An Assessment of the Integration of Palliative Care in the Health System of the Cape Metro District of South Africa.

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

Oct 2023

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Declaration

I, Juanita Olivia Arendse, hereby declare that the work on which this thesis is based is my original work (except where acknowledgments 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 of Cape Town to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

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Date: 14 Oct 2023

Acknowledgements

As with all things in my life, none of this would be possible without the wisdom, guidance, peace, and hope that I receive from you Lord! Thank you for acceleration and promise.

To Liz Gwyther and Virginia Zweigenthal, my PhD supervisors, thank you for accommodating the ebb and flow of this journey, as we battled through this PhD and a global pandemic, to further develop what is needed in understanding integration of health policy in the health system. Your guidance, kindness, constant encouragement, and commitment of your time is sincerely appreciated. Thank you, Virginia, for the cups of really great coffee along the way and for the long-distance support all the way from Scotland, Liz.

To my research assistant, Leticia Poggenpoel; transcriber, Jesmé Swartz; stats support, Masudah Paleker; fixer, Nicky van der Walt; voice of reason, Hilary Goeiman; real boss, Nobom Mzo; calmette, Nolufefe Zukelwa - a big thank you!

The informants of this study and their willingness to engage and even be vulnerable, I thank and salute you all for agreeing to participate so that we can learn and do better.

Thank you, Gio Perez, for kicking the chick out of the nest - it was just what I needed! To Keith Cloete and Saadiq Kariem who offered constant support, time off work and encouragement. Thank you for believing in me. To the many colleagues who kept on checking in, I needed that!

To my executive teams in Northern Tygerberg Sub-Structure and in the Chief Directorate Emergency and Clinical Services Support, thank you for holding the forte when I needed some time off to focus and write, and for walking this road with me.

To my network: Lighthouse Christian Centre Pastoral team, leaders and 'sisters in Christ'; my 'other' sister, Hanlie – thank you for praying and having faith; Aunty Helen - thank you for your constant encouragement and always checking in.

To Mummy and Daddy, Cynthia and Donald Moses, and my siblings Sammy and Dylan, thank you for your unconditional love and lifelong support for whatever I got my head stuck into.

To my soulmate Rick who has supported me every step of the way for the last 34 years, I could never do this without your love, and knowing that you believe in me! To our gifts, Dominic and Jordan, for being my number one cheerleaders, for being patient and supportive on this 5½-year journey and when the pandemic hit, for the respect, love and increased support. I could never thank the three of you enough. I love you immensely!

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Acronyms and Abbreviations

APCA IPOS:	African Palliative Care Association Integrated Palliative Outcome Scale
CBS:	Community Based Services
CDC:	Community Day Centre
CHC:	Community Health Centre
CFIR:	Consolidated Framework for Implementation Research
CHW:	Community Health Worker
CMD:	Cape Metro District
COPC:	Community Oriented Primary Care
DHS EXCO:	District Health Executive Committee
eCCR:	Electronic continuity of care records
EN:	Enrolled Nurse
ENA:	Enrolled Nurse Assistant
GSH:	Groote Schuur Hospital
HCBC:	Home and Community-Based Care
HCW:	Health Care Worker
HIMT:	Hospice and Intermediate Care Management Team
HIV:	Human Immunodeficiency Virus
HMUS:	Higher morphine usage site
HPCA:	Hospice Palliative Care Association
HPSR:	Health policy and systems research
ICF:	Intermediate Care Facility
IEC:	Information, Education & Communication
LMIC:	Low- and Middle-Income Country
LMUS:	Low morphine usage site
MHS:	Metro Health Services
NDOH:	National Department of Health
NPFSPC:	National Policy Framework and Strategy for Palliative Care
NHI:	National Health Insurance
NGO:	Non-government Organisation
OMT:	Operational Management Team
OPEXCO:	Operations Executive Committee
PC:	Palliative Care
PCTT:	Palliative Care Task Team
PDC:	People Development Centre

PHC:	Primary Health Care
QOL:	Quality of Life
SA:	South Africa
SLB:	Street Level Bureaucrat
SOP:	Standard Operating Procedure
SPICT:	Supportive and Palliative Care Indicator Tool
SPICT-SA:	Supportive and Palliative Care Indicator Tool – South Africa
SS:	Sub-Structure
SSMT:	Sub-Structure Management Team
TB:	Tuberculosis
UHC:	Universal Health Coverage and Universal Health Care
UN:	United Nations
WCGHW:	Western Cape Government Health and Wellness
WC:	Western Cape
WCP:	Western Cape Province
WHA:	World Health Assembly
WHO:	World Health Organisation

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Glossary

Buddy: An individual who is not a family member of the patient but is trusted by the patient to provide support on their palliative care journey and often accompanies them to clinical and support group visits.

Community: A unit of population, defined by a shared characteristic (for example, geography, interest, belief or social characteristic), that is, the locus of basic political and social responsibility, and within which everyday social interactions and most life activities of the people takes place.[2]

Continuum of Care: The care pathway that the patient could journey when accessing palliative care service. This includes the home, intermediate care facilities and hospices, the primary health care platform, level 1, 2 and 3 hospitals and the patient's journey could commence at any point in this care pathway.

Difficult Conversation: Breaking bad news and building hope for the patient and family or support buddy.

Health Care Worker: refers to and includes all role players involved the health care arena. Clerical and administrative staff are included.

Health Care Provider: refers to the actual providers of health care and excludes the clerical and administrative staff working in the health care arena.

Implementers: Service deliverers of the palliative care policy within the District Health System in the two learning sub-districts of the Metro District.

Integrated health services: The management and delivery of health services so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services through the different functions, activities and sites of care within the health system.[2]

Operational and Operations Managers

Operational managers are the nurse managers in charge of the entire smaller primary health care facility otherwise known as a clinic or community day centre, and the manager in charge of a unