (3) (para 1.1).

Thus, the resolution provided a framework to engage with governments to improve the availability of palliative care to all who need this care. Member states were required to report on progress towards integration of palliative care at the 2016 WHA meeting. The resolution was proposed by Panama and was co-sponsored by 10 members of the WHO executive committee, including South Africa. In discussing the resolution at the 67<sup>th</sup> WHA a number of countries asked to be included as co-sponsors, a sign of international commitment to palliative care. South Africa’s co-sponsorship of the resolution indicated the high level of support by the South African government for the integration of palliative care into the South African health care system. There is an expectation that the countries co-sponsoring the resolution, such as South Africa, plan to report significant progress for this integration within their own country at subsequent meetings of WHA.

#### 4.1.5 Policy context in South Africa

As described previously (page 12), South Africa signed the ICESCR in 1994 and ratified in 2015, and in doing so, committed to the progressive realisation of the rights contained in the ICESCR. The ICESCR frames the Right to Health as the right to enjoy the highest attainable standard of health, and places obligations on states to respect, protect and fulfil the Right to Health. The obligation to fulfil requires that the State facilitates, provides and promotes availability and accessibility to health services, including palliative care services. In explaining states’ obligations for the progressive realization of the Right to Health, General Comment 14 explains how

facilitating access to palliative care “requires States to adopt appropriate legislative, administrative, budgetary measures” towards implementing palliative care services(1) (para 33). The states obligation to fulfil the Right to Health includes the “obligation to adopt a national health policy with a detailed plan for realizing the Right to Health”(1) (para 36 ). In the context of palliative care, this would mean inclusion of palliative care in the country’s health plan.

There are government policy documents that include reference to palliative care: 1) the NHI White Paper which identifies palliative care as an essential component of primary health care(91); 2) Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17(118); and 3) the draft National Integrated Plan for Cancer Prevention and Control in South Africa 2015-2020(181). However, although the South African National AIDS Council identified that over 250,000 people die of HIV each year, palliative care is not included in the National Strategic Plan (NSP) on HIV, STIs and TB 2017–2022(182). This, in spite of input from government parties, NGOs and PLHIV, asking for the inclusion of palliative care in the NSP.

Government commitment and in-country expertise provides a foundation for the integration of palliative care into health systems in South Africa. In particular, the NHI White Paper is an explicit commitment by the state to progressively realise access to health care including palliative care(89).

#### 4.1.6 The South African Constitution

As described in Chapter Two, the South African constitution includes the Right to Health and the right of access to healthcare (Section 27 of the SA Constitution) (11); and the Constitutional Court has ruled on cases expressing the Right to Health, recognising the constraints in the South Africa setting due to limited resources. The National Health Council, during the discussion and approval of the National Policy Framework and Strategy for Palliative Care, instructed the Department of Health to develop an implementation plan and budget taking into account limited financial resources. Research has shown that palliative care is cost effective, reducing expenditure for both the health system and for patients, while improving quality of life and frequently extending life with better experience for patients(9).



The South African Constitution starts with the statement of values forming the foundation of the constitution being: *“Human dignity, the achievement of equality and the advancement of human rights and freedoms”*(Chapter 1, section1), and these values are repeated throughout the constitution, including in the Bill of Rights (11). The Palliative Care policy addresses issues of equality of access to palliative care and the role of palliative care on restoring and maintaining dignity of patients with advanced illness(121). Thus, the National Policy Framework and Strategy for Palliative Care will contribute to upholding these constitutional values. Ngwena writes that Section 27 attempts to secure equality in access to healthcare by removing barriers to accessing services and mitigating against problems such as rurality (83).

#### 4.1.7 Re-engineering of Primary Health Care

In 2009, the Minister of Health initiated health care reform in South Africa to redress the imbalance in care provided within a relatively well-resourced but costly private sector and the public sector, serving 84% of the population with 50% of the health care spend(90) (pages 15-16). In May 2010, a ministerial visit to Brazil took place to view the health system in Brazil, a country with similar economy and problems as South Africa. Following this visit, the government produced a strategy for Re-engineering PHC in South Africa(90). This initiative, together with plans to implement a National Health Insurance to be phased in over a 14-year period, aims to achieve universal, equitable and affordable health coverage(91). The Re-engineering of PHC is structured around the WHO strengthening health systems approach. At community level, strengthening of the District Management Team and harnessing the resources of stakeholders are key strategic goals.

The Re-engineering of Primary Health Care has four priority areas of focus. These are maternal, women and child health; HIV and tuberculosis; chronic non-communicable disease; and violence and injuries. Community Health Workers (CHW) are deployed in households, and focus on preventive and promotive health and adherence to treatment. The document describing the Re-Engineering of Primary Health Care also identifies that *“in addition to the work of the CHW there is also a role for lay workers. These include palliative care and activities of daily living which are labour intensive”*(169:18). The assumption that palliative care will be provided by lay workers

implies that palliative care is not seen as an essential service in the Re-Engineering of Primary Health Care, and violates the requirements for trained palliative care staff as part of the state obligation to fulfil the Right to Health. In addition, providing palliative care in patients' homes would probably add significantly to the workload of CHWs. Referral for palliative care is described as a CHW task while providing care in the home but it is not explicit as to whether hospices and other home-based care organisations will be expected to provide this care, and there is no statement regarding funding of such palliative care services.

In contrast, the NHI White Paper undertakes that *“All South Africans will have access to needed promotive, preventive, curative, rehabilitative and **palliative** health services that are of sufficient quality and are affordable without exposing them to financial hardships”*, but again does not describe how this is to be achieved(91) (para 30a).

One of the State obligations identified in General Comment 14 includes *“fostering recognition of factors favouring positive health results, e.g. research and provision of information”*(1)(para 37). This implies that the State should disseminate appropriate information about *“the availability of services supporting people in making informed choices about their health”*(1) (para 37). Health information is one of the key indicators of a country's response to the Right to Health described by Backman and colleagues(13). Many of the items described in this indicator relate to data collection and management rather than information regarding available services or service benefits(13). There is limited information available to the public about palliative care in South African health facilities and from the Department of Health's communication department. Although hospices and HPCA provide information about palliative care and arrange awareness campaigns, the reach of this information is uncertain and they do so at their own cost. The complexities of informational access is described in more detail in Chapter Five.

#### 4.1.8 Availability of palliative care internationally

In 2014, the WHO and WHPCA published a Global Atlas of Palliative Care and identified that over 20m people required end-of-life palliative care each year; of these 69% of people were over the

age of 60 and 78% of adults requiring this care were in low or middle-income countries(8). Children were 6% of the population requiring palliative care. The Global Atlas mapped country level provision of palliative care from a survey of 234 countries. The Atlas identified 75 countries (32%) as having no known hospice-palliative care activity(defined in the Atlas as Level 1). There were capacity-building efforts – conferences, training and lobbying activities in 23 countries (10%) (Level 2). Level 3 activities were described as isolated provision (74 countries, 31.6% - Level 3a) or generalized provision (17 countries, 7.3% - Level 3b). There were only 45 countries (19.3%) identified as having any level of integration of palliative care into the health system – 25, including South Africa, with preliminary integration (Level 4a) and 20 with advanced integration (level 4b) (8).

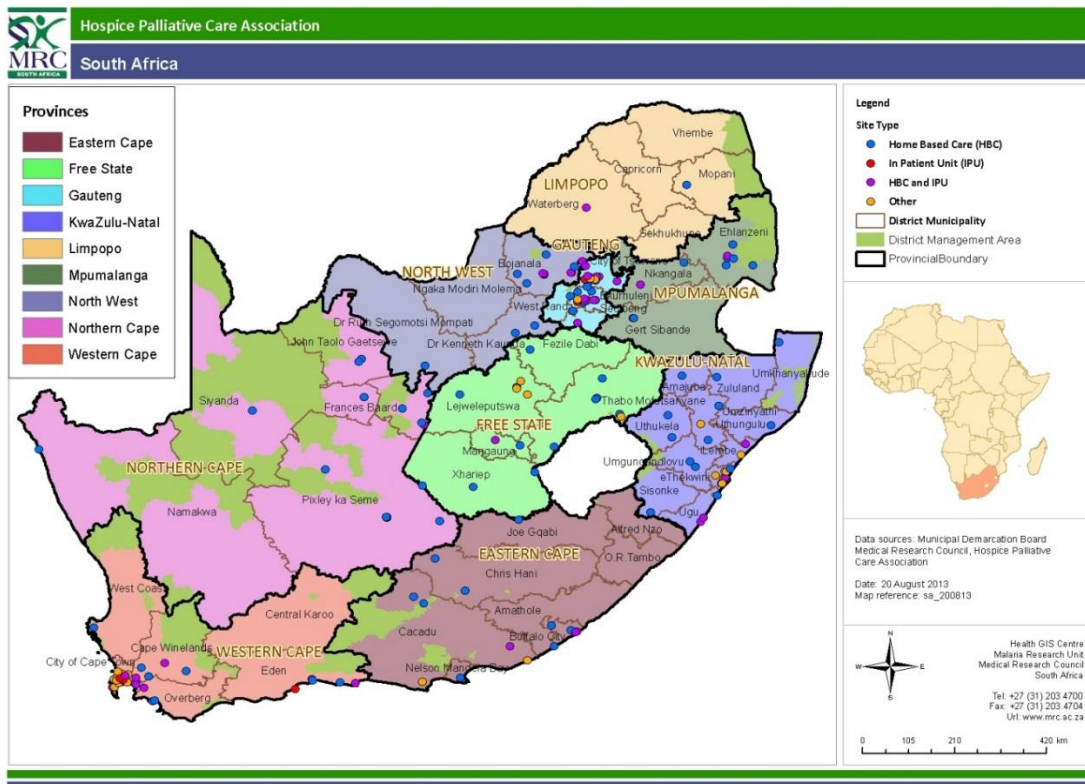
In 2007, Clark and colleagues conducted a study to identify development of hospice and palliative care services in Africa. The authors described that non-governmental organisations were the main providers of palliative care in Africa, and that there was little government funding with hospices being responsible for sourcing their own funds. Over half the African hospices were in South Africa with limited or no availability of hospice services in other African countries, other than Uganda. The majority of services provide home care with few hospital-based palliative care services(184). Clark and colleagues identified four countries in 2007 that were approaching integration of palliative care. In 2014, the Global Atlas described six countries approaching integration of palliative care into the health system with a seventh country, Uganda showing advanced integration of palliative care into the health system. The African Palliative Care Association is currently working with 25 countries to strengthen palliative care services(142).

#### 4.1.8 Availability of palliative care services in South Africa

The Hospice Palliative Care Association has mapped member organisations within the country and identified hospice services in 43 of 52 South African health districts. Figure 4.1 illustrates that there are large areas of the country not covered by HPCA member organisations providing palliative care. Hospice services were initially established in communities that could afford to donate funds to the hospice, and there it can be clearly seen that hospices are clustered in metropolitan areas. There is better reach to rural communities only in KwaZulu Natal. Limpopo

province is significantly under-served with only two hospice services in the province. The nine health districts without any hospice services are Alfred Nzo and Joe Gqabi in the Eastern Cape, Central Karoo in the Western Cape, John Taolo Gaetsewe in the Northern Cape, Ngaka Modiri Molema in North West Province, Sedibeng in Gauteng, and Capricorn, Vhembe and Sekhukhune in Limpopo.

Figure 4.1: Distribution of hospice services in South Africa (2010) Developed for HPCA by the Medical Research Council 2010.



The services in the Northern Cape and in most rural areas are distant from each other, and are not able to cover population needs adequately. For example, there is one hospice in the Namakwa Health District of the Northern Cape which has an area of 126 836km<sup>2</sup>. The hospice serves only the Richtersveld community, still an area of 9 608km<sup>2</sup>, but only one of six municipalities in Namakwa. These geographical inequities may potentially violate the Right to Health in that health services, including palliative care services, should be "available in sufficient quantity within the State party"(1)(para 12a). HPCA reports that in 2010 member organisations cared for 94,585 patients(103) These were described as category one patients (51%) – ambulant

patients requiring monthly interventions; category two patients (38%) – patients requiring weekly interventions; and category three patients (11%) – bed-bound and requiring more than three interventions a week.

International studies also comment on the challenges to ensure availability of palliative care in rural areas. They describe the greater reliance on family members to provide care in rural setting in Canada, Australia, the USA and the UK; and on volunteers in Africa(185-187).

#### 4.1.9 Growth and decline in South African hospice services

The first South African hospices were established in Johannesburg, Cape Town and Durban in the early 1980s. In 1987, fourteen hospices met to form the Hospice Association of South Africa, later changing the organisation's name to the Hospice Palliative Care Association. In the 1980s, patients requiring palliative care would be referred to the local hospice, and a professional nurse trained in palliative care would visit the patient in his home and carry out an initial assessment. From this a care plan would be developed and implemented, and the nurse would call on members of the hospice interdisciplinary team to provide care as appropriate to the patient's needs guided by the care plan. This model of care complies with the requirement of trained personnel to provide palliative care. With the advent of the AIDS epidemic and limited access to antiretroviral medication, hospices expanded their services to care for patients infected and affected by HIV. The province of KwaZulu Natal (KZN) had the highest prevalence of HIV, in 2002 the national sero-prevalence survey reported a prevalence of 36.5% amongst ante-natal attendees(188). In order to reach more patients and families, South Coast Hospice in Port Shepstone on the south coast of KZN developed a new model of care. Community members, who often were caring for family members or neighbours, were trained in basic care including palliative care principles. The community caregivers were employed by the hospice, and with the support and supervision of the professional nurse, became the primary caregivers to patients, also providing support to families. The professional nurse is still responsible for the development of the individualized care plan for patient and family. This model of care described by Defilippi and Cameron(189) became known as the Integrated Community-based Home Care (ICHC) model. This model of care integrated hospice resources with other relevant community service, including

government hospitals and clinics. The importance of linking care to prevention and treatment of HIV and AIDS was emphasized, with a goal of the ICHC model to reduce the incidence of HIV. The ICHC model was written up by the National Department of Health in the Best Practice series, and the Hospice Palliative Care Association was awarded a tender by the South African Department of Health to replicate the model in different settings – urban, peri-urban and rural, to cost the model and to develop a training curriculum for community careworkers. The University of KwaZulu Natal evaluated the programme and recommended that this model of care be implemented more widely with the comment: *“Whether this implementation should continue to centre around the hospice as main NGO is dependent on the capacity of this NGO and others in communities across the country”* (190:82).

In 2001, the HPCA developed a mentorship programme to encourage and assist member hospices to implement the ICHC model. Concurrently, HPCA developed standards for Governance, Management and Palliative Care, in conjunction with the Council for Health Services Accreditation of Southern Africa (CoHSASA)(191). CoHSASA is a quality improvement and accreditation body for healthcare facilities based in Africa, which aims to facilitate improvement in patient safety and quality of care through monitoring and evaluation of healthcare standards. The CoHSASA certificate of accreditation is acknowledged by HPCA by awarding the hospice a five-star rating. This accreditation validates the hospice as a functioning health facility providing quality comprehensive palliative care.

In 2004, HPCA applied for funding from the US government’s aid programme – the President’s Emergency Plan for AIDS Relief (PEPFAR), and were awarded an initial grant of US\$2m to strengthen existing hospices through the mentorship and accreditation programme; to develop new hospices with a goal of establishing a hospice in every health sub-district; and to establish centres for palliative learning to deliver palliative training programmes for persons affected by HIV/AIDS, community care givers, professional nurses, and medical practitioners. One of the objectives of the US funding was to develop new palliative care services. There were 52 hospices in HPCA membership in 2004, when this funding was first received; by 2010 there were a total of

202 hospice sites – 99 member hospices with 26 satellite services, and 61 development sites. Satellite sites are community branches of established hospices with a central administrative office and palliative care services in other parts of the city (Cape Town) or in neighbouring towns Grahamstown and Port Alfred. Development sites are NGOs or state facilities endeavouring to integrate palliative care into the service, with mentorship from HPCA staff or local hospices. Once the development site complies with entry level standards they are eligible for membership of HPCA. However, since 2013, it has been difficult for new organisations to become established and to obtain sustainable funding, and although HPCA membership increased to 108 member hospices in 2015, satellite services dropped to 18 and HPCA can no longer support development sites.

The HPCA received funding from PEPFAR to fund hospices services until 2013. A new grant was agreed in 2013, but this was no longer for funding hospices services but was to provide technical assistance to the government to integrate care and support services into government services, and more recently to support the South African government's National Adherence Strategy on HIV/AIDS to achieve the goals of 90-90-90 agreed by UNAIDS. The targets of this strategy are that 90% of people living with HIV know their status; 90% of people eligible for anti-retroviral treatment are receiving this treatment; and that 90% of people on HAART have undetectable viral load confirming successful treatment(192). The home care industry grew significantly to assist in providing care to people living with HIV. However, the change in strategy has impacted negatively on hospice funding and there is now limited funding for hospice and for home-based care, and many organisations have found it difficult to sustain services and to retain professional staff.

In responding to palliative care needs of patients living with HIV, hospices and palliative care services in South Africa and other parts of sub-Saharan Africa have developed strong services to provide community-based care(159). International funding has facilitated the growth in services and capacity building of HIV services. This has resulted in palliative care in South Africa operationalising the WHO definition of palliative care as early in the course of the illness in conjunction with treatment. Expertise developed in care of patients with cancer has been harnessed to care for people living with HIV(193)

#### 4.1.10 Funding for hospice services

Currently, hospices are funded primarily by donations from members of the community and corporate donors, and by grants from local and international trusts. Hospice care is provided free of charge to patients needing palliative care and charges are only made to patients with medical insurance for palliative care, which is a very small proportion of hospice patients.

Fundraising is therefore an important hospice activity. Fundraising events also serve to increase community awareness of the services provided by hospices, and attract volunteers to assist in hospice activities. Of note is the fact that WHA Resolution 67.19 recommends domestic funding from the state for palliative care urging government *“to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives”*(2) (para 1.2).

Some provincial departments of health provide limited grants for hospices on a year-by-year basis. Government funding is usually renewed annually, provided the hospice complies with reporting requirements. The department of social development also provides funding for hospice services in the Northern Cape province. Efforts are underway to improve government funding to NGOs providing palliative care.

The major cost of providing a palliative care service is staff costs. Providing domestically competitive salaries, an element of availability as described in General Comment 14 has proved challenging for many hospices, and salaried staff are often employed at a lower salary than staff in the state sector. Inadequate funding for staff has also been reported globally to impact adversely on reproductive health that highlights the fact that *“inadequate funding greatly limits the availability and quality of the (reproductive health) services”*(194). The current gap in funding has impacted negatively on hospices, forcing retrenchment of staff, closure of services and in some cases closure of hospices themselves.

#### 4.1.11 Human resources in palliative care

As described in Chapter One, the WHO definition of palliative care describes *“the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”*(30). South African hospices have salaried staff and volunteers to meet patients’ needs. For example, few SA hospices employ doctors but rely on general practitioners



who volunteer their time to provide medical care. As these doctors are volunteers, hospices are hesitant to request that the doctors train in palliative care. The state obligation to fulfil the Right to Health includes ensuring *“the appropriate training of doctors and other medical personnel”* and ensuring *“that health-care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups”*(1) (para 37).

All doctors will see patients with palliative care needs (133,195), and in order to provide palliative care for all patients who need palliative care, it is essential that generalist health care professionals are trained in palliative care during pre-service (undergraduate) training, and that they continue lifelong learning through formal Continuing Professional Development (CPD) programmes. Currently, there is no consistent training of doctors in palliative care and in pain management(196). The complex nature of palliative care, and the complexity of patient and family needs in the context of serious illness, mean that provision of comprehensive care requires an interdisciplinary team(30).

The WHA resolution recommends that there is basic training for all health care workers, intermediate training for health care professionals that routinely care for people with life-threatening conditions, and specialist palliative care training. This would ensure that palliative care services are available to all who need them(3).

Hospice nurses provide the foundation of palliative care. The nurse, trained in palliative care, does the first visit and assessment of the patient, and implements a care plan to address the individual needs of the patient and family, and often advises the doctor on the prescription of opioid medication for pain management. Hospice nurses are required to enrol in a one year training course in palliative nursing to ensure they have the necessary knowledge and skills to provide this care.

Social workers are also key staff members who provide individual and family counselling, assist with access to social grants and provide and co-ordinate bereavement care. Social workers and other hospice workers also address the care and support of orphaned children and children assessed as vulnerable because of their social and family circumstances. There are few palliative care training courses available for social workers in South Africa. Hospices have strong support

from local faith communities providing spiritual care, counselling and bereavement care. This is usually a volunteer function in hospices.

#### 4.1.12 Availability of palliative care services in the formal health care sector in South Africa

There are isolated pockets of excellence providing palliative care in the public health sector in South Africa(45). Chief of these services is Wits Palliative Care, designated the Gauteng Centre of Excellence for Palliative Care at Chris Hani Baragwanath Hospital in Soweto(41). The programme developed from a hospital-based palliative care team established in 1999, and ran the N'doro project (2003-2006) providing specialist palliative care services, outreach visits to the Soweto community, consultations for patients in Chris Hani Baragwanath Hospital, as well as training health care professionals, conducting research and undertaking advocacy activities for palliative care. An evaluation of the N'Doro project demonstrated a reduction in hospital costs and additional benefits to the hospital care system, by reducing congestion and ensuring that hospital beds are freed for acute care(41).

Jameson reported on the conversion of an unused ward at Settler's Hospital in Grahamstown, in the Eastern Cape in 2006 for palliative care(197). The ward staff were all trained in palliative care, with a daily ward round conducted by the nursing staff and palliative care doctor, and a weekly ward round by a larger group including staff from the ARV clinic, the hospice and the palliative care team. Patients admitted to the ward had either a cancer or HIV diagnosis. Evaluation of patient outcomes showed that HIV patients tended to need longer admission because of the complexity of their problems. The study concluded that that implementation of palliative care principles reduced the death rate of HIV patients admitted to the palliative care ward(197). However, the palliative care ward at Settler's Hospital was closed in 2016 as part of government cost-cutting initiatives.

Early hospital-based services were also established at Charlotte Maxeke Johannesburg Academic Hospital in 2001(40,45) and Steve Biko Academic Hospital in 2002(198). McCord Hospital in KZN opened a palliative care ward in 2006 but the hospital closed in 2012. An alternative model for the provision of palliative care is seen in Stellenbosch in the Western Cape, where Stellenbosch

Hospital has provided a ward to Stellenbosch Hospice; the hospice staffs the ward and the hospital provides medicines and support services to the 10-bed hospice(45).

Drawing on the UK Gold Standards Framework, van Niekerk and Cupido established a palliative care service, the Abundant Life programme at Victoria Hospital in Cape Town(168). Patients, mainly with advanced organ failure, and family members attend an outpatient group clinic held fortnightly. There is a multi-disciplinary approach that assists in educating the patient and family about their illness and prognosis, providing practical advice on coping with the illness as well as emotional support. In comparison with a control group, the Abundant Life patients were shown to have fewer admissions, fewer days in hospital, a higher rate of supported home deaths and lower hospital costs(168).

The limited number of hospital palliative care services is of concern(45); van Niekerk and Raubenheimer(133) conducted a point-prevalence survey of public hospital in-patients with palliative care needs in Cape Town in 2012. They concluded that 54.8% of patients in general medical wards had palliative care needs. They also commented on the young age of patients, and the high prevalence of end-stage renal failure and of HIV amongst those assessed as needing palliative care. A study of services provided in a large intermediate care centre in Cape Town in 2011 identified that the patients admitted to the palliative care ward were younger than those admitted for sub-acute care, and that 79% of the patients receiving palliative care had a diagnosis of HIV or TB(199).

#### 4.1.13 Availability of pain medication (essential drugs)

The fact that palliative care is provided in the NGO sector creates a barrier to the access of essential palliative care medicines, in particular opioid medication. Currently, only doctors can write prescriptions for opioid medication and a new prescription must be written each month. Patients referred to hospice are still registered with the state facility and access their medication from the referring facility. Patients who are bed-bound or home-bound and who require morphine for pain management have challenges to access medication. Opioid prescriptions may be written by the hospice doctor and taken to the hospital, where the doctor may have prescribing privileges (their prescriptions are recognized by the hospital pharmacy), by the

professional nurse or family member who collects the medication; alternatively, the patient must attend the health facility each time he or she requires a new prescription for the facility doctor to write the prescription. This is a burden to the patient who may not have access to transport or funds to pay for transport, or who may be too ill or too frail to travel to the hospital, and thus does not receive pain medication. There are additional barriers to pain management relating to lack of training of health care professionals in pain management and concerns regarding safety of opioids. Brennan and colleagues identify *“cultural, societal, religious, and political attitudes”* (75:205), as barriers to effective pain management. They state that *“the unreasonable failure to treat pain is viewed worldwide as poor medicine, unethical practice, and an abrogation of a fundamental human right”* (75:207).

#### 4.1.14 South African government support for palliative care

The South African government has worked closely with HPCA and hospices to improve availability of palliative care. Hospices have been recognised as key partners in health and welfare structures within health districts to ensure continuity of care for patients with chronic and life-threatening illness(121). This collaboration was highlighted at the meeting of African health departments described in Chapter One, which was held in Johannesburg in 2013 hosted by the then Deputy Minister of Health, Dr Gwen Ramakgopa to discuss the importance of palliative care in African countries. The Non-Communicable Disease (NCD) strategy describes the contribution of palliative care throughout the continuum of care, prevention treatment and care; the importance of palliative care interventions; planning for *“patients with advanced progressive illness to receive palliative care in the appropriate setting, including palliative home care”* (118:42); and palliative care training for all health care workers(118). The strategy also highlights the need to fully integrate prevention, management and care (including rehabilitative and palliative care) into the Re-engineering of Primary Health Care in South Africa. This integration would improve availability of palliative care to patients and families requiring this service. The NHI undertakes that *“All South Africans will have access to needed promotive, preventive, curative, rehabilitative and palliative health services that are of sufficient quality and are affordable, without exposing them to financial hardships”*, but does not describe how this is to be achieved(91) (para 30a).

Given this background, this chapter of the study was undertaken to assess availability of palliative care in South Africa.

#### 4.1.15 Problem statement

General Comment 14 describes availability in terms of functioning public health and health care facilities, goods and services. As described in Chapter one and illustrated in the map in this chapter South Africa has a network of hospices providing palliative care. However, there are few public sector palliative care services in South Africa. This limits the availability of palliative care to South African communities. There has also been limited training of health care personnel in palliative care, so that even in hospice services few doctors are trained in the discipline and rely on the professional nurses' advice in managing patients' pain. Although essential palliative care medicines are listed on SA Essential Drugs Lists, there may be barriers to the availability of opioid medication for management of pain, due to gaps in prescriber knowledge of pain management and analgesic prescribing, and misconceptions on the part of doctors, patients and families regarding opioid safety. The fact that South Africa has ratified the ICESCR means that palliative care should be seen as part of the state's Right to Health obligations. Thus, an obligation exists on the part of the state to ensure the availability of functioning palliative care services within public health facilities, trained medical and professional personnel receiving domestically competitive salaries, and essential palliative care medicines. Given the substantial need for palliative care services, identified in the preceding chapter, it is therefore necessary to establish the current availability of palliative care services, trained palliative care personnel and availability of essential medicines in South Africa.

#### 4.1.16 Aim and objectives

Aim: To describe availability of palliative care services in South Africa

Objectives:

1. To identify palliative care services in South Africa
2. To describe palliative care services in South Africa

3. To describe human resources within palliative care services and level of palliative care training
4. To describe the demographics of palliative care beneficiaries in South Africa
5. To describe perceptions of palliative care providers regarding availability of morphine
6. to compare availability of palliative care with need identified in Chapter Three

## 4.2 Methodology

### 4.2.1 Study design

Cross-sectional descriptive study of current palliative care services in South Africa in 2010.

### 4.2.2 Study site

The survey was conducted in two stages in all nine provinces of South Africa: Stage 1 to identify palliative care services; and Stage 2 to survey these organisations.

### 4.2.3 Study population

The study population was all managers of community-based organisations, faith-based organisations and all health care facilities within the public health sector identified by Department of Health or by PEPFAR as being funded for palliative care, or from the Hospice Palliative Care Association database of members.

### 4.2.4 Sampling

All identified palliative care organisations in South Africa were invited to take part in the study.

### 4.2.5 Data collection

Data collection tools were developed prior to initiating the research. The development of the tools is described first and then the 2-stage data collection of identifying the sites and conducting the survey of availability.

### 4.2.6 Data collection tools

i) To identify organisations that provide palliative care, data extraction sheets were developed to record name of the site, the manager's name and the email address for the manager. (Appendix A2 page 275)

ii) To obtain information from services identified as providing palliative care, a survey was developed using SurveyMonkey<sup>R</sup> (Appendix A3 page 276). The questionnaire was developed by

the researcher in discussion with palliative care colleagues, following review of the literature to identify essential palliative care practices, and in consultation with supervisors. Questions were developed to identify the health district served, elements of palliative care offered by the services, the cadres of staff providing palliative care, level of training of staff, and availability of medication for pain control specifically whether there was access to morphine at the service, whether there were barriers to access to morphine, and who prescribed morphine for patients cared for in the service. The elements of palliative care included in the questionnaire addressed type of care (home care, out-patient care, day care, in-patient care), pain and symptom management, treatment support, access to grants, access to food, spiritual counselling and bereavement counselling. Questions relating to patient numbers, patient demographics were part of the questionnaire. We included race as a question in the demographics to identify whether there may be any discrimination on the basis of race. Questions also assessed access to information, how patients/clients get information about the service were included.

In providing holistic care, hospices pay particular attention to culturally appropriate care. As the Right to Health element of Acceptability includes the fact that services should be culturally appropriate, respondents were asked to identify whether they provided culturally sensitive care and, if so, how they ensure that care is culturally sensitive.

With regard to human resources, the study did not ask how many staff were employed by the palliative care services, but which groups of staff were deployed and whether in part-time, full-time or in a volunteer capacity.; and what level of training staff had received.

In addition to the yes/no responses for the majority of questions, there were open-ended questions asking the following: How does your service assure culturally appropriate care? If there are barriers to patients being able to access morphine, please describe these barriers? How do your patients/clients get information about your services? The questions relating to culturally appropriate care were included to provide some consideration of the General Comment 14 element of Acceptability. The questions on access to morphine and information provided about the service relate to the element of Accessibility.

#### 4.2.7 Data collection method

i) The researcher introduced the research project to HPCA provincial staff at a meeting of the Provincial Palliative Care Development Co-ordinators (PPCDCs). The purpose of the research was explained to staff and a request was made to PPCDCs to identify palliative care sites guided by the data extraction sheets. A draft letter was provided to introduce the study to provincial departments of health personnel and to ask permission to obtain the required information. PPCDCs were identified by the HPCA Organisation Development manager as appropriate to conduct the investigation into palliative care services, as they were working with HPCA member organisations and other Non-Governmental Organisations (NGOs) or Faith Based Organisations (FBOs) intending to integrate palliative care into their services. They had already developed relationships with provincial Departments of Health, and were frequently approached to assess organisational capacity and development needs of NGOs funded by the provincial departments of health. HPCA staff were trained in data collection and research ethics prior to interviewing provincial DoH staff. The information obtained by HPCA staff was collated into a database of palliative care services. The Hospice Palliative Care Association was also approached with a request for access to the database of HPCA member organisations.

ii) A fourth year medical student was engaged as a research assistant (NRF grant number 74430) to administer the palliative care survey. She was trained in the administrative process, the research method of distributing the survey to eligible sites, and research ethics. She was provided with ethical approval letters from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee and from HPCA Research Ethics Committee. The research assistant created the database of sites providing palliative care within South Africa in conjunction with hospice staff in each province. She sent the web-link to managers at study sites by email. The research assistant also took responsibility to check responses to the survey, and encourage completion of survey documents to improve the response rate. Some sites opted to complete the questionnaire in hard copy and to fax the completed questionnaire to the research assistant. Prior to data analysis, the researcher reviewed the response rate and undertook a second round of distribution of the survey. She also phoned some of the initial non-responders to encourage their participation in the survey. Data collection efforts were ended after 8 months



#### 4.2.8 Data storage and management

Electronic responses to the survey were stored on SurveyMonkey<sup>R</sup> and password protected. Hard copy responses were filed and stored in a secure filing cabinet in the PI's office.

#### 4.2.9 Ethical considerations

The study was approved by the Human Research Ethics Committee at the University of Cape Town, ref number 320/2010 (Appendix C1 page 291) and by the HPCA Research Ethics Committee, ref number 06/10 (Appendix C2 page 292). Ethical approvals were renewed annually throughout the course of the research.

Hospices responding electronically to the survey were supportive of the survey conducted and provided the hospice name as part of the survey.

#### 4.2.10 Data analysis

The data was imported into an Excel spreadsheet for analysis. Pivot tables were used to report the services provided by organisations, the numbers of staff and volunteers engaged by the organisations, and the level of palliative care training of different categories of staff. Data on availability of morphine, employment of doctors and training of doctors was imported into Stata; Chi squared tests and Odds ratios (with 95% Confidence Intervals) were estimated, to assess whether there was a statistically significant association between availability of morphine and 1) employment of doctors; and 2) the training levels of doctors. In addition, analysis using Chi squared testing was conducted to determine whether there was a statistically significant association between report of barriers to patient access to morphine and 1) employment of doctors; and 2) the training levels of doctors. Further analysis calculated the Odds ratio for the association between morphine availability and rurality.

Data on number of patients receiving palliative care were not precise enough to provide an accurate estimate, as services were asked about the range of patient numbers. To estimate the number of people receiving palliative care a mid-point of the specified ranges were used.

## Content analysis of narrative responses

Three questions accepted narrative responses, including questions on provision of culturally appropriate care; availability of morphine; and providing information about the services.

Only four organisations responded to the question regarding the provision of culturally sensitive care. The responses to the question on availability of morphine were gathered into a single document and reviewed to identify themes emerging from the data. Coding of themes guided the content analysis of these responses. Quotes from participating organisations anonymised by using numbers instead of organisation name are presented supporting these themes.

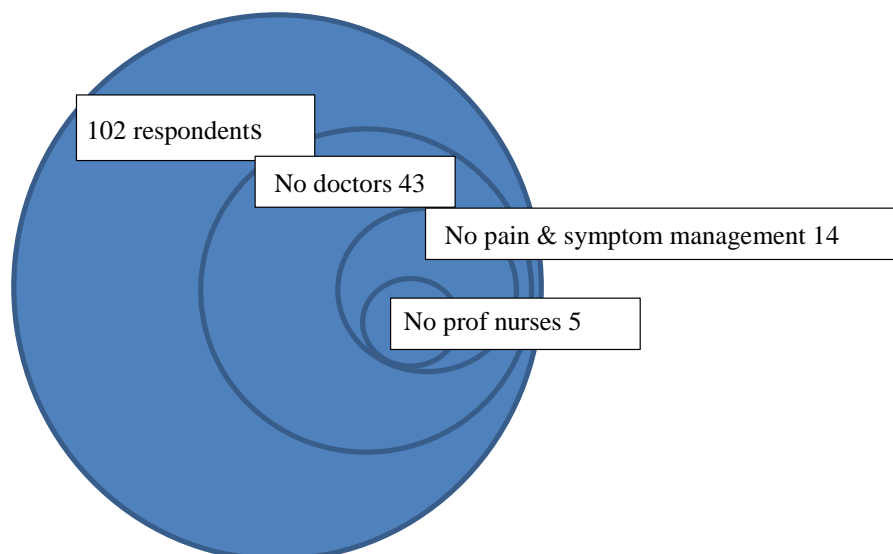
## 4.3 Results

### 4.3.1 Sites providing palliative care

There were 131 sites identified as providing palliative care in South Africa. The electronic survey was sent to all sites with an initial response from 60 sites. The follow-up of non-responding sites generated a further 44 responses to bring the response rate to 79.4%.

One hundred and two sites completed the palliative care survey - two sites reported that they do not provide a palliative care service and did not complete the survey. Of respondents, three sites were hospital-based palliative care services in the public health sector (2.88%). The remaining 101 services (97.12% of respondents) were Non-Government Organisations (NGOs).

*Figure 4.2: indicating gaps in palliative care service*

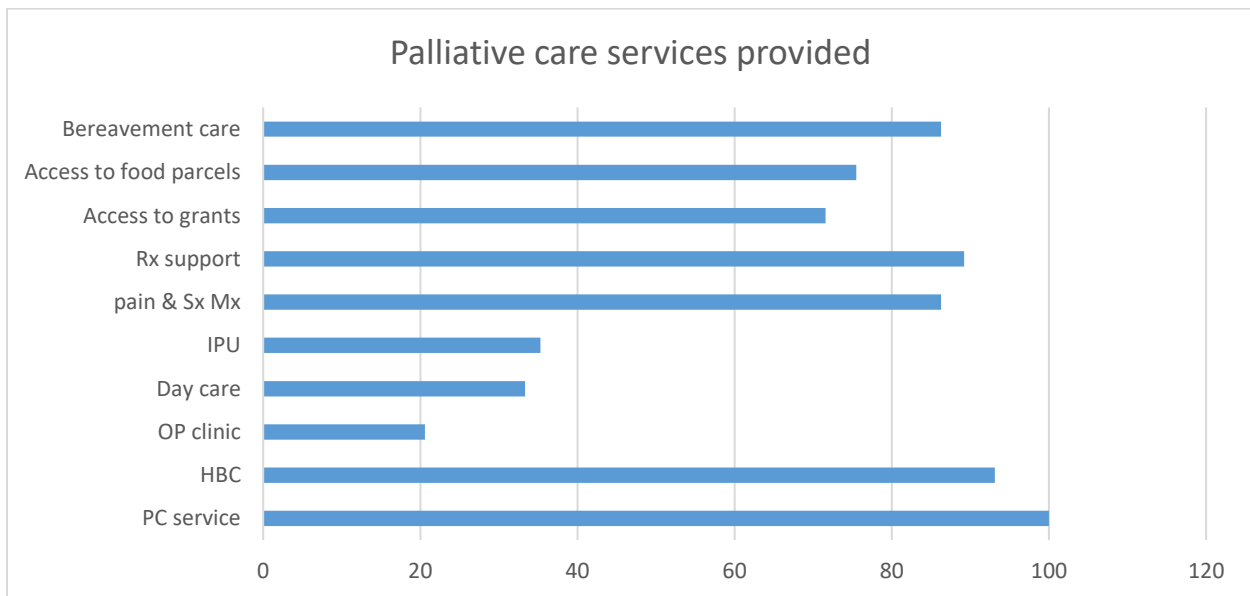




### 4.3.2 Elements of palliative care provided by sites

Figure 4.4 illustrates the elements of palliative care provided by respondents to the questionnaire (see below). The median number of elements of palliative care provided was eight; there were five sites providing only three or fewer elements of care. There were only three services that provided all elements of palliative care, but of the 13 sites providing 10 elements, three did not have in-patient care and nine had either day care or outpatient clinics – these two services often being interchangeable in the palliative care setting. Thirty-six services reported having in-patient care, 35% of services. The most commonly provided elements were Home-based care 93%, Counselling 92%, Treatment support 89%, Pain & symptom management 86%, Bereavement care 86%. There were 71% of services providing these 4 key elements of palliative care.

Figure 4.4: Palliative care services provided as percentage of total number of organisations

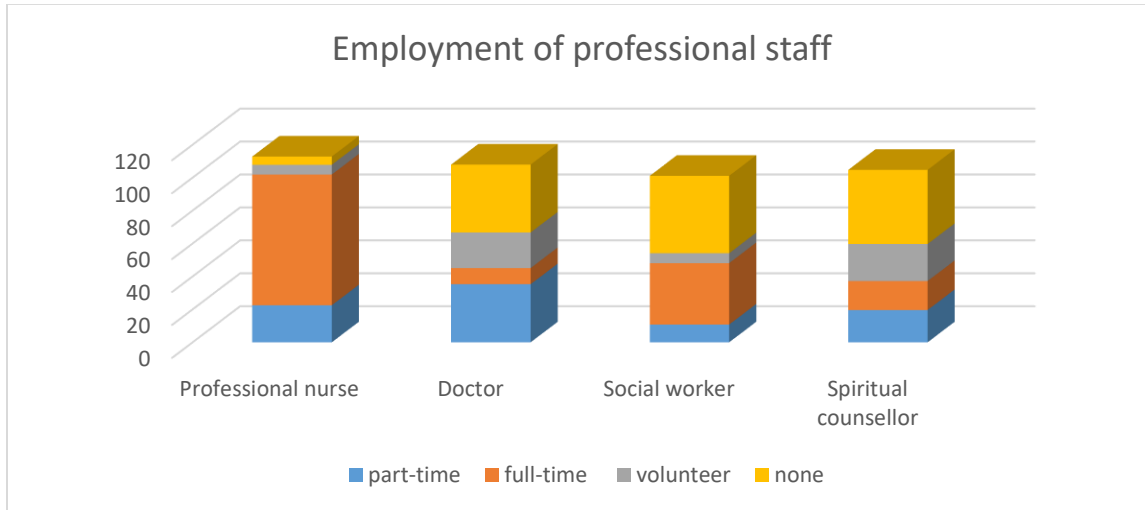


### 4.3.3 Human resources

The majority of services employed professional nurses, 79.4% with PNs employed full-time. Fifty-nine services (57.84%) have doctors working in the service; these are most frequently part-time employees. Ten services reported full-time medical staff and there is again a significant voluntary contribution by doctors (21.57%). There were five services (4.9%) without professional nurses;

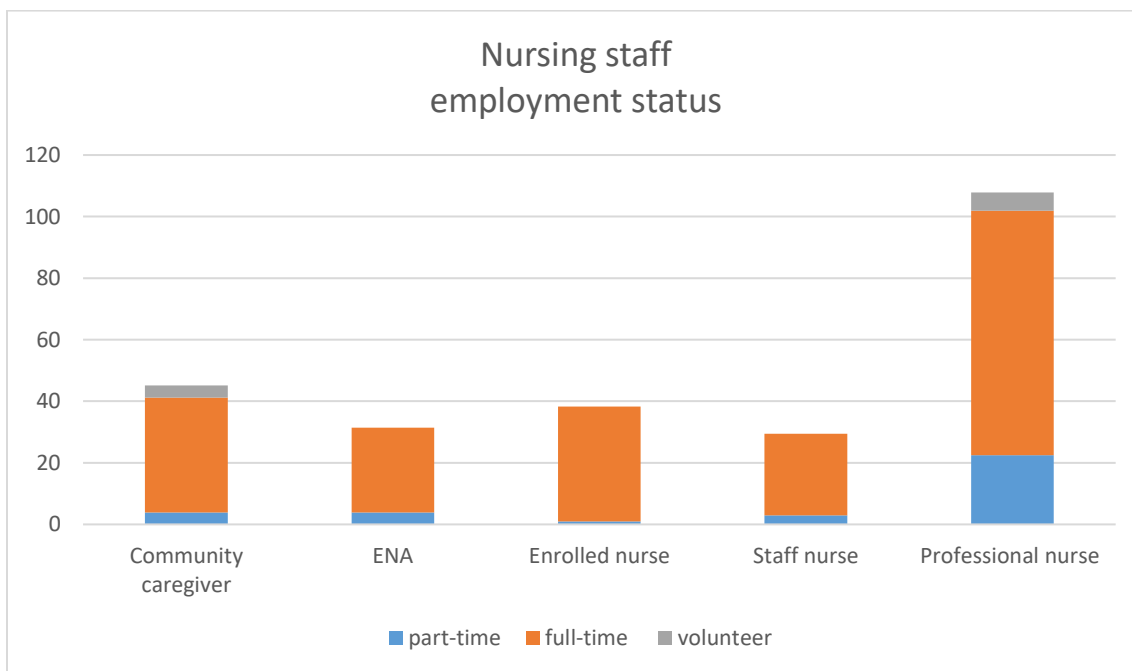
41.18% of services with no doctors; 47.06% with no social workers; and 45.09% with no spiritual counsellors (Figure 4.5).

Figure 4.5: Cadres of professional staff at site, part-time, full-time and volunteer



The most common cadre of palliative care worker is the professional nurse usually employed full-time. Part-time nurses and volunteer nurses also work at palliative care services. (Figure 4.6).

Figure 4.6: Employment of staff providing nursing care



There were 26.47% of organisations with neither social workers nor social auxiliary workers. Social workers and social auxiliary workers were usually in full-time employment, with 10.7% of organisations employing part-time social workers and 3.92% of organisations employing part-time social auxiliary workers (Figure 4.7).

Figure 4.7: Employment of counselling staff



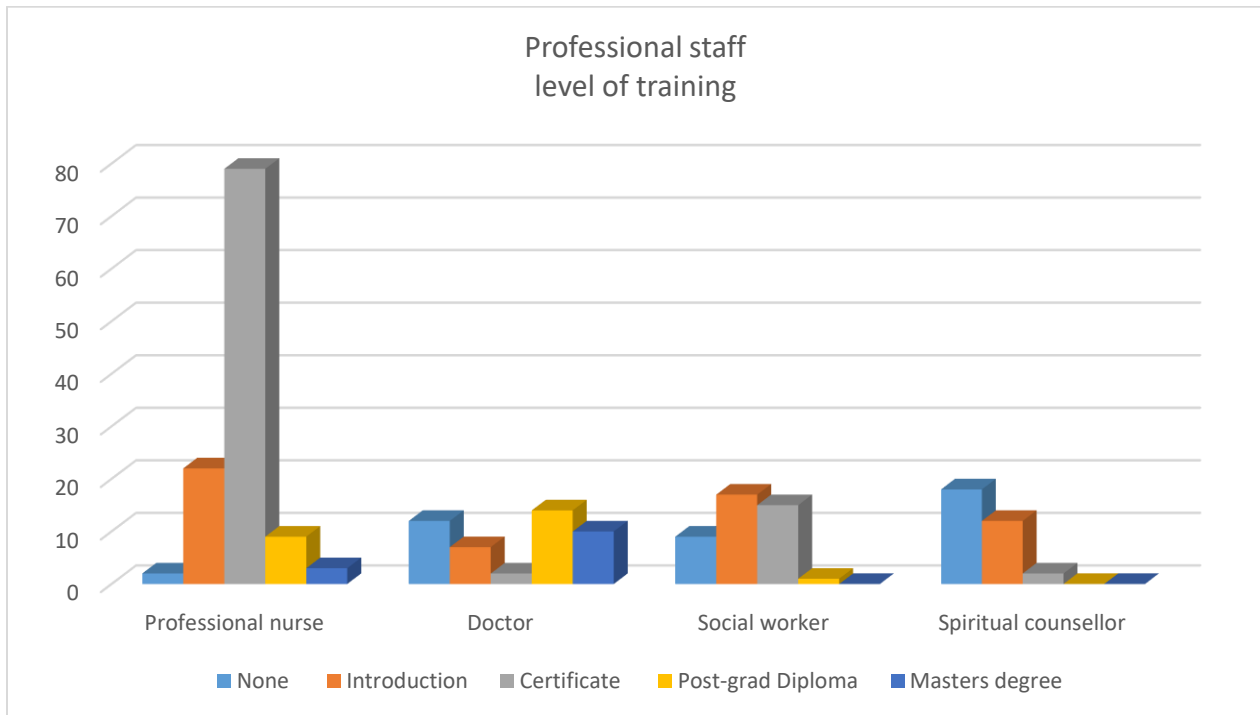
4.3.4 Organisations with limited staffing

Five services reported that they did not have professional nurses on their staff as employees or as volunteers. Of these services one reported employment of community caregivers and a full-time spiritual counsellor; two reported employment of social auxiliary workers and community caregivers; one reported employment of a social auxiliary worker, community caregivers, enrolled nurses, a volunteer social worker and a full-time spiritual counsellor; one reported employment of social auxiliary workers only.

#### 4.3.5 Staff trained in palliative care.

Services reported on the level of training of staff members but were not asked how many staff members had undertaken training. (See Figure 4.8 for training of professional staff and Figure 4.9 for training of non-professional staff).

Figure 4.8: Palliative care training of professional staff



##### 4.3.5.1 Nurses

Professional nurses are the group of palliative care staff most likely to have received training in palliative care, with 79 services reporting PNs trained in the one-year HPCA certificate course in palliative nursing care, nine services reporting PNs with a post-graduate diploma in palliative care, and three services reporting nurses with masters' degrees in palliative care. Twenty-two services have PNs with only a 5-day Introduction to Palliative Care as their palliative care training, and two services reported that the Professional nurse(s) had no training in palliative care

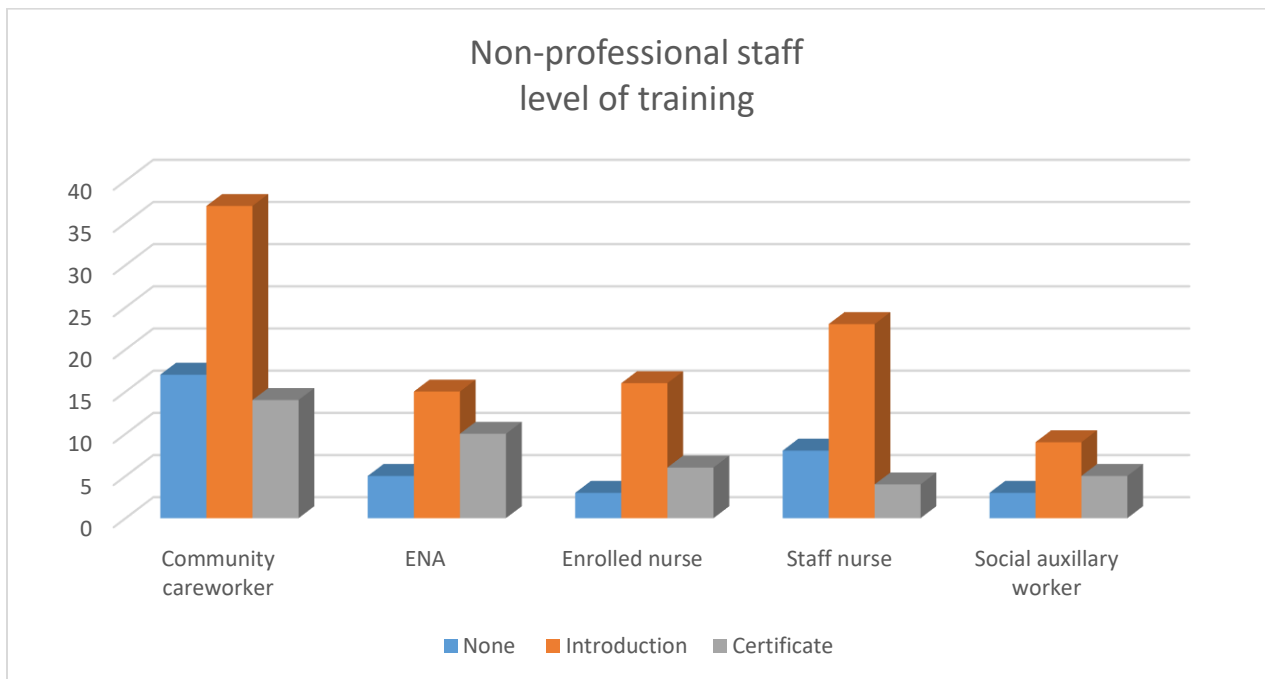
#### 4.3.5.2 Doctors

There are 14 services (13.73%) where doctors have a post-graduate diploma in palliative medicine, 10 with masters' degree (9. 81%), and two with a certificate in palliative care. In 12 services (11.76%), the doctors have not been trained in any form of palliative care, and in seven services the doctors have had a 5-day introduction to Palliative Care.

#### 4.3.5.2 Counselling staff

Social workers at 15 of the services, social auxiliary workers at six services and spiritual counsellors at two services had received certificate level training in palliative care; and one service employed a social worker who had completed a postgraduate diploma in palliative care. A number of services reported a 5-day introduction to palliative care as the training received by social workers (17), social auxiliary workers (23) and spiritual counsellors (12). However, there were also many services where the counselling staff had not received training in palliative care: social workers (9), social auxiliary workers (8), and spiritual counsellors (18).

Figure 4.9: Training of non-professional staff





#### 4.3.5.4 Community Caregivers

The second largest group of staff is the community caregivers, and in 14 services community caregivers had been to training on a certificate course in palliative care, 37 services had community caregivers who had completed an introduction to palliative care, and 17 services had community caregivers who were not trained in palliative care (Chart 4.8).

#### 4.3.6 Beneficiaries of palliative care

The survey asked the average numbers of patients cared for per month and the demographics of the patient population with regard to age group, gender and race.

Of the 102 responding services, there are 32 organisations caring for fewer than 100 patients per month – six caring for fewer than 20 patients per month, 11 services caring for between 21 and 50 patients per month, and 15 services caring for between 51 and 100 patients per month. There are 52 services that care for between 100 and 400 patients per month, and 18 services that care for over 400 patients per month. Taking a mid-point figure within these ranges, it is estimated that the responding services were providing care to an estimated 12,286 (mid-range) to a maximum 23,870 patients per month. However, there was a 19% non-response rate. Making an assumption that the non-responders were similar in size to the responders and had a similar average number of patients in care, an estimated 15,168 (mid-range) to maximum 29,469 people were cared for per month across South Africa in 2010.

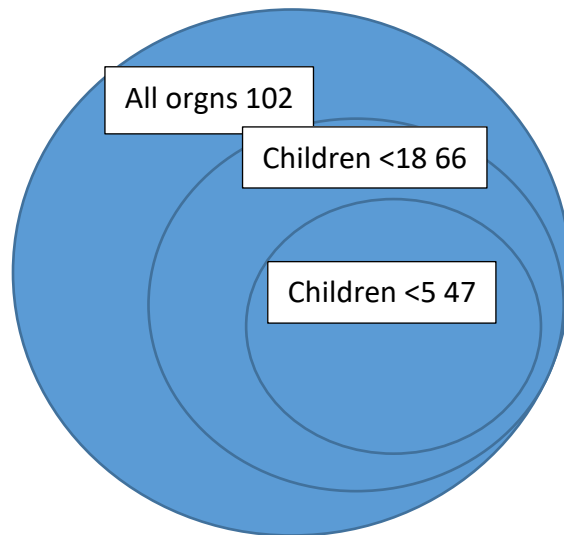
The majority of patients cared for by palliative care services are female (62%). The majority of patients cared for by the services surveyed are black patients (72%), with 17% coloured patients, 10% white patients and 1% Asian patients.

##### 4.3.6.1 Age categories of beneficiaries

Forty-three services cared for all age categories. However, 14 services did not identify the ages of patients cared for. Forty-seven services cared for children under the age of five, and 66 services

cared for children up to the age of 18. Only two of the services surveyed care only for children. Seventy-six services cared for patients above the age of 60 (See Figure 4.10 below).

Figure 4.10: Organisations that cared for children compared to all organisations (102)



#### 4.3.7 Services reporting providing culturally sensitive care

The survey found that 84 of the services answered the question relating to providing culturally sensitive care, and that this reported as achieved through employment of carers of the same culture as recipients of care (72 services) and speaking the same language as patients and families (73 services), through formal training in provision of culturally sensitive care (46 services) and through cultural awareness programmes (72 services). Four services responded “other” to the question: How does your service assure culturally appropriate care? and explained:

*“Appropriate care is given, as cross-cultural care”*

*“In certain instances where we cannot provide a caregiver of the same cultural and language group, staff are able to accommodate the patient's cultural needs”*

*“Cultural issues discussed at the Interdisciplinary team meetings”*

*“We have people from all cultures and religions working at \_ Hospice”*

#### 4.3.8 Availability of morphine

Of 102 palliative care services, 80 reported access to morphine for patients requiring pain control; 21 reported no access to morphine for pain control, and one service did not respond to the question. Ten services that did not have access to morphine reported that their patients did not require morphine. One service that did have access to medication reported that their patients did not require morphine.

Eighty-eight services reported on sources of morphine prescription when asked to report on who prescribed morphine; on average there were at least two sources of morphine prescriptions. Morphine was prescribed by hospital doctors (60.8% of services); doctors working at the service prescribed morphine at 42 services (41.2%); private doctors prescribed morphine for patients at 40 services (39.2%) and clinic doctors for 25 services (24.5%). Four services used doctors from all four sources for morphine prescriptions.

*Table 4.2: Availability of morphine and presence of doctor*

Presence of a doctor	Availability of morphine (%)
No doctor (n=43)	63
Volunteer (n=16)	81
Part-time (n=33)	91
Full-time (n=*10)	100

Services with full-time doctors ensure availability of morphine (100% availability), while part-time (91% availability) and volunteer doctors (81% availability) also make access to morphine more likely for patients compared to services that do not have doctors (63% availability). This difference was statistically significant ( $p=0.007$ ). The presence of any doctor in the service was associated with a greater likelihood of availability of morphine (Odds Ratio 7.06; 95% CI 2.35-21.24).

There was a high percentage of responding services (70.59%) where there were either no doctors or doctors had not received palliative care training. For PC services, the presence of a health

professional was associated with increased access to morphine, and this association was stronger when the doctor or nurse was trained in PC (Table 4.3).

*Table 4.3: Access to morphine compared to profession and training*

Morphine available	Doctor present	Doctor trained	Nurse present	Nurse trained
Odds Ratio	7.06	3.22	2.57	9.63
95% CI	2.38-21.24	0.88-11.87	0.41-16.41	0.40-15.41
Exact	26.68	18.32	23.76	63.66

Although Odds Ratios were increased for all categories, only the OR for the presence of a doctor was statistically significant. The majority of services (95.1%) employed professional nurses so it was not possible to infer statistical significance. Doctors with any level of palliative care training guarantee 100% availability of morphine to patients requiring pain control.

*Table 4.4: Access to morphine rural vs urban setting*

Morphine available		Rural services	Urban services	Total
No	#	18	4	22
	%	26.09	12.12	21.57
Yes	#	51	29	80
	%	73.91	87.88	78.43
Total	#	69	33	102

Availability of morphine was more likely in services in urban (88%) settings than in rural (74%) settings (Odds Ratio 2.55, confidence interval 0.79-8.20)

#### 4.3.9 Barriers to patients access to morphine

Access to morphine was used as a marker of provision of palliative care. Thirty-five services reported that there were barriers to their patients being able to access morphine; 48 services reported no barriers to access to morphine, and 16 services said that the question was not applicable to their service. Barriers were less of a problem in services employing a full-time

doctor. However, of the 10 services employing full-time doctors, 30% still reported barriers to accessing morphine. Services without a doctor were more likely to consider barriers to morphine availability as a problem not applicable to their patients. Of the services not employing doctors, 40% reported barriers to accessing morphine and 40% reported that their patients did not require morphine so that the questions was not applicable to that service, but this calls into question whether the service was providing palliative care.

#### 4.3.10 Qualitative analysis of barriers to access to morphine

Services were asked to comment on barriers to access to morphine. Thirty-five services described barriers under the following themes: availability of morphine in health facilities; staff issues; doctors not familiar with prescribing morphine; transport/travel to health facility; and issues with regard to monitoring administration of morphine. Organisations' responses are anonymised and simply presented as the numeral allocated to the organisation.

4.3.10.1 Availability of morphine in health facilities: Services that relied on other facilities to provide morphine, reported that sometimes supply was intermittent or stock ran out. This comment only applied to public sector clinics, district hospitals and provincial hospitals. Patients with medical insurance or funds to pay out-of-pocket expenses could get a prescription from a private doctor or hospice doctor and buy the medication at a private pharmacy:

*"Only Hospital doctors / private doctors could prescribe Morphine to our patients and that also depends on the availability of morphine at the hospital pharmacy. Even basic pain treatment like Panado tablets are not accessible in many cases and if it is available, Nurses will issue only 10-20 tablets per patient"* #86

*"For state patients to access morphine could be a lengthy process; and prescriptions are not always given."* #11

*"Morphine is only given out at the government hospital and is not always available."* #44

**4.3.10.2 Staff issues:** Hospices commented on the problems in employing full-time staff to meet the legislative requirements for administration of scheduled drugs. These problems were due both to lack of staff in some areas and funding constraints.

For example, an obstacle noted was the: *“Cost of 24 hour registered nurse cover to handle scheduled drugs”* #66

Hospices reported not having resident doctors or pharmacists for reasons of cost. This was complicated by adverse conditions of employment in rural sites where, for example, a hospice reported:

*“we struggle to keep a professional nurse on at the moment because of our remote location”* #50

**4.3.10.3 Doctors not familiar with prescribing of morphine:** A number of the organisations surveyed reported on doctors’ attitudes and knowledge of use of opioids as a barrier to availability of morphine for pain control. Doctors were reported as being *“Opioid-naïve”* and *“hesitant to prescribe Morphine.”* #77

Respondents reported the following concerns:

*“We find that a lot of GPs and even specialists and oncologists question the usage of morphine and think that we administer it too easily and too much.”* #39

*“There are no barriers to access but barriers to prescriptions as inadequate dosages or frequencies are often prescribed”* #77

**4.3.10.4 Transport/travel to health facility:** The distance from the health care facility was reported as a barrier for many patients in accessing pain medication. Patients in palliative care may be frail and find the travel to the clinic and the clinic visit too arduous. For example, respondents commented that:

*"We do the home-based care but the patients need to go to the hospital and get the prescription from the doctor if they need morphine"* #58

*"Patients are too ill to access public transport and spend hours at healthcare facility"* #61

*"Some patients are too ill to visit their local CHC monthly for repeat prescriptions"* #55

Worse still, the consequences are serious for patient outcomes:

*"Some patients died in pain, sometimes there is no doctor and sometimes they are too weak to go to the clinic for the prescription."* #16

#### 4.3.10.5 Monitoring administration of morphine:

The absence of a family member who could be identified to take responsibility for administering morphine in the home was also reported as a barrier. Furthermore, inadequate explanation of the use of morphine by the prescribing doctor or pharmacist dispensing morphine was also identified as a barrier for morphine administration in the home.

#### 4.3.11 Access to information about the service provided

In general, information about the responding organisations' services was widely disseminated. Only five organisations did not provide any information about their service to referral sites, patients and families or other NGOs. Seventy-eight organisations provide information to sites that refer patients to the palliative care service, 85 organisations provide information to patients and families, and 72 organisations provide information to other NGOs. Sixty-two organisations provide information to all three groups. There were varied methods reported for disseminating information about palliative care services offered by the organisations surveyed. Word of mouth was identified as an important method of sharing information about the service, including patients and families telling others about the care they receive. In addition, organisations surveyed described awareness campaigns, talks and use of traditional and social media to share information about the services. They also reported on the printed information such as pamphlets and posters that are available to publicise the service.

## 4.4 Discussion

### 4.4.1 Availability of palliative care

The objectives of this study investigating availability of palliative care in South Africa were: 1) to identify palliative care services in South Africa; 2) to describe the elements of palliative care provided by services in South Africa; 3) to describe the demographics of palliative care beneficiaries in South Africa; 4) to identify the human resources skills within palliative care services and level of palliative care training; 5) to determine perceptions of palliative care providers regarding availability of morphine; and 6) to appraise the availability of palliative care with need identified in Chapter Three. The four essential elements of the Right to Health - Availability, Accessibility, Acceptability and Quality - are inter-related, and some aspects of Accessibility and Acceptability will surface in this chapter examining the Availability of palliative care services in South Africa.

In discussing the study findings, consideration is given to elements defined by General Comment 14 as comprising the Right to Health, with particular focus on Availability of health services and resources for health; and to the WHA resolution 67.19 which urges governments to *“integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes”*(3) (para 1.1).

### 4.4.2 Palliative care services in South Africa

The study identified 131 services in South Africa as palliative care services from the HPCA database and from government and funder records as receiving funding for palliative care. Although seven public health hospital facilities were included in the 131 services invited to take part in the survey, one responded that they did not provide palliative care, and only 3% of respondents were from palliative care services within public health facilities. This suggests that palliative care services are not *“available in sufficient quantity”* in the public health sector as required by General Comment 14.

The remaining respondents were non-governmental services. There has been an increase in the number of hospices since the 2002 published report on status of palliative care(193). The 2007



review by Clark and colleagues noted that hospices need to source their own funding (184). This study confirms that the situation of palliative care being provided by NGOs still persists.

#### 4.4.3 Elements of palliative care provided by sites

In order to investigate whether the facilities were functioning with regard to the provision of palliative care, the survey asked about the range of services provided by the respondent services. The survey used both APCA components of palliative care(200) and the WHO definition of palliative care (30) to define a required range of services. In describing palliative care, APCA identifies four components of care relating to patient and family: 1) management of physical pain and symptoms, 2)the promotion of emotional and mental health, 3) social and practical support and 4) spiritual care (194). The WHO definition of palliative care includes the assessment and treatment of pain and other distressing symptoms, addressing psychosocial needs (including bereavement counselling), and spiritual needs to define a required range of services(28). Palliative care can be provided wherever the patient is, so hospital based palliative care, in-patient hospice palliative care, hospice home care and day care are all appropriate places for the delivery of palliative care. The survey showed that, of the 99 Non-Governmental Organisations (NGOs) responding to the survey, 36 had in-patient facilities and 94 provided care in the patients' homes confirming HPCA reports that the majority of hospice care in South Africa is provided in patients' homes(103). Professional nurses visit patients to provide palliative care, to supervise home based care workers and to encourage and support family members in the care they provide to the patients. There may be periods when it is essential for the patient to be in a hospital or hospice in-patient unit for management of complex problems such as pain or other symptom control.

Pain and symptom management are the foremost physical aspects of palliative care, and the relief of suffering from physical problems is a key component of a palliative care service. It is of concern that only 88 of the 102 services that responded to the survey identified that they provide pain and symptom management. Since pain relief is core to palliative care, this would suggest that the 14 services not providing pain and symptom management do not meet the General Comment 14 criterion of functioning services of sufficient quality(1). Equally important are the

psychosocial and spiritual care elements of palliative care. The results show that 86 services provide spiritual care, 88 provide bereavement care and 91 provide counselling services. Altogether 71% provided all four modalities - pain relief, spiritual care, bereavement care, and counselling. Thus, although some of the services do not meet the criteria for the provision of palliative care, the majority of services that responded to the survey are functioning palliative care services.

#### 4.4.4 Demographics

The services surveyed indicated that care was provided to all age categories, although less than half of the services care for children under the age of five years. The majority of patients cared for by palliative care services were female (62%). It is of note that studies have identified that men are cared for at home more often by their female relatives and that women needing care receive this from hospital or care organisations. Akintola identifies care as being a gendered issue and concerns that women who are already vulnerable because of their low socio-economic status carry the burden of care-giving together with efforts to earn an income for the family(201).

The majority of patients cared for by the services surveyed are black patients (72%), with 17% coloured patients, 10% white patients and 1% Asian patients. This correlates approximately to the demographics of South Africa as reported by StatsSA for 2011 of 79% black/African, 9% coloured, 2.5% Indian/Asian and 9% white. This indicates that palliative care services are available without discrimination with regard to race in palliative care services in South Africa. It may also indicate acceptability of services to all population groups as described by General Comment 14. The element of Acceptability described by General Comment 14 relates to being culturally appropriate and adhering to medical ethics (1). The organisations surveyed described that they included processes to enhance provision of culturally sensitive care employing staff of the same culture and speaking the same language as recipients of care, as well as formal training in culturally sensitive care and through cultural awareness programmes.

#### 4.4.5 Human resources for palliative care

The complex nature of palliative care and the complexity of patient and family needs in the context of serious illness mean that provision of comprehensive care requires an interdisciplinary

team. South African studies have documented the effectiveness of the palliative care team in the hospital setting (40,41,168). This study indicated a range of staff and volunteers that contributed to provision of palliative care as part of a multidisciplinary care team.

General Comment 14 describes the requirement for “*professional personnel receiving domestically competitive salaries*” to meet the element of Availability within the Right to Health. South African hospices follow the interdisciplinary model and have salaried staff and volunteers to meet these varied needs of patients and families. As in most developing countries, South African hospices have a reliance on volunteers. Volunteers are appreciated; but the reliance on volunteers makes the sustainability of the service uncertain and violates the requirement for staff with adequate remuneration. The study showed that of responding organisations with doctors on their staff, about a third (n=22) were providing their expertise on a voluntary basis. This had a positive impact on the availability of morphine for patients cared for in the organisations, since the presence of a doctor was associated with a 7-fold increased chance of morphine being available (Table 4.3). Five organisations did not have a professional nurse or doctor on their staff, which would call into question whether the organisation was equipped to provide palliative care at all. Without a professional nurse or doctor, it is not possible to assess and manage pain and other distressing symptoms.

In South Africa, hospice nurses provide the foundation of palliative care and this study found that the majority (95.2%) of the organisations surveyed employed professional nurses. Social workers are also key staff members who provide individual and family counselling, assist with access to social grants and provide and co-ordinate bereavement care. This study reports that 76% of respondents have social workers or social auxiliary workers at the service. Social workers and other hospice workers also address the care and support of orphaned children and children assessed as vulnerable because of their social and family circumstances. Thirteen services did not have counselling staff either employed or in volunteer capacity, and fewer services employed counselling staff than employed nurses. The counselling staff included social workers, social auxiliary workers and spiritual counsellors. Hospices have strong support from local faith communities providing spiritual care, counselling and bereavement care. A high proportion (37%) of the spiritual counsellors were volunteers.

#### 4.4.6 Level of palliative care training

General Comment 14 describes the requirement for “*trained medical and professional personnel*” to meet the element of Availability(1) (para 12a). WHA resolution 67.19 further urges “*the inclusion of palliative care as an integral component of the ongoing education and training offered to care providers*”(2) (para 1.4).

The state obligation to fulfil the Right to Health includes that states “*have to ensure the appropriate training of doctors and other medical personnel*” (para 36) and ensuring “*that health-care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups*”(1) (para 37). The WHA Resolution 67.19 recommends basic palliative care training for all health care workers, intermediate training for health care professionals that routinely care for people with life-threatening conditions, and specialist palliative care training(2). This would ensure that palliative care services are available to all who need them. In order to provide palliative care for all patients who need this care, it is essential that generalist health care professionals are trained in palliative care during pre-service (undergraduate) training, and that they continue lifelong learning through formal Continuing Professional Development (CPD) programmes. Education is one of the four pillars of the WHO public health Strategy for the integration of palliative care into a country’s health system(100). It is encouraging to note that, in 24 services surveyed in this study, doctors had completed postgraduate training in palliative medicine; although in contrast, the doctors in 19 services had little or no palliative care training. Morphine availability was assured in services where doctors had undertaken palliative care training. There were also 12 services where professional nurses had completed postgraduate training in palliative care, either a postgraduate diploma in palliative care or a masters’ degree in palliative care. Analysis showed that with a professional nurse trained in palliative care the odds of morphine being available to patients are 9.63 times greater (Table 4.3) than when there is no nurse trained in palliative care.

However, professional nurses in twenty-two services had completed only a five-day training course as an Introduction to Palliative Care, and nurses at two services had received no training in palliative care. In the light of the role nurses play in palliative care, it is important that training gaps are identified and that all nurses are trained in palliative care. The survey demonstrated a

variety of training levels for social workers, social auxiliary workers and spiritual counsellors, with few counselling professionals having adequate palliative care training, although 15 services had social workers who had completed a certificate level training in palliative care and one with a social worker who has a PG diploma in palliative care.

Psychosocial and spiritual care are important elements of palliative care and it would be a requirement of a palliative care service to engage competent trained counselling staff in order to meet patients' needs.

The current lack of palliative care training in South Africa means that few doctors are equipped to adequately assess and manage symptoms such as pain that are frequently experienced by people living with life-threatening conditions (202). International advocacy efforts often use adequacy of pain management and availability of pain medication as proxies to measure availability of palliative care. It is considered that focusing on a single factor makes efforts to integrate palliative care more manageable(8). Unfortunately, training in pain management is also inadequate both in South Africa and internationally. Wolfert and colleagues report from University of Wisconsin, the site of the Pain Policy Study Group WHO collaborating centre, that in spite of over 15 years of pain education efforts and practice guidelines, many physicians report inadequate knowledge of and little training in the use of opioids to manage chronic pain(203). The International Association for the Study of Pain (IASP) conducted a survey of undergraduate and postgraduate education in management of acute, chronic and cancer pain in developing countries of Africa, Asia, Eastern Europe and Latin-America where there are IASP chapters. Over 90% of respondents reported that the education they received in pain management as undergraduates was not sufficient to enable them to manage patients' pain appropriately(204). South African studies also highlight inadequate pain management (205). This was highlighted in this study with hospice comments about doctors' reluctance to prescribe morphine. It has been identified that due to lack of training in pain management doctors are reluctant to use morphine particularly in children(144). Palliative care training does focus on symptom management as part of clinical care, so integration of palliative care education in undergraduate and postgraduate curricula would improve knowledge and skills in managing pain.

As described above, the WHA resolution highlights the need for palliative care training. The South African Nursing Council (SANC) and the Health Professions Council of South Africa (HPCSA) can play a leading role in ensuring that undergraduate training of doctors, nurses and other health professionals includes palliative care; and that CPD programmes address the gap in training for professionals who are already qualified. The goal is to ensure basic training in palliative care for all health care workers. Thus, people needing this care could access it at any health care facility, and if the palliative care problem or problems are more complex referral to a specialist palliative care service would address these complex problems.

The Policy Framework and Strategy for Palliative Care developed following the completion of this study articulates the need to upgrade palliative care training for all health professionals(121). The SANC and HPCSA are represented on the National Steering Committee for Palliative Care, and will take steps to direct nursing schools and medical schools to include palliative care in the undergraduate curricula. In addition, the Pharmacy Council representative has reported that palliative care training is to be introduced into the curriculum for pharmacists and competencies for palliative care have been agreed for training of pharmacists (121). This step is consistent with state obligations to fulfil the Right to Health(1) ensuring training of health care professionals as an element of Availability. In many developed world countries, palliative care is included in training curricula for doctors and nurses(206). In recognition of the role played by community nurses in end of life care, the UK Department of Health funded a training programme for nurses and trained over 15,000 nurses in palliative care(38).

#### 4.4.7 Availability of morphine

The South African regulations for prescribing of morphine allow a medical practitioner to prescribe a schedule 6 medication for up to 30 days. So there are no legislative restrictions on appropriate availability of morphine. (207) The availability of morphine was used in this study as a proxy to identify availability of comprehensive palliative care services. Thus, the services that reported that their patients did not require morphine and those that did not provide pain and symptom management are not, in fact, providing comprehensive palliative care. South African

hospices do not have dispensaries and rely on government or private health services to prescribe and dispense medication for hospice patients. This affects the availability of morphine for hospice patients. This contrasts with the situation in Uganda where, in 2004, an amendment to the National Drug Policy and Authority Statute (1993) was passed to permit specialist palliative care nurses and clinical officers to prescribe morphine. This amendment has increased the accessibility of morphine to patients at home and in rural areas(208).

The lack of availability of morphine to patients in South Africa reported by respondents in this research study, and the barrier to accessibility of opioids such as hospital stock-outs, potentially violates the requirement of General Comment 14 for availability of essential drugs. Morphine is on all South African Essential Drug Lists (EDLs) and should be accessible at any state health facility(209). The intermittent supply of morphine described by the services surveyed is of concern. Relief of pain is a human right, and stock-outs or non-availability of morphine not only violates the right to pain relief but also the intent to provide compassionate, patient-centred care.

Hospice managers also reported an accessibility issue with regard to availability of morphine describing the distances from health facilities providing morphine as a barrier to access to morphine.

Hospice care has demonstrated that patients do not need to be in hospital for end-of-life care and, if they are able to access essential palliative care medicines such as morphine for pain management, they can remain at home and die in comfort and dignity in their own homes.

Of concern is the fact that 22 services reported that there was no access to morphine for their patients. Nineteen of these services are (86.36%) rural services. The likelihood of morphine being available to patients in a metropolitan setting are 2.55 times greater than for patients in a rural setting (Table 4.4). One of the services reported *“Some patients died in pain, sometimes there is no doctor and sometimes they are too weak to go to the clinic for the prescription”*(#16). This is a serious violation of patients’ human rights, it adds to their suffering and impacts on their autonomy and their dignity(75).

Failure of access to prescribed medication such as opiates for pain relief potentially violates the requirement of General Comment 14 that essential drugs as defined by the World Health Organisation should be available to people needing pain relief.

#### 4.4.8 Comparing the availability of palliative care with estimated palliative care need

An exploratory comparison of the number of patients receiving palliative care as estimated in this chapter is made with the number of patients estimated to require palliative care annually as calculated in Chapter Three from mortality data. This chapter has estimated a mid-range of 12,286 and a maximum of 23,640 patients in care per month reported by responding facilities. Assuming the non-responding facilities (comprising 19% of the entire population) had similar patient numbers, on average, as responding facilities, this suggests that monthly numbers receiving palliative care across South Africa are 15,168 (mid-range) to 29,469 (maximum) in palliative care.

The needs assessment described in Chapter Three determined that 258,268 people who died in 2010 needed palliative care. Assuming a constant rate of patient deaths throughout the year, there should, on average, be 129,134 people in care per month (calculated from  $258,268 \times 6$  person months over the year (or  $258268 \times 6 / 12$  per month)). Those responding provided care to between 9.5% and 18.3% of people needing palliative care in 2010. Taking into account an estimate of care provided by non-responding palliative care organisations, between 11.7% and 22.8% of people needing palliative care received this care in 2010.

There are some limitations to this comparison. Firstly, it may be the case that non-responding facilities are not similar to responders. If they have larger patient populations, this may narrow the treatment gap identified above. However, this is unlikely to have any major impact on the substantial gaps generated through this comparison. Secondly, comparing need based on mortality to need based on care provided may represent a mismatch of different kinds of patients – those terminally ill as opposed to those receiving palliative care early in their illness. However, such differences are likely to underestimate the gap as Chapter 3 has shown that need based solely on mortality under-estimates true palliative care need by missing patients with symptoms who are not yet at end-stage of their illness.



Thus, although these are imprecise measures, it is still clear that there is a significant gap between palliative care need and provision of palliative care; and that palliative care is not available to the majority of people requiring this care in South Africa.

#### 4.4.9 Realising a right to access to palliative care in the state sector

Different models of hospital palliative care have been described which aim at expanding the availability of palliative care in South Africa (40,45,197). Jameson describes a hospital in-patient facility(197) and a recent study investigated the use of in-patient beds by the emergency unit at a South African teaching hospital (210). The Abundant Life palliative care programme, in addition to providing palliative care in the hospital, assists families to care for patients in their own homes even at the end of life(168). Evaluation of the programme describes that 60% of deaths were at home for patients and families with palliative care support, compared to 19% in the group who had received usual care. These models provide an example of how to implement palliative care in the formal health care sector to ensure improved availability of palliative care in South Africa. The Abundant Life model of outpatient support has been investigated at a Community Health centre and was found to be replicable in this setting(211).

The National Policy Framework and Strategy for Palliative Care (NPFSPC) and provincial palliative care strategy plans are severely limited because there is no budget to support palliative care integration(121). The NPFSPC describes services in both the public health sector and in NGOs with a strong referral system to ensure patients are cared for in the most appropriate setting. The indicators developed by Backman and colleagues for the Right to health in health systems identify, as a requirement to realise the Right to Health, the development of a comprehensive national health plan and participation of marginalised groups in the development of the National Health Plan(13). The National Policy Framework and the political will to integrate palliative care into the health system can be harnessed to advance the right to access palliative care.

In South Africa currently, a relatively small NGO group currently provides the care of patients requiring palliative care. The study demonstrates that there are urban/rural disparities with regard to fewer services in rural health districts. This indicates discrimination by rurality, and

there is also discrimination with regard to geographic access to palliative care services if people have to travel a long distance to access the service, or when staff cannot reach patients outside of hospice areas.

Given that palliative care services in this study were meeting between 9.5% and 18.3% of the palliative care need in 2010, it appears that the current model of palliative care is failing to make palliative care services available to all people in need of this care. Moreover although the study has shown that only 71% of services reporting provision of palliative care were providing comprehensive palliative care, 13,7% of these services did not provide pain and symptom management and, thus, would not meet the General Comment 14 criterion of functioning services of sufficient quality.

In order to realise the state's obligation to ensure functioning public health and health-care facilities for palliative care in sufficient quantity, it is important that palliative care is integrated into the public health sector, building on 'pilot' models that have been implemented to meet patients' needs in the public sector. It will also be important for government support, in particular funding, to expand palliative care in the NGO sector, as promoted by both the African Ministers' consensus statement of 2013 and the WHA resolution WHA67.19. In particular, efforts are required to ensure availability of palliative care in rural settings to combat discrimination against people living in rural areas. The National Policy Framework and Strategy for Palliative Care provides an opportunity for the government to approach the provision of palliative care differently and to ensure availability and accessibility of palliative care services.

#### 4.4.10 Limitations of the study

Although there was an 81% response rate from known NGOs providing palliative care, there was a low response rate (28%) from known hospital palliative care services. It is difficult to predict the effect this may have had on the results of the survey. Hospitals have greater numbers of patients than non-governmental organisations. Whereas all patients in the NGO services responding to the survey are patients requiring palliative care, it is uncertain how many hospital

patients need palliative care. Van Niekerk and Raubenheimer estimated that 16.6% of patients in hospitals had a diagnosis requiring palliative care.

There were some design flaws in the survey document that would require attention if a comprehensive situational analysis is carried out in future to inform the National Policy Framework and Strategy for Palliative Care in South Africa. Firstly, services were asked only whether defined categories of health care workers were employed or volunteered at the services, rather than being asked for the numbers in each category. This was done to minimise burden and intrusiveness, in an attempt to maximise the likelihood of a response from the services. In addition, the number of hours or days worked by part-time or volunteer staff was not included.

Secondly, it would have been useful to know the level of training of each staff member rather than whether, for example, any doctor had qualified in palliative medicine. The way the question was asked therefore rounded estimates of training levels upward to the highest level achieved by any staff member in that category.

Thirdly, the statistics reported regarding numbers of beneficiaries of care were in broad ranges, and necessitated use of the median and ranges to estimate overall numbers of beneficiaries. Because of the imprecision, it was not possible to compare with accuracy the numbers receiving care from this survey to the statistics of the Burden of Disease database needing palliative care in Chapter Three. In particular, services were not asked how many deaths had occurred in the year, so essential data to relate availability to need was not collected from the services.

#### 4.5 Conclusion

Requirements for availability according to General Comment 14 are that there should be *“Functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party”*(1)(12a). This study has shown that the state is largely failing in its obligation to ensure availability of palliative care services; there are few public health facilities providing palliative care services within the state sector and hospice services outside the public sector carry the vast burden of palliative care provision in the country. However, it is known these services lack sufficient state funding(183). Government has

an obligation to attend to this violation of human rights and to ensure availability of palliative care within the formal health care sector both public and private and to pay particular attention to the lack of rural palliative care services. In addition, better support of the NGO sector would ensure provision of palliative care in the patient's own home and availability of palliative care in under-served communities. The WHA resolution urges governments to "*ensure adequate domestic funding ....for palliative care initiatives*" and "*to foster partnerships between governments and civil society... to support, as appropriate, the provision of services for patients requiring palliative care*"(2) (paras 1.2 and 1.8).

The needs assessment estimated that 258,268 people in South Africa needed end-of-life palliative care in 2010. There is a significant gap between the provision of palliative care and the estimated need. When we consider that the needs assessment estimate derived in Chapter Three is likely to be lower than the actual need, the gap between estimated need and current provision of palliative care is likely to be even greater. Even when care was provided, the analysis of access to morphine and reports of barriers to the access of morphine indicate further that full provision of palliative care is compromised by lack of access to prescribers and gaps in training of doctors.

Thus, the state has not met the obligations to promote, protect and fulfil the obligation of the right to palliative care as part of the Right to Health. Costing of palliative care services and the cost savings that appear to be evident with palliative care may assist in the argument for integration of palliative care services.

There are few palliative care services in the state sector but those that have been established provide best practice models on which to model palliative care services, as the South African government responds to the WHA call to strengthen the provision of palliative care and "*to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care*" (2) (para 1.1). It is important that the state ensures availability and accessibility of palliative care through adequate funding, promoting training of staff in facilities, and establishing palliative care services in health facilities and care homes – homes for the elderly and children's homes. Community-based palliative care continues to be an important element to ensure

availability of palliative care, especially for end-of-life care so that patients can receive quality compassionate care in their own homes.

This chapter has focused on the element of Availability described by General Comment 14 (1), building on the discussion of palliative care need in South Africa. It describes the nature and level of current service provision for palliative care, and the gap in care that needs to be addressed to ensure availability of palliative care services for all people who need this care. It concludes that palliative care services are not available in sufficient quantity in South Africa, with a particular lack of services in the rural areas which indicate discrimination by rurality. In addition, few medical and professional personnel have received palliative care training, and a significant proportion of personnel are volunteers thus not receiving domestically competitive salaries.

The following chapter will further explore how Palliative Care is a component of the Right to Health by describing accessibility of palliative care for patients with advanced chronic illness in three settings – an oncology service, HIV clinic and Motor Neuron Disease Society.

## CHAPTER FIVE: ACCESS TO PALLIATIVE CARE

### *Abstract:*

**Background:** *There is a lack of available palliative care in the public health sector and palliative care is still not available in many rural areas. Even where palliative care services are known to be available and affordable, there may be barriers to accessibility of palliative care that impact on patients' Right to Health. Aim: to describe the access of patients with advanced chronic illness to palliative care services. Objectives:*1) *to describe the proportion of patients with specified advanced chronic illnesses referred to palliative care services from three care settings; and 2) to describe whether patients received adequate palliative care within their current care setting as assessed by patient-reported outcomes measures. Methodology: this was a prospective cohort study conducted over a 4-month follow up period. Participants were recruited from three groups meeting the criteria of patients who would benefit from palliative care with the following diagnoses: patients with metastatic cancer, patients living with HIV with CD4 count of <200 cells/mm<sup>3</sup>, and patients diagnosed with motor neuron disease (MND). Participants responded to a questionnaire administered by a research assistant to report demographics and to identify other people or services assisting with their care. Participants were asked to respond to seven questions from the African Palliative Care Association (APCA) African Palliative Outcome Scale (POS), a validated palliative outcome scale, measuring care outcomes in three domains and information needs. The questionnaire was administered at first visit and followed up telephonically once a month over a 6-month period. Results: There were 160 participants; 79 HIV patients, 78 oncology patients and 11 MND patients. During the study, 43 patients died and only eight patients (5%) were referred for palliative care. Most patient outcomes improved significantly for patients in the HIV clinics. However, there was no significant improvement in patient-reported outcome measures (PROMs) amongst the cohort of oncology patients apart from improvement in symptoms; nor amongst MND patients. Conclusion: There was a mixed picture with regard to accessibility to palliative care within the three services. Few patients were referred to palliative care services. As judged from improvements in PROM scores, patients attending HIV clinics received good palliative care within the service, suggesting that palliative care appears to be integrated into routine HIV care. Patients attending the oncology service site and MND groups were neither referred for palliative care nor did they receive effective palliative care within the*

*service. This suggests obstacles to access to palliative care and failure of the state to fulfil the Right to Health.*

## 5.1 Introduction

The preceding chapters have described the need for palliative care in South Africa and demonstrated that the current availability of palliative care in this country falls short of the need. Chapter Five assesses access to palliative care at the local level, in selected health services in Cape Town where there are available palliative care services. The chapter investigates the element of Accessibility as described by General Comment 14(1) for patients with selected chronic illnesses who could benefit from palliative care, by following a cohort of patients with advanced illness.

### 5.1.1 Universal Health Coverage

Universal Health Coverage (UHC) is a concept that has been increasingly recognised and adopted by governments in the last 50 years, and is one of the health goals identified in the Sustainable Development Goals adopted by all members of the United Nations in 2015, with an ambitious over-arching goal to “*end poverty, protect the planet, and ensure prosperity for all*” (212). As previously explained, the World Health Organisation defines universal health coverage “*as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, which are of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship*”(4) . UHC has been described as the practical expression of the Right to Health(94), and commentators have identified that UHC is regarded as having its foundation in the Right to Health (94,213).

UHC “*embodies three inter-related concepts: **equity of access** to needed health care services for all those that need them, irrespective of their ability to pay; that the **quality of health services** is good enough to ensure the improvement of health of those receiving the services; and **financial risk protection** to ensure that the cost of using care does not put people at risk of financial hardship*”(4).

UHC therefore speaks directly to accessibility of quality, affordable health services, and the goal of UHC is based on the Right to Health. The integration of palliative care into the health system in tertiary, secondary and primary health care services has the potential to improve quality of care for patients in hospital, Community Health Centres, clinics and at home, whether the patient's own home or a care facility for the elderly or for children. The South African government has initiated health reforms to improve both the quality of healthcare in South Africa and funding of health care, through a National Health Insurance (NHI) working towards universal health coverage(214). The foundation of the NHI is argued to be the recognition of the right of access to health care and the need to progressively realise that right. If the NHI is to achieve universal coverage and to successfully reflect a state commitment to realizing progressively the Right to Health, it will be important to include funding for palliative care within the South African NHI.

The World Health Assembly resolution WHA 67.19 comments that *"inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care"*(3)(preamble) and that it is the ethical responsibility of governments to ensure access to palliative care. Therefore, the resolution urges all member states to integrate palliative care into country health systems, and identifies nine elements to follow in order to achieve this integration (3).

The South African government has acted on the recommendation of the resolution, and in April 2017 the National Health Council approved a Policy Framework and Strategy for Palliative Care with the goal of improving access to palliative care for all people living in South Africa. The Policy gives particular consideration to vulnerable people and marginalised populations(121). Thus, while both the NHI and the National palliative care policy include palliative care in the services to be provided by all health facilities and have the potential to improve access to palliative care, the implementation of such policies will be crucial to ensuring equitable access in practice. This study was designed and conducted prior to the development of a national Palliative care policy or a commitment to National Health Insurance. The new policy has the potential to improve access to palliative care, and this study could serve as a baseline to benchmark changes resulting from implementation of these initiatives.



### 5.1.2 Accessibility in terms of Right to Health

General Comment 14 describes accessibility in terms of four 'dimensions': non-discrimination, physical accessibility, economic accessibility or affordability, and informational accessibility. 1) Non-discrimination refers to accessibility of health services to all, including the most vulnerable and marginalized people in the country. 2) Physical accessibility describes that *'health facilities, goods and services are within safe physical reach for all sections of the population'*, (1)(para 12b) with particular consideration for vulnerable groups. General Comment 14 further explains that underlying social determinants of health, such as safe water and adequate sanitation facilities, should be within reach of community members. 3) Economic accessibility refers to affordability of health services and ensuring these services are affordable for all, and that poorer people *'should not be disproportionately burdened with health expenses compared with richer households'* 4) Information accessibility describes *'the right to seek, receive and impart information and ideas concerning health issues'*. It also emphasises that there should be confidentiality of personal health data(1) (page 12b) .

### 5.1.3 Recognising patients requiring palliative care

Although palliative care was developed to respond to needs of cancer patients, there are a number of publications that describe the value of palliative care for people with other illnesses (143,215-217). The recent WHO revised Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013-2020 states that comprehensive care of non-communicable diseases encompasses primary prevention, early detection/ screening, treatment, secondary prevention, rehabilitation and palliative care(218). The European Federation of Neurological Sciences recommends a palliative care approach from the time of diagnosis of Motor Neuron Disease (MND), for optimal management of patients with this condition(219).

In people living with HIV, identification of need for palliative care is complicated by the variability of physical symptoms, emotional and spiritual distress, social isolation and financial difficulties, compounded by experiences of stigma and discrimination. Pain is often undetected, under-reported and under-treated (220).

Clinicians may not consider palliative care as an option for their patient as they are strongly focused on curative treatment. As described in Chapter Three, a number of researchers have

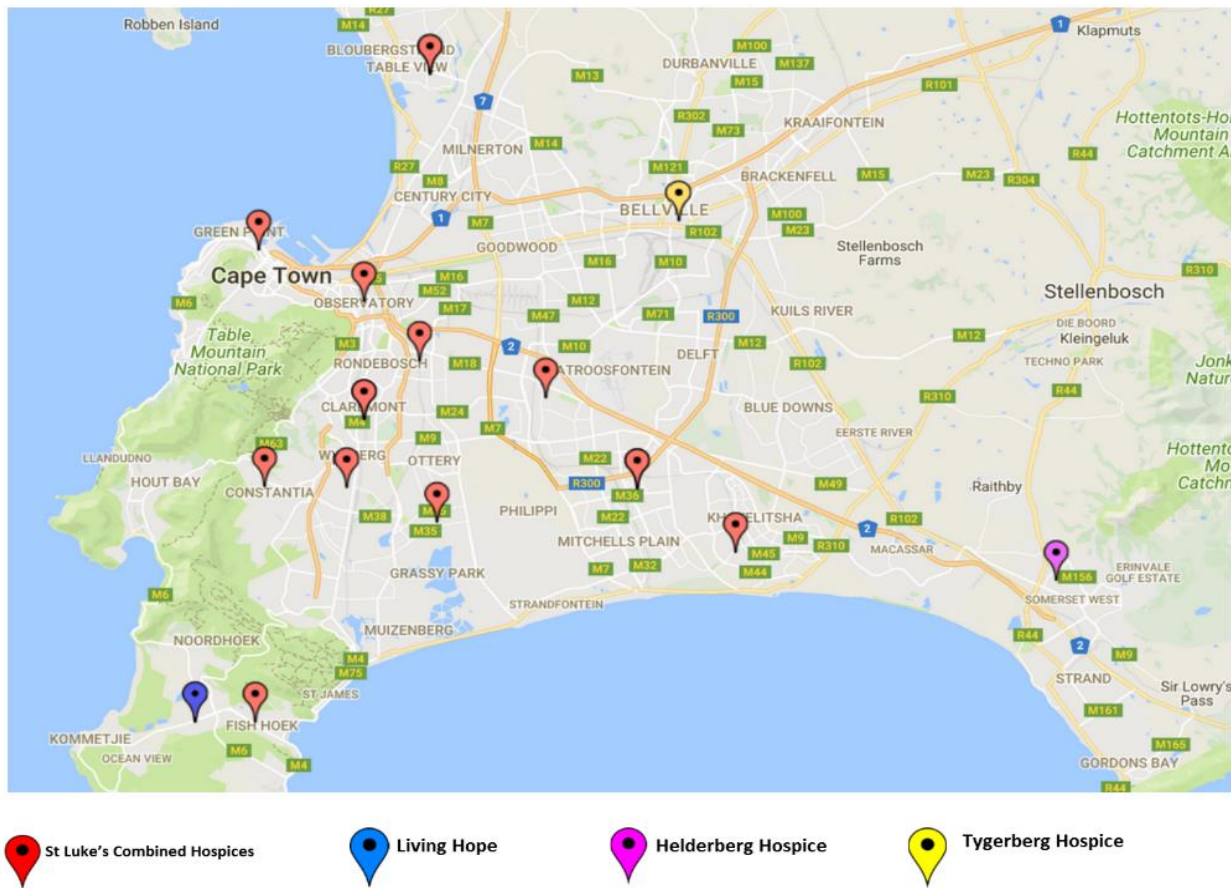
developed tools to assist the clinician to identify when a patient needs palliative care. These include the Gold Standards Framework Prognostic Indicator Guide(122), the Supportive and Palliative care Indicator Tool(123) and the NECPAL (Necesidades Paliativas [Palliative Needs]) Tool(124). Identifying the individual need for palliative care is the first step toward achieving access to palliative care.

#### 5.1.4 Physical accessibility of palliative care services in South Africa

Physical accessibility is closely linked to availability and, as described in the previous chapter, availability of palliative care services is limited in the current South African context. Currently, in South Africa, palliative care is largely provided by hospices in the non-governmental sector. The hospice model of care improves physical accessibility in that care is provided in the patients' own home; thus care is brought to the patient rather than the patient having to travel to a care facility to access palliative care. Hospices also provide a transport service for patients and family members attending day care activities at a hospice. This reduces the burden of physical access to outpatient palliative care for patients and families(221). However, hospices do not usually have a dispensary, so patients need to get their medication from the local clinic or hospital and a challenge in access to medication. There is still the cost to the patient or family member travelling to the health facility to access the required medication.

Coverage is less than adequate for large parts of South Africa. Hospice services are more available in metropolitan areas. The Cape Metro is well served in respect of hospices and the availability of these services would presume adequate physical accessibility of the palliative care. (See Chart 5.1 below).

Figure 5.1: Hospice services in Cape Town in 2010 (from Google maps)



HPCA reports that 98% of care provided by member hospices is provided as home care, with 2% of care being provided in hospice in-patient facilities (103). International studies indicate patient preference to be cared for at home and to die at home (164-166). However, reliance on home-based palliative care risks shifting the burden onto caregivers, and it is the exceptional country that provides care grants to a family caregiver(222). Moreover, there is also the psychosocial burden on caregivers if there is reliance on home-based palliative care (223.224).

As described in Chapter Four, there are some important examples of public sector palliative care that provide models for the integration of palliative care into the formal health care sector (40,41). Integration of palliative care into public health facilities should improve access to this care.

#### 5.1.5 Economic accessibility

Hospice care has traditionally been provided free of charge to patients and families facing economic constraints, and is charged when the patient has health insurance with a palliative care benefit. Hospice care provided in the patients' homes obviates transport costs; in addition, hospice services frequently provide transport for patients attending hospice day care centres in the community at no charge. This addresses costs that would otherwise be carried by the patient or family. Research has shown that patients receiving free public sector care for obstetric conditions, TB and HIV in South Africa experience significant costs accessing care, which are higher in the rural areas, and that transport costs in particular contribute to the cost of accessing health services(225).

A number of studies, internationally and within South Africa, have shown that appropriate palliative care saves costs and reduces hospital admissions (168,226-230). Despite this, there is still insufficient attention to and funding for palliative care services. At present, hospices raise funds from public appeals, corporate funders and donors, with less than 10% of funding from the government used to provide palliative care free of charge in South Africa.

#### 5.1.6 Information accessibility

Information accessibility describes '*the right to seek, receive and impart information and ideas concerning health issues*'(1) (para 12b). Informational accessibility is possibly the least successful dimension of palliative care accessibility(34). Hunt and Backman describe the importance of access to health information in enabling people to "*claim quality services*", and that this transparency is a feature of an effective health system(13).

There are two issues relating to informational access. One is the lack of knowledge and understanding of palliative care on the part of health care workers, so that referral to palliative care services is not forthcoming. Most health care professionals have received little or no training in palliative care, and may be uninformed about the services and benefits of palliative care and are also currently not equipped to provide palliative care themselves(8). The second is misconceptions amongst the general public regarding hospice and palliative care. The general public is averse to considering serious illness or the possibility of death until they experience illness. Thus, people do not consider palliative care as an option until late in the illness, if ever.

Misinformation about palliative care arises from the public perception that palliative care is only about care for the dying. This results in patients and family being reluctant to accept hospice care early, when there can be significant benefit to the patient(231). McIlpatrick comments that care at the end of life requires a fundamental shift in attitudes regarding advanced illness amongst the general public and health care professionals to include palliative care as a key component of the continuum of care(34).

The state has an obligation to provide accurate information to the public to ensure that they are aware of services available to them. In the South African context, language may also be a barrier to information access under circumstances where the health care professional does not speak the patient's language. For example, Haricharan and colleagues describe the violation of information access to the Deaf in not having access to sign-language interpreters when attending health care facilities(232). Patients seek information from their doctors but they also obtain information from other sources, and in the case of end-of-life care, there are many things that influence patients' response to the suggestion of referral to palliative care(233). The 2016 application of Advocate Robin Stransham-Ford for the right to end his life by means of administration of a lethal dose of medication illustrates lack of information about palliative care. Stransham-Ford made the statement that he had researched his options fully (article 45.4.3 of affidavit) and the only option acceptable to him was to end his life. However, when he received palliative care, he said did not know that hospice care was available in his home or that the doctor would visit him at home. He thought that he would have to go to hospital when his wish was to die at home(234). This information is freely available but had not been sourced by Stransham-Ford's personal research.

#### 5.1.7 Non-discrimination

Hunt and Backman identify that equity and non-discrimination are fundamental elements of the Right to Health, and that health systems must be responsive to particular needs of disadvantaged populations (46). They recommend that outreach programmes are implemented to ensure equity

of access for disadvantaged groups. They define equity as “*equal access to health-care according to need*” (46:83).

In discussing equity of access to palliative care for all in need without discrimination, Burt notes the current inequality with regard to access to palliative care, not only in different countries of the world but also within developed countries. She also highlights the influence of age, population group, socio-economic status and diagnosis on discrimination and equity of access(235). Gardiner also identifies attitudinal barriers to palliative care for older people in the acute hospital setting, and describes difficulties clinicians have in switching from a curative approach(236).

South African hospices have a stated policy of non-discrimination, with many hospices formally expressing that services are provided to anyone requiring palliative care regardless of age, race, religion, gender, sexual orientation or ability to pay for the service. However, there is inequity of access to palliative care services, in that hospices were initially developed in communities that were able to provide the financial support for the service. Establishment of hospices in poorer communities depended on donor funding and limited government grants(184). Chapter Four confirmed the gaps in coverage of hospice services in the country, with a limited number of hospice services particularly in rural areas. Non-discrimination implies provision of palliative care on an equitable basis with respect to urban-rural differences and to patients that are vulnerable in other ways such as being poor or unemployed. Hospices provide home care services but limit their areas of coverage to be able to provide care to patients within their catchment. The distances in South Africa make it impractical for hospice staff to travel beyond these areas. Thus, increased coverage of care is critical to ensuring adequate access to palliative care.

#### 5.1.8 Referral and integration for improved access to palliative care

There are two pathways for patients to achieve access to palliative care services. One is referral at an appropriate stage of clinical condition through referral pathways to specialist palliative care(123,237), while the second is through integrating palliative care into normal primary care, such as for patients with HIV(220). These are not mutually exclusive categories, but both require better understanding of palliative care amongst health care professionals than is the current

situation. The WHO recommends that palliative care should not be separate from disease-specific care, but that the two approaches should be integrated(159). Similarly, the American Society of Clinical Oncology identified progress in integrating palliative care into oncology services in the USA noting that *“hospice is a widely available and excellent model for managing end-of-life care and should be better utilized”*(238:3053). Both pathways rely on the employment of health care professionals who are trained and competent to provide palliative care; as well as guidelines and care pathways for palliative care being defined.

This thesis does not undertake to investigate all aspects of accessibility with regard to the provision of palliative care, but focuses on physical accessibility - whether palliative care is provided to the patients in their current care setting; and on an aspect of informational accessibility with regard to referral of patients to palliative care.

#### 5.1.9 Problem Statement

The assessment of palliative care need in South Africa (Chapter Three) and the description of the availability of palliative care services in South Africa (Chapter Four) demonstrate a number of gaps in meeting the need for palliative care. There is a lack of available palliative care in the public health sector and, although the NGO sector has partly filled this gap in some areas, palliative care is still not available in many rural areas. Even where palliative care services are known to be available and affordable, there may be barriers to accessibility of palliative care that impact on patients' Right to Health. For example, it is not known whether patients requiring palliative care are referred to hospice services as specialist palliative care services; and/or whether people with advanced illness receive palliative care in their current care settings. This information will assist in understanding whether patients manage to access available palliative care services. The World Health Assembly resolution on palliative care describes *“that it is the ethical duty of health care professionals to alleviate pain and suffering”* and that all health care workers *“who routinely work with patients with life-threatening illnesses”* should be trained to provide this care(2) (preamble and para1.4). If health care professionals provide palliative care within routine care, it may be that patients do not require referral to specialist palliative care services.

This study therefore investigates accessibility of palliative care in Cape Town, where hospice palliative care services are well-established, in order to gain an understanding of whether patients at a stage of illness that requires palliative care are receiving this care.

#### 5.1.10 Aim and Objectives

**Aim:** The aim of the study was to assess the proportion of patients with advanced chronic illness who accessed palliative care services in three care settings in Cape Town.

**Objectives:**

- 1) to describe the proportion of patients with specified advanced chronic illnesses referred to palliative care services from three care settings
- 2) to describe whether patients received adequate palliative care within their current care setting as assessed by patient-reported outcomes measures.

## 5.2 Methodology

### 5.2.1 Study design

A prospective cohort study of patients with chronic illness was conducted at four sites in Cape Town. Three cohorts of patients were assembled: 1) with HIV infection with CD<sub>4</sub> count less than 200 cells/mm<sup>3</sup>; 2) with metastatic cancer; and 3) with motor neuron disease.

These disease groups were chosen to reflect a diversity of conditions for which palliative care is indicated.

### 5.2.2 Study sites

The study was conducted in the Cape Metropolitan Health District of the Western Cape provinces of South Africa. Sites identified include: 1) a tertiary hospital radiation oncology department, from all combined oncology outpatient clinics and from the male and female oncology wards; 2) two ARV clinics at primary care facilities; and 3) the W Cape Motor Neuron Disease (MND) Society. The sites were chosen through purposive sampling to include patients who met the required selection criteria below. The tertiary academic hospital is one of two public sector treatment centres for cancer in the Cape Metropole and linked to the University of Cape Town.



The ARV clinics were chosen because they (a) have a large number of HIV positive patients; (b) are situated in lower socio-economic communities and, (c) are sites familiar with research activities. The Motor Neuron Disease Society MND runs three support groups for patients with advanced illness and their family members. All three support groups were agreeable to introducing the research to patients and inviting their participation in the research.

### 5.2.3 Study population

The study population included patients with advanced illness eligible for palliative care and identified family members. The illnesses identified for inclusion in the study were: 1) metastatic cancer, as patients with metastatic cancer are traditionally those more frequently referred for palliative care; 2) HIV with CD<sub>4</sub> count less than 200 cells/mm<sup>3</sup>, as patients with low CD<sub>4</sub> count have extensive care needs; and 3) Motor Neuron Disease, as this is an illness for which there is no active treatment, and interventions to assist patients are palliative in nature.

#### Selection criteria:

##### Inclusion criteria:

##### Adult patients

Diagnosis of advanced illness: metastatic or stage 4 cancer, or HIV with CD<sub>4</sub> count <200, or Motor Neuron Disease (MND)

##### Exclusion criteria:

Children under the age of 18 years

Patients too frail to take part in the survey

Patients considered not cognitively able to answer questionnaires

### 5.2.4 Sampling

Consecutive patients identified as meeting the selection criteria were to be approached to take part in the study. Sample size was estimated for each group based on anticipated access to palliative care services. It was estimated a priori that 75% of cancer patients in the public sector accessed hospice care in the advanced stage of their illness; for HIV positive patients, 20-30% of patients with CD<sub>4</sub> count <200 were thought to access palliative care; for MND patients, because the only available intervention is palliative, it was estimated 90% were using palliative care. We accepted 10% precision for each group with a 95% confidence level. (see Table 5.1 below).

Table 5.1: Sample size calculation

	Cancer patients	HIV patients	MND patients
Expected proportion	75.00%	20.00-30.00%	90.00%
Precision	10.00%	10.00%	10.00%
Confidence level	95%	95%	95%
<b>Sample size</b>	<b>72</b>	<b>61-80</b>	<b>34</b>

The information we received while planning the study was that there were 12 MND patients being cared for by MND Society in Cape Town, so we elected to approach all 12 patients to invite them to take part in the study. With only 12 patients in the study, the precision achievable is 17%.

#### 5.2.5 Data collection tools

The data collection tools were designed to measure two specific outcomes - the first being referral to a recognised palliative care service, and the second being patient-reported outcome measures (PROMs) for palliative care, to identify whether the participants' palliative care needs were met by the service they were attending - respectively, oncology, HIV and MND.

- 1) A questionnaire was designed to collect demographic data relating to the patient's age, gender, race and diagnosis (Appendix A4 page 281). Qualitative data was gathered in respect of other people or services providing care to the patients. The inclusion of information on age and gender is relevant to the General Comment 14 element of Acceptability described as *"respectful of medical ethics and culturally appropriate, sensitive to gender and life-cycle requirements"*(1)(para 12c) Patients were then asked a single open-ended question "Do you have other people or services helping with your care?", and the interview continued to explore assistance patients received informally in the community or through formal care organisations.
- 2) The African Palliative Care Association (APCA) African Palliative Outcome Scale (POS) was used to assess whether patients received adequate palliative care within their current care setting. The POS was developed by researchers at Kings College London to evaluate

the holistic approach of palliative care in patients whose clinical condition may be deteriorating, but whose physical, psychosocial and spiritual problems can still be improved (239), and adapted and validated for use in an African setting (240). The APCA African POS asks participants to rate their problems on a scale of 0-5 for 7 items, grouped into 4 domains: (i) physical – pain, other symptoms; (ii) psychosocial – worry, ability to share; (iii) spiritual – life worthwhile, being at peace; and (iv) informational – having enough information to plan for the future. For patients, there are 7 response items and for family perceptions or experience three items. The family items are not reported in this study. This questionnaire was researcher-administered at the initial visit, and subsequently completed by telephonic interviews each month for a period of six months, to document change in the items over time.

The data collections tools – questionnaire and APCA African POS survey (Appendix A5 page 282) as well as information sheets and consent forms (Appendix B1 page 285) – were translated into isiXhosa and Afrikaans so that the participant was interviewed in their language of choice. Use was made of back-translation to verify the accuracy of the translated version.

#### 5.2.6 Research assistants

Two research assistants were recruited to undertake data collection for this arm of the study. Both were experienced hospice social workers with skills in working with patients with advanced illness. They were trained in the research methods and in research ethics. They already had a good understanding of the vulnerabilities of people with advanced illness and respectful attitudes in communicating with patient and family member concerns. Training in research ethics enhanced their skills in approaching potential participants with sensitivity. They understood the requirement to explain the research study clearly, and to check that potential participants understood the implications of participating in the study to obtain fully informed consent. Training in when and how to invoke the distress protocol resonated with their training in social work and counselling skills. Once the research assistants were familiar with the research methods and with research ethics, the PI and research assistants introduced the research study to the research sites. At each site, a staff member to act as study liaison was identified either by the

head of the study site or by the research assistant. At the oncology unit this was a consultant oncologist; at the HIV clinics this was an administrator; at the MND Society this was the professional nurse co-ordinating the MND support groups.

#### 5.2.7 Recruitment of participants

The study site identified a study liaison staff member who identified patients meeting the inclusion criteria, assisted in the oncology service by the professional nurses at oncology clinics and wards. If the patients' were in agreement she gave their names to the research assistant. The research assistant approached the potential participant and explained the research study in the participant's language of choice, English, isiXhosa or Afrikaans, and invited the potential participant to take part in the research. One of the research assistants was first language isiXhosa speaker and fluent in English, the other was fluent in English and in Afrikaans. During the study they worked closely together and were able to refer appropriately to each other to accommodate participants' language preferences. At each study site, the research assistant checked that the potential participant understood the implications of the research study. Potential participants were encouraged to ask questions about the study, and the research assistants responded to any queries. There was no coercion or incentive to take part. Participants were assured that if they chose not to take part in the research, or chose to withdraw from the research study at any time, their treatment would not be prejudiced in any way and they would continue to receive standard care. Potential participants were assured of confidentiality and informed that participants would not be identified by name but by a research study number. If the patient was willing to take part in the research, they were asked to sign informed consent for the study. Once consent was given, the research assistants conducted the interviews. At each site, the research assistants explained the study to the patient and family member if they had accompanied the patient to the study site. The discussion was in the potential participant's first language.

Recruitment of participants followed a slightly different process at the different sites.

##### 5.2.7.1 Cancer participants at a tertiary level hospital in Cape Town

Patients with metastatic or stage 4 cancer were recruited from outpatient clinics for cancer of the lung, head and neck, gynaecology, breast, oesophagus and gastro-intestinal tract, and from

inpatient male and female oncology wards. The majority of staff were helpful in identifying participants suitable for the research study who met the criteria, and the professional nurse in the Breast Clinic made the social workers room available for interviews with participants from any of the outpatient clinics. Some clinics drew up a list of potential participants to assist the research assistants in identifying participants. There were a few barriers encountered in recruitment of patients, with some oncology staff not understanding the research and concerned that the research may interrupt normal work. However, the oncologist who acted as study liaison promoted the research study, and this assisted in acceptance of the research assistants at the combined oncology clinics. Patients were recruited at any visit, not necessarily their first visit, and length of time receiving oncology treatment was also not a recruitment consideration.

#### 5.2.7.2 HIV participants at ARV clinics

There were some delays in initiating the research at HIV clinics. At one clinic, introduction of the project was delayed because of a serious fire at the clinic in the week of the proposed meeting. Subsequently the two research assistants visited the clinics and introduced the research topic to staff at the clinics. Initially the research staff were given access to folders at clinic A to identify possible participants, but staff at clinic A decided to identify potential participants themselves, and the research assistants approached staff at clinic B to follow the same procedure. The clinic staff assisted in timing the participants' interviews with research assistants so as to fit these in with the participants' clinic appointments, so that participants saw the clinical staff according to their clinical needs, and while waiting for the next intervention would meet the research assistants for their interviews.

#### 5.2.7.3 MND participants

The principal investigator met with the professional nurse who is the co-ordinator of the Motor Neuron Disease Society to explain the study. Thereafter, the professional nurse invited the research assistants to attend each of the three support group meetings of the MND patients. The research assistants explained the study to MND patients and their family carers and invited participation in the research. There was some delay in recruiting MND participants while participants considered the implications of the research. Many patients had difficulty in

communication because of the extent of their illness affecting speech. One patient who was invited to take part in the study agreed verbally but wanted to discuss the research with the family before consenting to the study. Unfortunately, he died soon after the discussion and before the research started. One patient was newly diagnosed with MND and took some time to understand her illness and MND Society services before providing consent.

#### 5.2.8 Data collection procedure

There were monthly data collection points, starting with the face-to-face interview conducted at the time of recruitment. Subsequent interviews were conducted telephonically, once a month for six months, to identify patient outcomes over a six-month time period. At the initial interview, the research assistant administered the questionnaire and made a note of the responses on the hard copy questionnaire and recorded the interview. Following the short interview on care provided to the participant, the research assistant administered the APCA POS to the participant. Interviews with the participants took approximately 20-30 minutes. Subsequent interviews were shorter because demographic information was not collected again, and participants became familiar with the research tool.

Recordings of the interviews were uploaded to an intranet site on the UCT IT platform, with password protections accessible only by study staff with password access. The interviews were transcribed by professional transcribers and where necessary translated into English.

#### 5.2.9 Data storage and confidentiality

Participants were not identified by name but given a unique reference number for the research study, which was kept apart from the research data, locked in a separate filing cabinet to ensure privacy and confidentiality. Interviews were confidential and participants were identified by number only. Taped interviews were uploaded to the project management website, to which only the PI, research assistants and transcribers had access.

#### 5.2.10 Ethical considerations

The study was approved by the Faculty of Health Sciences Human Research Ethics Committee (HREC) at the University of Cape Town (UCT) ref number 320/2010 (Appendix C1 page 293), by

the tertiary hospital CEO and by the manager of specialised health services in the City of Cape Town. Ethics approval was also obtained from HPCA REC (06/2010) (Appendix C2 page 294). Ethical approval was renewed annually. Permission to conduct the research in the Radiation Oncology Department was given by the head of the department. Permission to conduct research at the study sites was provided by facility managers through the Provincial Research sub-directorate.

#### Vulnerable populations

Patients with advanced illness are recognised as vulnerable participants in the context of research. Potential participants may feel obliged to take part in research to ensure continued good care and attention. They may feel that this is a way to express appreciation for care. Research assistants were trained in research ethics and the content and administration of the questionnaire. Participants were fully informed of the research prior to giving consent for participation in the research. They were assured that they would continue to receive normal care whether they chose to take part or not; or whether they decided to withdraw from the study. The research assistants were also trained in the study Distress Protocol that allowed for the interview to be interrupted if the participant exhibited physical or emotional distress, an appropriate intervention to be offered, and the interview either ended or continued at the choice of the participant.

#### 5.2.11 Data analysis

Demographic data and data collected from the APCA POS were captured in Microsoft Excel. Demographic and referral data were analysed in Excel. Stata 12 was used for the statistical analysis of the APCA African POS data (StataCorp, Stata Statistical Software). . Means, medians, minimum and maximum scores were reported for all data collections points. The Shapiro-Wilk test indicated that palliative care outcome measures were not normally distributed, hence the non-parametric Wilcoxon signed rank test was used as a comparison of median values for each of the seven items of the APCA POS questionnaire This analysis (Wilcoxon signed rank test) was conducted for patient outcomes at four months as well as at six months because of the high rate of attrition. The medians at baseline and at four months, and the medians at baseline and six

months were used to compare changes in the APCA POS items across the three diagnoses - cancer, HIV and MND. For all analyses, a P-value <0.05 was considered the threshold of statistical significance.

Qualitative data from the open-ended question and discussion following the question was analysed through content analysis. The transcribed interviews were read and re-read to identify themes emerging from the data. There was a process of constant comparison as further transcripts were analysed. The themes explore elements of care provided to participants, and direct quotes were identified to support the thematic framework.



### 5.3 Results

In total 160 patients were recruited: 71 oncology, 78 HIV, and 11 MND patients, age and gender for each sub-cohort are illustrated in Table 5.2.

*Table 5.2 Demographic characteristics reported for each sub-cohort of patients by diagnosis*

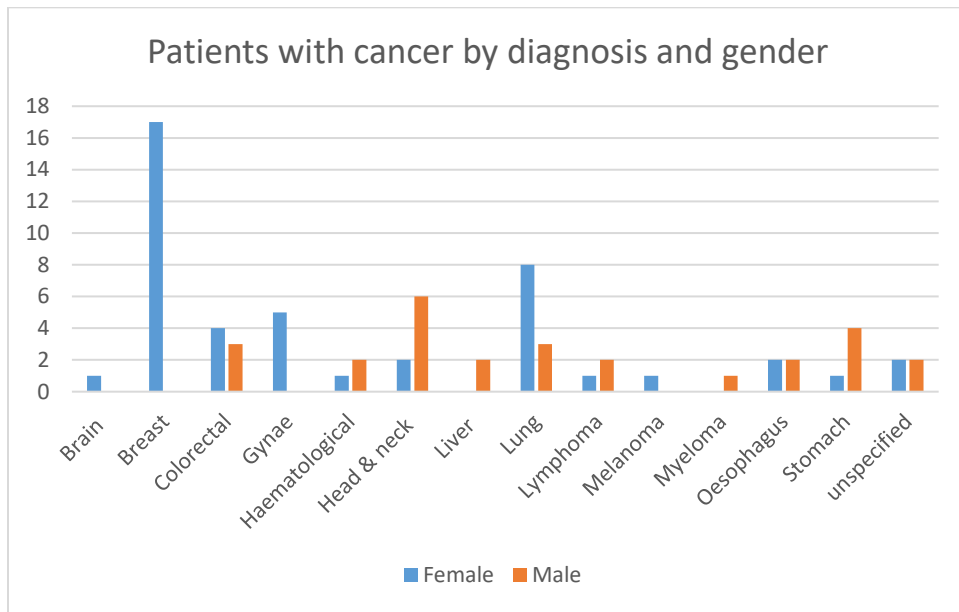
DIAGNOSIS	GENDER	AGE						TOTAL
		18 - 29 YRS	30 - 39 YRS	40 - 49 YRS	50 - 59 YRS	60 - 69 YRS	70 - 79 YRS	
ONCOLOGY (n=71)	MALE	5	2	3	6	9	1	26
	FEMALE	4	7	15	11	7	1	45
HIV/AIDS (n=79)	MALE	3	11	12	3		1	30
	FEMALE	21	19	6	2	1		49
MOTOR NEURON DISEASE (n=11)	MALE			2	3	2	1	8
	FEMALE			1	1		1	3

#### Cancer diagnoses

There were a number of different cancer diagnoses.

Figure 5.2 describes the different cancer diagnoses by gender. See below

Figure 5.2: Patients with cancer by gender and diagnosis



### 5.3.1 Referral to palliative care

At the start of the study, four oncology patients and three motor neuron patients were receiving hospice care, and as they were already receiving palliative care they were not included in further analysis beyond the baseline interview. During the study, eight cancer patients out of 71 (11.3%) were referred to the hospice. No patients with HIV or with MND who were not already in palliative care were referred for palliative care during the study. In total 5% of participants were referred to hospice.

Table 5.3: Proportion of patients referred to hospice by month 6

Diagnosis	# patients interviewed (incl in analysis)	# pts already in hospice care	# pts referred to hospice	Proportion referred during study
Cancer	71 (68)	4	8	11.3%
HIV	78(78)	0	0	0.0%
MND	11 (8)	3	0	0.0%

### 5.3.2 Other people or services involved in patients' care

Family, friends and faith communities were the most common groups provided additional care to patients on the study as noted in Table 5.4 below.

*Table 5.4: Care received other than palliative care services*

Other people/services	Oncology (72)		HIV (78)		MND (11)	
	n	%	n	%	n	%
Family	66	91.7	62	79.5	11	100
Friends	44	61.1	36	46.2	7	63.6
Faith community	40	55.6	14	17.9	4	36.4
Professional care services (totals)	7	9.7	14	17.9	5	45.5
Home care	6	8.3	10	12.8	3	27.3
Nursing service	1	1.4	3	3.8	1	9.1
Frail care	0	0.0	1	1.3	1	9.1
District hospital or CHC	0		3	3.8	0	
Clinic	0		3	3.8	0	
Social worker	0		2	2.6	0	0.0
Support group	0		2	2.6		
Other	0		1Neighbour	1.3	1Driver	9
None	3	4.2	3	3.8	0	0.0

For HIV patients, 45.6% of patients reported that family members were the only care provided apart from that of the HIV clinic; for cancer patients, 20.8% reported that family were the only care providers apart from the oncology clinic; for MND patients, 27.3% reported family as the only care providers apart from the MND society nurse. Only 13.6% of patients reported any additional support from state services towards their care. Cancer patients and MND patients had greater involvement of family and friends in their care than HIV patients. HIV patients reported fewer outside services providing care and support.

### 5.3.3 Content analysis

An open-ended question was asked of patients in respect of other people or services providing care, and the discussion was recorded, transcribed and analysed to capture patients' care experience. Apart from the discussion that arose from the main informal care providers – family and friends – the qualitative data was limited. However, the patient quotes add richness to the quantitative data, providing detail of the care provided by informal care providers. The themes generated through thematic analysis are presented in Table 5.5 below.

*Table 5.5: Themes generated through content analysis*

Themes – who provides care?		
1. Emotional support	2. Practical Support	3. Isolation
i) Emotional support	i) Transport	i) Feeling/being alone
ii) Spiritual support	ii) Food	ii) Be away from home
	ii) Financial	iii) Not knowing about hospice
	iv) Care in the home	

#### 5.3.3.1 Emotional support

##### i) Emotional support from family and friends

Participants reported emotional and practical support from family and friends, and how this assisted them in coping with their illness. Patients spoke of concerns about stigma that were allayed by responses from friends and family. Family were important in encouraging patients to attend health facilities for care. Family provided care throughout the day and night if necessary; family members providing care were parents, adult children and siblings. Participants also commented on the care they received from hospice:

*“As my sister she was able to come from the Eastern Cape and came to take care of me here, after having heard that I wasn’t well”* HIV 48

*“My daughter she was the one that went with me through this... the young generation take more interest when you go into a doctor’s surgery they will then ask questions”*

Onc 11

*“My family, my sister has come down from Johannesburg. She’s been here for two weeks..... I’m moving to my cousin’s house and they are taking me in”* MND 2

However, sometimes the interaction with friends and family was overwhelming:

*“It’s sometimes too much, it’s too much. You know, we, I tell him, too much people. The social worker asked me, do I get visitors and all and help? I cry I get too much. I need a little quiet.”* Onc 1

## ii) Spiritual support

Spiritual support is provided by family and friends as well as by the faith community. The responses elaborating on spiritual care were from the oncology patients. Faith is bound up in family, with faith being central to participants’ family and community life, and many people were providing support sometimes through prayer. Spiritual support made it easier to cope with the illness, with some respondents expressing that their belief in God would carry them through this difficult time:

*“Prayers at the mosque, my brother will always sit and pray with me. I’ve got lots of relatives that’s like making prayers for us there.”* Onc 12

*“If I can’t go to church, then they will come to me....I think by praying it makes it also easier for me, and with the help that I get from friends and family ... even in the cancer there’s life. Even at home my family also knows, treat me normal. I’m not dead, I’m still alive – the grace of God is still there.”* Onc 3

### 5.3.3.2 Practical support

Family, friends and the faith community provided a great deal of practical support, covering transport, helping with food, financial support, and practical care in the home. The comments on these aspects of care emphasise the extent to which family and friends subsidise patient care; without the care provided by the family, patients would need to be cared for in health facilities. The practical care in the home allows patients to stay at home even though they are living with serious illness.

i) Transport:

*"If I have to be here by the hospital, he comes five o'clock in the morning to come pick me up."* Onc 12

*"Yes they help me, they would perhaps take me to the clinic when I'm ill.."* HIV 32

ii) Food:

*"My mother is at home but she's 75, she's getting old now, and she can every time cook for me."* Onc 12

*"My sister, she is looking after me and sometimes she buy me some food, that's a balanced diet food."* HIV 10

iii) Financial support:

*"they also help me with money since I'm not working and my husband is also unemployed"*

Onc 10

*"My brother, he is the one who helps me when I don't have money, when he also doesn't have money, I am able to lend him and he likewise you see."* HIV 40

*"The other thing is that if I wasn't fortunate enough to have had an insurance policy which has paid me out some money I would have not even be able to think of having employed carers – as it is the carers take up all that money but my wife has to pay the extra."*

MND 5

iv) Practical care in the home:

This ranged from cleaning, shopping, fetching medication and making sure there was food in the house.

*"My eldest brother and his wife - they mostly help me where cleaning the house is concerned. And my best friend – she will pop in like every day. She will now, how will I say, go to the shop to buy whatever I need. And she will come and fetch my medication at the hospital every month. She will come with me when it's my doctor's appointment"* Onc 3

*"(My sister) Since I'm not working, so she is the one who is responsible for what am I going to eat, my rent and so forth."* HIV 10

*“(My sister) she’s helping me with the washing up, cleaning of the house, making my bed, etcetera, and sometimes when I battle to put my clothes on. I’ve got friends who come in and buy groceries for me, and I can call on them if I have a need or if I fall or something like that.*

MND 2

### 5.3.3.3 Isolation

In contrast to the experiences described above, some participants expressed their isolation and the fact that they had no-one to provide care. In addition, participants who were ill experienced social isolation due to their illness.

i) Feeling/being alone:

*“I have no other people helping me or assisting me in any other way.”* Onc 16

*“My family I wouldn’t say is helping me because I parted from it some time ago. I live with my husband only but he is not here. Everybody in my family is no longer here, my mother passed away, my father passed away”*

HIV 24

*“Friends, I have one or two and now and again they try and help, so always this becomes a very lonely life because people tend to go away.”*

MND 4

ii) Being away from home

*“and even my husband it’s just that he is older than me...so now it’s not in his memory...even this about my being ill is not in his memory...I left him at home and came here to the children; he is at home in the rural area”*

Onc 11

*“My family is far, it’s my mother who is at home but she also phones at times and would ask whether I’m fine”*

HIV 43

iii) Not knowing about hospice

Many participants did not know about hospice with comments such as *“I don’t know that thing.”* *“What is a hospice?”* *“What is that?”* *“What are you talking about?”*

Of note is a young man of 18 years old who had travelled to Cape Town from the Eastern Cape to seek medical care and was alone in Cape Town. This is a poignant story of complete isolation,

and also his lack of awareness of other services providing care, in particular hospice care. The oncology service had not referred him for hospice care. (Onc 18)

He was asked who takes care of him: *“My parents take care of me nicely because they brought me up, they have provided for my education, they wished that I go on; it’s just because of this situation of not being well, I became ill, but even then, they did not forsake me, they cared for me. They tried that I get help there in the Eastern Cape but there was none ..., I’ve been to Mthatha, and I’ve been to East London, to Butterworth...There was no help until I have come to be here”*

The interview continued:

**I (interviewer):** Okay and then your friends, do you have friends that care for you?

**P (Patient):** *Yes, on the side of friends I’m not a person who has them, no*

**I:** Here in Cape Town, are there church people that you feel care for you, perhaps they will come and check on you, perhaps they phone and do this and that or they help?

**P:** *No*

**I:** Okay the Hospice, is there a hospice that takes care of you?

**P:** *What is a hospice?*

**I:** A hospice is an organization; it’s an organization that cares for people

**P:** *No there is none*

**I:** Is there help that you get there at home, or people who... or the people who go around to homes who are called home based carers?

**P:** *no there are none*

**I:** and then are there nurses that sometimes come and check on you at home?

**P:** *No there are none*

**I:** Is there other help that you get from other people?

**P:** *No there is none*

#### 5.3.4 Loss to follow up

Twenty-seven cancer patients (39.1% of the total cancer participants enrolled at the start of the study) remained in the study through to the last follow-up, completing all six interviews.



Equivalent retention for HIV and MND patients was 43 HIV patients (55.1%) and seven MND patients (87.5%), respectively (Table 5.6).

*Table 5.6: Loss to follow up*

	Loss to follow up		Reason for loss to follow up			
	Lost to follow up	% loss	No tel. contact	Death	Withdrew	Transfer
Diagnosis and Measurement point	n		n	n	n	n
<b>Cancer (n=71)</b>						
Month 2	14	19.7	8	6	0	0
Month 3	9	32.4	1	8	0	0
Month 4	15	53.5	0	15	0	0
Month 5	2	56.3	1	1	0	0
Month 6	2	59.2	1	1	0	0
Cumulative loss to follow up	42	59.2%	11	31	0	0
<b>HIV (n=78)</b>						
Month 2	11	14.1	10	1	0	0
Month 3	6	21.8	2	3	1	0
Month 4	3	25.6	0	1	1	1
Month 5	7	34.6	6	0	0	1
Month 6	7	43.6	2	1	1	3
Cumulative loss to follow up	34	43.6%	20	6	3	5
<b>MND (n=8)</b>						
Month 2	0	0.0	0	0	0	0
Month 3	0	0.0	0	0	0	0
Month 4	0	0.0	0	0	0	0
Month 5	0	0.0	0	0	0	0
Month 6	1	12.5	0	0	1	0
Cumulative loss to follow up	1	12.5%	0	0	1	0

The majority (57.1%) of loss to follow up for HIV patients was loss of telephonic contact, either wrong numbers being given, or change in cell phone numbers, or no reply at the number. It may also be that the patient had died and was therefore not contactable by phone. Of loss to follow

up for patients with cancer, this was mostly (73.8%) due to the participant’s death. This was 43.6% of the total number of participants with cancer enrolled. In addition, six HIV patients (7.7%) died during the study. Four patients withdrew from the study giving reasons for withdrawal; two HIV patients were back at work and no longer available for interviews, a third HIV patient did not want to discuss her condition on the phone as she was worried that her husband might hear. The MND patient’s condition had deteriorated and he was no longer able to speak clearly.

### 5.3.5 Analysis of APCA African POS patient reported outcome measures

Patient-Reported Outcome Measures: Month 1 (M1) to Month 6 (M6). Statistically significant changes are highlighted in yellow for positive change and in blue for negative change.

Pain and other symptoms are the two measures of physical well-being of the APCA African POS

#### i) Patient-reported pain

*Table 5.7: Pain reported over the 6-month period*

Diagnosis & Measurement points	n	Mean	median	min	max	Wilcoxon signed rank test	
Cancer	month 1	69	2.84	3	0	5	M1-M4 prob
	month 2	55	2.91	3	0	5	0.9486
	month 3	44	2.96	3	0	5	
	month 4	30	2.03	2	0	5	M1-M6 prob
	month 5	30	2.27	2.5	0	5	0.5593
	month 6	27	1.93	2.0	0	5	
HIV	month 1	78	1.83	1.5	0	5	M1-M4 prob
	month 2	67	1.36	0	0	5	0.0001
	month 3	61	1.07	0	0	5	
	month 4	57	0.86	0	0	5	M1-M6 prob
	month 5	50	0.70	0	0	5	0.0001
	month 6	43	0.19	0	0	5	
MND	month 1	8	1.86	2	0	4	M1-M4 prob
	month 2	8	1.63	1	0	4	0.5115
	month 3	8	1.50	1.5	0	4	
	month 4	8	1.63	1.5	0	4	M1-M6 prob
	month 5	8	1.13	1	0	4	0.1573
	month 6	7	1.00	0	0	4	

Pain is scored 0-5 with 0 being no pain and 5 the worst possible pain. Pain levels decreased for the 3 groups of patients, but this improvement was only of statistical significance for HIV patients (Table 5.7).

ii) Symptoms other than pain

Table 5.8: Symptoms other than pain

Diagnosis & Measurement points	n	mean	median	min	max	Wilcoxon signed rank test	
Cancer	month 1	68	2.87	3	0	5	M1-M4 prob 0.1039
	month 2	54	2.96	3	0	5	
	month 3	44	2.93	3	0	5	M1-M6 prob 0.0329
	month 4	30	2.37	3	0	5	
	month 5	30	2.23	3	0	5	
	month 6	27	2.19	2	0	5	
HIV	month 1	78	2.41	2	0	5	M1-M4 prob 0.0001
	month 2	67	2.03	2	0	5	
	month 3	61	1.66	1	0	5	M1-M6 prob 0.0001
	month 4	57	1.33	0	0	5	
	month 5	50	0.96	0	0	5	
	month 6	43	0.49	0	0	5	
MND	month 1	8	2.50	2.5	0	5	M1-M4 prob 0.6816
	month 2	8	1.75	2	0	4	
	month 3	8	2.38	2.5	0	4	M1-M6 prob 1.0000
	month 4	8	2.50	3	0	4	
	month 5	8	1.75	1.5	0	4	
	month 6	7	2.29	3	0	4	

Symptoms other than pain were identified by the patient themselves, and scored 0 for no symptoms and 5 for very severe symptoms. Symptoms improved for the three groups of patients (Table 5.8). This improvement was only of statistical significance for cancer patients after 6 months, and at both 4 and 6 months for HIV patients.

iii) Worry

Table 5.9: Worry

Diagnosis & Measurement points	n	mean	median	min	max	Wilcoxon signed rank test	
Cancer	month 1	69	3.13	4	0	5	M1-M4 prob 0.4917
	month 2	55	3.13	3	0	5	
	month 3	44	3.07	3	0	5	M1-M6 prob 0.1860
	month 4	30	2.50	3	0	5	
	month 5	30	2.47	3	0	5	
	month 6	27	2.15	1	0	5	
HIV	month 1	78	2.17	2	0	5	M1-M4 prob <b>0.0001</b>
	month 2	67	1.64	0	0	5	
	month 3	61	1.36	0	0	5	M1-M6 prob <b>0.0001</b>
	month 4	57	1.16	0	0	5	
	month 5	50	0.98	0	0	5	
	month 6	43	0.35	0	0	5	
MND	month 1	8	1.63	0.5	0	5	M1-M4 prob 0.6816
	month 2	8	1.38	0.5	0	4	
	month 3	8	1.63	1	0	5	M1-M6 prob 0.9289
	month 4	8	1.63	0	0	5	
	month 5	8	1.75	0	0	5	
	month 6	7	1.57	0	0	5	

Worry is scored 0-5, with 0 being no worry and 5 very anxious. Worry decreased for the three groups of patients, but this improvement was only of statistical significance for HIV patients (Table 5.9).

iv) Ability to share

Table 5.10: Able to share

Diagnosis & Measurement points	n	mean	Median	min	max	Wilcoxon signed rank test	
Cancer	month 1	69	2.74	3	0	5	M1-M4 prob 0.2966
	month 2	55	2.80	3	0	5	
	month 3	44	2.77	3	0	5	M1-M6 prob <b>0.0026</b>
	month 4	30	2.70	3	0	5	
	month 5	30	2.13	2	0	5	
	month 6	27	1.67	1	0	5	
HIV	month 1	78	2.51	3	0	5	M1-M4 prob <b>0.0317</b>
	month 2	67	2.34	3	0	5	
	month 3	61	2.02	2	0	5	M1-M6 prob <b>0.0002</b>
	month 4	57	1.65	0	0	5	
	month 5	50	1.26	0	0	5	
	month 6	43	0.65	0	0	5	

MND	month 1	8	2.25	1.5	0	5	M1-M4 prob 0.5564
	month 2	8	2.13	2	0	5	
	month 3	8	2.38	3	0	5	M1-M6 prob 0.7029
	month 4	8	2.75	3	0	5	
	month 5	8	2.25	2	0	5	
	month 6	7	1.86	1	0	5	

Ability to share is scored 0-5, with 0 being not able to share concerns with others (or disclose to others) and 5 being able to share openly with others. Ability to share worsened for all three groups, and this was significant in the HIV group and cancer group by month 6 (Table 5.10). Worry and ability to share are the two measures of psychosocial well-being of the APCA African Palliative Outcome Scale.

v) Life worthwhile

*Table 5.11: Life worthwhile*

Diagnosis & Measurement points	n	Mean	Median	min	max	Wilcoxon signed rank test	
Cancer	month 1	69	3.71	4	0	5	M1-M4 prob 0.2287
	month 2	55	3.85	4	0	5	
	month 3	44	4.09	5	0	5	M1-M6 prob 0.2692
	month 4	31	4.58	5	2	5	
	month 5	30	4.33	5	1	5	
	month 6	27	4.56	5	2	5	
HIV	month 1	78	3.56	4	0	5	M1-M4 prob <b>0.0001</b>
	month 2	67	4.00	5	0	5	
	month 3	61	4.15	5	0	5	M1-M6 prob <b>0.0001</b>
	month 4	57	4.30	5	0	5	
	month 5	50	4.56	5	0	5	
	month 6	43	4.74	5	0	5	
MND	month 1	8	4.13	5	1	5	M1-M4 prob 0.7705
	month 2	8	4.75	5	3	5	
	month 3	8	4.75	5	3	5	M1-M6 prob 0.0861
	month 4	8	3.87	5	0	5	
	month 5	8	4.38	4.5	3	5	
	month 6	7	4.86	5	4	5	

Feeling that life is worthwhile is one of the measures of spiritual well-being. It is measured on a scale of 0-5, with 0 being life is not worthwhile at all and 5 being life is worthwhile in all aspects. The baseline scores for life worthwhile were relatively high leaving little room for improvement. Life worthwhile improved for all three groups but was only of statistical significance for the HIV patients (Table 5.11).

vi) At peace

Table 5.12: At peace

Diagnosis & Measurement points	n	mean	median	min	max	Wilcoxon signed rank test	
Cancer	month 1	69	3.70	4	0	5	M1-M4 prob 0.1949
	month 2	55	3.71	4	0	5	
	month 3	44	3.91	4	0	5	
	month 4	31	4.32	5	1	5	M1-M6 prob 0.2259
	month 5	30	3.97	4.5	1	5	
	month 6	27	4.26	5	2	5	
HIV	month 1	78	3.63	4	0	5	M1-M4 prob <b>0.0006</b>
	month 2	67	4.03	5	0	5	
	month 3	61	4.39	5	0	5	M1-M6 prob <b>0.0001</b>
	month 4	57	4.51	5	0	5	
	month 5	50	4.66	5	0	5	
	month 6	43	4.86	5	2	5	
MND	month 1	8	3.63	3.5	2	5	M1-M4 prob 0.4602
	month 2	8	4.13	5	2	5	
	month 3	8	4.13	4.5	3	5	M1-M6 prob 0.4446
	month 4	8	4.00	4	2	5	
	month 5	8	3.88	4	1	5	
	month 6	7	4.00	4	2	5	

Being at peace is the second item measuring spiritual well-being of the APCA African Palliative Outcome Scale, and is scored from 0-5, with 0 being not at all at peace and 5 being completely at peace. Being at peace improved for all three groups but was only of significance for the HIV patients (Table 5.12).

vii) Help and advice

Table 5.13: Help and advice

Diagnosis & Measurement points	n	mean	median	min	max	Wilcoxon signed rank test	
Cancer	month 1	69	2.46	3	0	5	M1-M4 prob
	month 2	55	2.35	2	0	5	0.9462
	month 3	44	2.16	1.5	0	5	
	month 4	30	2.37	2	0	5	M1-M6 prob
	month 5	30	2.53	2.5	0	5	0.8919
	month 6	27	2.59	3	0	5	
HIV	month 1	78	1.60	0	0	5	M1-M4 prob
	month 2	67	1.12	0	0	5	
	month 3	61	0.98	0	0	5	0.0044
	month 4	57	0.82	0	0	5	M1-M6 prob
	month 5	50	0.58	0	0	5	0.0001
	month 6	43	0.23	0	0	5	
MND	month 1	8	2.38	2.5	0	5	M1-M4 prob
	month 2	8	3.13	3.5	0	5	0.4658
	month 3	8	3.38	4.5	0	5	
	month 4	8	3.38	4	0	5	M1-M6 prob
	month 5	8	3.50	4.5	0	5	0.2123
	month 6	7	3.71	5	0	5	

Having enough help and advice to plan for the future is measured for 0-5, with 0 not having any help and advice to plan for the future and 5 being completely satisfied with the help and advice provided to plan for the future. Having enough help and advice to plan for the future showed some improvement for cancer patients and MND patients, but this improvement was not statistically significant. HIV patients' perception of help and advice was that this element decreased over the 6-month period (Table 5.13).

### 5.3.6 Analysis of sub-set of patients with high pain scores

i) Oncology patients

Seventeen oncology patients reported pain scores of 5/5 at point of first interview. Table 5.14 below reports pain scores for these patients with high pain levels who remained in the study.

N indicates the number remaining in the study; only four patients remained at the end of six months; 11 died during the study; two were not contactable on the telephone number provided for the second interview, one of whom was referred to hospice in month one. These two patients and an additional three patients who died only completed the baseline interview.

*Table 5.14: Oncology patients with pain scores 5/5 at baseline*

Diagnosis & Measurement points	n	Mean	median	min	max	
Cancer	month 1	17	5.00	5	5	5
	month 2	12	4.75	5	3	5
	month 3	9	5.00	5	5	5
	month 4	4	2.25	2	0	5
	month 5	4	3.00	3.5	0	5
	month 6	4	2.50	2.5	0	5

Only two patients of the original 17 were referred to hospice, and they were lost to follow up (one death and one not available which may be due to death) before the second scheduled interview, so there are no recorded patients referred to palliative care after the baseline interview. It is thus not possible to assess whether pain was controlled while in hospice care. While there was an improvement in mean pain scores from month 4, there was one patient whose pain scores remained 5/5 for the whole six months of the study and who was not referred for palliative care. Of the 17 patients with cancer with the highest possible pain scores at the outset, the nine patients with cancer remaining in the study at month 3 all reported similarly maximum pain scores at month 3.

ii) HIV patients with high pain scores

There were 14 patients with HIV who scored maximum pain levels (5) at outset. Although the analysis of change in pain scores indicate that there was good pain control at the two HIV clinics, there was also a subset of patients with 5/5 pain scores at recruitment, one of whom scored this level of pain throughout the study. Two of the 14 patients were from clinic A and the other 12 from clinic B. At month 2, there were still 6/14 patients who has 5/5 pain scores, and by month 5 there were still five patients with 5/5 pain. Three patients are known to have died during this



study. The other five were not contactable by telephone. Of the 14 patients with HIV reporting maximal pain scores at outset, most (n=11) remained in the study at month 3. Median and mean pain scores improved compared to baseline (Table 5.15).

*Table 5.15: HIV patients with pain levels 5/5 at baseline*

Diagnosis & Measurement points	n	Mean	median	min	max	
HIV	month 1	14	5.00	5	5	5
	month 2	12	3.33	4	0	5
	month 3	11	2.82	4	0	5
	month 4	11	2.55	3	0	5
	month 5	11	2.55	3	0	5
	month 6	8	0.88	0	0	5

### 5.3.7 Summary

Of the 160 participants recruited for the study, only 96 (60%) completed four interviews and only 51.9% at six interviews. These intervals (four months and six months) were used for comparing changes in patient-reported outcome data over time. There were very few referrals to palliative care services - only 11.3% of patients with cancer and no patients from the other services; this despite the fact that 31 patients with cancer and six patients with HIV died during the study period, and the fact that all patients were recruited based on inclusion criteria that meant all patients could benefit from palliative care. PROMs improved significantly for HIV patients on all seven items but this was not the case for patients with cancer and MND.

Patient interviews presented a picture of the extent to which family, friends and faith community provided emotional, spiritual and practical support to patients. The interviews also showed the isolation experienced by some patients, especially those who had travelled from homes outside of Cape Town to seek medical care.

## 5.4 Discussion

This study investigated the two pathways for patients to access to palliative care services; referral to specialist palliative care and whether palliative care is integrated into health care services. The World Health Organisation (WHO) recommends that palliative care should not be separate from disease-specific care, but that the two approaches should be integrated(8). This study was conducted in Cape Town where hospice palliative care services are well-established and available as shown in the map Figure 5.1 (page 145)

### 5.4.1 Demographics of study participants

As may be expected, the patients with HIV were a younger age group. Amongst patients with HIV, female participants were younger (mostly between 18 and 39 years of age), while the majority of male participants were older (between the ages of 30-49 years of age). This is consistent with the age and gender distribution of the HIV epidemic in South Africa, as described in the South African National HIV Prevalence, Incidence and Behaviour Survey, 2012(241). Oncology patients' ages ranged widely, with the majority of female cancer participants between the ages of 40-60 years of age, and male cancer patients between 50-70 years of age. This study population is marginally younger than reported by Globocan in 2012 (242), which identified higher incidence of cancer in women in South Africa between the ages of 55-64 and in men 60-69 (242). Breast cancer patients accounted for 30% of the oncology patients recruited, which may have been due to the fact that the interview room assigned to the research assistants was in the Breast Clinic, and the researchers were more visible to the staff at the Breast Clinic. This may also explain why there were more female patients amongst the oncology cohort.

The motor neuron disease patients were between the ages of 40-79 years. The literature describes that the onset of MND is usually between the ages of 55-65 years (243). Unlike the HIV and cancer cohorts, there were more men in the MND group.

## 5.4.2 Access to palliative care

### 5.4.2.1 Referral to palliative care

This study used selection criteria for participants that ensured that all 160 patients recruited were eligible for palliative care. None of the six patients in the HIV patient cohort who died were referred for hospice care prior to their death. No MND patients were referred to hospice services in the course of the study; and only eight patients with cancer were referred. This is a very low referral rate of patients with advanced illness. All participants were eligible for palliative care, but it is particularly surprising that patients who were near death did not access palliative care services. In addition, although all participants were eligible for palliative care by reason of the stage of their illness, only seven patients were already receiving palliative care at the time of recruitment, four cancer patients and three MND patients. In addition to the number of patients who died during the study, nearly one-quarter of oncology patients had high (maximum) scores for pain, and high pain scores persisted for some participants throughout the study. Although patients with HIV experienced improvement in pain over the period of the study, there was also a sub-set of patients with HIV who had high pain scores, with five of these patients still experiencing maximum scores for pain at month 5. Even if patients were not identified as being terminally ill, the high level of pain, other symptoms and worry indicate a need for palliative care referral.

### Factors that affect referral to palliative care

The low referral rate in this study is of concern, and it is important to consider some of the barriers to access to palliative care through referral. Hospices services are available in Cape Town (Chart 5.1), and clinicians in the oncology, HIV and MND services are aware of hospice and refer patients to hospices. Thus, for these patients, the problem is not availability of services.

### Clinicians' knowledge and skills

Doyle and Woodruff, writing for the International Association of Hospice and Palliative Care online Manual of Palliative Care, describe a number of barriers to access to palliative care, including that physicians may not recognize the severity of the illness thus delaying referral to palliative care(130). Research has shown that oncologists may be reluctant to refer patients for palliative care, as this is perceived to be taking away patients' hope(244). The fact that in this study clinicians did not refer patients for palliative care may be because they do not understand

palliative care, or were reticent in suggesting palliative care or hospice services to patients. Ganca identifies that clinicians find it difficult to convey a poor prognosis, but that doctors who had an understanding of palliative care were less anxious about communicating prognosis and care plans(119). Research suggests that oncologists are reluctant to discuss prognosis despite patients' expressing a wish to have such discussions(245). This reluctance to discuss the reality of the illness may serve as a barrier to accessibility of palliative care. To address the difficulties doctors experience in discussing serious prognosis and the benefits of palliative care, a number of training courses have been developed for health care professionals, locally and internationally (246).

If the delay in referral of study participants to a hospice service was due to the fact that palliative care was only seen as terminal care by the referring doctors, one could still have expected 43 referrals to hospice – the number of patients who died during the study. Yet this was not the case in this study. The lack of referral may be due to clinicians not recognising the severity of the illness until too late. Harding and colleagues identified that HIV clinicians considered that the patient is 'not sick enough' or 'not ready' for a discussion on palliative care, thus delaying implementing palliative care interventions that could have been of benefit to patients and families(215). As discussed in Chapter 3, there are a number of indicator tools that advise when to refer patients for palliative care, and these will assist doctors to decide when the palliative care discussions should take place.

#### Informational access

Regarding the dimensions of accessibility, for this cohort of patients it appears that informational access may not be adequately fulfilled in the setting of the study. The very low referral rate of patients with advanced illness suggests that clinicians may not have informed patients with regard to palliative care options, and that patients may not have been aware of their prognosis or the benefits of palliative care.

It has been identified that patients receiving palliative care want clear and full information, and involvement in health care decisions(247). However, there is sometimes a problem of ambivalence, and it has been described that patients swing from wanting to know to not wanting to know. This complicates the discussions between doctor and patient in addressing the issue of

referral to hospice or to a palliative care service. Clinicians need training in communication skills to be able to navigate this discussion, and to ensure that patients are provided with all the information they need in order to make an informed decision, explaining the benefits of palliative care. McIntyre and colleagues identify the importance of involving the patient as an active participant in the process of achieving access to healthcare services(248). The clinician must understand the benefit of palliative care in order to provide full information to the patient. The services surveyed in Chapter Four reported providing information about palliative care in various ways, including awareness campaigns, use of traditional and social media printed materials such as pamphlets and posters. However, the participants of this study on accessibility of palliative care were largely unaware of hospice and palliative care and would be reliant on the clinicians to explain the care offered and to make a referral.

#### Patient perceptions

Alternatively, patients may have refused referral to hospice because of the meaning they ascribed to hospice and the difficulty in accepting the seriousness of their illness(130) . Many people have the perception that hospice is only care for dying people and participants in the study may have declined referral to hospice if they did not want to think of the fact that they may be dying. This attitudinal barrier to accessing palliative care also described in the UK by McIlfratrick and colleagues(34). Attitudinal barriers may reflect both an aspect of Accessibility due to poor information and counselling and as an aspect of Acceptability of palliative care not adequately considered in General Comment 14; that of patient acceptance of the stage of their illness and/or acceptance of the need for palliative care. McIlfratrick and colleagues found that fears, anxieties and myths about palliative care and hospice care resulted in public knowledge of palliative care being limited(34). This poor community awareness or understanding of palliative care impacts negatively on equitable access to palliative care, and on the quality of care for patients at the end of their lives and in bereavement(34).

The findings of this study suggest that even with the availability of specialist palliative care services through hospice care in Cape Town, patients experience problems of accessibility of palliative care.

#### 5.4.2.2 Patient-reported palliative care outcomes

The second objective of the study was to describe patient-reported palliative care outcomes within patients' current care setting. This would identify whether the participants had received palliative care within the service without requiring referral to a specialist palliative care service. The analysis of patient-reported outcome changes over time was examined for patients still in the study after a 4 and then 6-month period. There was a high level of attrition - half of the oncology patients recruited for the study died in the course of the study, with higher numbers dying in month one and month three. The low referral rate and late referral meant it was not possible to assess improvement in outcomes for the few patients (n=9) referred to hospice.

The overall improvement in PROMS scores for patients with HIV without referral to palliative care services suggests that palliative care was well integrated into routine care for these patients. The analysis of patient reported outcomes for the 30 oncology patients still in the study at month four showed modest but non-significant improvements for all items (except able to share) though not significantly. The modest improvements may have been limited by sample size.

The MND patients recruited for this study were under the care of a professional nurse of the MND Society, and the baseline scores for this cohort of patients were relatively satisfactory, with less room for improvement than the cancer and HIV patients. Symptoms other than pain were the most troublesome, and these problems did not change over the course of the study. Mitchell and Borasio describe that palliative care can alleviate all signs and symptoms of MND(249). Alleviation of symptoms was not evident in this small group of patients. However, there is evidence that palliative outcome scores are not fully sensitive to the needs of MND patients, and additional measures should be developed and tested in order to improve the sensitivity for MND(250). O'Brien and colleagues investigated barriers to access of palliative care amongst MND patients, and described lack of knowledge about services available to patients as a barrier (251). This emphasises the need to ensure informational accessibility amongst people with MND.

The study did not review patients' medication charts, so it is uncertain whether the improvement in patient reported outcomes amongst patients with HIV was solely due to treatment of HIV or to management of symptoms or both. It is of interest that the two outcomes that deteriorated - ability to share, and having enough help and advice to plan for the future - are outcomes that

rely on counselling. It may be that the attention to counselling is greater at the start of HIV treatment, and that attention to counselling declines over time; alternatively, it may be that with the massive scale up of treatment services in South Africa(252) and concerns for maintaining adherence of large numbers of patients, the focus of counselling may have shifted from patient-identified concerns to adherence counselling, resulting in deterioration in reported ability to share feelings with family and friends, and having enough help and advice to plan for the future.

#### 5.4.3 Analysis of pain scores

There was a sub-set of patients with HIV and with cancer who reported high pain levels of 5/5 at the start of the study and high pain scores that persisted throughout the study. There is a place for referral to specialist palliative care services for specific problems such as management of pain. It is of concern that their pain was not controlled, given that the WHO argues that it is possible to achieve complete pain relief for 90% of cancer pain (170,253). This indicates a need for training in palliative care and pain management for oncologists. Cherny maintains that given the benefit to patients from palliative care, it is a *“moral and clinical imperative”* for oncologists to include palliative care for their patients with advanced illness(254:1335). Palliative care is still not generally taught in medical schools and nursing schools in South Africa, so there is lack of knowledge and skills in palliative care amongst health professionals. The lack of knowledge and training in pain management is evidenced in publications citing unbearable pain as a reason to support a change in South African law to allow a person experiencing unbearable suffering the right to die(255). In contrast, the World Health Assembly resolution A67.19, states that it is *“the ethical duty of health care professionals to alleviate pain and suffering”*, independent of whether the disease can be cured(3) (preamble).

#### 5.4.4 Spiritual well-being

It is worth emphasising that for all three groups of patients, the two items assessing spiritual well-being - life worthwhile and feeling at peace - recorded relatively high scores at the baseline, and that these items remained high throughout the study. This indicates a low level of existential distress, in spite of the fact that participants were living with serious illness.

#### 5.4.5 Additional care providers

As described in Results, a significant contribution to patient care is provided by informal carers, many of whom are family members. The care provided by informal carers places considerable practical, emotional, financial and social burdens on a family member not trained in caring. Caring for persons with HIV has been shown to be a major source of stress for caregivers of persons with HIV in South Africa(223,256) and for family carers of MND patients (251,257). However, the shift of the responsibility for care from the health system to the family is associated with a shift in the cost of care to the family. This potentially allows the state to evade its obligation to ensure access to palliative care and the family becomes part of the unofficial workforce in health care.

Ewing and colleagues recommend that there should be an assessment of the carers' needs for support, and that this support should be provided by the health system(224). However, even in developed countries where caregiver support is recognised as a need and responsibility of the state, practical support of family carers is provided by palliative care services rather than by the state(258). The WHA recommends support for families and informal caregivers as one of the responsibilities of member states (3) (para 1.3).

The need for care in the home was particularly highlighted when analysing participant interviews and identifying a number of participants who had no additional care, feeling alone and isolated. Patients who had travelled, for example, from the Eastern Cape to receive treatment in Cape Town, felt the lack of family support keenly. This calls into question the lack of essential medical services in the Eastern Cape, but also the perception that receiving clinical care is more important than being with family. It is a desperate situation to consider that a patient may deteriorate and die without returning home. This is another compelling reason for involvement of hospice as, with realistic understanding of the likely progression of the illness, hospices can support patients close to the end of life to return home.

#### 5.4.6 Accessibility of palliative care

This study has identified problems related to access to palliative care for three groups of patients meeting the criteria for benefiting from palliative care. The state has an obligation to ensure that there are health facilities, goods and services within safe physical reach of the people requiring these services(1). Currently there are few public health services that provide palliative care and,



in this study, none of the sites in this study had designated palliative care services or used appropriate referral pathways to available services. The obligation to protect the Right to Health and the obligation to fulfil the Right to Health require that health care professionals are trained in palliative care and have the skills to provide this care. The obligation to fulfil the Right to Health describes appropriate health policies, training of health care professionals, ensuring health facilities to provide palliative care. Fulfilment of these obligations would ensure provision of palliative care in all health facilities. At the time of the study, there was no palliative care policy for South Africa, and palliative care services were, and in many places still are, only available through NGOs. In 2017, the National Health Council approved a national policy for palliative care, and provincial departments of health are developing palliative care strategies to integrate palliative care services into the public health sector. In order to fulfil the Right to Health, the state is also required to provide informational access so that communities are aware of the healthcare services available to them. This includes relevant public communication, posters and other materials to raise awareness of palliative care services and the benefits of palliative care. McIlfratrick recommends a public health approach to help eradicate social taboos linked to palliative care(34). The state must be involved in or lead strategies to increase public awareness and understanding of palliative care. McIntyre describes access to care as empowerment of the individual to use healthcare services, and their ability to benefit from the service, explaining that even if there is a service in the community, the individual may not be empowered to use the service(259). This view is borne out by this study.

A number of HIV patients reported additional care from home-based carers. Personalized care provided in the patient's home assists with emotional support, adherence to treatment and identification of problems requiring attention(260,261). However, the fact that so much care is provided by families is an example of private individuals carrying a burden the state takes for granted. This may represent an evasion of state responsibility. However, as previously described many people wish to be at home(165,166) and the WHA resolution recognises this by recommending that governments ensure there is adequate support for families and caregivers (3) (para 1.3).

#### 5.4.7 Limitations of the study

Recruitment met the required sample size for the oncology and HIV groups, but only one-quarter of the required sample size in the MND group. Many MND patients attending the MND support groups were too frail to take part in the study or had difficulty with communication. The lower number of MND patients in the study indicates that the original estimate of precision was 21% rather than 10%.

There was high attrition during the course of the study and this should have been anticipated and factored into the study planning, to recruit higher numbers of cancer patients in particular so that the required sample size completed the study. Palliative care research recognises the probability of attrition as participants are frail and may be close to death. It is important to build a credible evidence-base for palliative care and during research, protecting the vulnerable participant is a high priority in palliative care.

In conducting the research, there was a failure of the protocol in that the distress protocol was not appropriately used for the patients suffering overwhelming pain. The research assistants were experienced social workers, familiar in dealing with emotional distress, but who overlooked the physical distress experienced by these patients. The follow up telephone calls were not immediately collated with prior responses, so that there was not recognition of the ongoing pain experience. However a pain score of 5/5 should have been reported to the patient's doctor for his/her attention, and this is an oversight of the PI in not adequately briefing the research assistants.

This study did not investigate referral practices amongst the treating doctors, so cannot identify the specific barriers to referral in the three settings. It would have been useful to collect data on informational access, whether patients had been offered referral to palliative care or told about palliative care. The question simply asked whether other services were involved in care of the patient and hospice was included amongst services suggested. The fact that many patients responded with "what is hospice?" possibly gave enough indication that the service was not offered to patients.

An additional question on knowledge and attitudes towards hospice would have provided objective data on ambivalence towards hospice and palliative care, and would have provided useful data to guide informational access.

### 5.5 Conclusion

This study demonstrates a complex picture with regard to the state obligation to fulfil the right to access to palliative care services, with the lack of referral to palliative care services such as hospice and the lack of palliative care within public health services, but with seeming integration of palliative care in services for patients with HIV. There was minimal improvement of APCA POS scores for cancer patients and MND patients and the persistence of maximum levels of pain for some cancer and some HIV patients is of particular concern, and violates the right to pain relief, bringing to mind the comment of Special Rapporteur, Juan E. Méndez, comparing denial of pain relief to torture(6).

The European Society for Medical Oncology (ESMO) policy statements on palliative care explain the role of oncologists in providing supportive care, palliative care and end-of-life care(254). If similar policies were adopted in South Africa, early palliative care would be provided in oncology, HIV and other chronic disease services, and referral to hospice for end-of-life care could improve patient experience. The European Federation of Neurological Sciences recommends a palliative care approach from the time of diagnosis of MND(219).

In order for the state to fulfil the obligation to provide access to palliative care, the state should ensure integration of palliative care into primary healthcare and hospital services (as advised by WHO); ensure training of health care professionals in palliative care; and either fund specialist palliative care in the hospital setting or contract NGOs to deliver the specialist service. These considerations have been addressed in the National Policy Framework and Strategy for Palliative Care guiding the Department of Health on implementation of the policy(121).

The current challenges to access of palliative care as identified in this study constitute a violation of the Right to Health. Palliative care should be provided in any care setting to improve physical access to palliative care. Information access can be improved with additional awareness campaigns regarding palliative and end-of-life care. There are two aspects of informational access

that are important 1) patients having information on services to which they are referred by clinicians and being empowered to act on this information; and 2) the clinician providing such information.

Tailored training for clinicians on the services provided by hospice and palliative care organisations, and training on how to hold difficult conversations with patients and families, as well as how to build hope in the face of news of serious non-curable illness would improve patient care and would help to prevent clinicians being complicit in denying access to palliative care. Goals of the training would be: 1) to improve awareness and understanding of palliative care; 2) to strengthen referral networks; 3) to integrate palliative care into existing services through training of all health care workers; and 4) to implement policies and guidelines for palliative care. These measures would assist in improving access to palliative care for patients with advanced illness, and in providing appropriate care to patients at the end of their lives with support to family members, both in caring for patients and in supporting their emotional needs and bereavement care.

In addition to the essential elements of Availability, Accessibility and Acceptability, General Comment 14 describes the importance of Quality in recognizing the Right to Health. Chapter Six will investigate Quality of Palliative Care provided in South Africa in assessing palliative care as part of the Right to Health in South Africa.

## CHAPTER SIX: THE QUALITY OF PALLIATIVE CARE - AN ESSENTIAL ELEMENT OF THE RIGHT TO HEALTH

*“The staff are caring for me as if I am their own”*

Participant WH01

### *Abstract:*

**Background:** General Comment 14 describes Quality as an essential element of the Right to Health. In order to ensure equity in healthcare, the quality of care should be assured for all people requiring care. One of the measures of quality is an assessment of technical aspects of care – structure, process and outcomes - and another is a measure of patient experience of care or patient-reported outcomes. **Aim:** To evaluate the quality of care delivered to patients requiring palliative care in hospice and non-hospice NGO services in South Africa. **Objectives:** 1) to describe the change in patient reported outcomes over a 4-6 week period to evaluate the quality of care provided to patients; and 2) to explore patient perceptions of the quality of care provided by the NGO services. **Methodology:** this was a prospective cohort study conducted in 19 accredited hospices and 16 non-hospice home-based care organisations in the same health districts, with purposive sampling of hospice services and convenience sampling of non-hospice services. The study used the APCA African POS, a validated palliative outcome scale, to evaluate quality of care provided by the NGOs. Participants also responded to a questionnaire asking about their experience of care. **Results:** There were 459 patient participants recruited to the study and 253 family members. The results of the study show significant improvement in patient reported outcome measures in both hospice and non-hospice sites. Pain, other symptoms and worry improved most in the hospice setting and spiritual care outcomes improved most for patients in non-hospice NGOs. Content analysis of the narrative questions identified five themes of quality of care, place of care, staff values and attitudes, information-sharing and problems experienced by participants. **Conclusion:** The essential element of Quality is evident in care provided by NGOs to patients with advanced illness. It is evident that care is patient-centred and staff exhibit respect and compassion that are important in upholding patient dignity which is both a right itself and central to the right to health.

## 6.1 Introduction

Chapters Four and Five have described two of the essential elements of the Right to Health described in General Comment 14, Availability and Accessibility(1). Chapter Six evaluates the quality of palliative care provision in the non-governmental sector as the fourth essential element of the Right to Health, that of Quality, and describes some aspects of Acceptability. The study sites for this part of the thesis are accredited hospice services providing home-based palliative care and non-hospice home-based care services in five provinces of South Africa.

### 6.1.1 Quality as described in Human Rights documents

As described in previous chapters, there are four essential elements for the Right to Health described in General Comment 14. The element of Quality is the fourth element and overlaps with the element of Acceptability; Acceptability being described as “*respectful of medical ethics and culturally appropriate*”(1) (para 12c).

General Comment 14 describes the element of Quality as follows: “*As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality. This requires, inter alia, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation*” (1) (para12d).

Home-based palliative care is provided in patient homes whatever the setting. Many South Africans live in informal housing without running water and adequate sanitation. Hospices and home-based care organisations provide care in any home and for homeless people. In the context of the provision of care, it is challenging to care for a seriously ill patient who is home-bound without access to running water and acceptable sanitation facilities. However, it was beyond the scope of this research study to include an assessment of the social determinants of health. This chapter focuses on quality of palliative care provided and patients’ perceptions of care. The issues of qualified clinical personnel and availability of morphine as a measure of access to essential palliative care medicines were addressed in Chapter Four.

### 6.1.2 Quality in healthcare

In describing the role of human rights in healthcare reform, Rudiger and Meier provide guidance to assess the element of quality and identify that “*uniform quality standards and independent quality control*” (262:80) should be implemented; and that “*disparities in quality of care received by different population groups should be eliminated*”(262:80).

The WHO publication “Everybody’s Business” describes the six building blocks to strengthen a country’s health system(263). The first of these describes “*Good health services are those which deliver effective, safe, quality personal and non-personal health interventions*”(263: 3) Quality is also highlighted as the need for quality medical products. The WHO recognise that there are competing demands for limited resources and that the intention to provide “*services are effective, of assured quality and safe*” (263:3), with “*health providers are responsive to patients’ demands*” (263:7) is a complex process. The building blocks approach is designed to guide policy makers as part of healthcare reform. Focus on leadership and management of health services is another building block designed to improve both access to health services and quality of health services. The WHO advises that issues of patient safety and quality of care will require procedures for licensing and inspection of health services.

The importance of standardised programmes is highlighted in the report Better Health for Poor Children, where the implementation of Integrated Management of Childhood Illnesses (IMCI) has been found to dramatically improve the quality of care to sick children(264). The report also emphasises the concern that the poor are disadvantaged in terms of availability and accessibility of health services, and the quality of care they receive.

### 6.1.3 Assessing quality

Donabedian describes the difficulty in defining quality but recommends evaluating structure, process and outcomes(265). Brook and colleagues describe two aspects of quality of care – the first being appropriate care of high technical quality, where it is clear that benefit outweighs risk; and the second that patients are treated in ‘*a humane and culturally appropriate manner*’, and to be involved in decisions regarding their care(266:282). It may be noted that General Comment 14 locates ‘*culturally appropriate care*’ as part of Acceptability(1). Thus, one of the measures of

quality is an assessment of technical aspects of care – structure, process and outcomes - and another is a measure of patient experience of care or patient-reported outcomes.

#### 6.1.4 Quality of health care in South Africa

A number of commentators have highlighted problems with regard to quality of health care in South Africa, and the discrepancies between private healthcare and care in public health facilities. Harris and colleagues comment on the fact that many poor or disadvantaged people are denied access to quality health care despite their greater need(132). Ngwena states that *“the lottery of income, geographical location, and race, in particular, had been for three centuries the primary determinant of the quantity and quality of health care services received by South Africans”*(83 :28-29). McIntyre and Gilson identify that the perception of poor quality healthcare services is often a deterrent to use of those services(248). In a later paper, they also identify that without increased funding for health care, quality will be affected by shortages of medication and increased workload of staff, so that it will be important to increase funding for healthcare to protect the quality of care provided(267).

In 2007, the South African Department of Health published *“A Policy on Quality in Health Care for South Africa”*(268). This document highlights national aims for improvement, including improved access to health care, increasing patient participation and attention to patient dignity, preventative and promotive health efforts, and appropriate use of health care services. The South African government's commitment to an NHI reflects intent to improve access to quality healthcare, protect financial risk and avoid catastrophic health expenditure(91).

#### 6.1.5 Quality improvement

In line with the growth in the field of Quality Improvement in Health Care(269), the Hospice Palliative Care Association in conjunction with the Council for Health Standards for Southern Africa (COHSASA) developed comprehensive standards for governance, management and care(191) for use in assessing quality of palliative care provided to patients and families, and to serve as the basis for accreditation by COHSASA. These standards apply in whatever setting the care is provided with additional elements applicable to an in-patient facility. Areas for



development are identified and hospices are provided with mentorship and guidance to assist them to meet the standards(221), and HPCA provides certificates documenting progress of hospices towards accreditation through a star rating award until the accreditation survey conducted by COHSASA. The 12 elements of the HPCA standards are: 1) Management and leadership (including quality improvement ); 2) Human resource management; 3) Administrative support; 4) Facilities and equipment; 5) Risk management; 6) Access to care and patients' rights; 7) Interdisciplinary team; 8) Holistic patient care; 9) Medication management; 10) Support services; 11) Education and research; 12) Fundraising (191).

There are commonalities between the HPCA standards and elements of the Right to Health described in General Comment 14. These include non-discrimination, access to care (including access to essential medicines), providing culturally appropriate care and quality care with trained personnel. Thus, in the context of palliative care provided in South Africa, the technical aspects of quality are described in the HPCA Standards of Palliative Care, and the patient experience of care is assessed through regular surveys of patient-reported outcome measures.

#### 6.1.6 Office of Health Standards Compliance

The South African government has embarked on an ambitious 'quality improvement programme' with a number of different initiatives. In order to ensure the National Health Insurance can deliver Universal Health coverage with access to quality health services and protection from '*catastrophic*' health costs(91:19) an Office of Health Standards Compliance (OHSC) was established in September 2013, with the authority to inspect and accredit health facilities. The domains of the National Core Standards are Patient Rights, Cleanliness, Waiting Times, Safe and Effective Care, Infection Control, and Medicines. Describing the duty with regard to Patient Rights the standards emphasise the duty of healthcare staff to treat patients and family members with respect (268). Compliance with health standards will promote compliance with the element of quality described by General Comment 14(1) (para 12d).

The OHSC standards do not yet include measures specific to palliative care and, although mandated to do so, the OHSC does not yet assess and accredit NGO or private health services which is potentially problematic, even life threatening. In 2016, the Gauteng Department of

Health implemented the Gauteng Mental Marathon Project to move mental health patients from a health facility, Life Esidimeni, to community-based care provided by non-governmental organisations, ostensibly as a cost-saving initiative by the Gauteng Department of Health(269). This resulted in the death of 144 mental health patients, with 1418 patients “*exposed to trauma and morbidity*”(270) (para 2), and 44 patients missing. In his arbitration ruling, Justice Moseneke describes the hearing as a “*harrowing account of death, torture and disappearance of utterly vulnerable*” people (270) (para 1). Apart from his severe censure of the Gauteng Department of Health officials, Justice Moseneke identifies that the NGOs were operating without licences, and that they did not have the competence, experience or management capacity to accept the patients into their care(270). This provides strong motivation to regulate NGO community-based care through the development of standards and accreditation of services.

#### 6.1.7 Measures of quality in hospice sector through PROMs

In the field of palliative care, measuring patient outcomes requires the recognition that one of the expected outcomes while providing palliative care is a patient’s death, and that care is provided in the context of progressive illness. However, the goal of palliative care is quality of life even with progressive illness. This aligns with the concept of “*the highest attainable standard of health*” considering the “*individual’s biological preconditions*”(1) (para 9). Hearn and Higginson comment that there was a gap in the original symptom assessment and quality of life tools developed to assess outcomes for patients with advanced illness. They suggest that palliative care, as patient-centred care, should respond to issues important to the patient(238). Palliative care practitioners focus on improving and, where possible, eliminating distressing symptoms such as pain; and providing psychosocial and spiritual support to assist patients and their families cope with the illness and losses resulting from the illness. Thus, assessing the quality of palliative care requires measures focused on control of distressing symptoms, and psychosocial and spiritual support.

Higginson and colleagues at Kings College London (KCL) developed the Palliative Care Outcome Score (POS) to assess the goals of palliative care, through a simple easy to administer

questionnaire(238). One of the key aspects of the POS is that it is practical to administer to patients who are likely to be fatigued by long assessment questionnaires because of their advanced illness(238). In discussing patient outcomes and the problem of using quality-adjusted life years (QALYs) in assessing outcomes in palliative care, Normand proposes development of a Palliative Care Yardstick (PaLY) based on QALYs, and adding dimensions important to patients and families at the end of life(271). However, he identifies that POS currently provides insight into benefits to patients and families and what matters to them (264). A version of POS suitable for use in Africa was developed (272) and validated in Africa by the African Palliative Care Association and researchers at KCL(240). The APCA African POS was developed as a tool to research provision of palliative care, and to conduct audits of care in hospices and palliative care services for the purpose of quality improvement. It was also found to provide an opportunity for patients to engage in discussion with palliative care staff in areas of care that may have been overlooked. Selman and Harding identify the importance of clinical audits to measure and improve quality of care, describing the patient's right to quality care in whatever setting the care is provided – hospital or home (273).

Studies in South Africa and East Africa have also utilised APCA African POS to assess quality of care (41,274,275). Lowther and colleagues used the APCA POS as a measure of effectiveness of palliative care in a randomised control trial of people living with HIV on anti-retroviral treatment(275). Patients were allocated to a control arm of usual HIV care and an intervention arm of HIV care provided by a nurse trained in palliative care. The time patients had to talk to their HIV palliative care nurse resulted in better pain management, additional counselling and health education, and better understanding of patient concerns. The authors suggested that the time to talk at the first visit resulted in improved care that reduced the number of visits or time taken at subsequent consultations (275).

#### 6.1.8 Quality and dignity

Backman and colleagues(13), in describing indicators for human rights in health systems, note that the requirement for good quality services includes positive health care worker attitudes and

that patients should be treated with respect. Chochinov describes *“kindness, humanity and respect”* as the *“core values of medical professionalism”*(109), and essential elements in conserving people’s dignity when they find themselves as patients with the healthcare system (109). He proposes that clinician Attitudes, Behaviour, Compassion and Dialogue are the A, B, C, D, of *“dignity-conserving care”* (101:84). Dialogue, described as *“a critical element of dignity conserving care”* (103:186), acknowledges the patient as a person and assists in getting to know the patient, so that the clinician understands a person’s preferences for care and can elicit goals of care. These four fundamentals should be combined to enhance the patient’s sense of being valued and self-respect, which are critical to the person’s sense of dignity(103). They are echoed in the South African Constitution which states that *“Everyone has inherent dignity and the right to have their dignity respected and protected”*(11) (para 10).

There has been a focus on patient-centred care in attempts to improve the experience of health care users in many countries, including South Africa(276,277). However, although the term patient-centred is used, it is referred to infrequently in official documents and usually without definition. For example, the National Health Insurance white paper makes only one mention of patient-centredness. This is in describing quality of care which is described as *“the safe, effective, patient-centred, timely, efficient and equitable provision of healthcare services to achieve desired health outcomes”*(91)(para 28). However, there is no definition of patient-centredness. In discussing quality improvement measures in healthcare, Groene describes patient-centredness as an important aspect of quality improvement and identifies patient level measures of patient-centred care as improving patients’ rights, as well as improving the care process and health outcomes (276). Chochinov notes that patient-centred care - valuing the patient, according them respect and seeking to understand their experience, enhances their sense of extrinsic dignity(109). The palliative care approach describes the patient and family as the unit of care, and the importance of good communication skills to elicit patient concerns in order to relieve patient suffering(119). Discussion with the patient assists in understanding patient preferences, an important element of acceptability, and informs the development of an individual care plan to guide the palliative care team.

Respect for the patient assists in preserving the dignity of patients, even when the illness has impacted on their view of themselves as intact persons with a subsequent perception of loss of dignity(109). This focus on respect is the foundation of quality care, and assists in promoting the element of acceptability described in General Comment 14 as being “*respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals*”(1) (para 12c).

#### 6.1.9 Home-based care services: palliative care and general care

Palliative care can be provided in any setting. A review of palliative care in hospital, hospice and home in the developed world identified different models of care, including integration of hospice in-patient care and hospice home care. The study found a high level of satisfaction with home care, but cautioned that home-based palliative care must also involve the inter-disciplinary team and that staff needed adequate training in palliative care(278). A number of studies have identified that the model of palliative care delivery in Africa is mainly through home-based care, relying mainly on family and community volunteers with support from professionals (279--281). Staff also provide support and training of family members providing care. Concerns have been raised about the training and competence of the home-based carers, and how to access medicines for home-bound or bed-bound patients (280).

The impact of the HIV epidemic in sub-Saharan Africa (SSA) resulted in a growth of community-based home care services, some of which have strong links to the formal health care sector. Some of these services also provide palliative care from diagnosis and including end-of-life care as described in the WHO definition(279,281). However, many home-based care services do not have staff trained in palliative care or the support required to provide holistic palliative care, and thus do not qualify as palliative care services. Downing and colleagues describe that often elements of palliative care are missing from general home-based care services: such as assessment and management of pain and other distressing symptoms; *emotional support; spiritual care; bereavement care and support; effective supervision*” of home-based carers(282:303). Grant and colleagues, reporting in 2011, stated that palliative care is “*available to less than 5% of those who need it*” in Africa (281:1). Home-based care describes a model of care which is seen as an

inexpensive model of care that is also a preferred choice of patients and families(282). Home-based carers who are usually recruited from the communities they serve, and may be of the same culture as patients provide culturally-appropriate care, affirming the requirement of Acceptability as described by General Comment 14(1).

Downing and Jack reviewed the provision of palliative care in rural settings in both the developed world and in developing countries(187). The review identified that palliative care can be “*grafted onto existing home-based care programmes*”(187:383). Challenges in the rural communities include shortage of health care workers and difficulty in accessing palliative care training and support for the health care providers. Models of palliative care were adapted to meet the needs of the particular community, such as the development of home-based palliative care teams as outreach from 13 hospitals in Tanzania (284). Island Hospice in Zimbabwe provided training to community volunteers to add palliative care to existing home-based care teams developed in response to the HIV epidemic (285).

In the South African setting, most palliative care is provided by hospices, and HPCA report that the majority of patients (98%) in hospice care receive palliative care in the home (103). Although some South African hospices have in-patient facilities, this is more costly and, consistent with the experience elsewhere, most patients prefer to be cared for at home (165-167).

In the 1990s, South Coast Hospice in Kwa-Zulu Natal, in response to the HIV epidemic at a time when anti-retroviral medication was unavailable in South African public health facilities, piloted a model of care later adopted by the majority of South African hospices(221). The Integrated Community-based Home Care (ICHC) model relied on ‘highly trained’ community caregivers and volunteers, who were supervised by hospice professional staff to care for patients in their own communities. In addition to providing care, the community caregivers train the family and neighbours in basic nursing, infection control, mouth care and pressure care(221). An evaluation of the original programme identified that the quality of care was good, and the respectful care provided to the PLHIV enhanced their self-esteem and well-being(190).

With training and support of health care workers and support of family carers, quality palliative care therefore can be provided in the home or in any setting where a patient needs this care. However, it needs to be clear that not all home-based care includes palliative care.

#### 6.1.10 Problem Statement

Quality of care is an important element of provision of healthcare, in particular for patients with advanced illness. Quality is also part of the Right to Health, for which the state has particular obligations. To date, palliative care in South Africa has mostly been provided through the NGO sector, in the form of home-based care in the patient's home and/or hospice care in a hospice in-patient facility. The national palliative care policy identifies models of care that integrate palliative care into public health facilities, but the policy is not yet implemented and there are few palliative care services in the public health sector leaving NGOs as the foremost provider of palliative care in South Africa.

However, even though delivered through non-state providers, access to palliative care remains a rights obligation on the state. The obligation to fulfil the right to palliative care imposes on the state a duty to either provide care directly, or to facilitate the provision of care by others that meets the elements of Availability, Accessibility, Acceptability and Quality. The study thus far has demonstrated serious need for palliative care in South Africa. It has shown limited availability of services and that access is compromised even when services are available. This part of the study aims to evaluate quality of palliative care where provided at NGO sites, in order to assess the element of Quality as part of the Right to Health described in General Comment 14. As a secondary goal, it also analyses patient experience of care, to describe Acceptability as an element of the right to palliative care. In understanding Quality and Acceptability of care in the NGO sector, the study considers how palliative care is implemented in South Africa as part of the Right to Health.

### 6.1.11 Aim and objectives

Aim: to evaluate the quality of care delivered to patients requiring palliative care in hospice and non-hospice services in South Africa

Objectives:

- 1) to describe the change in patient reported outcomes over a 4-6 week period as a measure of the quality of care provided to patients
- 2) to explore patient perceptions of the quality of care provided by the NGO services.

## 6.2 Methodology

### 6.2.1 Study design

This is a prospective cohort study using primarily quantitative but also some qualitative methods

### 6.2.2 Study sites

The study was designed to be carried out in 40 NGO service sites (both hospice and non-hospice services) in five provinces - Eastern Cape, Free State, Gauteng, KwaZulu-Natal and Western Cape - out of the nine provinces in South Africa. The selected provinces included both urban and rural provinces. In 2012, when the study was conducted there were 23 accredited hospices members of HPCA, of which 20 were located in the five provinces identified. These 20 hospices were selected through purposive sampling and 20 non-hospice sites were selected through convenience sampling in the same provinces. The selection of the five provinces was therefore based on practical reasons for data collection but they also covered diverse populations from different ethnic groups and different areas of different socio-economic circumstances.

### 6.2.3 Study population

Patients and family members cared for by the NGO staff at the above sites.

#### 6.2.3.1 Selection criteria

- 1) Selection of study sites:

Selection criteria for hospice NGOs was that the hospices should be accredited by the Council of Health Services Accreditation of South Africa.

There is not yet a system of regulation and accreditation of health NGOs in South Africa, so the selection criteria for non-hospice NGOs was (a) the provision of home-based care and (b) being located within the geographic region of the selected hospice, for



convenience of data collection. These sites were selected from a list of sites funded by provincial department of health conditional grants, and by proximity to the hospice study site to contain costs of transport.

## 2) Selection of participants:

Inclusion criteria:

Patients admitted to the NGO service within the past week

Family members attending patient at first interview

Exclusion criteria:

Children under the age of 18 years

Patients too frail to take part in the survey

Patients not cognitively able to answer questionnaire

### 6.2.4 Sampling

A two-stage sampling process was undertaken. First, non-governmental organisations were stratified by hospice and non-hospice status. Twenty of the hospice sites were selected through purposive sampling as fully accredited hospices that are members of the HPCA, and 20 non-hospice sites were selected as serving the same areas as the selected hospices in five provinces across South Africa. Then, within each organisation, 16 patients receiving care were selected, along with family members, for participation in the study over a month.

### 6.2.5 Sample Size

Sample size was calculated using the Stata command `sampsi` based on hypothesis testing for a change in pain scores. This estimate was calculated based on an Alpha of 0.05, a power of 0.9, a change in pain score from 2.6 (sd =1) to 1.4 (sd =1). The planned number of sites was 40 with an assumption of equal numbers of hospice and non-hospice patients. The pain scores used in this calculation were based on results from previous evaluation studies of change in pain score over a 6-week period for patients receiving hospice care(282). It was assumed variances were the same in the two groups. This translated into recruiting 16 patients from each hospice or non-hospice service.

Previous audits of hospice care found that approximately 60% of patients will have family members present to respond to the second part of the questionnaire, so it was planned to include 360 family members in the study. Convenience sampling of consecutive new patients admitted within the past week to each of the identified services was conducted until 16 patients had been recruited per site.

#### 6.2.6 Data collection tools

##### 1) Questionnaire

A draft questionnaire (Appendix A6 page 284) was developed to collect demographic data on participants. The questionnaire was developed, recognising that potential participants may be ill and frail, and that the questionnaire should be short so as not to tire the participant. The questionnaire included 12 questions, initially recording age, gender, race and diagnosis, and then asking about referral to the NGO service, and experience of the service. Race was included in the questionnaire to provide information relating to acceptability of the service, acceptability being described as respectful of peoples and communities. The questionnaire has initially asked about participants' ethnicity but this term appeared to be confusing to participants so research assistants explained the concept in terms of race which, unfortunately, is still a recognised social construct in South Africa. Thus race has been used as a proxy to assess whether care was available and accessible to all cultures. The questionnaire ended with an enquiry as to how the patient would choose to be cared for.

An advisory group was convened to consider the question of dignity in healthcare and to assist in formulating the questionnaire. The group advised that rather than using the term dignity, the questionnaire should include the question "How would you like to be cared for?", to elicit a spontaneous response without introducing the concept of dignity directly as this may introduce bias.

##### 2) Survey document

The interview then moved to questions from the APCA African Palliative Outcome Score (POS) (Appendix A5 page 282) which was also used and described in the Accessibility study (Chapter 5). It was also translated into Sesotho by the University of Free State for this study.

### 6.2.7 Recruitment and training of research staff

A research co-ordinator, experienced in research and in the use of the APCA African POS, provided oversight of data collection in the five selected provinces as well as the recruitment and training of research assistants in each of the five provinces. Training of the research assistants included 1) an introduction to the research project and the data collection process; and 2) research ethics, which included providing full information about the project at recruitment and seeking voluntary informed consent. The patient information sheets, consents forms and questionnaires were translated into the predominant language of the provinces in which the study took place. They were administered in the languages of choice of the patients and in which the research assistants were fluent (Appendix B2, page 288)

The training also covered the use of the APCA African POS, and included role play to experience the practical aspect of conducting the structured interview. Some of the research assistants were experienced in using the APCA African POS as an audit tool. In Gauteng province the research assistant trained for the project withdrew because of pressure of work, and a new research assistant was recruited and trained by the research co-ordinator prior to data collection commencing. This resulted in the data collection period in Gauteng being only four weeks and impacted data analysis.

The research assistants were provided with research packs that included 1) a copy of the letter of ethical approval from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee; 2) letters requesting permission to conduct the study in NGO sites in the province (Appendix D2 page 296); 3) the training material on the research project; and 4) data collection instruments, including information sheets for potential participants, consent forms, and data collection forms. The research assistants arranged printing of required documentation, and after data collection couriered completed anonymised data collection sheets to the research co-ordinator for data capture.

### 6.2.8 Recruitment of participants

Recruitment occurred in a three-step process and followed the same process in both hospice and non-hospice services. Firstly, the research assistants introduced the project to staff at the

research sites at a meeting at the facility. They explained the study to them and requesting assistance in identifying eligible participants and in providing a private space for interviews of patients and family members. Then, NGO staff identified potential participants according to inclusion criteria, told the patient about the study and introduced them to the research assistant. Then, if they were amenable, the research assistant explained the study in detail from the participant information sheet which was given to the potential participant in the participant's first language. The nature of their participation was explained, along with confirmation that a decision not to participate would not adversely affect their care. Those who chose to participate provided written consent to take part in the research. Participants were recruited from in-patient care, day care or support groups and followed-up at home. There are few in-patient beds in the NGO sector (hospice and non-hospice) and in-patient stay is of short duration, so most participants recruited were out-patients. Participants who had a family member present were asked if the research participant could also ask questions of the family member. With consent of the patient, the family member was provided with information about the research, and invited to take part in the research project and to sign voluntary informed consent. Participant recruitment took place over a 9-month period from November 2012 to July 2013.

#### 6.2.9 Data collection process

Following informed consent, the research assistant conducted the interview in the participant's home language and recorded the responses on the questionnaires.

The patient participant was asked 12 questions relating to their illness, including three open-ended questions about their experience or care; and seven questions from APCA APOS. If a family member was present and had consented to participate in the study, s/he responded to the three APCA APOS family questions.

The research assistant asked for contact details from the participants, in order to contact the participants for follow up telephonic interviews to determine any change in APCA APOS scores over the following five weeks (to week 6). The APCA POS was therefore administered

telephonically every week to each participant for six weeks, except in Gauteng where the study started late and follow-up interviews ended after four weeks.

The questionnaire asked people to rate the problems based on the last three days experience, so a week between interviews allows for change between one interview and the next. The six-week follow up allowed assessment of how quickly problems were addressed by the care service, whether there was improvement in outcomes over time and whether the response was sustained. Each follow-up interview (every week) was shorter (approximately 5-7 minutes) than the initial interview as the participant became familiar with the questions with every repeat administration. Because the questionnaire asked about symptoms over the past three days, research assistants were given a maximum period of three days to achieve contact with patients, otherwise the overlap would compromise the weekly schedule timing. Patients who have advanced illness may be frail and tired, so a short interview was thought to be manageable for this group of participants.

The research assistant recorded the responses on the questionnaires, and also made a note if there had been no response and the reason why any subsequent interviews could not be completed.

#### 6.2.10 Data storage and confidentiality

The research assistants recorded patients' names on a separate master document with the study identifier. These documents were secured in a locked cabinet in the research assistants' offices, separate from the files containing completed questionnaires. Copies of completed questionnaires were transferred to the research coordinator's office in Cape Town by courier and securely stored in a locked cabinet. The completed questionnaires were taken to the study data capturer to input all data onto Excel spreadsheets and then returned to the PI for secure storage. The PI received data from the data capturer, checked for missing data and corresponded with research assistants to obtain missing data or clarify outliers.

Confidentiality was assured in that only the research assistants had the names of the participants, and the master sheet was stored securely by the research assistants separately from the questionnaires which were identified only by study number.

### 6.2.11 Ethical considerations

#### Ethical approval

The study was approved by the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee (320/2010) (Appendix C1 page 293), and by the Hospice Palliative Care Association Research Ethics Committee (06/2010) (Appendix C2 page 294). Recertification of the study was received annually until study closure.

#### Vulnerable population

Consideration was given to the fact that potential participants were patients and family members in palliative care services and home-based care services. As such patients were vulnerable in their state of physical health, and both patients and family members were vulnerable due to anxiety with regard to the patient's illness. It is recognised that there is likely to be a high rate of attrition in palliative care research because participants may become too frail to continue or may die during the course of the study. There is a research imperative to provide best quality care, and to develop an evidence-base to the practice of palliative care in South Africa to improve this care where possible. In the interest of beneficence and improving care to this population, the research was conducted recognising the need for particular consideration due of the vulnerability of people cared for in palliative care.

Research assistants were recruited from staff trained in palliative care with experience in compassionate care of people facing the diagnosis of life-threatening illness. They were respectful of participants' vulnerability and trained in how to inform potential participants fully, with consideration of each person's understanding of the research. Research participants were assured that consent should be voluntary and freely given, and were re-assured that their usual care would not be compromised if they chose not to take part in the study or to withdraw from the study at any time.

#### Distress Protocol

A distress protocol was developed for the study based on a distress protocol used in the implementation of the APCA African POS. Any participant who became either physically or emotionally distressed during the interview would be offered the opportunity to cease the interview, and either abandon the interview or restart when they were comfortable.

The distress protocol includes an option for the interviewer to inform the participant's care staff of the participant's distress with the participant's permission. The hospice manager had agreed to provide additional counselling for the participant should this be necessary.

## 6.2.12 Data analysis

### 6.2.12.1 Statistical analysis of demographic data and patient outcomes

Demographic data was analysed using Excel and presented in table format and as graphs.

#### APCA POS scores

Data was captured in Microsoft Excel, and Stata 13 was used for statistical analysis of Reported Outcome Measures Patient (PROMs) as measured by APCA African POS (StataCorp, Stata Statistical Software, release 13, 2012). The Shapiro-Wilk test indicated that the PROMs were not normally distributed, hence the non-parametric Wilcoxon signed rank test was used to compare baseline with follow-up data, and the Wilcoxon sum rank test was used for comparing independent groups.

Descriptive statistics included mean, median and the range, and the results were presented graphically using the box-and-whisker plots. For all analyses, a P-value <0.05 was considered the threshold of statistical significance.

Analysis was carried out comparing change in PROMs for each of the seven items: (a) over a 4-week period; and (b) over a 6-week period, from baseline. The significance of the measures of change were reported. Time periods were reported as T1 (baseline) and weekly thereafter (T2 to T6 being week 2 to week 6). There was high attrition following week 4 so it was decided to compare results after a 4-week period to baseline as well as after a 6-week period to baseline. It has been found in earlier studies that psychosocial and spiritual items require 3-4 weeks before showing an improvement, thus analysis was not done for earlier intervals.

#### Variables

The first three outcomes for patients - Pain, Symptoms other than pain (identified by the patients themselves) and Worry - are scored 0-5 best to worst, as is Family Worry; for example, no pain = 0 and worst pain = 5.

The following four outcomes for patients (Able to share, At peace, Life worthwhile and Help and advice to plan for the future), and two outcomes for family (Family information and Family

confidence) scored 0-5 worst to best; for example, help and advice to plan for the future 0 = not enough help and advice, and 5 = as much help and advice as needed.

The data for hospice and non-hospice sites were analysed separately which allowed for a comparison between the 2 groups.

Logistic regression was conducted to compare change in patient-reported outcomes according to group – hospice or non-hospice.

#### 6.2.12.2 Content analysis

Qualitative data from the narrative responses were analysed using content analysis. The comments were brief responses to open-ended questions and not from an in-depth interview. The responses were captured in the full data set on Excel, and narrative responses were read and re-read to guarantee immersion in the data and to identify themes emerging for the data. Coding of content was carried out, and themes and sub-themes were identified and reported, using participant quotes to illustrate the themes and subthemes to support the thematic framework.

### 6.3 Results

#### 6.3.1 Recruitment into study

There were 459 patients recruited to participate in the study and 253 family members. This was less than anticipated as fewer NGOs took part than planned, and there was lower recruitment at some study sites than planned. Nineteen hospice sites (95% of sampled hospice sites) took part and 15 non-hospice sites (75% of sampled NGO sites).

Planned recruitment for 34 sites was 510 patients; however, 459 patients were recruited in total. This represented 90% of the overall estimated sample, and 95% of the sample from responding facilities. Of respondents, 56% were in care through hospice and 44% from non-hospice NGOs. More non-hospice NGOs were identified in the W Cape than in other provinces, as there was a higher number of hospice and non-hospice NGOs receiving funding in the W Cape than in other provinces. Data collection started late in the E Cape and no non-hospice sites were included. Data collection started two weeks late and ended in Gauteng after week 4. Recruitment in KZN was well below target.

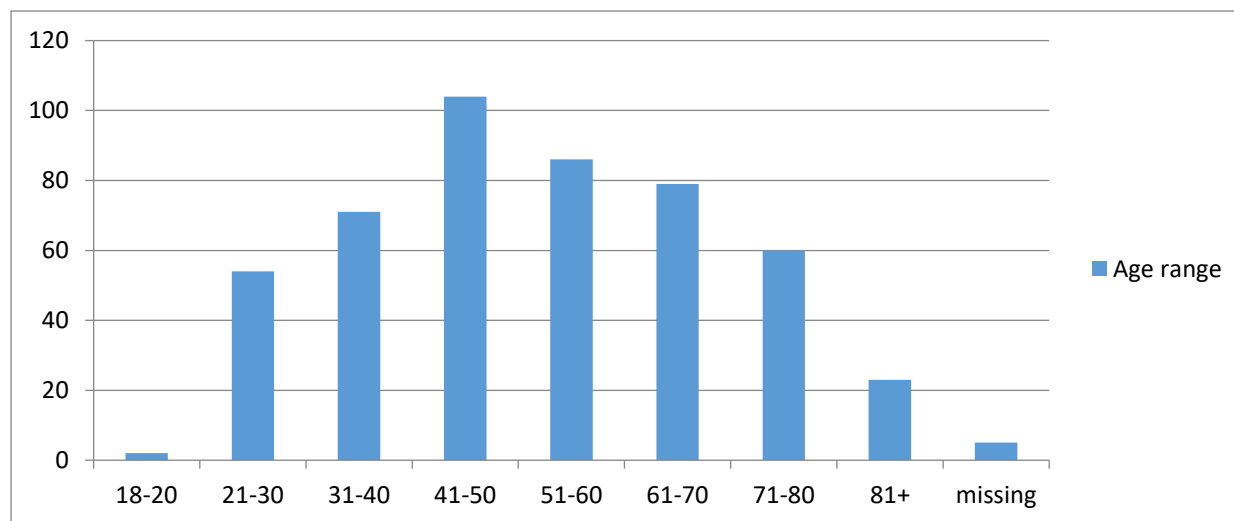


*Table 6.1: Number of organisations and patients per province*

Province	# hospices	# patients	# family	# non-hosp	# patients	# family
E Cape	3	48	45	-	-	-
Free State	3	47	45	3	48	47
Gauteng	4	64	21	4	64	31
KZN	4	33	25	3	34	6
W Cape	4	65	28	5	56	5
Total	19	257	164	15	202	89

Of the anticipated 360 family members, 253 were recruited representing 70% of the intended sample size. The majority (164 or 65%) were from hospice services and fewer (90 or 35%) from non-hospice services.

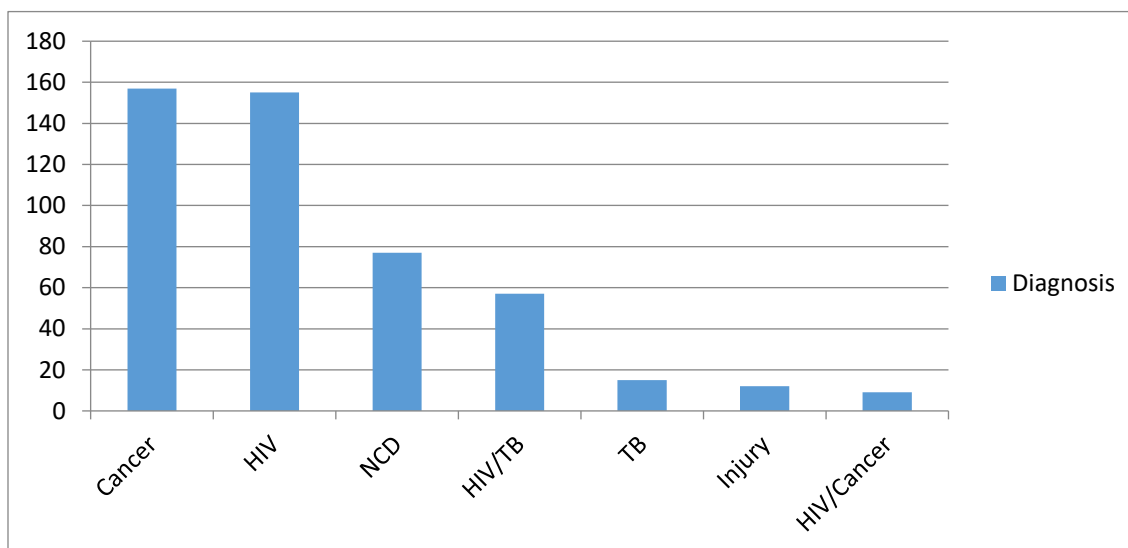
*Figure 6.1: Patient demographics by age*



*Table 6.2: Patient demographics by gender and race*

Gender	Number	percent
Female	275	59.91
Male	184	40.09
<b>Race</b>		
African black	265	57.73
Asian	11	2.40
Coloured	103	22.44
White	73	15.90
Not specified	7	1.53

Figure 6.2: Diagnoses of all patient in care (both hospice and non-hospice) (n=459)



Of the 78 patients with a NCD diagnosis other than cancer, 43.6% were diagnosed with cardiovascular disease, and the rest included chronic obstructive airways disease, stroke, arthritis, diabetes, renal failure and epilepsy. See Figure 6.2.

### 6.3.2 Comparison of the two groups: hospice and non-hospice

#### Gender

The percentage of male patients in hospices (42%) was slightly higher than in non-hospice NGOs (34%), but this difference was not statistically significant ( $p=0.08$ ).

#### Diagnosis

The primary diagnoses recorded for the participants are detailed below (Table 6.3).

Table 6.3: Primary diagnoses for participants by hospice and non-hospice

Diagnosis	Hospice n=256	Non-hospice n=203
Cancer	53.5%	13.8%
HIV	25.0%	29.1%
TB	2.3%	14.3%
TB/HIV co-infection	13.3%	8.8%
Chronic disease	5.9%	34.0%

There were significant differences in the diagnoses of the patients in the care of hospice and non-hospice services. There were more cancer patients in the hospice group, and more patients with chronic disease (such as cardiovascular disease and chronic obstructive airways disease) in the non-hospice services ( $p < 0.001$ ).

### 6.3.3 Loss to follow-up

There was significant attrition during the study, and results are presented for change in POS items at week 4 and at week 6. There were 421 patients still in the study at week 4 (87% of those present at baseline) 231 hospice 190 non-hospice; and 257 (53% of those present at baseline) patients still present in the study at week 6 - 140 hospice 117 non-hospice. If the Gauteng patients are removed from the baseline number of patients to allow for the fact that the interviews were not conducted in Gauteng after week 4, the retention is 77.6% of participants in the other four provinces.

*Table 6.4: Participants retained in the study*

# participants	# recruited	# week 4	% completed week 4	# week 6	% completed week 6
Hospice	273	231	84.62%	140	51.28%
Non-hospice	211	190	90.05%	117	55.45%
Total	484	421	86.98%	257	53.10%

The reasons for loss to follow-up are shown in Tables 6.5 and 6.6. Once the participant was lost to the study they did not return to the study. There was low loss to follow-up in the first four weeks of the study (4.5% per week). The majority of participants lost to the study (113) were those from Gauteng province, where the research assistant was not able to complete data collection in weeks 5 and 6 (See Table 6.5). Of the remaining participants, 59 were identified as not contactable (noted as not available), either because of changing contact details, movement from original place of residence and place of care. Some of the patients identified as not available

may also have died. There were known reasons for 82 participants who did not complete the study (Table 6.6).

*Table 6.5: Reasons for loss to study by week*

	Died		Not available		Withdrew		Other service		Total	
	Hosp	Non-hosp	Hosp	Non-hosp	Hosp	Non-hosp	Hosp	Non-hosp		
Week 2	12	2	1	1		5		1	22	4.5%
Week 3	8	2	2		3	4	2		21	4.5%
Week 4	6	2	4		2	2	2	2	20	4.5%
Week 5	2	3	60	59	2	2	3		131	42.1%
Week 6	2		15	7	1	2	6		33	11.9%
Total by site	30	9	82	67	8	15	13	3	227	
Total	39		149		23		16			

*Table 6.6: Reasons for loss to study by site (excluding Gauteng participants)*

# participants lost to study	Death	Not available	Withdrew	Other service
Hospice	30	30	8	13
HBC	9	12	15	3
Total	39	42	23	16

#### 6.3.4 Analysis of patient-reported outcomes for patients and identified family members

Data collected through the APCA African POS was analysed to compare change over time between weeks 1 – 4 (Tables 6.8-6.10) and between weeks 1-6. (Tables 6.12-6.15)

Table 6.7: Change over time between week 1 – 4 for group 1: hospice services

	ALL PROVINCES	N	Mean	Median	Min	Max	P-value (T1 vs T4)
Pain 0=no pain to 5=worst pain	T1	206	2.82	3	0	5	<b>&lt;0.001</b>
	T2	206	2.17	2	0	5	
	T3	206	1.76	2	0	5	
	T4	206	1.54	1	0	5	
Symptom 0=no other symptoms 5=severe symptoms	T1	204	2.02	2	0	5	<b>&lt;0.001</b>
	T2	204	1.49	1	0	5	
	T3	204	1.26	1	0	5	
	T4	204	1.08	0	0	5	
Worry 0=none 5=overwhelming	T1	204	2.55	3	0	5	<b>&lt;0.001</b>
	T2	204	2.08	2	0	5	
	T3	204	2.01	2	0	5	
	T4	204	1.90	2	0	5	
Able to share 0=not able to share 5=able to share freely	T1	204	4.01	5	0	5	<b>0.026</b>
	T2	204	4.04	5	0	5	
	T3	204	4.14	5	0	5	
	T4	204	4.30	5	0	5	
Life worthwhile 0=not at all 5= all the time	T1	200	3.94	5	0	5	<b>0.029</b>
	T2	200	4.12	5	0	5	
	T3	200	4.12	5	0	5	
	T4	200	4.18	5	0	5	
At peace 0=not at peace 5= all the time	T1	202	3.75	5	0	5	<b>0.010</b>
	T2	202	4.00	4	0	5	
	T3	202	4.12	4.5	0	5	
	T4	202	4.18	4.5	0	5	
Help and advice 0=not enough 5=as much as wanted	T1	195	4.06	5	0	5	0.773
	T2	195	4.15	5	0	5	
	T3	195	4.22	5	0	5	
	T4	195	4.29	5	0	5	

### 6.3.4.1 Hospice patients

All elements of patient reported outcomes improved in the survey of 206 hospice patients who were retained in care over a 4-week period. All outcomes were statistically significant save for help and advice. The trend was similar over the other time intervals, but was not assessed for statistical significance. The largest improvement occurred for pain, symptoms other than pain, and worry. The indicator Help and advice started at high levels so had little room for improvement.

*Table 6.8: Compare change over time between week 1 – 4 for hospices - family outcomes*

	ALL PROVINCES	N	Mean	Median	Min	Max	P-value (T1 vs T6)
Family information 0=no information 5=as much information as wanted	T1	119	4.63	5	0	5	0.3126
	T2	119	4.71	5	0	5	
	T3	119	4.79	5	1	5	
	T4	119	4.78	5	2	5	
Family Confidence 0=not at all confident 5=very confident in providing care	T1	116	4.59	5	1	5	0.017
	T2	116	4.68	5	1	5	
	T3	116	4.72	5	1	5	
	T4	116	4.72	5	1	5	
Family worry 0=not at all worried 5=severe worry	T1	113	3.05	3	0	5	<0.001
	T2	113	2.65	3	0	5	
	T3	113	2.44	2	0	5	
	T4	113	2.41	2	0	5	

### 6.3.4.2 Family members of hospice patients

There was also improvement in measures amongst the 119 family members (Table 6.9). All three measures were significantly improved apart from Family Information, which started at a high level of 4.63/5 but still improved slightly to 4.78/5.

Table 6.9: Compare change over time between week 1 – 4 for group 2: non-hospice

	ALL PROVINCES	N	Mean	Median	Min	Max	P-value (T1 vs T4)
Pain 0=no pain to 5=worst pain	T1	192	2.5	2	0	5	<0.001
	T2	192	2.04	2	0	5	
	T3	192	1.88	2	0	5	
	T4	192	1.71	1	0	5	
Symptom 0=no other symptoms 5=severe symptoms	T1	187	1.91	2	0	5	<0.001
	T2	187	1.58	1	0	5	
	T3	187	1.55	1	0	5	
	T4	187	1.3	0	0	5	
Worry 0=no worry to 5=overwhelming worry	T1	186	2.54	2.5	0	5	<0.001
	T2	186	2.18	2	0	5	
	T3	186	1.86	2	0	5	
	T4	186	1.77	1	0	5	
Able to share 0=not able to share 5=able to share freely	T1	190	3.73	5	0	5	0.2754
	T2	190	3.72	5	0	5	
	T3	190	3.71	5	0	5	
	T4	190	3.94	5	0	5	
Life worthwhile 0=not worthwhile at all 5= all the time	T1	178	3.79	5	0	5	<0.001
	T2	178	4.06	5	0	5	
	T3	178	4.17	5	0	5	
	T4	178	4.23	5	0	5	
At peace 0=not peace 5= all the time	T1	189	3.73	4	0	5	<0.001
	T2	189	4.02	4	0	5	
	T3	189	4.23	5	0	5	
	T4	189	4.24	5	0	5	
Help and advice 0=not enough H&A 5=as much as wanted	T1	184	3.32	4	0	5	0.3656
	T2	184	3.3	4	0	5	
	T3	184	3.52	5	0	5	
	T4	184	3.6	4	0	5	
Family information 0=no information 5=as much as needed	T1	65	4.22	5	0	5	0.175
	T2	65	4.35	5	0	5	
	T3	65	4.4	5	1	5	
	T4	65	4.52	5	2	5	
Family Confidence 0=not at all confident 5=very confident in providing care	T1	63	4.35	5	0	5	0.011
	T2	63	4.54	5	1	5	
	T3	63	4.52	5	0	5	
	T4	63	4.57	5	1	5	
Family worry 0=not at all worried 5= very worried	T1	59	3.02	3	0	5	0.001
	T2	59	2.92	3	0	5	
	T3	59	2.39	2	0	5	
	T4	59	2.31	2	0	5	

### 6.3.4.3 Non-hospice patients and family members

For the non-hospice participants, there was a significant improvement in five of the seven patient items (Table 6.7) and two of the three family member items (Table 6.8) amongst 192 patients and 65 family members surveyed. Most significant changes for patients were improvement in pain levels, improvement in symptoms other than pain and improvement in worry. In addition, the spiritual items measured showed significant improvement – feeling that life is worthwhile and feeling at peace.

*Table 6.10: Comparison of baseline (week 1) POS items for hospices and non-hospice services*

Baseline Items	Hospice			Non-hospice			P-value group 1 versus group 2
	N	Mean	Median	N	Mean	Median	
Pain	256	2.79	3	227	2.56	3	0.181
Symptom	256	2.03	2	227	2.05	2	0.814
Worry	256	2.59	3	227	2.55	3	0.873
Able to share	257	4.01	5	226	3.72	5	0.110
Life worthwhile?	252	3.93	5	214	3.71	4.5	0.143
At peace	257	3.8	5	226	3.68	4	0.322
Help and advice	250	4.02	5	225	3.25	4	<0.001
Family Information	165	4.52	5	89	4.12	5	0.041
Family Confidence	160	4.47	5	88	4.1	5	0.260
Family worry	158	3.13	3	85	3.05	3	0.691

For both groups, the most severe problems at baseline were pain, worry/anxiety and other symptoms; in addition, family worry was a problem. In general, all other POS items were of less concern. The only significant difference between the two groups at baseline was that hospice patients had received more help and advice prior to the interview.

### 6.3.4.4. Analysis at week 6.

There were improved APCA POS item scores for both hospice and non-hospice patient and family reported outcomes at week 6 (See Tables 6.9 and at 6.10). The only measure that did not significantly improve was ability to share, both amongst hospice patients and non-hospice patients.



Table 6.11: Compare change over time between weeks 1 – 6 for hospice patients

	ALL PROVINCES	N	Mean	Median	Min	Max	P-value (T1 vs T6)
Pain 0=no pain 5=worst pain	T1	114	2.68	3	0	5	<0.001
	T2	114	2.14	2	0	5	
	T3	114	1.79	2	0	5	
	T4	114	1.42	1	0	5	
	T5	114	1.25	1	0	5	
	T6	114	0.99	0	0	5	
Symptom 0=no other symptoms 5=severe symptoms	T1	113	2.29	2	0	5	<0.001
	T2	113	1.6	1	0	5	
	T3	113	1.24	1	0	5	
	T4	113	1.12	0	0	5	
	T5	113	0.95	0	0	5	
	T6	113	0.82	0	0	5	
Worry 0=no worry 5=overwhelming worry	T1	113	2.71	3	0	5	<0.001
	T2	113	2.04	2	0	5	
	T3	113	2.06	2	0	5	
	T4	113	1.85	2	0	5	
	T5	113	1.45	1	0	5	
	T6	113	1.27	1	0	5	
Able to share 0=not able to share 5=able to share freely	T1	114	4.4	5	0	5	0.217
	T2	114	4.3	5	0	5	
	T3	114	4.4	5	0	5	
	T4	114	4.53	5	0	5	
	T5	114	4.53	5	0	5	
	T6	114	4.5	5	0	5	
Life worthwhile 0=not worthwhile at all 5=w'while all the time	T1	111	4.02	5	0	5	0.001
	T2	111	4.24	5	0	5	
	T3	111	4.26	5	0	5	
	T4	111	4.45	5	0	5	
	T5	111	4.46	5	0	5	
	T6	111	4.55	5	0	5	
At peace 0=not peace at all 5= feels at peace all the time	T1	112	3.69	5	0	5	<0.001
	T2	112	4.06	5	0	5	
	T3	112	4.27	5	0	5	
	T4	112	4.51	5	1	5	
	T5	112	4.51	5	0	5	
	T6	112	4.58	5	1	5	
Help and advice 0=not enough help & advice 5= as much help and advice as wanted	T1	107	4.13	5	0	5	<0.001
	T2	107	4.48	5	0	5	
	T3	107	4.5	5	0	5	
	T4	107	4.62	5	0	5	
	T5	107	4.7	5	0	5	
	T6	107	4.71	5	0	5	

Table 6.12: Compare change over time between weeks 1 – 6 for non-hospice patients

	ALL PROVINCES	N	Mean	Median	Min	Max	P-value (T1 vs T6)
Pain 0=no pain 5=worst pain	T1	92	2.82	3	0	5	<0.001
	T2	92	2.37	2	0	5	
	T3	92	2.14	2	0	5	
	T4	92	2.00	2	0	5	
	T5	92	1.76	1	0	5	
	T6	92	1.54	1	0	5	
Symptom 0=no other symptoms 5=severe symptoms	T1	89	2.25	2	0	5	<0.001
	T2	89	1.92	2	0	5	
	T3	89	1.73	2	0	5	
	T4	89	1.4	1	0	5	
	T5	89	1.53	1	0	5	
	T6	89	1.52	1	0	5	
Worry 0=no worry 5=overwhelming worry	T1	90	2.74	3	0	5	<0.001
	T2	90	2.32	2.5	0	5	
	T3	90	1.78	2	0	5	
	T4	90	1.88	2	0	5	
	T5	90	1.78	1	0	5	
	T6	90	1.47	1	0	5	
Able to share 0=not able to share 5=able to share freely	T1	90	3.57	5	0	5	0.4965
	T2	90	3.58	5	0	5	
	T3	90	3.58	5	0	5	
	T4	90	3.74	5	0	5	
	T5	90	3.71	5	0	5	
	T6	90	3.57	5	0	5	
Life worthwhile 0=not worthwhile at all 5=w'while all the time	T1	87	3.97	5	0	5	0.013
	T2	87	4.34	5	0	5	
	T3	87	4.43	5	0	5	
	T4	87	4.39	5	0	5	
	T5	87	4.31	5	0	5	
	T6	87	4.39	5	0	5	
At peace 0=not peace at all 5= feels at peace all the time	T1	91	3.54	4	0	5	<0.001
	T2	91	4.08	4	0	5	
	T3	91	4.36	5	0	5	
	T4	91	4.34	5	0	5	
	T5	91	4.44	5	0	5	
	T6	91	4.47	5	0	5	
Help and advice 0=not enough help & advice 5= as much help and advice as wanted	T1	86	3.23	5	0	5	0.025
	T2	86	3.34	5	0	5	
	T3	86	3.73	5	0	5	
	T4	86	3.91	5	0	5	
	T5	86	3.88	5	0	5	
	T6	86	3.9	5	0	5	

Table 6.13: Compare change over time between weeks 1 – 6 hospice family outcomes

	ALL PROVINCES	N	Mean	Median	Min	Max	P-value (T1 vs T6)
Family information 0=no information 5=as much as needed	T1	85	4.64	5	0	5	0.012
	T2	85	4.78	5	0	5	
	T3	85	4.86	5	1	5	
	T4	85	4.85	5	2	5	
	T5	85	4.81	5	1	5	
	T6	85	4.91	5	1	5	
Family Confidence 0=not at all confident 5=very confident in providing care	T1	82	4.62	5	1	5	0.008
	T2	82	4.79	5	2	5	
	T3	82	4.8	5	3	5	
	T4	82	4.76	5	2	5	
	T5	82	4.79	5	2	5	
	T6	82	4.84	5	2	5	
Family worry 0=not at all worried about the patient/client 5= very worried	T1	81	3.21	3	0	5	<0.001
	T2	81	2.69	3	0	5	
	T3	81	2.44	2	0	5	
	T4	81	2.27	2	0	5	
	T5	81	1.95	1	0	5	
	T6	81	2.02	2	0	5	

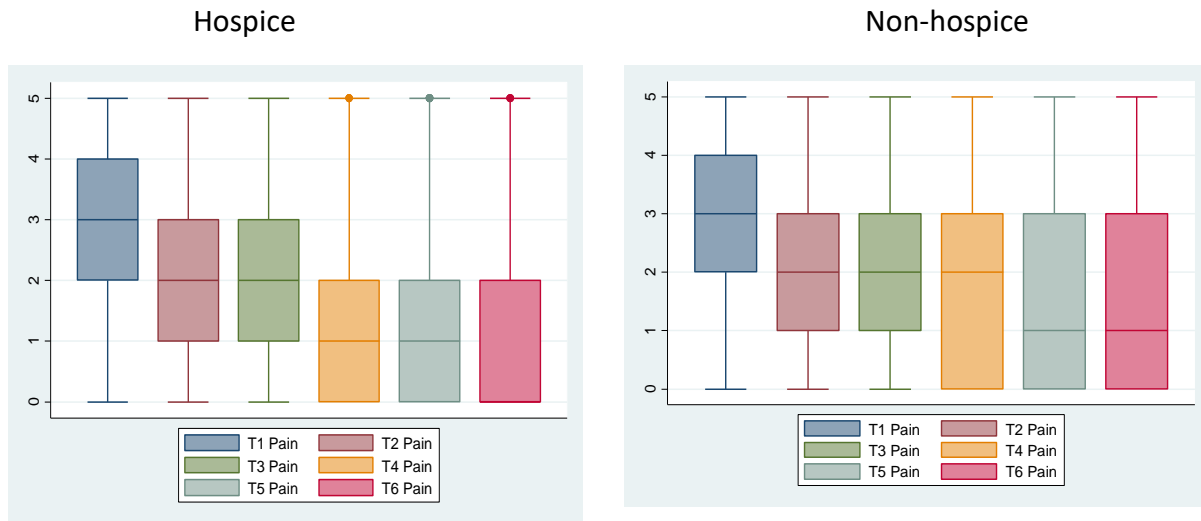
Table 6.14: Compare change over time between weeks 1 – 6 non-hospice family outcomes

	ALL PROVINCES	N	Mean	Median	Min	Max	P-value (T1 vs T6)
Family information 0=no information 5=as much as needed	T1	51	4.39	5	0	5	0.007
	T2	51	4.57	5	0	5	
	T3	51	4.63	5	1	5	
	T4	51	4.71	5	2	5	
	T5	51	4.75	5	2	5	
	T6	51	4.73	5	2	5	
Family Confidence 0=not at all confident 5=very confident in providing care	T1	48	4.67	5	0	5	0.0144
	T2	48	4.79	5	2	5	
	T3	48	4.81	5	2	5	
	T4	48	4.85	5	2	5	
	T5	48	4.75	5	0	5	
	T6	48	4.88	5	2	5	
Family worry 0=not at all worried about the patient/client 5= very worried	T1	45	2.82	3	0	5	<0.001
	T2	45	2.67	3	0	5	
	T3	45	2.27	2	0	5	
	T4	45	2.24	2	0	5	
	T5	45	1.91	1	0	5	
	T6	45	1.69	1	0	5	

### 6.3.4.5 Box-and-whisker plots for change in Patient Reported Outcomes (PROMs)

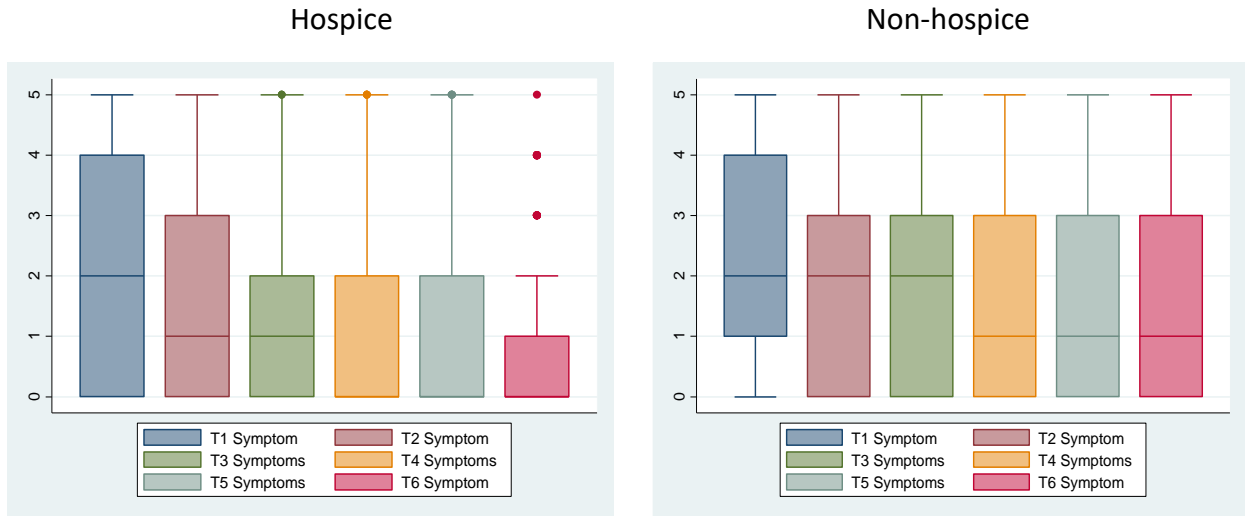
The box-and-whisker plots provide a visual representation of these results for items that showed >40% change from baseline to week 6

Figure 6.3: Pain



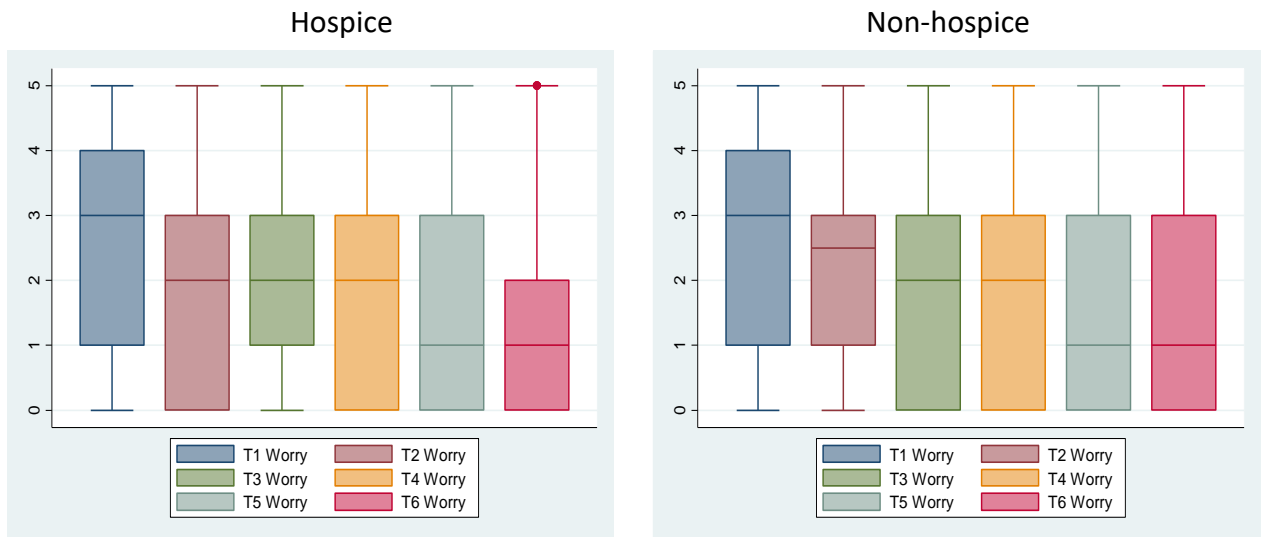
Both groups of services showed good intervention to achieve pain control; both groups demonstrating good response by the first week. The hospice group achieved pain levels of 1/5 earlier (Week 4) and to a greater degree (pain level below 1/5) by week 6.

Figure 6.4: Symptoms



Both groups and both achieved good symptom control for patients during the period of the study. The hospice group achieved symptom control to levels of 1/5 earlier (by week 2) and to a greater degree (symptoms below 1/5 by week 4) than the non-hospice group.

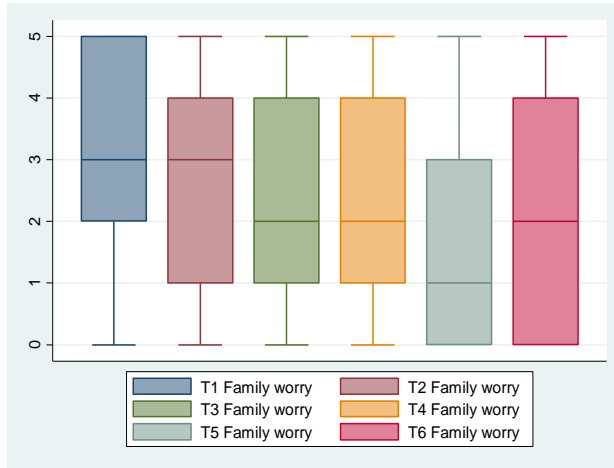
Figure 6.5: Worry



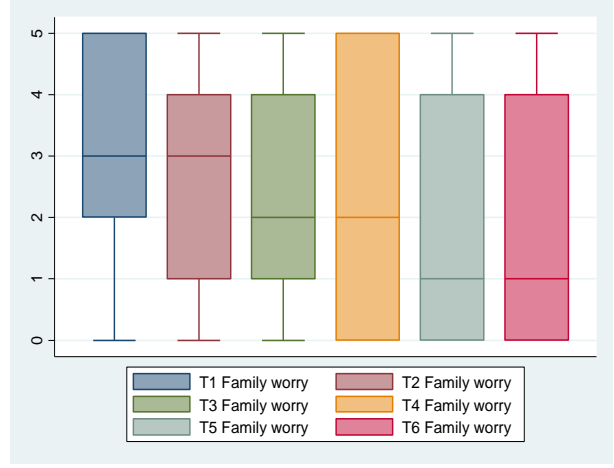
Both groups of service providers assisted with good emotional support to improve patient worry, achieving level of 1/5 by week 5.

Figure 6.6: Family Worry

Hospice



Non-hospice



Again both groups of service providers assisted to improve family worry, achieving level of 1/5 by week 5.

Regression analysis identified that although there were differences in Patient Reported Outcome measures between the hospice and non-hospice participants, apart from Symptoms these differences were not statistically significant. (see Appendix D5, page 307)

Logistic regression symptoms comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 382

LR chi2(1) = 8.83

Prob > chi2 = 0.0030

Log likelihood = -258.85308

Pseudo R2 = 0.0168

---

cat_diff_sy~m	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]
group	.5387205	.1129711	-2.95	0.003	.3571613 .8125736
_cons	2.041875	.6497139	2.24	0.025	1.094413 3.809579

---

### 6.3.5 Analysis of Patient Questionnaires

The patient questionnaire asked questions at the first visit about care received, three of which required Yes/No responses and three of which required narrative responses.

Table 6.16 Patient responses to questionnaire

Question	Yes	%	No	%	missing	%
1) Do you think you would have benefitted from being referred to the organisation earlier in your illness?	281	58%	46	9.5%	157	32%
2) Do you think it was not necessary to refer you to the organisation?	169	35%	143	29.5%	172	35.5%
3) Do you think you have benefitted from the care you have received at the organisation?	313	65%	2	0.4%	169	35%

In analysing these questions it became clear that question 2 was unclear and some people chose not to answer yes or no but answered “*It is important*”. One-third of participants did not answer these questions. Fifty-eight per cent of participants felt that they would have benefitted from being referred to the organisation earlier in their illness, and 65% said they had benefitted from the care they received from the organisation. These percentages were much higher amongst those who answered the question (85.9% and 99.6%, respectively).

### 6.3.6 Content analysis narrative questions

#### Themes

Responses to the narrative questions were made by 316 people (65% of the study participants). Five key themes emerged from the narrative questions on participants’ experience of care (See table 6.16).

Table 6.16 Summary of themes

1. Quality of care	2. Place of care	3. Staff attitudes & values	4. Information sharing	5. Problems experienced
1.1 Quality of care	2.1 Preferred place of care	3.1 Values exhibited by carers	4.1 Learning about illness and self-care	5.1 Further counselling & support
1.2 Satisfaction with care	2.2 Comparison to past care	3.2 Attitudes of care	4.2 Information sharing	5.2 Physical problems
1.3 Gratitude for care				5.3 Access to medication 5.4 Food security and financial need

### 6.3.6.1 Quality of care

#### i) Quality of care

Many patients commented that their experience of care from the hospice or non-hospice organisation was good, using the terms ‘good’, ‘very good’ and ‘great’. There were also a number of superlatives in these responses, for example, participants used the descriptions “*fantastic*” (ER07), “*awesome*” (SG09) and “*Nothing but wonderful, such peace and kindness.*” (SLA13) Other respondents framed the “*good care*” as being because “*they also talk to me*” (ER12) or that “*Staff are caring for me as if I am one of their own*” (WH01).

#### ii) Satisfaction with care

Satisfaction with care was a strong theme that emerged in analysing responses to the question “How would you like to be cared for?” Participants used this opportunity to express satisfaction with their care and gratitude to the staff providing the care. Twenty-four people said they were happy with the care, and 16 used the specific term satisfied, for example, “*I am satisfied with my care at hospice*”(LH04). Other participants expressed their experiences of care as respectful and empathetic: “*At hospice we’re treated with dignity & respect*” (SLA10); “*Few are called, few are chosen. These people are chosen to*



*care for us. I am very happy with the care because I can see the real empathy in their eyes.” (WH02)*

iii) Gratitude for care

Many participants spoke of their appreciation of the care they had received, for example, *“I am very thankful. I feel uplifted after the visits by the home care visitors” (STB13)* and *“I feel really well cared for and can only commend hospice for what they are doing.”(SG01); “I am very grateful for the care provided by the support group” (N15)*

6.3.6.2 Place of care

1) Preferred place of care

Many people wanted to be at home, though some participants described that in-patient hospice care was better than being at home. Although the question was “How would you choose to be cared for?” 49 people (19% of those who answered the question) gave the answer as *“at home”* or *“to be visited at home”* or *“at home by my family”*, answering ‘where’ rather than ‘how’, for example, *“To be cared for at home” (STB15), “Visited at home and admitted if symptoms persist” (STB7), “At the hospice” (KZN11), “Being cared for by my family with help from hospice” (STF13).*

Although many patients would prefer to be cared for at home there were also concerns about being at home: *“My family struggle to care for me because they don’t know what to do” (BET09)*

ii) Comparison to past experiences of care

A number of patients compared the care they were now receiving with past experiences of care. Some of these comments came from patients admitted to the hospice in-patient unit and some from patients cared for at home by home-based carers: *“This place is much better than hospital”(HH3), “The sisters are heaven-sent; they know their story and help at every step. It is ten times better than hospital care. Good support to family.”(ER01) “The care is secure and I feel right about it. At hospital I don’t get this kind of service.” (LH10) Nobody is angry, they assist us & they wash us all the time (HH7)*

Comparisons with state facilities included a description of problems faced: *“The clinic gave me problems, I lost my card and defaulted treatment and the clinic wouldn’t help me without my card. (the organisation) helped me to get treatment again at the clinic”* (N10), *“At the clinic they are rude sometimes”* (BET02)

#### 6.3.6.3 Staff attitudes and values

i) Values exhibited by carers

Some of the participants – patients or family members - responded to the question “What has been your experience of care at the organisation?” with statements describing values ascribed to the staff. Many of these values highlight values of compassion and care, and warm interpersonal relationships between staff and patients: *“We were treated with patience and empathy”* (STB10), *“Staff were respectful, honest and sympathetic”* (STB11), *“Very good genuine people”* (WITS02) *“Such a blessing, the staff are helpful and caring”* (KZN13).

ii) Attitudes of care

Both the desired attitudes in caring and the attitude of caregivers were emphasised in answering this question. Nineteen respondents answered the question “How would you like to be cared for?” with the response *“With love”*; 17 people replied *“With respect”*, and four *“with dignity”*. For example, participants described *“To be respected”* (LH1) and *“To be comforted”* (LH10) as important. Another participant was more specific: *“Respect, I do not want to be treated as an invalid”* (SLA08)

In describing staff attitudes respect was also highlighted, as follows: *“The respect and self-worth is important”*(HH1) and *“Respect and dignity. Everything is fine. I didn’t want to come to hospice originally. My doctor persuaded me to come.”* (SLA11) Another participant described that: *“Hospice helped with acceptance, love, care and compassion”* (SLA10)

#### 6.3.6.4 Information sharing

i) Learning about the illness and self-care

Participants expressed appreciation for the help and advice, and the sharing of information provided by the staff with some general statements and with subthemes of learning about the illness and learning self-care. For example, participants described their experience with both hospice and non-hospice services as *“Helpful & good experience in learning”*(STF12), *“They’ve helped me to understand my sickness”*(DRH08), *“I’ve been empowered to be self-sufficient”* (ERHC08), *“They show me how to take care of myself”* (STF2)

ii) Importance of information sharing

Participants spoke of the importance of receiving information regarding their illness, how they could help disseminate information. For example, *“My family and I are more informed”* (STB8), *“I need more information to share with other youths”* (ERHC06) Another important aspect was hearing the truth about their illness to help with planning. With one participant saying *“If doctors can’t fix me, they must be truthful so I can go home to my family. They must say if this is witchcraft or not”* (LH02)

#### 6.3.6.5 Problems experienced

There were a number of people who expressed particular problems at this first interview as they were enrolled into the care service. Problems are grouped in subthemes described as follows:

i) Further counselling and support

Participants described gaps in psychosocial and spiritual care and social isolation, for example, *“More counselling would help”*(ER05) *“To help with taking my treatment”* (WH4) *“My children do not have time for me. I will be happy if you can talk to my children”* (T8),

ii) Physical care

There were participants at the start of the study who needed pain management. The APCA POS survey did demonstrate improvement in pain scores. Of the eight patients who spoke of the problem they had with pain, three had improved pain scores, one withdrew from the study as her husband died, one died before the second interview, and three

continued to have severe pain. Participants spoke about *“Better pain care”* (LHBC01), *“I want more pain control”* (WH10)

In addition, functional ability was a problem for some participants leading to the following comments *“I need help with physio so that I can walk”* (LHBC12), *“More assistance with physiotherapy”* (SG11)

iii) Access to medication

Access to medication emerged as a distinct theme from both hospice and non-hospice patients at their first interview, although the requests for better pain control may be linked with this theme. The NGOs (hospice and non-hospice) do not have dispensaries, and patients access medication from the health facility they are registered with or from private pharmacies dispensing according to prescription from private doctor; as is evidenced by the following comments: *“Getting medication is sometimes a problem”*(SG04), *“Improved access to medication after medical aid is exhausted”* (SG03), *“Better assistance with medication”* (BET03)

iv) Food security and financial needs

The need for food was highlighted by a number of participants, for example, *“There is no food. ARVs are difficult to take without food”*(WH15), *“I would like to grow my own vegetables”* (ERHC08), *“More assistance with food parcels”*(BET01)

The two issues of financial problems and worry about food were combined: *“I need social support. I am not able to work and there is no food for the family”* (LH8), *“I wish for a grant and for enough food in the house”* (KZN08), *“The care is very good but I struggle financially”* (SG12)

The narrative responses to the survey questionnaire demonstrated a high regard for the care received from staff at both hospice and non-hospice organisations. Participants expressed satisfaction with the care they received and appreciation for this care, which contrasted with previous care experiences. The information sharing was also appreciated to assist participants to understand their illness and to take care of themselves. Nonetheless, some important obstacles to quality care were identified.

## 6.4 Discussion

### 6.4.1 Quality as element of the Right to Health

The nineteen hospice NGOs that took part in the study on quality of palliative care provision had all been accredited by the Council for Health Services Accreditation (CoHSASA), and designated 5-star status by the Hospice Palliative Care Association of South Africa (HPCA). The standards of management, governance and palliative care used by CoHSASA to assess palliative care organisations account for structure and process as measures of quality(265). However, this study was designed to assess patient reported outcomes as an additional measure of quality of palliative care, one that is not addressed by Donabedian. Patients who participated in the study were all receiving home-based care, although some of the hospice patients were recruited while admitted to a hospice in-patient unit for short-term stay. Follow-up interviews were conducted telephonically with the patients at home.

### 6.4.2 Patient demographics

The results show that the ages of patients participating in the study were normally distributed between ages of 20-81+, and most participants were within the 41-50 age range. There were more female than male patients in the group, and this was a significant difference for patients in non-hospice services. This raises potential questions with regard to acceptability of the care being provided from the perspective of men. Research has shown that men tend to present late for care and that men tend not to take on the caregiving role, so that women may require help from a home-based care service(201).

Family members were interviewed if present at the time of recruitment, and there were fewer family members available for interview in the non-hospice group of patients. The research does not indicate the reason for fewer family members being present in the non-hospice group. It may be because family members are encouraged to accompany patients to hospice day care and to be involved, and to learn about providing care from hospice staff.

Loss to follow up was high after four months, as the research assistant in Gauteng was not able to complete the study. Adjusting for this fact, 77.6% of patients were retained in the study for the full 6 weeks in the other four provinces. There were some referrals to other services and 23 patients withdrew from the study. In addition, there were 44 deaths.

### 6.4.3 Patient reported outcomes

The use of Patient Reported Outcome Measures (PROMs) has received attention in research and quality improvement programmes in palliative care. The European Association Palliative Care Task Force on Outcome Measures published a white paper reviewing the use of PROMs, and recommended use of validated tools in research and in quality improvement programmes in the clinical setting(286). The authors describe that use of PROMs puts patients at the centre of research and clinical care, and helps clinicians to identify and address what matters to the patient.

The goal of palliative care is to improve quality of life. A challenge in measuring quality of life is that this is a subjective concept, and the person best placed to report on or to measure quality of life is the person him or herself. Palliative care seeks to improve physical, psychosocial and spiritual distress. The use of the APCA African POS in this study measured patient reported outcomes related to physical, psychosocial and spiritual well-being in a cohort of patients with advanced illness, to assess quality of care through improvement of these aspects of quality of life over a 4-6 week period. The value of the APCA African POS in undertaking an audit of patient care was confirmed by Downing and colleagues(287). They found that the tool had had a marked impact on improving quality of care through its use in Africa, and emphasised the need for those using the tool to be well-trained on its use (286). As part of the PRISMA study (“Reflecting the **P**ositive **d**ive**R**sities of European **p**riorities for **r**e**S**earch and **M**easurement in end-of-life **c**Are”) on outcome measures, Downing and colleagues evaluated outcome measures used in Africa. They identified APCA African POS as the most commonly used outcome measure in Africa, and that it was seen as a useful tool to guide clinical care, especially with the confidence of a measure validated for use in Africa(287).

The quality of care audit shows good care provided by both accredited hospices and by non-hospice NGOs providing home-based care. The improvement in POS items for patients in hospice care was sustained throughout the 6-week period, with greater impact on holistic elements of care, physical, psychosocial and spiritual care, as anticipated for a service focusing on palliative care. Both groups provided good support to family members. Findings at four weeks were more

or less similar to findings at six weeks, suggesting that the loss to follow up did not introduce bias into the results.

In general, care provided in the home, whether by hospice or non-hospice services, resulted in better patient and family outcomes. The quality palliative care provided by accredited hospices could be anticipated, as this is the field of practice for hospices services and there is a national audit and quality improvement programme amongst hospices. This study confirms that those patients who access hospice care received good quality palliative care. Those patients receiving care from non-hospice services also received good quality palliative care. Thus community-based home care provided by NGOs (hospice or non-hospice) has been shown to provide quality palliative care. If patients do not get access to palliative care, quality of care does not improve over time, as evidenced by the study on Accessibility (Chapter Five).

Both the imperative to measure quality of healthcare and the tragedy of the Gauteng Mental marathon case in Gauteng in 2016 provide compelling reasons to introduce a survey and accreditation system for community-based health and welfare organisations in South Africa (269,270,288).

Of the initial sample of 484 participants, nearly ten per cent (44 patients, 9.1%) died before the end of the study. The sustained and enhanced improvement in patient reported outcomes seems to be in contradiction to the declining health status of the patients who were identified as experiencing progressive illness. People adjust to illness and, provided their most urgent problems such as pain, other physical symptoms and anxiety are addressed, they experience good quality of life and the palliative care goal of living as actively as possible until their death. This is reflected in the results of the patient survey; that the problems identified by patients had been addressed appropriately.

#### 6.4.4 Patient experience of care: Acceptability

Rudiger and Meier identify acceptability and dignity as measures to evaluate the public health recognition of human rights(262). This study included questions to assess acceptability through asking participants about their experience of care from the services (hospice and non-hospice) at the first interview. Patients were appreciative of the care they received, and the majority agreed

they had benefitted from this care and that they would have benefitted from an earlier referral to the service. There were very few problems that patients described in their care experience. Patients also appreciated the values exhibited by staff, as well as the sharing of information that meant they were more informed about their illness, understood the illness better and learned how to take care of themselves. These experiences were contrasted favourably with experiences in other health care settings. Although some patients described hospice in-patient care as better than at home, the majority of participants would choose to be at home with the hospice or home care service providing care in the home. The gaps in care related to psycho-social issues, with some participants expressing the wish for further counselling, and participants identifying a need for food or help to access grants. Participants also indicated that loneliness and social isolation was a problem.

#### 6.4.5 Love

In analysing the open-ended questions of this study, an unexpected word that kept appearing is 'love'. As described above, this response came up frequently in answer to the question "How would you choose to be cared for?", but also was a response when asked if the participant had any other comments. It is not a term usually associated with healthcare, but is clearly important to patients in this group of participants. Is this the ultimate goal for person-centred care? There is no fundamental right to love, but the expectation of receiving love had an impact on the patients' experience of quality of care.

The words of compassion, respect, caring and dignity often associated with hospice care also came out of these interviews. It may be easier for staff in an NGO, with fewer numbers of patients to care for, to exhibit these qualities but these attitudes can be developed as part of the health care professionals' role, as advised by , so that compassionate care is provided in all health care settings.

#### 6.4.6 Respect and dignity

The study questionnaire deliberately avoided the term dignity to see what terms emerged spontaneously from the participants interviewed during the study. Comments that resonated with respect and dignity were to do with the concept of 'not being treated as an invalid'. Once a



person enters the healthcare system they seem to lose their identity as a person and become a cipher and it is difficult to re-establish one's personhood, both in one's own view of self but especially in the eyes and attitudes of healthcare workers. In the South African setting, Himonga has related the values of *Ubuntu* to dignity, explaining that *Ubuntu* describes the essence of being human, recognising the value and worth of each individual who is entitled to respect and dignity(87). The patient experiences identified in this study give a sense of the respect and dignity they received.

In his work on dignity-conserving therapy for patients who are terminally ill, Chochinov describes the importance of attributes such as 'continuity of self', and a sense of control as important aspects of preserving dignity(110). He describes dignity-conserving interventions such as '*maintaining normalcy*' (110:438). Other key aspects of care that conserve dignity are respecting the patient's privacy, social support and attitudes of the carers. In another paper, Chochinov describes that healthcare professionals who treat patients with respect, and value them as individuals apart from their illness, can enhance patients' sense of dignity(109). In this study, participants described positive attitudes of staff as being "*respectful, honest and sympathetic*" (STB11), enhancing "*respect and dignity*"(SLA 11) and describing that "*The respect and self-worth is important*" (HH1). The patient-centred approach of the healthcare workers in the NGOs that took part in this study comes through clearly in the participants' responses, and is epitomised by the quote that introduces this chapter: "*The staff are caring for me as if I am their own*" (WH01).

#### 6.4.7 Limitations of the study

A major limitation was the timing and co-ordination of research assistants in the provinces. In two provinces, Gauteng and E Cape, the study was slow to start as the research assistants initially recruited were not able to take on the task of recruiting and consenting of participants and then conducting interviews. Two additional research assistants were recruited and trained. The research assistant in Gauteng was only available for a limited period and thus data was only collected over 4 weeks for the participants in Gauteng. This may have reduced the power of hypothesis testing for differences between hospice and non-hospice services.

The limited qualitative data was collected through open-ended questions. The depth and richness of data would have been improved though adding a strong qualitative element using individual interviews. However, this was beyond the scope of this research study.

#### 6.5 Conclusion

The delivery of palliative care meets the framing of the general Comment 14 element of quality with regard to provision of palliative care as part of the Right to Health. Thus, provision of palliative care as a human right meets international human rights law standards, because it is delivered in ways that are of good quality. The previous chapter showed that, however, access is a problem, but this study shows that once you get access to palliative care, whether hospice or non-hospice NGO services, quality of care is generally good and patient outcomes improve over time. The description of Acceptability within General Comment 14 is limited to being “*respectful of medical ethics and culturally appropriate*” (1) (para 12c). The patient responses to the open-ended questions within this study provided a much wider account of Acceptability and demonstrates the patient-centredness that Stewart describes as being associated with patient satisfaction and better patient outcomes(289). The availability of these services to patients regardless of gender, age and race indicate sensitivity to cultural, gender and life cycle needs of the patients cared for. The respect and compassion shown to patients by NGO carers are attitudes that have been shown in research studies to enhance patients’ sense of dignity, and this was described by many of the participants.

This part of the study is the final empirical research undertaken to evaluate palliative care as part of the Right to Health in South Africa. The next chapter will synthesise all the studies in this thesis and reflect on how the different studies provide evidence for the expression of palliative care as part of the Right to Health and the gaps in realising this right with regard to palliative care in South Africa.

## CHAPTER SEVEN: CONCLUSION

### 7.1 Overview

This thesis explores how palliative care can be understood as part of the human right to health and operationalised through the framework of General Comment 14(1) by undertaking four nested studies using General Comment 14 as a framework for the research. The four studies are: 1) an estimate of the need for palliative care; 2) a description of the Availability of palliative care; 3) an investigation of Accessibility of palliative care in an area where services are available; and 4) an investigation into the Quality and Acceptability of care in the NGO sector. Thus, the essential elements described in General Comment 14 provide a means to frame an exploration of the Right to Health in practice.

The thesis shows that there is substantial need for palliative care in South Africa, but that availability of palliative care services is limited, at best 22.8% of people needing palliative care received this care in 2010. Even where services are available, the study of three patient groups in Cape Town suggested that access to palliative care is uncertain, threatening to violate the health rights of a large portion of the South African population. However, once people access palliative care services in the NGO sector, the quality and acceptability are generally good. This indicates that when palliative care is available and accessible, it provides dignity and a quality of care that meets the requirements of General Comment 14.

General Comment 14 includes reference to palliative care, and the Special Rapporteurs on Health and on Torture and other Cruel, Inhuman or Degrading Treatment have expressed the importance of investing in palliative care(5,6). These statements by the special rapporteurs are significant, not only in recognising the need for palliative care, but also in bringing palliative care into human rights discourse. Publications describe the importance of palliative care and advise on the integration of palliative care into a country's health system(8,100). However, less is known about the implementation of palliative care as a Human Right especially in low and middle income countries. This thesis has therefore addressed the question "How is palliative care part of the Right to Health?"

Subsequent to completing the field work for this study, the World Health Assembly resolution on palliative care was adopted unanimously by member states in 2014(3). This resolution clearly expresses the ethical responsibility of governments to ensure access to palliative care. The resolution also emphasises the ethical duty of health care workers to relieve suffering whether physical, psychosocial or spiritual(23). The South African government developed the National Policy Framework and Strategy for Palliative Care which was approved by the National Health Council in April 2017 (121). In her introduction to the palliative care policy, the Director-General of the national Department of Health recognises South Africa as a “*country rich with lessons on human rights,*” and emphasises that the WHA Resolution “*reminds us that access to integrated palliative care is a basic human right*”(121:3).

With the inclusion of palliative care in the NHI (89), the NDOH has taken a further step to consolidating the provision of palliative care as part of the right to health, consistent with the notion of UHC as the practical application of the Right to Health (94).

## 7.2 Needs assessment

The needs assessment based on mortality data shows that the need for palliative care is considerable. The mortality data from 2010 indicated that at least 258,268 people (47% of all deaths) would have benefited from palliative care. The average need for palliative care for the South African population is 698.5 persons per 100,000; 0.7% of the country’s population. This is consistent with the MRC/WHO estimate of 0.75% of a country’s population(158). Nevertheless, this study suggests that this figure is probably an underestimate of need, as palliative care is applicable early in the course of a life-threatening or life-limiting illness and not just in the year before death. Although an under-estimate, the needs assessment reported in this thesis provides a baseline when implementing the National Policy Framework and Strategy for Palliative Care adopted in 2017 subsequent to this study’s fieldwork.

A more accurate estimate could be achieved through the use of a palliative care indicator tool, and extrapolating from individual palliative care need to a national estimate, rather than using national mortality data to identify need. This is a more work intensive method as it requires clinicians to identify and report patients with palliative care needs. However, one of the validated

measures within the Supportive and Palliative Care Indicator Tool (SPICT) is the number of unplanned hospital admissions for the diagnosis that requires palliative care<sup>(123)</sup>. Hospital admission data is available in South Africa in routine health information systems. Thus, the SPICT, if adapted and validated for the South African setting could potentially provide a better population needs assessment for palliative care in South Africa. This approach presumes appropriate primary health care for the patient's life-limiting condition. The SPICT criterion of persistent symptoms despite optimal treatment of underlying condition(s) would also have to be met. However, the moderate overestimate of people needing palliative care based on unplanned hospital admissions would be balanced in terms of benefit to the patient of closer attention to management of the condition and optimising treatment.

### 7.3 Assessment of the essential elements of the Right to Health

General Comment 14 describes these elements as inter-related, and some of the data collected during the course of this research study related to more than one element beyond the topic being investigated.

**Availability** requires that functioning health care facilities are available in sufficient quantity in the country, with trained personnel receiving domestically competitive salaries and with essential drugs. This study identified that there are insufficient palliative care services within South Africa to meet the palliative care needs of the population with an estimate of less than 22% of people needing palliative care receiving this care. Moreover, most palliative care services are in the NGO sector and have precarious funding, not adequately supported by the state. Availability of palliative care is also unequal in geographic distribution, with rural areas worse off with regard to supply of palliative care services. This inequity also relates to supply of professional staff and consequent access to morphine, an essential palliative care medication. The likelihood of availability of morphine in the palliative care services was higher for hospices in urban areas where doctors are concentrated. It was also evident that comprehensive palliative care relied on volunteer staff rather than all palliative care staff receiving 'domestically competitive salaries'. The burden of care, sometimes including financial contributions, falls on other caregivers, such as family and friends. In terms of General Comment 14, the South African government has failed

to fulfil the Right to Health in respect of palliative care, in that there are few palliative care facilities in public health facilities, and palliative care is not yet included in medical and nursing curricula, so that health care staff are not equipped to provide palliative care. The growth in hospice services during a period of external funding from the US government through the PEPFAR program focused on HIV resulted in improved availability of palliative care. However, since the external funding has been redirected away from palliative care, the number of hospices has declined due to financial constraints.

**Accessibility** is described in terms of four overlapping dimensions of non-discrimination, physical accessibility, economic accessibility and informational accessibility. Palliative care should be accessible to everyone in South Africa, given the demonstrated high need for palliative care and inequitable availability of palliative care services, the study on access was conducted in an area with good availability of palliative care services (see Chart 5.1 on page 145). The study considered two pathways for access to palliative care, the first being the integration of palliative care into the primary service, measured using the APCA POS tool(240). The key finding of improvement in patient reported outcome measures (PROMs) suggests that the majority of patients attending HIV clinics received good palliative care that was integrated into routine HIV care, and that HIV care generally responds to patients' needs. This contrasted with the oncology and MND clinics where PROMs did not improve, suggesting that palliative care has not been integrated into these services. The second way to access palliative care services is through referral but all three services have very poor referral rates, much lower than were anticipated for sample size estimation. There were patients (including some living with HIV) who experienced severe pain not controlled by routine care and who would have benefited from referral to a palliative care service. The failure to refer is of great concern, considering the relatively high numbers of patients who died and the patients who experienced severe pain throughout the study. The reasons for lack of referral and poor access to palliative care services were not explored in the study. However, the findings suggest a violation of the patients' right to access to palliative care in the hospital setting. It is suggested that a hospital palliative care consultancy team would improve access both in

respect of providing palliative care and as a resource to develop the capacity of hospital staff to develop knowledge and skills in palliative care(40,41).

A key process in referral for palliative care is sharing information with people who would benefit from palliative care. General Comment 14 describes informational access in terms of the right to seek, receive and impart information about health problems. It may be that clinicians do not inform patients about palliative care and that patients are either not assertive enough to insist on referral for palliative care or are reluctant to accept palliative care. Information programmes to educate communities and patients about the benefits of palliative care and how to access this care would be beneficial. Kellehear(290) describes “*widespread confusion among patients, families, concerning the needs of people living with life-threatening illness or bereavement*. He identifies the need to provide education to the public (and the media) and suggests that the people should direct their own information and education needs with regard to palliative care and that this relies heavily on community-participation(290:111-2).

This study has highlighted a weakness in General Comment 14 in relation to patients’ preference in using a service, described by McIntyre and colleagues as ‘*cultural access*’(259). General Comment 14 provides a limited description of **Acceptability**, limiting this to respect of medical ethics and culturally appropriate, respecting confidentiality and designed to improve an individual’s health status. It does not address the issue that people do not want to accept care that is perceived to be end-of-life care at a time when they cannot acknowledge the seriousness of their illness. Thus acceptability with regard to patient preference is dependent on appropriate informational access. At the stage of advanced illness where cure is not possible the focus of palliative care is on improving quality of life including control of distressing symptoms. Patient choice or preference for care is influenced by fears and anxieties and lack of information about benefits of palliative care(233), which may result in palliative care not being seen as an acceptable option of care. Yet, in Chapter Six, when patients who had successfully accessed palliative care, most study participants agreed that they had benefitted from referral to hospice services, and that they should have been referred earlier in the course of their illness.

Chapter Four confirmed that the demographic profiles of beneficiaries of palliative care were similar to the population of the country. In addition, palliative care services reported that



attention is given to the provision of culturally appropriate palliative care, by training staff in culturally appropriate care, employing staff from different cultures and promoting cultural awareness within the service. Thus, the requirement to be culturally appropriate appears to be met by current palliative care services although this was not formally researched in this study.

**Quality** as described by general Comment 14 requires that health facilities, goods and services must be of good quality. Two aspects of quality are the requirement for skilled clinical staff and the availability of essential palliative care medication both of which were found to be inadequate in the survey conducted in Chapter Four. In assessing quality in healthcare, Brook and colleagues describe two aspects of quality of care – the first being technical quality, and the second patient perceptions and involvement in care(266). This study assessed two groups of services - hospice services already accredited by the Council for Health Services Accreditation for Southern Africa against palliative care standards to meet the requirement for technical quality; and non-hospice services which had not been accredited against these standards. Quality of care based on patient-reported outcome measures at the two groups of services was found to be good. A question may therefore be raised as to whether accreditation according to a set of standards is necessary. In the field of quality in healthcare, standards are accepted as a valid measure of quality of a service(262,266). The South African Office of Health Standards Compliance is legislated for in the National Health Act and assesses public health care facilities. However, other than HPCA member hospices, NGO facilities are not assessed. The impact of not regulating the non-governmental sector in South Africa was evidenced in the alarming loss of life, and impact on patients and families of placement of mental health patients from the Life Esidimeni service in un-licensed NGOs in the Gauteng Mental Marathon project(269,270).

As well as the APCA POS results showing improvement in patient outcomes, the narrative response from patients identified satisfaction with care received and appreciation of staff attitudes and values. Patients commented on respectful care and the fact that their dignity was upheld. Brennan observes that dignity is a common foundation of both human rights and palliative care, and the experience of participants in this study confirms the attention of palliative care services to preserving individual dignity(107). Participants also appreciated the information-

sharing that assisted them in decision-making, a key component of person-centred care(289). This study has demonstrated that it is possible to provide quality palliative care with compassion and love upholding the patient's dignity -*"At hospice we're treated with dignity & respect"* (SLA10). The quality of care provided in the NGO sector contrasts to care in the hospital setting where pain and symptom management, patient anxiety and well-being are not the focus of care as seen in Chapter Five. While hospital patients continued to experience problems impacting on their wellbeing, patients in hospices and other home-based care organisations were treated by staff with a patient-centred approach, listening to the patient problems and addressing these problems, engaging with patients to understand their wishes for care and goals for care as evidenced in patient interviews.

#### 7.4 The use of General Comment 14 as framework for the study

At the start of the research study, General Comment 14 was identified as a conceptual framework to assess how palliative care is part of the Right to Health in South Africa. It has been a useful framework to identify the gaps in provision of palliative care in South Africa, and areas to address as the South African government implements the Policy Framework and Strategy for Palliative Care approved by the National Health Council in 2017. However, there are aspects of the Right to Health that are not covered by General Comment 14, and gaps within the element of Acceptability as described above. Acceptability should include patient preference or choice as a component of Acceptability. This resonates with McIntyre's comment that access to healthcare requires empowerment of an individual to use healthcare, and how health systems respond to the needs of patients and communities(248). London also emphasises the importance of community engagement and agency in realising the Right to Health(98). General Comment 14 describes the importance of involving the community in setting priorities and planning healthcare services but does not include these considerations as part of the element of Acceptability. The thesis identifies the need to link Informational Accessibility and Acceptability as the individual who is not informed about the service is not able to make an informed choice to use the service. This is an additional example of how the elements are inter-related and overlap.

In addition, General Comment 14 does not address dignity, a common foundation of both Human Rights and palliative care, in a practical way. Study participants in Chapter Six reported that the respect, care and love they received from both the hospice and non-hospice services had contributed to their sense of dignity. As discussed earlier, Brennan distinguishes between intrinsic dignity which is inherent and inalienable for all individuals, and extrinsic or attributed dignity that can be destroyed by illness and loss of independence(107). Chochinov explains the role of the health care practitioner in restoring or maintaining patient dignity through valuing and demonstrating respect for the individual (109).

The International Convention on Economic, Social and Cultural Rights states that “*these rights derive from the inherent dignity of the human person*”(10)(preamble). This statement emphasises the importance of ensuring patients have access to palliative care as part of the Right to Health. This thesis has shown problems with Availability and Accessibility of palliative care in South Africa. However, once a person has access to care the quality of care is good and patient dignity is maintained or restored.

### 7.5 Palliative care as a component of comprehensive care

In recent years, palliative care has been increasingly recognised both globally and nationally as “*a component of comprehensive care*”(3) (Title). This is the stated goal of the WHA resolution on palliative care(2). Palliative care is identified as one of the five pillars of Universal Health Coverage.

In the South African setting, two subsequent policies explicitly note the importance of palliative care. The National Health insurance white paper(91) identifies palliative care as an essential primary health care service, and the National Policy Framework and Strategy for Palliative Care (NPFSPC) describes palliative care services at all levels of healthcare, and a referral system to facilitate patient care at the appropriate level of care(121). The policy framework recognises the importance of providing guidance to clinicians on identifying patients who would benefit from palliative care, and acknowledges the work of the SPICT and GSF groups in laying the groundwork for a palliative care indicator tool that can be adapted to the South African setting (122,123). The NPFSPC includes an implementation plan at national and provincial level but currently, there is

no budget allocation for this implementation, which may prove an obstacle to realising this important initiative. The violations of the Right to Health with regard to Availability and Accessibility of palliative care identified during this study can only be corrected if there is an allocation of funding to address these issues.

South Africa ratified the International Convention on Economic, Social and Cultural Rights in 2015 and as such has an obligation to domesticate the elements of the convention through legislative, budgetary and programmatic measures. This includes funding for the training of health care workers, funding for the employment of trained staff, and the development of services within both the public health and NGO sectors. The NGO sector has demonstrated good Quality of care when palliative care is available and accessible. The state can devolve responsibility for palliative care to NGOs and the National Policy identifies the key role of community-based care and hospices; but the state still has the responsibility to fund the services. The WHA recommends that governments ensure that there is domestic funding for palliative care, as well as adequate trained human resources and quality improvement programmes(3). Many studies have shown cost-saving through the introduction of palliative care services, most recently described in the 2018 MRC investment study into the implementation of ward-based primary health care outreach teams(158).

#### 7.6 A Rights-Based Approach

The discussion above describes the public health efforts to provide palliative care services in South Africa. Why then do we need to consider a Rights-Based Approach to motivate for improved palliative care services? As is evident throughout the world, there are insufficient resources to meet the health care needs of the population even in well-resourced countries(259). This means that there are competing priorities for the health care budget. General Comment 14 recognises budgetary constraints, and describes state obligations to realise the Right to Health (and thus, palliative care as part of the Right to Health) as a process of progressive realisation. The Lancet commission on palliative care notes that policy and funding initiatives focus on *“extending life and productivity”*, as a result of which palliative care and efforts *“to alleviate pain or increase dignity at the end of life”* are neglected(9). It is important to balance health priorities

and research, and cost assessments have shown the value of palliative care in saving cost for the health system, and improving quality of care for people accessing this care. Current approaches still result in significant use of non-beneficial treatment. A systematic review of care in 44 countries, reported that 38% of people at the end of life receive non-beneficial treatments, with associated costs to the health system and families without benefit to the patient(291).

As has been documented by a number of authors, a Rights-Based Approach provides a framework for accountability(13,49). Backman and colleagues developed a comprehensive set of 172 indicators to measure implementation of the Right to Health in health systems(13). Backman and colleagues maintain that it is necessary to use indicators to measure development towards progressive realisation of the Right to Health. The Right to Health which includes palliative care, places legal obligations on the South African government and indicators based on the elements of the Right to Health described in General Comment 14 would provide guidance to the government in integrating palliative care into the health system. In addition, a set of indicators to assess the integration of palliative care as part of the Right to Health would hold the South African government accountable in ensuring that palliative care is Available, Accessible, Acceptable and of good Quality in South Africa. This would ensure that people needing palliative care would be able to access quality palliative care timeously.

## 7.7 Recommendations

### 7.7.1 Further research

There are a number of areas for further study identified during this research. These include economic access and informational access; issues pertaining to Acceptability not described in General Comment 14. In addition, Schools of Public Health may be interested in researching the concepts of a Palliative Care Yardstick (PaLY) (270) and of Suffering Adjusted Life Years (SALYs)(9) as possible public health measures of palliative care need. (See point 7.7.1.5 below)

**7.7.1.1 Economic access:** With regard to economic access, it would be important to estimate the cost of providing palliative care in different settings, including assessment of cost savings from different perspectives: the health system, the health facility, the care provider (such as hospice) and the patient and family. In particular, exploring what are the hidden costs and examining whether the transfer of responsibility of care from public health facilities to the NGO sector and to families, shift the cost of care unreasonably to the NGO and to families would be important questions to answer?

**7.7.1.2 Informational access:** Patients, families and communities should be provided with clear information regarding palliative care, including the benefits of palliative care and how to access palliative care. Health care providers should be trained in palliative care and develop skills in breaking bad news and building hope for patients with a new serious diagnosis. They should be able to provide basic palliative care and should recognise when to refer to a palliative care service. (See point 7.7.1.4 below)

**7.7.1.3 Acceptability:** Acceptability of palliative care with regard to patient choice and preferences is an area that would benefit from further research as well as patient and family readiness to accept a referral to palliative care. This links closely to points described above with regard to informational access and it would be useful to conduct research amongst communities in South Africa to investigate community understanding of palliative care.

**7.7.1.4 Identifying patients who need palliative care:** To identify patients who need palliative care, it is necessary to adapt and validate a palliative care indicator tool for South Africa. In the needs assessment study and the acceptability study, it became clear that a palliative care indicator tool will be important to establish an objective method to identify people who would benefit from palliative care in the clinical setting. The Supportive and Palliative Care indicator

Tool (SPICT) has been demonstrated to be a valid tool to identify people in need of specialist palliative care in the developed world(123). A South African specific tool that is relevant for both communicable and non-communicable diseases would help clinicians to provide palliative care to patients and to refer patients for palliative care.

**7.7.1.5 Greater accuracy in estimating population need:** This research identified that although assessment of need provided a baseline for South Africa as the palliative care policy is implemented, mortality data provides an underestimate of need and a more robust method of estimating country level palliative care need is needed. The Palliative Care Yardstick (PaY)(271) and Suffering Adjusted Life Years (SALYs)(8) have been proposed as public health measures of country level palliative care need. A simpler approach may be to use hospitalisations as described in the SPICT measure to develop and implement a robust method for estimating population need for palliative care.

## 7.7.2 Additional recommendations

**7.7.2.1 Implementation of NPFSPC:** This policy document, approved by the National Health Council in 2017, has the potential to fully realise the right to palliative care as part of the Right to Health through the training of HCWs, development of services in health facilities and communities (NGO sector); and to provide adequate funding for implementation, including funding of NGO services. With budgetary constraints experienced by the health department and competing priorities, it will be important to monitor government commitment to implementation. Both national and provincial departments of health recognise the imperative for palliative care, and both the potential cost-saving of the policy and better outcomes experienced by patients receiving appropriate palliative care.

**7.7.2.2 Training in palliative care:** Core competencies for healthcare workers should be agreed and palliative care integrated into healthcare curricula. A key factor contributing to a successful care plan for patients requiring palliative care has been training of health care professionals from clinical disciplines and the implementation of appropriate palliative guidelines and procedures for care. The WHA resolution identifies oncologists, internal medicine specialists, geriatricians and paediatricians as groups that should undertake intermediate training in palliative care. It will

be important to work with statutory health professions councils and academic institutions to integrate palliative care into health care curricula. This would comply with the requirement of General Comment 14 for trained medical and professional personnel. (1) (para12a)

**7.7.2.3 Development of public information programmes about palliative care:** The development and broadcasting of public information programmes can sensitise communities to the availability and benefits of palliative care. The focus of these programmes would be to address issues that result in fears and anxieties in respect of a palliative care referral, and to promote understanding of palliative care as an intervention that helps patients and families when facing serious illness, providing care in the patient's own home. Thus, providing informational access to communities in line with General Comment 14 requirements.

**7.7.2.4 To implement support programmes for families and informal carers:** This research study showed that families and friends contribute a major portion of patient care. Both the WHA and NPFSPC identify the need to support families and informal carers through information about illness and care; and to provide accessible support from palliative care professionals when necessary.

**7.7.2.5 To implement quality improvement programmes in palliative care:** Quality improvement programme are useful to audit and improve quality of care with regard to technical aspects and patient experience. This research did not investigate the technical aspects of Quality, but the National Health Act mandates survey and accreditation of health facilities including community-based services and NGOs. The APCA POS proved a useful tool to measure patient outcomes identifying gaps in care in the chapter on Accessibility, and the improved outcomes experienced in services focused on patient needs. Both accreditation and audit of care would provide assurance of Quality of palliative care in current and new services complying with the requirement described in general Comment 14 that facilities, goods and services should be of good quality .



7.7.3 To develop a framework to monitor state accountability with regard to Availability, Accessibility, Acceptability, and Quality of palliative care in South Africa.

Backman and Hunt proposed a framework of indicators to monitor state progress towards realising the Right to Health(13). Drawing on their approach, a similar framework with a palliative care focus is proposed below (Table 7.1) which can be used to ensure that palliative care is realised as part of the right to health in South Africa. The CESCR makes provision for Civil Society to report on State performance with regard to progress towards realisation of the Right to Health when State's report on their performance with regarding to social and economic rights, including health. This framework can provide a basis for a Civil Society report specifically on palliative care. The UN documents guiding measurement and evaluation of implementation and realisation of Human Rights also provide a useful framework for this evaluation (292). The Structural, Process and Outcome indicators for the realisation of the Right to Health provide a strong foundation for the assessment of a State's progress towards realisation of the Right to Health (293). A recommendation of this study is to include these documents in further evaluation of implementation of the Right to Health in member States.

Thus, this thesis has set a baseline against which to measure progressive realisation of the Right to Health in respect of palliative care and proposes a framework of indicators to monitor progress towards realising palliative care as part of the Right to Health.

Table 7.1 Proposed framework of indicators to monitor state progress towards realising the Right to Health with palliative care focus

Essential elements of the RtH (GC14)	Factors considered in each element	Indicators	What is in place	What action needs to be taken?
Availability of functioning palliative care facilities and services	Underlying determinants of health: safe potable water, adequate sanitation	% households with safe potable water & adequate sanitation	Not assessed	Implementation of National PC policy (high priority)  National Policy identifies need to train 10% of HCWs/year Budget required for PC staffing  Regular review of EDLs
	Place of care: palliative care in hospitals, clinics, care facilities, support for community-based and home-based care	% health facilities with palliative care service	Few PC facilities, mostly in NGO sector	
	Professional personnel trained in palliative care	% HCP trained in palliative care by facility	To be assessed	
	Professional palliative care personnel receiving market-related salaries	# palliative care professionals employed	Chapters on PC & pain management in EDL	
Essential palliative care medicines	% essential palliative care meds (WHO) on SA EDL			
Accessibility Non-discrimination [on the grounds of race, colour, sex, language, religion, political or other opinion, national or	Facilities with access to all to receive palliative care, especially vulnerable or marginalized groups, such as ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons	% facilities with palliative care services # policies relating to palliative care access for vulnerable groups	To be assessed	PC Steering Committee to publish position statement on PC for vulnerable populations

social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status]	with disabilities and persons with HIV/AIDS.			
Physical accessibility	Sufficient palliative care facilities within safe reach of all Access to rural communities Access for people living with disabilities	% rural facilities with palliative care services, % with policies describing access to palliative care for PLWD	Situational analysis planned	Identify models of palliative care for different settings, pilot in 2 sub-districts in Cape Town
Economic accessibility	Palliative care affordable for all, especially socially disadvantaged groups	# services providing palliative care at limited/no cost to patient	PC part of NHI (UHC in South Africa)	Implement NHI
Informational access: the right to seek, receive and impart information about palliative care	Doctors knowledgeable about palliative care & refer patients for palliative care Communities receptive of information about palliative care  Patients and families informed of palliative care and recognise benefit of palliative care	Audit # pts eligible for palliative care cf # referred # community information activities/ brochures/waiting room videos % facilities using informational		Develop PC indicator tool for SA to identify people eligible for PC  Communication strategy for PC for different audiences

		brochures for patients and families		
Acceptability GC 14 does not provide advice to address reluctance of patients to accept referral to palliative care because of misperceptions of PC being only for dying patients	Palliative care that is respectful of culture, especially minorities  Sensitise to gender  Sensitive to life cycle requirements (palliative care for children, adolescents, adults including older people)	# policies referring to care for different cultures, material available in different languages # information brochures appropriate to gender and age appropriate		Position statements & appropriate communication strategy
Quality Health facilities, goods & services should be of good quality	Skilled palliative care personnel  Scientifically approved palliative care medicines and equipment  Measure of quality of palliative care	% HCPs trained in palliative care % facilities with palliative care medicines and equipment % facilities conducting annual audit of care	To be determined through national situational analysis	Ensure training of HCWs, employment of trained personnel Set standards and conduct regular audit of services

This Framework can also be used to report a State's progress to Respect, Protect and Fulfil the obligation towards realisation of Palliative Care as part of the Right to Health. The current status and planning for the integration of palliative care in South Africa is noted in the table above.

## 7.8 Conclusion

The evidence derived from this thesis highlights the fact that palliative care is not yet operationalised as part of the Right to Health in South Africa. The need is great but availability of palliative care services is insufficient to meet the need. Access is poor even where palliative care services are available. However, when access is achieved, quality of care is generally good in both hospice and non-hospice services and patient outcomes improve over time. Palliative care values patients as individuals and provides respectful patient-centred care. In South Africa *Ubuntu* describes the essence of being human, the value and worth of each individual entitling them to respect and dignity – dignity being common foundation to both human rights and palliative care. A framework to assess the practical application of palliative care as part of the Right to Health can identify current gaps and the progressive realisation of the right both in South Africa and in other countries implementing the World Health Assembly resolution on palliative care.

## REFERENCES

- (1) United Nations Economic and Social Council. General Comment No. 14 (2000): The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights). Geneva, United Nations, 2000 (E/C.12/2000/4)
- (2) Mpinga EK, London L, Chastonay P. Health and human rights: epistemological status and perspectives of development. *Medicine, Health Care and Philosophy*. 2011 Aug 1;14(3):237-47.
- (3) World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course. 2014;67.19(67th).
- (4) World Health Organization. Universal Health Coverage. 2017; Available at: [http://www.who.int/healthsystems/universal\\_health\\_coverage/en/](http://www.who.int/healthsystems/universal_health_coverage/en/). Accessed March/03, 2018.
- (5) Hunt P. Statement on the right of everyone to the highest attainable standard of physical and mental health. 2009. UN Human Rights Council. Available from [http://www.hospicecare.com/resources/pain\\_pallcare\\_hr/list.html](http://www.hospicecare.com/resources/pain_pallcare_hr/list.html). Accessed January 15, 2013.
- (6) Méndez JE. Report of the Special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. 2013(Twenty-second session). [https://www.ohchr.org/documents/hrbodies/hrcouncil/regularsession/session22/a.hrc.22.53\\_english.pdf](https://www.ohchr.org/documents/hrbodies/hrcouncil/regularsession/session22/a.hrc.22.53_english.pdf) Accessed September 16, 2013.
- (7) Radbruch L, de Lima L, Lohman D, Gwyther E, Payne S. The Prague Charter: urging governments to relieve suffering and ensure the right to palliative care. *Palliat Med* 2013 Feb;27(2):101-102.
- (8) Connor SR, Sepulveda MC. *Global Atlas of Palliative Care at the End of Life*. 2014.
- (9) Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete XJ, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet* 2017.
- (10) United Nations. *International Covenant on Economic, Social and Cultural Rights*. 1966
- (11) South African Government. *Constitution of the Republic of South Africa*. 1996.
- (12) Bradshaw D, Groenewald P, Laubscher R, Nannan N, Nojilana B, Norman R, et al. Initial burden of disease estimates for South Africa, 2000: original article. *South African Medical Journal* 2003;93(9):p. 682-688.

- (13) Backman G, Hunt P, Khosla R, Jaramillo-Strouss C, Fikre BM, Rumble C, et al. Health systems and the right to health: an assessment of 194 countries. *The Lancet* 2008;372(9655):2047-2085.
- (14) Assembly UG. Universal declaration of human rights. Retrieved February 1948;22:2010.
- (15) United Nations. International Covenant on Civil and Political Rights. 1966.
- (16) United Nations. Committee on Economic, Social and Cultural Rights. 2018. [https://www.ohchr.org/Documents/HRBodies/CESCR/OHCHR\\_Map\\_ICESCR.pdf](https://www.ohchr.org/Documents/HRBodies/CESCR/OHCHR_Map_ICESCR.pdf) Accessed March/03 2018
- (17) London L. What is a human-rights based approach to health and does it matter? *Health and Human Rights*. 2008 Jan 1:65-80
- (18) Mann JM. Medicine and public health, ethics and human rights. *Hastings Cent Rep* 1997;27(3):6-13.
- (19) Barzelatto J. *Medical ethics and human rights: guiding principles*. London: Commonwealth Medical Association; 1994.
- (20) Ewert EG, Baldwin-Ragaven L, London L. Training trainers in health and human rights: implementing curriculum change in South African health sciences institutions. *BMC medical education*. 2011 Dec;11(1):47.
- (21) London L, Baldwin-Ragaven L. Human rights and health: challenges for training nurses in South Africa. *Curationis* 2008;31(1):5.
- (22) Baldwin-Ragaven L, De Gruchy J, London L. An ambulance of the wrong colour. *Health professionals, human rights and ethics in South Africa* 1999.
- (23) London L, Baldwin-Ragaven L. Human rights obligations in health care: main article. *CME: Your SA Journal of CPD: Ethics* 2006;24(1):p. 20-24.
- (24) Ens C, Chochinov HM, Gwyther E, Moses S, Jackson C, Thompson G, et al. Postgraduate palliative care education: Evaluation of a South African programme. *South African Medical Journal* 2011;101(1):42-44.
- (25) AE Fourie. *A Needs Assessment for palliative care training in undergraduate students at the University of Stellenbosch University of Cape Town*; 2015. (Dissertation, University of Cape Town)
- (26) Statistics South Africa. *Mid-year population estimates 2016*. 2016;2017(09/12).

- (27) World Bank Group (US). 2017; Available at: <https://data.worldbank.org/products/wdi>. Accessed 24/04, 2018.
- (28) Alexander P. Rebellion of the poor: South Africa's service delivery protests—a preliminary analysis. *Rev Afr Polit Econ* 2010;37(123):25-40.
- (29) Heywood M. South Africa's treatment action campaign: combining law and social mobilization to realize the right to health. *Journal of Human Rights Practice* 2009;1(1):14-36.
- (30) World Health Organization. WHO Definition of Palliative Care. 2002; Available at: <http://www.who.int/cancer/palliative/definition/en/>. Accessed June 06, 2011.
- (31) Gwyther L, Krakauer E, Mwangi-Powell F. Worldwide Hospice Palliative Care Alliance Policy statement on Definition of Palliative Care. 2011; <http://www.thewhpc.org/resources/item/defining-palliative-care>. Accessed March 3, 2010.
- (32) Doyle D, Hanks GWC, MacDonald N. *Oxford Textbook of Palliative Medicine*. Oxford; Oxford University Press; 1998.
- (33) Meier DE. Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Q* 2011;89(3):343-380.
- (34) McIlfatrick S, Noble H, McCorry NK, Roulston A, Hasson F, McLaughlin D, et al. Exploring public awareness and perceptions of palliative care: A qualitative study. *Palliat Med* 2014;28(3):273-280.
- (35) Together for Short Lives. Categories of life threatening and life limiting diseases. 2015; Available at: <http://www.icpcn.org/disease-categories/>. Accessed March/3, 2017.
- (36) Hamilton J. Dr. Balfour Mount and the cruel irony of our care for the dying. *CMAJ* 1995 Aug 1;153(3):334-336.
- (37) Clark D. From margins to centre: a review of the history of palliative care in cancer. *The lancet oncology* 2007;8(5):430-438.
- (38) UK Department of Health and Social Care. *End of Life care Strategy: Promoting high quality care for adults at the end of their life*. 2008.
- (39) HospiceUK. Funding for Hospices. 2018; Available at: <https://www.hospiceuk.org/media-centre/facts-and-figures>. Accessed 05/09, 2017.
- (40) Kirk J, Collins K. Difference in quality of life of referred hospital patients after hospital palliative care team intervention: clinical practice: *SAMJ forum*. *South African Medical Journal* 2006;96(2):p. 101-102.



- (41) Hongoro C, Dinat N. A cost analysis of a hospital-based palliative care outreach program: Implications for expanding public sector palliative care in South Africa. *J Pain Symptom Manage* 2011;41(6):1015-1024.
- (42) Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AG, Cook A, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 2003;25(2):150-168.
- (43) The Economist Intelligence Unit. The 2015 Quality of Death Index: Ranking palliative care across the world. 2015.
- (44) Connor SR. Hospice and palliative care: The essential guide. : Routledge; 2017.
- (45) Gwyther L, Krause R, Cupido C, Stanford J, Grey H, Credé T, De Vos A, Arendse J, Raubenheimer P. The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. *South African Medical Journal*. 2018;108(2):86-89.
- (46) Hunt P, Backman G. Health systems and the right to the highest attainable standard of health. *Health Hum Rights* 2008:81-92.
- (47) Grodin MA, Tarantola D, Annas GJ, Gruskin S editors. Health and Human Rights in a Changing World. First ed. New York & Oxford: Routledge; 2013.
- (48) Mann J. Health and human rights: if not now, when? *Health Hum Rights* 1997:113-120.
- (49) London L. Human rights and public health: Dichotomies or synergies in developing countries? Examining the case of HIV in South Africa. *The Journal of Law, Medicine & Ethics* 2002;30(4):677-691.
- (50) Mpinga EK, Verloo H, London L, Chastonay P. Health and human rights in scientific literature: a systematic review over a decade. *Health and Human Rights: An International Journal* 2011;13(2).
- (51) Tarantola D, Gruskin S. Human rights approach to public health policy. *Health and Human Rights in a Changing World* 2013:43.
- (52) [http://www.who.int/publications/almaata\\_declaration\\_en.pdf](http://www.who.int/publications/almaata_declaration_en.pdf) accessed 23 March 2014
- (53) Beard TC. Declaration of Alma Ata. *The Lancet* 1979;313(8109):217-218.
- (54) Hunt P. The human right to the highest attainable standard of health: new opportunities and challenges. *Trans R Soc Trop Med Hyg* 2006;100(7):603-607.

(55) Gruskin S, Mills EJ, Tarantola D. History, principles, and practice of health and human rights. *The Lancet* 2007;370(9585):449-455.

(56) London L. Confinement for extensively drug-resistant tuberculosis: balancing protection of health systems, individual rights and the public's health [Review article]. *The International Journal of Tuberculosis and Lung Disease* 2009;13(10):1200-1209.

(57) Gostin L, Mann JM, Gostin L. Towards the development of a human rights impact assessment for the formulation and evaluation of public health policies. *Health Hum Rights* 1994:58-80.

(58) Friedman EA, Gostin LO. Pillars for progress on the right to health: harnessing the potential of human rights through a Framework Convention on Global Health. *Health Hum Rights* 2012 Jul 15;14(1):E4-19.

(59) London L. 'Issues of equity are also issues of rights': Lessons from experiences in Southern Africa. *BMC Public Health* 2007;7(1):14.

(60) Braveman P, Gruskin S. Defining equity in health. *J Epidemiol Community Health* 2003 Apr;57(4):254-258.

(61) <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> accessed 14 June 2019

(62) <https://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf> accessed 14 June 2019

(63) Andrea P, Fergusson C. Human Rights, Health and Poverty Reduction Strategies. 2008;HR/pub/08/05.

(64) Meier BM. Advancing health rights in a globalized world: responding to globalization through a collective human right to public health. *The Journal of Law, Medicine & Ethics* 2007;35(4):545-555.

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

(66) Somerville M. Human rights and medicine: the relief of suffering. *International human rights law: theory and practice*. Montreal: Canadian Human Rights Foundation 1992:505-522.

(67) Pope Benedict XVI. Message of His Holiness Benedict XVI for the Fifteenth World Day of the Sick 2006. 2006;  
[http://www.vatican.va/holy\\_father/benedick\\_xvi/messages/sick/documents/hf\\_ben-xvi](http://www.vatican.va/holy_father/benedick_xvi/messages/sick/documents/hf_ben-xvi). Accessed 06/07, 2013.

- (68) Ahmedzai SH, Costa A, Blengini C, Bosch A, Sanz-Ortiz J, Ventafridda V, et al. A new international framework for palliative care. *Eur J Cancer* 2004;40(15):2192-2200.
- (69) Cousins MJ, Brennan F, Carr DB. Pain relief: a universal human right. *Pain* 2004;112(1):1-4.
- (70) 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;6(3):341-343.
- (71) Radbruch L, Foley K, De Lima L, Prail D, Fürst CJ. The Budapest Commitments: setting the goals. *Palliat Med* 2007;21:269-271.
- (72) Radbruch L, Payne S, De Lima L, Lohmann D. The Lisbon challenge: acknowledging palliative care as a human right. *J Palliat Med* 2013;16(3):301-304.
- (73) Prail D. Hospice care is a human right. *International journal of palliative nursing* 2005;11(9):467.
- (74) Chochinov HM. *Quality End-of-Life Care: The Right to Every Canadian*. 2000.
- (75) Brennan F, Carr DB, Cousins M. Pain management: a fundamental human right. *Anesth Analg* 2007 Jul;105(1):205-221.
- (76) International Narcotics Control Board. Ensuring balance in national policies on controlled substances. 2015; Available at [http://www.incb.org/documents/Publications/AnnualReports/AR2015/English/Supplement-AR15\\_availability\\_English.pdf](http://www.incb.org/documents/Publications/AnnualReports/AR2015/English/Supplement-AR15_availability_English.pdf). Accessed 07/03, 2016.
- (77) Gwyther L, Brennan F, Harding R. Advancing palliative care as a human right. *J Pain Symptom Manage* 2009;38(5):767-774.
- (78) Nowak M and Hunt P. Special Rapporteurs on the question of Torture and the Right of everyone to the highest attainable standard of physical and mental health. Letter to Mr D. Best, Vice-Chairperson of the Commission on Narcotic Drugs, December 10 2008 Available at [http://www.ihra.net/Assets/1384/1/SpecialRappo\\_rteursLettertoCND012009.pdf](http://www.ihra.net/Assets/1384/1/SpecialRappo_rteursLettertoCND012009.pdf). Accessed September 1, 2009
- (79) Burki TK. WHO resolution on access to palliative care. *The Lancet Oncology* 2014.
- (80) Organisation of African Unity. African (Banjul) Charter on Human and Peoples' Rights. 1986; Available at: [http://www.achpr.org/files/instruments/achpr/banjul\\_charter.pdf](http://www.achpr.org/files/instruments/achpr/banjul_charter.pdf). Accessed 06/05, 2015.

- (81) Hassim A, Heywood M, Berger J. Health and democracy: a guide to human rights, health law and policy in post-apartheid South Africa.
- (82) Motari M, Kirigia J. Realizing the Right to Health in the Who African Region: Issues, Challenges and the Way Forward. Health Systems and Policy Research 2016.
- (83) Ngwena C. The recognition of access to health care as a human right in South Africa: is it enough? Health Hum Rights 2000:26-44.
- (84) Singh JA, Govender M, Mills EJ. Do human rights matter to health? The Lancet 2007;370(9586):521-527.
- (85) Chinkin C. Health and human rights. Public Health 2006;120:52-59.
- (86) Forman L. Ensuring reasonable health: Health rights, the judiciary, and South African HIV/AIDS policy. The Journal of Law, Medicine & Ethics 2005;33(4):711-724.
- (87) Himonga C. The Right to Health in an African Cultural Context: the Role of Ubuntu in the Realization of the Right to Health with Special Reference to South Africa. Journal of African Law 2013;57(02):165-195.
- (88) Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D. The health and health system of South Africa: historical roots of current public health challenges. The Lancet 2009;374(9692):817-834.
- (89) Republic of South Africa. National Health Act. 2004.
- (90) Pillay Y, Barron P. The implementation of PHC re-engineering in South Africa. 2012; Available at: <https://www.phasa.org.za/wp-content/uploads/2011/11/Pillay-The-implementation-of-PHC.pdf>. Accessed 05/21, 2016.
- (91) South African Department of Health. National Health Insurance for South Africa: Towards Universal Health Coverage. 2015; Available at: [https://www.gov.za/sites/www.gov.za/files/National\\_Health\\_Insurance\\_WhitePaper10Dec2015.pdf](https://www.gov.za/sites/www.gov.za/files/National_Health_Insurance_WhitePaper10Dec2015.pdf). Accessed 01/22, 2018.
- (92) Matsoso MP, Fryatt RJ, Andrews G. The South African Health Reforms, 2009-2014: Moving Towards Universal Coverage. : Juta; 2015.
- (93) Pillay Y. Core Messages on the National Health Insurance Policy. 2015.

- (94) Ooms G, Latif LA, Waris A, Brolan CE, Hammonds R, Friedman EA, et al. Is universal health coverage the practical expression of the right to health care? BMC International Health and Human Rights 2014;14(1):3.
- (95) Sachs JD. Achieving universal health coverage in low-income settings. Lancet 2012 Sep 8;380(9845):944-947.
- (96) Kieny M, Evans DB. Universal health coverage. EMHJ 2013;19(5).
- (97) South African Department of Health. The Patients' Rights Charter. 2011; Available at: <http://www.akeso.co.za/wp-content/uploads/Patient-Rights-Charter.pdf>. Accessed 03/17, 2015.
- (98) London L. Making human rights work for the public's health: equity and access 2007;Global Forum Update on Research for Health Volume 4:54-58.
- (99) Morris C, Connor S, Gwyther L. WHPCA Position paper: Palliative care: a needed and essential service within universal health coverage. 2016; Available at: <http://www.thewhpc.org/resources/category/whpca-position-statements>. Accessed 11/14, 2017.
- (100) Stjernswärd J, Foley KM, Ferris FD. The public health strategy for palliative care. J Pain Symptom Manage 2007;33(5):486-493.
- (101) Hinton J. Dying. 1967.
- (102) Gwyther E. South Africa: the status of palliative care. J Pain Symptom Manage 2002;24(2):236-238.
- (103) Hospice Palliative Care Association. Annual Reports; Available at: <http://www.hpca.co.za/category/annual-report.html>. Accessed 02/09, 2014.
- (104) Gwyther L. NSP review: No NSP indicators to help patients in pain. 2013; Available at: <http://section27.org.za/wp-content/uploads/2014/10/NSP-review-9-web.pdf>. Accessed 09/02, 2014.
- (105) Hunt P. Interpreting the international right to health in a human rights-based approach to health. Health Hum Rights 2016;18(2):109. \
- (106) Mann J. Dignity and health: The UDHR's revolutionary first article. Health Hum Rights 1998:30-38.

- (107) Brennan F. Dignity: A unifying concept for Palliative Care and human rights. *Progress in Palliative Care* 2013, 22:2, 88-96, DOI: 10.1179/1743291X13Y.0000000064
- (108) Jacobson N. Dignity and health: a review. *Soc Sci Med* 2007;64(2):292-302.
- (109) Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ* 2007 Jul 28;335(7612):184-187.
- (110) Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Social science & medicine*. 2002 Feb 1;54(3):433-43.
- (111) Chochinov HM. Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA* 2002;287(17):2253-2260.
- (112) Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005 Aug 20;23(24):5520-5525.
- (113) Saunders C. The evolution of palliative care. *Patient education and counseling*. 2000 Aug 1;41(1):7-13.
- (114) Stevens A, Raftery J. *Health care needs assessment: the epidemiologically based needs assessment reviews. Second series.* : Radcliffe Publishing; 1996.
- (115) World Health Organisation. *Health Systems Strengthening Glossary*. 2011; Available at: [http://www.who.int/healthsystems/Glossary\\_January2011.pdf](http://www.who.int/healthsystems/Glossary_January2011.pdf). Accessed 01/26, 2016.
- (116) Higginson IJ, Hart S, Koffman J, Selman L, Harding R. Needs assessments in palliative care: an appraisal of definitions and approaches used. *J Pain Symptom Manage* 2007;33(5):500-505.
- (117) South African Government. *Delivery agreement for outcome 2: A long and healthy life for all South Africans*. 2010; Available at: <https://www.gov.za/documents/delivery-agreement-outcome-2-long-and-healthy-life-all-south-africans>. Accessed 01/26, 2016.
- (118) South African Department of Health. *Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17*. 2013;RP06/2013.
- (119) Ganca L, Gwyther L, Harding R, Meiring M. What are the communication skills and needs of doctors when communicating a poor prognosis to patients and their families? A qualitative study from South Africa. *SAMJ: South African Medical Journal* 2016;106(9):940-944.
- (120) Lynn J. Serving patients who may die soon and their families: the role of hospice and other services. *JAMA* 2001;285(7):925-932.

(121) South African Department of Health. National Policy Framework and Strategy for Palliative Care. 2017.

(122) Thomas K. The GSF prognostic indicator guidance. *End of Life Care* 2010;4(1):62-64.

(123) Hight G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ Support Palliat Care* 2014 Sep;4(3):285-290.

(124) Gómez-Batiste X, Martínez-Muñoz M, Blay C, Amblàs J, Vila L, Costa X, et al. Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. *BMJ Supportive & Palliative Care* 2013;3(3):300-308.

(125) Maas EA, Murray SA, Engels Y, Campbell C. What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice. *BMJ Support Palliat Care* 2013 Dec;3(4):444-451.

(126) Connor S, Sisimayi C, Downing J, King E, Ken PLA, Yates R, et al. Assessment of the need for palliative care for children in South Africa. *Int J Palliat Nurs* 2014;20(3):130-134.

(127) Higginson I. Health care needs assessment: palliative and terminal care. Health care needs assessment. Oxford: Wessex Institute of Public Health Medicine 1997;183:260.

(128) Maslow, A. H. (1968). *Toward a Psychology of Being*. New York: D. Van Nostrand Company

(129) Bradshaw J. (1972) "A taxonomy of social need." in McLachlan G (ed.) *Problems and progress in medical care*. Seventh series NPHT/Open University Press.

(130) Doyle D, Woodruff R. *The IAHPC Manual of Palliative Care*. 2013; Available at: <https://hospicecare.com/what-we-do/publications/manual-of-palliative-care/>. Accessed 17/06, 2015.

(131) Coovadia H, Jewkes R, Barron P, Sanders D, McIntyre D. The health and health system of South Africa: historical roots of current public health challenges. *The Lancet* 2009;374(9692):817-834.

(132) Harris B, Goudge J, Ataguba JE, McIntyre D, Nxumalo N, Jikwana S, et al. Inequities in access to health care in South Africa. *J Public Health Policy* 2011:S102-S123.

(133) van Niekerk L, Raubenheimer PJ. A point-prevalence survey of public hospital inpatients with palliative care needs in Cape Town, South Africa. *South African Medical Journal* 2013;104(2):138-141.

- (134) Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med* 2014 Jan;28(1):49-58.
- (135) Stevens A, Gillam S. Needs assessment: from theory to practice. *BMJ* 1998 May 9;316(7142):1448-1452.
- (136) Addington-Hall J, McCarthy M. Regional Study of Care for the Dying: methods and sample characteristics. *Palliat Med* 1995 Jan;9(1):27-35.
- (137) Franks PJ, Salisbury C, Bosanquet N, Wilkinson EK, Lorentzon M, Kite S, et al. The level of need for palliative care: a systematic review of the literature. *Palliat Med* 2000 Mar;14(2):93-104.
- (138) Rosenwax LK, McNamara B, Blackmore AM, Holman CD. Estimating the size of a potential palliative care population. *Palliat Med* 2005 Oct;19(7):556-562.
- (139) Gomez-Batiste X, Martinez-Munoz M, Blay C, Amblas J, Vila L, Costa X, et al. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: a cross-sectional study. *Palliat Med* 2014 Apr;28(4):302-311.
- (140) Gomez-Batiste X, Martinez-Munoz M, Blay C, Espinosa J, Contel JC, Ledesma A. Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. *Curr Opin Support Palliat Care* 2012 Sep;6(3):371-378.
- (141) Currow DC, Abernethy AP, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. *Palliat Med* 2004;18(3):239-247.
- (142) Rhee JY, Luyirika E, Namisango E, Powell RA, Garralda E, Pons JJ, et al. *APCA Atlas of Palliative Care in Africa*. 2017.
- (143) Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage* 2006;31(1):58-69.
- (144) Henley LD. End of Life in HIV-infected Children Who Died in Hospital. *Developing World Bioethics* 2002;2(1):38-54.
- (145) Connor S, Sisimayi C. Assessment of the need for palliative care for children: three country report: South Africa, Kenya and Zimbabwe. London: United Nations Children's Fund (UNICEF), International Children's Palliative Care Network (ICPCN) 2013.
- (146) Statistics South Africa. Mortality and causes of death in South Africa, 2007: Findings from death notification. 2009;P0309.3.



- (147) Bradshaw D, Pillay-Van Wyk V, Laubscher R, Nojilana B, Groenewald P, Nannan N, et al. Cause of death statistics for South Africa: Challenges and possibilities for improvement. South African MRC Burden of Disease Research Unit 2010.
- (148) Nojilana B, Groenewald P, Bradshaw D, Reagon G. Quality of cause of death certification at an academic hospital in Cape Town, South Africa. SAMJ: South African Medical Journal 2009;99(9):648-652.
- (149) Burger EH, Van der Merwe L, Volmink J. Errors in the completion of the death notification form. 2007.
- (150) Naledi T, Househam KC, Groenewald P, Bradshaw D, Myers JE. Improving data to reduce the burden of disease: lessons from the Western Cape. SAMJ: South African Medical Journal 2009;99(9):641-642.
- (151) Pieterse D, Groenewald P, Bradshaw D, Burger EH, Rohde J, Reagon G. Death certificates: Let's get it right! SAMJ: South African Medical Journal 2009;99(9):643-644.
- (152) Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. Eur J Cancer 2011;47(1):51-56.
- (153) Farrant L, Gwyther L, Dinat N, Mmoledi K, Hatta N, Harding R. The prevalence and burden of pain and other symptoms among South Africans attending HAART clinics. SAMJ: South African Medical Journal 2012;102(6):499-500.
- (154) Lokker M, Gwyther L, Magona P, Riley J, Van Zuylen L, Van der Heide A, et al. The prevalence and burden of physical and psychological symptoms in patients with heart failure attending a South African public hospital. Eur J Heart Failure 2013:S307.
- (155) National Centre for Health Statistics. ICD10 Mortality Manual 2a 2014. 2014; Available at: [https://www.cdc.gov/nchs/data/dvs/2a\\_2014.pdf](https://www.cdc.gov/nchs/data/dvs/2a_2014.pdf). Accessed 11/08, 2015.
- (156) Fraser LK, Miller M, Aldridge J, McKinney PA, Parslow RC. Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010 Final Report for Together For Short Lives. 2013.
- (157) Ahmad O, Boschi-Pinto C, Lopez A, Murray CLJ., Lozano R, Inoue M. Age Standardization of Rates: A new WHO Standard. 2001.
- (158) Daviaud E, Besada D, Budlender D, Kerber K, Sanders D. Saving Lives Saving costs: Investment Case for Community Health Workers in South Africa. 2018;ISBN: 978- 1-928340-32-4.

(159) World Health Organization. A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients. 2004;ISBN: 978 92 4 159543 8.

(160) White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. BMC medicine. 2017 Dec;15(1):139.

(161) Statistics South Africa. Mortality and causes of death in South Africa, 2011: Findings from death notification. 2014;P0309.3.

(162) Institute of Health Metrics. Prevalence data in South Africa. 2012.

(163) Norval D. Symptoms and sites of pain experienced by AIDS patients. South African Medical Journal 2004;94(6):450-454.

(164) Harding R, Defilippi K, Cameron D. What palliative care-related problems do patients with drug-resistant or drug-susceptible tuberculosis experience on admission to hospital? A cross-sectional self-report study. Palliat Med 2016;30(9):862-868.

(165) Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol 2012 Aug;23(8):2006-2015.

(166) 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.

(167) Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013 Feb 15;12:7-684X-12-7.

(168) DesRosiers T, Cupido C, Pitout E, van Niekerk L, Badri M, Gwyther L, et al. A hospital-based palliative care service for patients with advanced organ failure in sub-Saharan Africa reduces admissions and increases home death rates. J Pain Symptom Manage 2014;47(4):786-792.

(169) Pillay Y, Re-engineering Primary Health Care in South Africa. Discussion document, November 2010.

(170) World Health Organization. Cancer pain relief: with a guide to opioid availability. : World Health Organization; 1996.

(171) Aindow A, Brook L. World Health Organisation Essential Medicines List for Children (EMLc); Palliative Care. 2008; Available at: [http://www.who.int/selection\\_medicines/committees/subcommittee/2/palliative.pdf](http://www.who.int/selection_medicines/committees/subcommittee/2/palliative.pdf). Accessed 06/02, 2017.

- (172) International Association for Hospice and Palliative Care. World Health Organization Essential Medicines in Palliative Care. 2013; Available at: [http://www.who.int/selection\\_medicines/committees/expert/19/applications/PalliativeCare\\_8\\_A\\_R.pdf](http://www.who.int/selection_medicines/committees/expert/19/applications/PalliativeCare_8_A_R.pdf) . Accessed 06/02, 2017.
- (173) International Association for Hospice and Palliative Care. IAHPC History. 2017; Available at: <https://hospicecare.com/about-iahpc/who-we-are/history/>. Accessed 06/02, 2017.
- (174) Baxter S. WHPCA Advocacy Toolkit. 2005; Available at: <http://www.thewhpca.org/resources/category/advocacy-resources>. Accessed May 03, 2014.
- (175) Cousins, Michael J. "Relief of acute pain: a basic human right?." (2000): 3-4.
- (176) Human Rights Watch. "Please, do not make us suffer any more..." . 2009;ISBN: 1-56432-449-4.
- (177) Brennan F, Hall P, Gwyther L. Worldwide Hospice Palliative Care Alliance: Palliative Care and Human Rights. 2010; Available at: <http://www.thewhpca.org/resources/item/position-paper-on-palliative-care-as-a-human-right>. Accessed 04/05, 2017.
- (178) Human Rights Watch. Needless Pain Government Failure to Provide Palliative Care for Children in Kenya. 2010;ISBN: 1-56432-668-3.
- (179) Human Rights Watch. Uncontrolled Pain Ukraine's Obligation to Ensure Evidence-Based Palliative Care. 2011;ISBN: 1-56432-768-X.
- (180) Lohman D. Pain care as a human right. Pain Practice 2014;14(3):199-203.
- (181) South African Department of Health. draft National Policy Framework and Strategy on Cancer. 2016.
- (182) South African National AIDS Council. National Strategic Plan on HIV, TB and STIs 2017-2022. 2017.
- (183) Mayosi BM, Lawn JE, van Niekerk A, Bradshaw D, Abdool Karim SS, Coovadia HM. Health in South Africa: changes and challenges since 2009. The Lancet 2012;380(9858):2029-2043.
- (184) 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;33(6):698-710.
- (185) Evans R, Stone D, Elwyn G. Organizing palliative care for rural populations: a systematic review of the evidence. Fam Pract 2003;20(3):304-310.

- (186) Wilson DM, Justice C, Sheps S, Thomas R, Reid P, Leibovici K. Planning and Providing End-of-life Care in Rural Areas. *The Journal of Rural Health* 2006;22(2):174-181.
- (187) Downing J, Jack BA. End-of-life care in rural areas: what is different? *Curr Opin Support Palliat Care* 2012 Sep;6(3):391-397.
- (188) South African Department of Health. Summary Report National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2002. 2003.
- (189) Defilippi KM, Cameron S. Promoting the integration of quality palliative care—the South African Mentorship Program. *J Pain Symptom Manage* 2007;33(5):552-557.
- (190) Uys L. Evaluation of the integrated community based home care model. *Curationis* 2001;24(3):75-82.
- (191) Hospice Palliative Care Association. Palliative Care Standards. 2014; Available at: <http://www.hpca.co.za/category/other.html>. Accessed 08/25, 2016.
- (192) South African Department of Health. Adherence Guidelines for HIV, TB and NCDs. 2016.
- (193) Defilippi KM, Cameron S. Expanding the reach of palliative care to community-based home care programs. *J Pain Symptom Manage* 2010;40(1):3-5.
- (194) London L, Schneider H. Globalisation and health inequalities: Can a human rights paradigm create space for civil society action? *Soc Sci Med* 2012;74(1):6-13.
- (195) Lloyd-Williams M, Macleod RDM. A systematic review of teaching and learning in palliative care within the medical undergraduate curriculum. *Med Teach* 2004;26(8):683-690.
- (196) Bateman C. Pain management-the global sound of silence. *SAMJ: South African Medical Journal* 2015;105(8):621-623.
- (197) Jameson C. The role of a palliative care inpatient unit in disease management of cancer and HIV patients. *South African Medical Journal* 2007;97(9):849-852.
- (198) Gwyther L. Palliative care in chronic disease. *SAMJ: South African Medical Journal* 2014;104(2):114-115.
- (199) Mabunda SA, London L, Pienaar D. An evaluation of the role of an intermediate care facility in the continuum of care in Western Cape, South Africa. *International Journal of Health Policy and Management* 2018;7(2):167.

- (200) African Palliative Care Association. What is palliative care? 2017; Available at: <https://www.africanpalliativecare.org/awareness/what-is-palliative-care/>. Accessed 07/12, 2016.
- (201) Akintola O. Gendered home-based care in South Africa: more trouble for the troubled. *African journal of AIDS research* 2006;5(3):237-247.
- (202) Hosking M. Opioid use in palliative care. *Continuing Medical Education* 2003;21(5).
- (203) Wolfert MZ, Gilson AM, Dahl JL, Cleary JF. Opioid analgesics for pain control: Wisconsin physicians' knowledge, beliefs, attitudes, and prescribing practices. *Pain Medicine* 2010;11(3):425-434.
- (204) Bond M. A decade of improvement in pain education and clinical practice in developing countries: IASP initiatives. *British journal of pain* 2012;6(2):81-84.
- (205) de Villiers M, Maree JE, van Belkum C. The influence of chronic pain on the daily lives of underprivileged South Africans. *Pain Management Nursing* 2015;16(2):96-104.
- (206) Gamondi C, Larkin P, Payne S. Core competencies in palliative care: an EAPC white paper on palliative care education: part 2. *European Journal of Palliative Care* 2013.
- (207) [https://www.nda.agric.za/doaDev/sideMenu/fisheries/03\\_areasofwork/Aquaculture/AquaPolGUIDLeg/Legislation/MedicinesRelatedSubstancesControlAct101of1965.pdf](https://www.nda.agric.za/doaDev/sideMenu/fisheries/03_areasofwork/Aquaculture/AquaPolGUIDLeg/Legislation/MedicinesRelatedSubstancesControlAct101of1965.pdf) accessed 14 June 2019
- (208) Jagwe J, Merriman A. Uganda: delivering analgesia in rural Africa: opioid availability and nurse prescribing. *J Pain Symptom Manage* 2007 May;33(5):547-551.
- (209) South African Department of Health. Standard Treatment Guidelines and Essential Medicines List. 2018; Available at: <http://www.health.gov.za/index.php/component/phocadownload/category/197>. Accessed 05/03, 2015.
- (210) Robertson C. An evaluation of the Palliative Care Unit at Groote Schuur Hospital. An evaluation of the palliative care unit at Groote Schuur Hospital 2015. (Dissertation, University of Cape Town)
- (211) Morgan JM. A prospective cohort study and evaluation of an end-of-life programme intervention in a primary health care setting. A prospective cohort study and evaluation of an end-of-life programme intervention in a primary health care setting 2014. (Dissertation, University of Cape Town)

- (212) United Nations. Sustainable Development Goals. 2015; Available at: <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>. Accessed 27/03, 2017.
- (213) Sridhar D, McKee M, Ooms G, Beiersmann C, Friedman E, Gouda H, et al. Universal health coverage and the right to health: from legal principle to post-2015 indicators. *International journal of health services* 2015;45(3):495-506.
- (214) Ataguba JE, McIntyre D. Paying for and receiving benefits from health services in South Africa: is the health system equitable? *Health Policy Plan* 2012 Mar;27 Suppl 1:i35-45.
- (215) Harding R, Easterbrook P, Higginson IJ, Karus D, Raveis VH, Marconi K. Access and equity in HIV/AIDS palliative care: a review of the evidence and responses. *Palliat Med* 2005 Apr;19(3):251-258.
- (216) Murtagh FE, Preston M, Higginson I. Patterns of dying: palliative care for non-malignant disease. *Clin Med* 2004 Jan-Feb;4(1):39-44.
- (217) Selman L, Harding R, Beynon T, Hodson F, Coady E, Hazeldine C, et al. Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't". *Heart* 2007 Aug;93(8):963-967.
- (218) World Health Organisation. Global action plan for the prevention and control of NCDs 2013-2020. 2013; Available at: <http://www.who.int/nmh/publications/ncd-action-plan/en/>. Accessed 27/03, 2015.
- (219) Andersen PM, Abrahams S, Borasio GD, de Carvalho M, Chio A, Van Damme P, et al. EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)—revised report of an EFNS task force. *European journal of neurology* 2012;19(3):360-375.
- (220) Simms V, Higginson IJ, Harding R. Integration of palliative care throughout HIV disease. *The Lancet infectious diseases* 2012;12(7):571-575.
- (221) Defilippi K. Integrated community-based home care: Striving towards balancing quality with coverage in South Africa. *Indian Journal of Palliative Care* 2005;11(1):34.
- (222) Dumont S, Jacobs P, Fassbender K, Anderson D, Turcotte V, Harel F. Costs associated with resource utilization during the palliative phase of care: a Canadian perspective. *Palliat Med* 2009 Dec;23(8):708-717.
- (223) Harding R, List S, Epiphaniou E, Jones H. How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliat Med* 2012 Jan;26(1):7-22.

- (224) Ewing G, Brundle C, Payne S, Grande G, National Association for Hospice at Home. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *J Pain Symptom Manage* 2013;46(3):395-405.
- (225) Cleary S, Birch S, Chimbindi N, Silal S, McIntyre D. Investigating the affordability of key health services in South Africa. *Soc Sci Med* 2013;80:37-46.
- (226) Fassbender K, Fainsinger RL, Carson M, Finegan BA. Cost trajectories at the end of life: the Canadian experience. *J Pain Symptom Manage* 2009;38(1):75-80.
- (227) Gómez-Batiste X, Tuca A, Corrales E, Porta-Sales J, Amor M, Espinosa J, et al. Resource consumption and costs of palliative care services in Spain: a multicenter prospective study. *J Pain Symptom Manage* 2006;31(6):522-532.
- (228) Paz-Ruiz S, Gomez-Batiste X, Espinosa J, Porta-Sales J, Esperalba J. The costs and savings of a regional public palliative care program: the Catalan experience at 18 years. *J Pain Symptom Manage* 2009;38(1):87-96.
- (229) Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med* 2014 Feb;28(2):130-150.
- (230) Mosoiu D, Dumitrescu M, Connor SR. Developing a costing framework for palliative care services. *J Pain Symptom Manage* 2014;48(4):719-729.
- (231) Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non–small-cell lung cancer. *N Engl J Med* 2010;363(8):733-742.
- (232) Haricharan HJ, Heap M, Coomans F, London L. Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a Deaf woman in Cape Town, South Africa. *Disability & Society* 2013;28(1):54-66.
- (233) Harrison N, Cavers D, Campbell C, Murray SA. Are UK primary care teams formally identifying patients for palliative care before they die? *Br J Gen Pract* 2012 May;62(598):e344-52.
- (234) Nkosi Rogers Attorneys & Conveyancers. *Stransham-Ford v Minister of Justice and Correctional Services and Others*. 2015.
- (235) Burt J, Raine R. The effect of age on referral to and use of specialist palliative care services in adult cancer patients: a systematic review. *Age Ageing* 2006 Sep;35(5):469-476.
- (236) Gardiner C, Cobb M, Gott M, Ingleton C. Barriers to providing palliative care for older people in acute hospitals. *Age Ageing* 2011 Mar;40(2):233-238.

- (237) Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *International Perspectives on Public Health and Palliative Care* 2012;30.
- (238) Ferris FD, Bruera E, Cherny N, Cummings C, Currow D, Dudgeon D, et al. Palliative cancer care a decade later: accomplishments, the need, next steps—from the American Society of Clinical Oncology. *Journal of Clinical Oncology* 2009;27(18):3052-3058.
- (239) Hearn J, Higginson I. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Palliative Care Core Audit Project Advisory Group. Quality in Health Care* 1999;8(4):219-227.
- (240) Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. *Health Qual Life Outcomes* 2010;8(10):1477-7525.
- (241) Shisana O, Rehle T, Simbayi LC, Zuma K, Jooste S, Zungu S, et al. South African National HIV Prevalence, Incidence and Behaviour Survey, 2012.
- (242) International Agency for Research on Cancer. *Globocan 2012: Estimated cancer Incidence, Mortality and Prevalence Worldwide*, 2012.
- (243) Daude A. A review of cases of motor neurone disease seen at Groote Schuur Hospital from 2005 to 2010. 2015 (Dissertation University of Cape Town)
- (244) Bruera E, Sweeney C. Palliative care models: international perspective. *J Palliat Med* 2002;5(2):319-327.
- (245) Hagerty RG, Butow PN, Ellis PM, Dimitry S, Tattersall MH. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol* 2005 Jul;16(7):1005-1053.
- (246) Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA internal medicine* 2014;174(12):1994-2003.
- (247) Hagerty RG, Butow PN, Ellis PM, Lobb EA, Pendlebury SC, Leighl N, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol* 2005 Feb 20;23(6):1278-1288.
- (248) McIntyre D, Gilson L. Putting equity in health back onto the social policy agenda: experience from South Africa. *Soc Sci Med* 2002;54(11):1637-1656.
- (249) Mitchell JD, Borasio GD. Amyotrophic lateral sclerosis. *Lancet* 2007 Jun 16;369(9578):2031-2041.



- (250) Hughes RA, Aspinall F, Higginson IJ, Addington-Hall JM, Dunckley M, Faull C, et al. Assessing palliative care outcomes for people with motor neurone disease living at home. *Int J Palliat Nurs* 2004;10(9):449-453.
- (251) O'Brien MR, Whitehead B, Murphy PN, Mitchell JD, Jack BA. Social services homecare for people with motor neurone disease/amyotrophic lateral sclerosis: Why are such services used or refused? *Palliat Med* 2012;26(2):123-131.
- (252) Malaza A, Smith J, Mdaka N, Haynes R, Shezi S. *The 90-90-90 Compendium: An Introduction to 90-90-90 in South Africa*. 2016.
- (253) Wilcock A. *Symptom management in advanced cancer*. : Radcliffe Publishing; 2001.
- (254) Cherny NI, Catane R, Kosmidis P, ESMO Taskforce on Supportive and Palliative Care. ESMO takes a stand on supportive and palliative care. *Ann Oncol* 2003 Sep;14(9):1335-1337.
- (255) Moodley K. The Fabricius decision on the Stransham-Ford case-an enlightened step in the right direction. *SAMJ: South African Medical Journal* 2015;105(6):434-435.
- (256) Orner P. Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care* 2006;18(3):236-240.
- (257) Bede P, Oliver D, Stodart J, van den Berg L, Simmons Z, O Brannagain D, et al. Palliative care in amyotrophic lateral sclerosis: a review of current international guidelines and initiatives. *J Neurol Neurosurg Psychiatry* 2011 Apr;82(4):413-418.
- (258) Hudson P, Payne S. Family caregivers and palliative care: current status and agenda for the future. *J Palliat Med* 2011;14(7):864-869.
- (259) McIntyre D, Thiede M, Birch S. Access as a policy-relevant concept in low-and middle-income countries. *Health Economics, Policy and Law* 2009;4(02):179-193.
- (260) Wringe A, Cataldo F, Stevenson N, Fakoya A. Delivering comprehensive home-based care programmes for HIV: a review of lessons learned and challenges ahead in the era of antiretroviral therapy. *Health Policy Plan* 2010 Sep;25(5):352-362.
- (261) Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Prevalence, burden, and correlates of physical and psychological symptoms among HIV palliative care patients in sub-Saharan Africa: An international multicenter study. *J Pain Symptom Manage* 2012;44(1):1-9.
- (262) Rudiger A, Meier BM. A rights based approach to health care reform. *Rights-based approaches to public health* 2011:69-86.

- (263) World Health Organization. Everybody's Business Strengthening Health Systems to Improve Health Outcomes. Everybody's Business Strengthening Health Systems to Improve Health Outcomes 2007;ISBN 978 92 4 159607 7.
- (264) World Health Organization. Better Health for Poor Children. 2002;WHO/FCH/CAH/02.5.
- (265) Donabedian A. Evaluating the quality of medical care. Milbank Q 2005;83(4):691-729.
- (266) Brook RH, McGlynn EA, Shekelle PG. Defining and measuring quality of care: a perspective from US researchers. Int J Qual Health Care 2000 Aug;12(4):281-295.
- (267) Gilson L, McIntyre D. Removing user fees for primary care in Africa: the need for careful action. BMJ 2005 Oct 1;331(7519):762-765.
- (268) South African Department of Health. Core Standards Framework for the Assessment of Health Establishments . 2011.
- (269) Freeman MC. Global lessons for deinstitutionalisation from the ill-fated transfer of mental health-care users in Gauteng, South Africa. The Lancet Psychiatry. 2018 Sep 1;5(9):765-8.
- (270) Moseneke JD. Gauteng Mental Marathon project Arbitration Award. 2018. In the arbitration between: families of mental health care users affected by the Gauteng Mental Marathon Project. <http://www.gauteng.gov.za/government/departments/office-of-the-premier/Life%20Esidimeni%20Documents/Life%20Esidimeni%20arbitration%20award%20by%20retired%20Deputy%20Chief%20Justice%20Dikgang%20Moseneke.pdf> Accessed May 29, 2018
- (271) Normand C. Measuring outcomes in palliative care: limitations of QALYs and the road to PaLYs. J Pain Symptom Manage 2009 Jul;38(1):27-31.
- (272) Powell RA, Downing J, Harding R, Mwangi-Powell F, Connor S. Development of the APCA african palliative outcome scale. J Pain Symptom Manage 2007;33(2):229-232.
- (273) Selman L, Harding R. How can we improve outcomes for patients and families under palliative care? Implementing clinical audit for quality improvement in resource limited settings. Indian J Palliat Care 2010 Jan;16(1):8-15.
- (274) Harding R, Powell RA, Namisango E, Merriman A, Gikaara N, Ali Z, et al. Palliative care-related self-report problems among cancer patients in East Africa: a two-country study. Supportive Care in Cancer 2014;22(12):3185-3192.
- (275) Lowther K, Harding R, Simms V, Ahmed A, Ali Z, Gikaara N, et al. Active ingredients of a person-centred intervention for people on HIV treatment: analysis of mixed methods trial data. BMC infectious diseases 2018;18(1):27.

- (276) Groene O. Patient centredness and quality improvement efforts in hospitals: rationale, measurement, implementation. *International Journal for Quality in Health Care* 2011;23(5):531-537.
- (277) Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, et al. Preferences of patients for patient centred approach to consultation in primary care: observational study. *BMJ* 2001 Feb 24;322(7284):468-472.
- (278) Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AG, Hood K, Douglas HR, Normand CE. Palliative care in hospital, hospice, at home: results from a systematic review. *Annals of Oncology*. 2002 Oct 1;13(suppl\_4):257-64.
- (279) Mwangi-Powell FN, Powell RA, Harding R. Models of delivering palliative and end-of-life care in sub-Saharan Africa: a narrative review of the evidence. *Curr Opin Support Palliat Care* 2013 Jun;7(2):223-228.
- (280) Harding R, Higginson IJ. Palliative care in sub-Saharan Africa. *The Lancet* 2005;365(9475):1971-1977.
- (281) Grant L, Downing J, Namukwaya E, Leng M, Murray SA. Palliative care in Africa since 2005: good progress, but much further to go. *BMJ Support Palliat Care* 2011 Sep;1(2):118-122.
- (282) Downing J, Powell RA, Mwangi-Powell F. Home-based palliative care in sub-Saharan Africa. *Home Healthc Nurse* 2010 May;28(5):298-307.
- (283) Report to W Cape DoH GF project Quality of care. 2010 (unpublished)
- (284) Nanney E, Smith S, Hartwig K, Mmbando P. Scaling up palliative care services in rural Tanzania. *J Pain Symptom Manage* 2010 Jul;40(1):15-18.
- (285) Di Sorbo PG, Chifamba DD, Mastrojohn J,3rd, Sisimayi CN, Williams SH. The Zimbabwe Rural Palliative Care Initiative: PCI-Z. *J Pain Symptom Manage* 2010 Jul;40(1):19-22.
- (286) Bausewein C, Daveson BA, Currow DC, Downing J, Deliens L, Radbruch L, et al. EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services—Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement. *Palliat Med* 2016;30(1):6-22.
- (287) Downing J, Simon ST, Mwangi-Powell FN, Benalia H, Daveson BA, Higginson IJ, et al. Outcomes' out of africa': the selection and implementation of outcome measures for palliative care in Africa. *BMC palliative care* 2012;11(1):1.

(288) Leatherman S, Ferris TG, Berwick D, Omaswa F, Crisp N. The role of quality improvement in strengthening health systems in developing countries. *Int J Qual Health Care* 2010 Aug;22(4):237-243.

(289) Stewart M. Towards a global definition of patient centred care. *BMJ* 2001 Feb 24;322(7284):444-445.

(290) Kellehear A, O'Connor D. Health-promoting palliative care: a practice example. *Critical Public Health* 2008;18(1):111-115.

(291) Cardona-Morrell M, Kim J, Turner RM, Anstey M, Mitchell IA, Hillman K. Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem. *Int J Qual Health Care* 2016 Sep;28(4):456-469.

(292) [https://www.ohchr.org/Documents/Publications/Human\\_rights\\_indicators\\_en.pdf](https://www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf)  
accessed 14 June 2019

(293) [https://www.ohchr.org/Documents/Issues/HRIndicators/SDG\\_Indicators\\_Tables.pdf](https://www.ohchr.org/Documents/Issues/HRIndicators/SDG_Indicators_Tables.pdf)  
accessed 14 June 2019

APPENDICES

How is palliative care part of the Right to Health? The South African evidence

A. Data collection tools

Sub-study: Needs Assessment for palliative care (Chapter 3)

A1. Mortality data spreadsheet abstracted from Medical Research Council Burden of Disease study: Mortality data for 2010, South Africa

Death Year	Death Month	Age year	Sex	Pop Group	Death Prov	Death Inst	Underlying cause ICD-10	Age5

A2 Data collection sheet – Palliative care sites by province

Sub-study: Availability of palliative care (Chapter 4)

Province	Name of site	Health district	sub	Manager's name	e-mail address

Appendix A3: Data collection sheet – Survey of palliative care sites

Sub-study: Availability of palliative care (Chapter 4)

How is palliative care part of the Right to Health? The South African evidence

Thank you for taking time to complete this questionnaire. The information from these questions will contribute to a study investigating the availability of palliative care services in South Africa and identifying gaps in the provision of palliative care in South Africa. The survey will take about 15-20 minutes to complete. There are 17 questions to complete. Please click Next to view the questions as there is information you may want to collect before starting the survey

1. What is the name of your organisation?

Name of organisation: \_\_\_\_\_

Health sub-district: \_\_\_\_\_

2. Do you provide a palliative care service?

Yes/No

3. Which of the following services do you provide?

Home-based care	
Outpatient clinic	
Day care	
In-patient admission	
Pain and symptom management	
Treatment support	
Counselling	
Access to grants	
Access to food parcels	
Spiritual care	
Bereavement care	

4. Which of the following staff members (paid or voluntary workers) work at your organisation? Please also indicate whether they have received palliative care training.

Staff member	Part-time	Full-time	Volunteer
Doctor			
Professional nurse			
Staff nurse			
Enrolled nurse			
ENA			
Community caregiver			
Social worker			
Auxillary social worker			
Spiritual counsellor			

5. Please indicate whether members of each category of staff have received palliative care training and to which level of training. (Please note that we are not asking for the number of staff members that have completed the training. For example if one or two professional nurses have completed the HPCA Short Course in Palliative Nursing Care please tick the certificate box even if there are 3 PNs on your staff)

Staff member	None	Introduction	Certificate course	Diploma	Master's degree
Doctor					
Professional nurse					
Staff nurse					
Enrolled nurse					
ENA					
Community caregiver					
Social worker					
Auxillary social worker					
Spiritual counsellor					



4. How many palliative care patients does your organisation care for on average per month?

0-20

21-50

51-100

101-150

151-200

200-300

300-400

400-500

>500

5. Which age groups receive care from your staff and volunteers?

0-4

5-11

12-18

19-25

26-40

41-60

60-75

75+

6. Please give patient demographics by gender:

Male \_\_\_\_%

Female \_\_\_\_%

7. Please give patient demographics by race:

Black \_\_\_\_\_%

Coloured \_\_\_\_\_%

Asian \_\_\_\_\_%

White \_\_\_\_\_%

8. Does your organization provide culturally appropriate care? Yes/No

9. If, yes, HOW does your service ensure culturally appropriate care?

Caregivers are of the same culture as patients

Caregivers have been trained in culturally appropriate care

Caregivers are aware of patients' culture

Caregivers speak the same language as patients

Other (please specify)

---

10. Do your patients receive morphine (or another strong opioid medication) if they require pain relief?

Yes/No

11. Who prescribes morphine if it is needed?

The patients we care for do not require morphine

Your organisation's doctor

Clinic doctor

Hospital doctor

Private doctor

12. Are there any barriers to your patients being able to access morphine?

Yes/No/Not applicable

13. If yes, please describe these barriers:

---

---

---

---

14. Do you have information leaflets for the following groups:

- |  |        |
|--|--------|
| Referral sites (doctors, clinics, hospitals) | Yes/No |
| Patients and family members                  | Yes/No |
| Community organisations                      | Yes/No |

15. How do your clients/patients get information about your services?

---

---

---

***How is palliative care part of the Right to Health in South Africa?: access to care***

Participant number:

Dear participant,

We are a group of researchers wanting to know more about the care you are receiving for your illness. If you choose to take part in this research we will ask you to complete a questionnaire each time you come to the clinic/outpatients for a 4- 6 month period. The questionnaire will take 10-15 minutes to complete the first time and 5-10 minutes at other visits. Your name will not appear on the questionnaire but there will be a unique number linked to a list of participants which will be kept in a locked cabinet to ensure confidentiality of any information collected during the research.

Please complete the following:

Tel number:

Age:

Gender:        Male    Female

Ethnic group:

What illness are you being treated for at this clinic/outpatient department?

---

Do you have other people or services helping with your care?

Family

Friends

Frail care

Faith community

Hospice

Home care

Nursing service

Other \_\_\_\_\_

Appendix A5: APCA AFRICAN Patient Outcome Scale

Sub-studies: Accessibility of palliative care study (Chapter 5) and Quality of palliative care study(chapter 6)

**APCA AFRICAN Patient Outcome Scale**

<b>ASK THE PARTICIPANT</b>	
<b>Q1.</b> Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	<b>0 (no pain)- 5 (worst/overwhelming pain)</b>  0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
<b>Q2.</b> Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	<b>0 (not at all)- 5 (overwhelmingly)</b>  0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
<b>Q3.</b> Have you been feeling worried about your illness in the past 3 days?	<b>0 (not at all)- 5 (overwhelming worry)</b>  0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
<b>Q4.</b> Over the past 3 days, have you been able to share how you are feeling with your family or friends?	<b>0 (not at all)- 5 (yes, I've talked freely)</b>  0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
<b>Q5.</b> Over the past 3 days have you felt that life was worthwhile?	<b>0 (no, not at all)- 5 (yes, all the time)</b>  0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
<b>Q6.</b> Over the past 3 days, have you felt at peace?	<b>0 (no, not at all)- 5 (Yes, all the time)</b>  0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>
<b>Q7.</b> Have you had enough help and advice for your family to plan for the future?	<b>0 (not at all)- 5 (as much as wanted)</b>  0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/>

APCA African POS questions for family members

Quality of palliative care study (chapter 6)

<b>ASK THE FAMILY CARER</b>	
<p><b>Q8.</b> How much information have you and your family been given?</p>	<p style="text-align: center;"><b>0 (none)- 5 (as much as wanted)</b></p> <p style="text-align: center;">N/A <input type="checkbox"/></p> <p style="text-align: center;"><b>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></b></p>
<p><b>Q9.</b> How confident does the family feel caring for _____?</p>	<p style="text-align: center;"><b>0 (not at all)- 5 (very confident)</b></p> <p style="text-align: center;">N/A <input type="checkbox"/></p> <p style="text-align: center;"><b>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></b></p>
<p><b>Q10.</b> Has the family been feeling worried about the client over the last 3 days?</p>	<p style="text-align: center;"><b>0 (not at all)- 5 (severe worry)</b></p> <p style="text-align: center;">N/A <input type="checkbox"/></p> <p style="text-align: center;"><b>0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/></b></p>

## Appendix A6: Questionnaire on quality of care

### Sub-study: Quality of palliative care (Chapter 6)

How is palliative care part of the Right to Health? The South African evidence

Dear participant,

We are a group of researchers wanting to know more about the care you are receiving for your illness. If you choose to take part in this research we will ask you to complete a questionnaire each week for 4-6 weeks. The questionnaire will take 10-15 minutes to complete the first time and 5-10 minutes at other visits. Your name will not appear on the questionnaire but there will be a unique number linked to a list of participants which will be kept in a locked cabinet to ensure confidentiality of any information collected during the research.

Please complete the following:

- 4) Age: \_\_\_\_\_
  - 5) Gender:        Male    Female
  - 6) Race: \_\_\_\_\_
  - 7) What illness are you being treated for? \_\_\_\_\_
  - 8) When were you referred to \_\_\_\_\_ (*organisation name*) \_\_\_\_\_?
  - 9) Who referred you to the organisation? \_\_\_\_\_
  - 10) Do you think you would have benefitted from being referred to the organisation earlier in your illness? \_\_\_\_\_
  - 11) Do you think it was not necessary to refer you to the organisation? \_\_\_\_\_
  - 12) Do you think you have benefitted from the care you have received at the organisation?  
\_\_\_\_\_
  - 13) What has been your experience of care at ..... (study site)?  
\_\_\_\_\_
  - 14) How would you choose to be cared for?  
\_\_\_\_\_
  - 15) Do you have any other comment you would like to make about your care?  
\_\_\_\_\_
-

## B. Information sheets and consent forms

### Appendix B1: Access to care

Sub-study: A prospective cohort study of the accessibility of palliative care for patients with chronic illnesses who would benefit from palliative care (Chapter 5)

**Information Sheet for:**  
***How is palliative care part of the Right to Health in South Africa: access to care***

Dear participant,

Thank you for giving your time to hear about our study.

This information sheet tells you about a study that you may wish to take part in. You may have some further questions to help you decide whether you want to take part. You can ask any further questions from your clinical team, from the researcher, or using the telephone numbers at the end. Thank you for thinking about whether you want to take part. Please take your time to make a decision.

#### **What is the purpose of the study?**

We are looking at how people's care needs and how these needs are helped by the different services people may access.

#### **Do I have to take part?**

No, you don't have to take part. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part, your care will NOT be affected in ANY WAY. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

#### **What will happen if I take part?**

An experienced researcher will speak to you and ask you questions about you and your health, and this may include any pain or other problems you have. It will take around 10-15 minutes for the first interview. We would like to hear about care each time you visit the clinic or outpatients department, the second questionnaire will take a shorter time to complete. We would like to hear about your care for 4-6 visits. This information sheet is for you to keep.

#### **Benefits of the study**



There are no direct benefits to the study for participants although people who have been interviewed using these questionnaires find that they are good points for discussion with care providers. The anticipated benefits are in identifying people's care needs and in trying to meet those needs.

### **Risks of the study**

Although many people find it useful to discuss these questions, there may be a risk that a question causes distress. If any of the questions cause you to feel distressed in anyway, you are free to withdraw from the study and will still receive your usual care. In addition a counselor will be available to assist you.

### **Will my taking part in this study be kept confidential?**

All the information which we collect during the interview will be kept strictly confidential. You will not be identified in any way, and your personal details (for example name and address) will be kept separately from the information you give. We will use a number and not your name on any information you give us. No-one outside the study will have access to the information you give us.

For patients in this study we will record their illness. That information will be treated as confidentially as all the other information you give us, and no-one outside this study will be able to find out your name or any other information that would identify you.

We also ask your permission to interview a family member that you nominate about your care. The information you have shared with us will not be disclosed to your family member unless this is requested by you.

### **How will I know about the results of the study?**

At the end of the study a report will be sent to the clinic/outpatient department and to the people who took part in the study.

### **Who is organising the research?**

If you need to talk to anyone about this research, you can contact the following people:

If you have any questions about the study:

*Dr Liz Gwyther, University of Cape Town: Tel 021-4066174*

If you have any questions about your human rights or any ethical issues about the study:

*UCT Research Ethics Committee:*

Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

**Consent form for: How is palliative care part of the Right to  
Health in South Africa: access to care**

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.
3. **I agree to take part in the above study.**
4. I agree to an interview with my family member.....

Name \_\_\_\_\_

Signature/Mark \_\_\_\_\_

Date \_\_\_\_\_

Researcher: Signature \_\_\_\_\_

Date: \_\_\_\_\_

Witness: Name  
(from clinical team or family member)

Signature \_\_\_\_\_

Date: \_\_\_\_\_

**Information Sheet for:**  
***How is palliative care part of the Right to Health in South Africa: quality of care***

Dear Participant,

Thank you for giving your time to hear about our study.

This information sheet tells you about a study that you may wish to take part in. You may have some further questions to help you decide whether you want to take part. You can ask any further questions from your clinical team, from the researcher, or using the telephone numbers at the end.

Thank you for thinking about whether you want to take part. Please take your time to make a decision.

**What is the purpose of the study?**

This is a study to assess the quality of care and support provided to patients and families by this organisation. This will also give us the opportunity to improve our service and ensure that we are meeting your needs.

**Do I have to take part?**

No, you don't have to take part, your participation in this assessment is entirely voluntary. If you do agree to take part, you are free to withdraw from the interview at any time without giving us any reason. Whether or not you take part, your care will NOT be affected in ANY WAY. If you do agree to take part, you will be asked to sign a consent form, which shows that you have agreed to do so. You can take some time to think about whether you would like to take part, and you may want to talk it over with your family, friends or someone in your care team.

**What will happen if I take part?**

If you agree, the nurse will ask you about how you have been feeling over the past three days. There are 7 questions for the patient to answer and 3 for your family carer. This should take about 20 minutes for the first interview. We will ask you to complete the interview each week for 4-6 weeks. The interviews would usually become shorter as you become familiar with the questions.

There are no right or wrong answers; we only want to know what you think. Please tell the nurse if you feel too tired or sick to answer the questions

This information sheet is for you to keep.

### **Benefits of the study**

There are no direct benefits to the study for participants although people who have been interviewed using these questionnaires find that they are good points for discussion with care providers. The anticipated benefits are in identifying people's care needs and in trying to meet those needs.

### **Risks of the study**

Although many people find it useful to discuss these questions, there may be a risk that a question causes distress. If any of the questions cause you to feel distressed in anyway, you are free to withdraw from the study and will still receive your usual care. In addition a counselor will be available to assist you.

### **Will my taking part in this study be kept confidential?**

All the information which we collect during the interview will be kept strictly confidential. You will not be identified in any way, and your personal details (for example name and address) will be kept separately from the information you give. We will use a number and not your name on any information you give us. No-one outside the study will have access to the information you give us.

We also ask your permission to interview a family member that you nominate about your care. The information you have shared with us will not be disclosed to your family member unless this is requested by you.

### **How will I know about the results of the study?**

At the end of the study a report will be sent to the organisation and to the people who took part in the study.

### **Who is organising the research?**

If you need to talk to anyone about this research, you can contact the following people.

If you have any questions about the study:

*Dr Liz Gwyther, University of Cape Town: Tel 021-4066174*

If you have any questions about your human rights or any ethical issues about the study, please contact:

*UCT Research Ethics Committee:*

Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

# Consent form for study How is palliative care part of the Right to Health in South Africa: quality of care

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my care being affected.
3. I agree to take part in the above study.
4. I agree to an interview with my family member.....

Name \_\_\_\_\_

Signature/Mark \_\_\_\_\_

Date \_\_\_\_\_

Researcher: Signature \_\_\_\_\_

Date: \_\_\_\_\_

Witness: Name

(from clinical team or family member)

Signature \_\_\_\_\_

Date: \_\_\_\_\_

C. Ethical Approvals Appendix C1.

University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty  
Faculty of Health Sciences Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
e-mail: sumayah.ariefdien@uct.ac.za

26 August 2010

HREC REF: 320/2010

**Dr L Gwyther**  
School of Public Health & Family Medicine

Dear Dr Gwyther

**PROJECT TITLE: HOW IS PALLIATIVE CARE PART OF THE RIGHT TO HEALTH?  
SOUTH AFRICAN EVIDENCE**

Thank you for addressing our concerns.

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

**Approval is granted for one year till the 28<sup>th</sup> August 2011.**

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the REC. REF in all your correspondence.**

Yours sincerely

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, HSF HUMAN ETHICS**

Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

sAriefdien

## Appendix C2. Hospice Palliative Care Association Research Ethics Committee

Suite 11a, Lonsdale Bldg, Lonsdale Way, Pinelands 7405

P O Box 38785, Pinelands, 7430, South Africa

Tel: 021 531 0277 Fax: 021 531 1706

Email: [hpc@iafrica.com](mailto:hpc@iafrica.com)

[www.hospicepalliativecaresa.co.za](http://www.hospicepalliativecaresa.co.za)



4 December 2010

Dr L Gwyther  
CEO Hospice Palliative Care Association  
[liz@hpc.co.za](mailto:liz@hpc.co.za)

Dear Dr Gwyther

**Protocol : How is palliative care part of the right to health? South African evidence. L. Gwyther, HPCA. Ref.: 06/10**

The above protocol was reviewed by the Hospice Palliative Care Association Research Ethics Committee at its meeting held on 28 September 2010. Queries were raised and have now been addressed. The protocol is given full ethics approval.

Please note the following :

- Copies of the translated Information to Participants and Informed Consent documents, together with an undertaking from a person competent in both the local language and English, that the translations are accurate needs to be submitted;
- An original signed copy of the amended protocol and supporting documentation (as approved) must be submitted to the HPCA offices in Cape Town.
- Ethics approval is valid for one year only;
- Application for recertification of the protocol should be submitted a couple of months prior to the 28 September 2011 to ensure continuous approval;
- ANY changes to an approved protocol must be reviewed by the Research Ethics Committee.

It would be appreciated if, once the study has been completed, a summary of the results could be submitted to the REC so that these can be placed on the web-site.

I would like to take this opportunity to wish you well with your research.

Yours sincerely

DR N MALAN  
Deputy Chair : Hospice Palliative Care Research Ethics Committee  
Reg. No. : REC-250408-005

### no end to caring

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

Association Incorporated under sec.21 Reg no. 86/01887/08. NPO no.003-462.

Patron: Archbishop Emeritus Desmond M. Tutu

Board: B Campbell-Ker (Chairperson), S Blakeman, S Fakroodeen (vice-chair), B Kuwane, S Mogotlane, E Scrimgeour, T Thompson, R Wienekus, E Willis, M Wollheim

## D Supporting documents

### Appendix D1. Letter requesting permission to conduct study at study sites

Sub-study: A prospective cohort study of the accessibility of palliative care for patients with chronic illnesses who would benefit from palliative care (Chapter 5)

The Facility Manager

Date

Dear

How is palliative care part of the right to health? South African evidence.

I am writing to invite outpatient department/clinic to join us as a study site in our research.

Palliative care is the care of patients with active, progressive, far-advanced disease, for whom the focus of care is the relief and prevention of suffering and the quality of life. Palliative care should be provided in the context of a continuum of care and not only at the end of life. Palliative care is applicable early in the course of a life-threatening illness alongside disease-oriented care intended to cure or to prolong life.

Palliative care is provided in many settings although most commonly hospices are seen as the site of provision of palliative care.

The study is a prospective cohort study planning to follow patients with advanced illness and assessing patients' access to palliative care over a 4-6 month period.

We will be using the APCA African Patient Outcome Scale to assess patient needs and measure outcome of patient care. The APCA African POS was developed and validated within Africa, and is a brief multidimensional tool for patients and families affected by life-limiting disease.

We will introduce the research study to your staff. The researcher will be fully trained and knowledgeable regarding the approved protocol. This study will not be beginning until we have full ethical approval.

I am writing to outline some basic study information.

- *Who are we recruiting?*



We are recruiting a total of 170 adult patients with advanced illness – cancer, HIV or motor neuron disease. The patients will come from 4 different services to cover the disease profiles.

- *How will patients be approached to ask them if they want to take part?*

We ask that your staff identify patients who meet the criteria, and then explain that we are recruiting to a study using questionnaires that ask about their health that would last about 15-20 minutes the first time of completing the questionnaire and then 10 minutes a subsequent visits (4 or 6 visits in all) If patients are interested in taking part a researcher will speak to them and give further information. If they agree to take part, the researcher will ask for informed consent. The questionnaire is entitled “The Right to Health in South Africa: access to care” and does not directly ask about palliative care but about different elements of care.

- *How will data collection happen?*

The researcher will then conduct the interview if the patient has given consent. The researcher will hold and store the data in a locked store and will keep the personal information (e.g. name) separate from the questionnaire data. The patient’s name will not appear on the questionnaire which will only have a study number as an identifier.

- *What if a patient becomes distressed?*

All respondents will have the opportunity to halt the interview at any time, and will have debriefing (i.e. time to talk without data being collected) at the end of the interview. If the researcher is concerned about respondent distress, they will inform one of the clinical team and will let the patient know that they are doing so

- *What are the responsibilities of the study site?*

We are asking you to assist in identifying patients who meet the study criteria and to introduce them to the researcher who will discuss the research with them and ask for their informed consent.

We are also asking that should a patient become distressed during the interview that your counselling staff would be prepared to provide the necessary support for the participant. We have found in previous studies that participants welcome the opportunity to respond to questions asked in the Patient Outcome Score and that distress is infrequent. Please would you note your agreement to provide this support when you respond to our request to conduct research within your facility. If you do not have the resources to provide counselling support, we will identify a counsellor who can be on call if required, should a participant express distress or should the researcher identify possible distress.

- *What about study feedback?*

We will liaise closely with you to let you know the number of interviews complete and the remaining interviews needed. We will also produce a dissemination brief on the findings for display within your service, and this will be written in lay language.

We look forward to working with you and fixing the date for launch once we have full ethical approval, translated materials, and have identified the researcher.

Please don't hesitate to contact me should you require further information in the meantime. I will remain the Principal Investigator throughout the study, and encourage you to raise any thoughts with our researcher or with me. You may raise any ethical concerns with the UCT Research Ethics Committee contact

Yours sincerely,

Dr Liz Gwyther.

[Liz.Gwyther@uct.ac.za](mailto:Liz.Gwyther@uct.ac.za)

Tel 021-4066174

*UCT Research Ethics Committee:*

Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

Appendix D2. Letter requesting permission to conduct study at study sites  
(Part 4: To describe quality of palliative care in the NGO setting)

The Manager

NGO

Date

Dear

How is palliative care part of the right to health? South African evidence.

I am writing to invite your organisation to join us as a study site in our research.

It is recognized that palliative care is an appropriate and compassionate response to the needs of patients with life-threatening illness. The international palliative care community describes palliative care and pain relief as a human right. To date, in South Africa, palliative care has largely been provided to relatively few patients and mostly within the NGO setting.

The study is a prospective cohort study planning to evaluate the quality of care provided to patients in the palliative care setting.

We will be using the APCA African Patient Outcome Scale to assess patient needs and measure outcome of patient care. The APCA African POS was developed and validated within Africa, and is a brief multidimensional tool for patients and families affected by life-limiting disease. The researcher will ask patients about how they have been feeling over the past three days. There are 7 questions for the patient to answer and 3 for the family carer. This should take about 20 minutes for the first interview. We will repeat the interview each week for 4-6 weeks. The interviews would usually become shorter as participants become familiar with the questions.

We will introduce the research study to your staff. The researcher will be fully trained and knowledgeable regarding the approved protocol. This study will not be beginning until we have full ethical approval.

I am writing to outline some basic study information.

- *Who are we recruiting?*

We are recruiting a total of 16 adult patients with advanced illness – cancer, HIV or other advanced illness from each participating NGO.

- *How will patients be approached to ask them if they want to take part?*

We ask that your staff identify patients who meet the criteria, and then explain that we are recruiting to a study using questionnaires that ask about their health that would last about 15-20 minutes the first time of completing the questionnaire and then 10 minutes a subsequent visits (4 or 6 visits in all) If patients are interested in taking part a researcher will speak to them and give further information. If they agree to take part, the researcher will ask for informed consent.

- *How will data collection happen?*

The researcher will then conduct the interview if the patient has given consent. The researcher will hold and store the data in a locked store and will keep the personal information (e.g. name) separate from the questionnaire data. The patient's name will not appear on the questionnaire which will only have a study number as an identifier.

- *What if a patient becomes distressed?*

All respondents will have the opportunity to halt the interview at any time, and will have debriefing (i.e. time to talk without data being collected) at the end of the interview. If the researcher is concerned about respondent distress, they will inform one of the clinical team and will let the patient know that they are doing so

- *What are the responsibilities of the study site?*

We are asking you to assist in identifying patients who meet the study criteria and to introduce them to the researcher who will discuss the research with them and ask for their informed consent.

We are also asking that should a patient become distressed during the interview that your counselling staff would be prepared to provide the necessary support for the participant. We have found in previous studies that participants welcome the opportunity to respond to questions asked in the Patient Outcome Score and that distress is infrequent. Please would you note your agreement to provide this support when you respond to our request to conduct research within your facility. If you do not have the resources to provide counselling support, we will identify a counsellor who can be on call if required, should a participant express distress or should the researcher identify possible distress.

- *What about study feedback?*

We will liaise closely with you to let you know the number of interviews complete and the remaining interviews needed. We will also produce a dissemination brief on the findings for display within your service, and this will be written in lay language.

We look forward to working with you and fixing the date for launch once we have full ethical approval, translated materials, and have identified the researcher.

Please don't hesitate to contact me should you require further information in the meantime. I will remain the Principal Investigator throughout the study, and encourage you to raise any thoughts with our researcher or with me. You may raise any ethical concerns with the UCT Research Ethics Committee contact

Yours sincerely,

Dr Liz Gwyther.

[Liz.Gwyther@uct.ac.za](mailto:Liz.Gwyther@uct.ac.za)

Tel 021-4066174

*UCT Research Ethics Committee:*

Mrs Lamees Emjedi

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

Appendix D3. ICD-10 2010 version:

to inform expert group in advising ICD-10 codes to use in Needs Assessment study (Chapter 3)

WHO <http://apps.who.int/classifications/icd10/browse/2010/en>

I Certain infectious and parasitic diseases

A00-A09 Intestinal infectious diseases

A15-A19 Tuberculosis

A20-A28 Certain zoonotic bacterial diseases

A30-A49 Other bacterial diseases

A50-A64 Infections with a predominantly sexual mode of transmission

A65-A69 Other spirochaetal diseases

A70-A74 Other diseases caused by chlamydiae

A75-A79 Rickettsioses

A80-A89 Viral infections of the central nervous system

A90-A99 Arthropod-borne viral fevers and viral haemorrhagic fevers

B00-B09 Viral infections characterized by skin and mucous membrane lesions

B15-B19 Viral hepatitis

B20-B24 Human immunodeficiency virus [HIV] disease

B25-B34 Other viral diseases

B35-B49 Mycoses

B50-B64 Protozoal diseases

B65-B83 Helminthiases

B85-B89 Pediculosis, acariasis and other infestations

B90-B94 Sequelae of infectious and parasitic diseases

B95-B98 Bacterial, viral and other infectious agents

B99-B99 Other infectious diseases

## II Neoplasms

C00-C97 Malignant neoplasms

D00-D09 In situ neoplasms

D10-D36 Benign neoplasms

D37-D48 Neoplasms of uncertain or unknown behaviour

## III Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism

D50-D53 Nutritional anaemias

D55-D59 Haemolytic anaemias

D60-D64 Aplastic and other anaemias

D65-D69 Coagulation defects, purpura and other haemorrhagic conditions

D70-D77 Other diseases of blood and blood-forming organs

D80-D89 Certain disorders involving the immune mechanism

## IV Endocrine, nutritional and metabolic diseases

E00-E07 Disorders of thyroid gland

E10-E14 Diabetes mellitus

E15-E16 Other disorders of glucose regulation and pancreatic internal secretion

E20-E35 Disorders of other endocrine glands

E40-E46 Malnutrition

E50-E64 Other nutritional deficiencies

E65-E68 Obesity and other hyperalimentation

E70-E90 Metabolic disorders

## V Mental and behavioural disorders

F00-F09 Organic, including symptomatic, mental disorders

F10-F19 Mental and behavioural disorders due to psychoactive substance use

F20-F29 Schizophrenia, schizotypal and delusional disorders

F30-F39 Mood [affective] disorders

F40-F48 Neurotic, stress-related and somatoform disorders

F50-F59 Behavioural syndromes associated with physiological disturbances and physical factors

F60-F69 Disorders of adult personality and behaviour

F70-F79 Mental retardation

F80-F89 Disorders of psychological development

F90-F98 Behavioural and emotional disorders with onset usually occurring in childhood and adolescence

F99-F99 Unspecified mental disorder

## VI Diseases of the nervous system

G00-G09 Inflammatory diseases of the central nervous system

G10-G14 Systemic atrophies primarily affecting the central nervous system

G20-G26 Extrapyrarnidal and movement disorders

G30-G32 Other degenerative diseases of the nervous system

G35-G37 Demyelinating diseases of the central nervous system

G40-G47 Episodic and paroxysmal disorders

G50-G59 Nerve, nerve root and plexus disorders

G60-G64 Polyneuropathies and other disorders of the peripheral nervous system

G70-G73 Diseases of myoneural junction and muscle



G80-G83 Cerebral palsy and other paralytic syndromes

G90-G99 Other disorders of the nervous system

VII Diseases of the eye and adnexa

VIII Diseases of the ear and mastoid process

IX Diseases of the circulatory system

I00-I02 Acute rheumatic fever

I05-I09 Chronic rheumatic heart diseases

I10-I15 Hypertensive diseases

I20-I25 Ischaemic heart diseases

I26-I28 Pulmonary heart disease and diseases of pulmonary circulation

I30-I52 Other forms of heart disease

I60-I69 Cerebrovascular diseases

I70-I79 Diseases of arteries, arterioles and capillaries

I80-I89 Diseases of veins, lymphatic vessels and lymph nodes, not elsewhere classified

I95-I99 Other and unspecified disorders of the circulatory system

X Diseases of the respiratory system

J00-J06 Acute upper respiratory infections

J09-J18 Influenza and pneumonia

J20-J22 Other acute lower respiratory infections

J30-J39 Other diseases of upper respiratory tract

J40-J47 Chronic lower respiratory diseases

J60-J70 Lung diseases due to external agents

J80-J84 Other respiratory diseases principally affecting the interstitium

J85-J86 Suppurative and necrotic conditions of lower respiratory tract

J90-J94 Other diseases of pleura

J95-J99 Other diseases of the respiratory system

XI Diseases of the digestive system

K00-K14 Diseases of oral cavity, salivary glands and jaws

K20-K31 Diseases of oesophagus, stomach and duodenum

K35-K38 Diseases of appendix

K40-K46 Hernia

K50-K52 Noninfective enteritis and colitis

K55-K63 Other diseases of intestines

K65-K67 Diseases of peritoneum

K70-K77 Diseases of liver

K80-K87 Disorders of gallbladder, biliary tract and pancreas

K90-K93 Other diseases of the digestive system

XII Diseases of the skin and subcutaneous tissue

XIII Diseases of the musculoskeletal system and connective system

XIV Diseases of the genitourinary system

N00-N08 Glomerular diseases

N10-N16 Renal tubulo-interstitial diseases

N17-N19 Renal failure

N20-N23 Urolithiasis

N25-N29 Other disorders of kidney and ureter

N30-N39 Other diseases of urinary system

N40-N51 Diseases of male genital organs

N60-N64 Disorders of breast

N70-N77 Inflammatory diseases of female pelvic organs

N80-N98 Noninflammatory disorders of female genital tract

N99-N99 Other disorders of the genitourinary system

XV Pregnancy, childbirth and the puerperium

XVI Certain conditions originating in the perinatal period

P00-P04 Fetus and newborn affected by maternal factors  
and by complications of pregnancy, labour and delivery

P05-P08 Disorders related to length of gestation and fetal  
growth

P10-P15 Birth trauma

P20-P29 Respiratory and cardiovascular disorders specific  
to the perinatal period

P35-P39 Infections specific to the perinatal period

P50-P61 Haemorrhagic and haematological disorders of  
fetus and newborn

P70-P74 Transitory endocrine and metabolic disorders  
specific to fetus and newborn

P75-P78 Digestive system disorders of fetus and newborn

P80-P83 Conditions involving the integument and  
temperature regulation of fetus and newborn

P90-P96 Other disorders originating in the perinatal period

XVII Congenital malformations, deformations and chromosomal  
abnormalities

Q00-Q07 Congenital malformations of the nervous  
system

Q10-Q18 Congenital malformations of eye, ear, face and  
neck

Q20-Q28 Congenital malformations of the circulatory  
system

Q30-Q34 Congenital malformations of the respiratory  
system

Q35-Q37 Cleft lip and cleft palate

Q38-Q45 Other congenital malformations of the digestive system

Q50-Q56 Congenital malformations of genital organs

Q60-Q64 Congenital malformations of the urinary system

Q65-Q79 Congenital malformations and deformations of the musculoskeletal system

Q80-Q89 Other congenital malformations

Q90-Q99 Chromosomal abnormalities, not elsewhere classified

XVIII Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified

XIX Injury, poisoning and certain other consequences of external causes

XX External causes of morbidity and mortality

XXI Factors influencing health status and contact with health services

XXII Codes for special purposes

#### **Appendix D4 WHO Definition of Palliative Care (28)**

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

Palliative Care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance the quality of life, and will also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

#### **WHO Definition of Palliative Care for Children**

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children with life-threatening or chronic disorders and their families is as follows; (WHO;1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, and even in children's homes.

## Appendix D5 Regression analysis comparing hospice and non-hospice PROMs

Regression analysis compared 2 groups of patients/family members for 10 items:

1)Pain, 2)symptoms, 3)worry, 4)able to share, 5)life worthwhile, 6)at peace, 7)help and advice, 8)family worry, 9)family confidence, 10)family information

### 1. Pain

Logistic regression Pain comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 385

LR chi2(1) = 2.53

Prob > chi2 = 0.1120

Log likelihood = -263.41152                      Pseudo R2 = 0.0048

---

cat_diff_pain	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]
group	.7205647	.1487623	-1.59	0.112	.4807733 1.079955
_cons	1.993966	.6340228	2.17	0.030	1.069204 3.718561

---

### 2. Symptoms

Logistic regression Symptoms comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 382

LR chi2(1) = 8.83

Prob > chi2 = 0.0030

Log likelihood = -258.85308                      Pseudo R2 = 0.0168

---

cat_diff_sy~m	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]
group	.5387205	.1129711	-2.95	0.003	.3571613 .8125736
_cons	2.041875	.6497139	2.24	0.025	1.094413 3.809579

---

### 3. Worry

Logistic regression Worry comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 380

LR chi2(1) = 0.52

Prob > chi2 = 0.4699

Log likelihood = -263.13478 Pseudo R2 = 0.0010

---

cat_diff_wor~y	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]	
group	1.160978	.2398693	0.72	0.470	.7743861	1.740566
_cons	.8060272	.2544063	-0.68	0.494	.4341952	1.496285

---

#### 4. Able to share

Logistic regression Able to share comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 383

LR chi2(1) = 0.26

Prob > chi2 = 0.6123

Log likelihood = -166.12661 Pseudo R2 = 0.0008

---

cat_diff_ab~e	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]	
group	1.154802	.3288055	0.51	0.613	.6609158	2.017759
_cons	4.379228	1.877121	3.45	0.001	1.890327	10.14514

---

#### 5. Life worthwhile

Logistic regression Life worthwhile comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 380

LR chi2(1) = 0.00

Prob > chi2 = 0.9562

Log likelihood = -229.52836 Pseudo R2 = 0.0000

```
-----+-----  
cat_diff_li~e | Odds Ratio Std. Err. z P>|z| [95% Conf. Interval]  
-----+-----  
Group | .9876377 .2238975 -0.05 0.956 .6333303 1.540157  
_cons | .4201601 .1461417 -2.49 0.013 .212494 .8307741  
-----+-----
```

## 6. At peace

Logistic regression: At peace comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 384

LR chi2(1) = 7.92

Prob > chi2 = 0.0049

Log likelihood = -170.65652 Pseudo R2 = 0.0227

```
-----+-----  
cat_diff_at~e | Odds Ratio Std. Err. z P>|z| [95% Conf. Interval]  
-----+-----  
group | 2.231452 .6579218 2.72 0.006 1.252043 3.977004  
_cons | 1.617196 .6672192 1.17 0.244 .7204035 3.630359  
-----+-----
```

## 7. Help and advice



Logistic regression Help and advice comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 371

LR chi2(1) = 0.57

Prob > chi2 = 0.4486

Log likelihood = -202.95678 Pseudo R2 = 0.0014

---

cat_diff_he~e	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]	
Group	1.20494	.2971909	0.76	0.450	.7430566	1.95393
_cons	2.457205	.9178382	2.41	0.016	1.18166	5.109638

---

#### 8. Family worry

Logistic regression: Family worry comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 185

LR chi2(1) = 1.01

Prob > chi2 = 0.3146

Log likelihood = -90.665597 Pseudo R2 = 0.0055

---

cat_diff_fa~y	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]	
group	1.515151	.6396903	0.98	0.325	.6623423	3.466009
_cons	2.42	1.368238	1.56	0.118	.7990178	7.329499

---

#### 9. Family confidence

Logistic regression: Family confidence comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 189

LR chi2(1) = 1.59

Prob > chi2 = 0.2067

Log likelihood = -43.895539

Pseudo R2 = 0.0178

---

cat_diff_fa~e	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]	
Group	2.5	1.977093	1.16	0.247	.5306132	11.77883
_cons	4.72	4.602538	1.59	0.112	.6981093	31.91248

---

#### 10. Family information

Logistic regression: Family information comparing group 1 (hospice) and group 2 (non-hospice)

Number of obs = 194

LR chi2(1) = 0.16

Prob > chi2 = 0.6863

Log likelihood = -59.851036

Pseudo R2 = 0.0014

---

cat_diff_fa~n	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]	
group	1.245378	.6853771	0.40	0.690	.4235005	3.662255
_cons	7.350254	5.494774	2.67	0.008	1.69815	31.81476

---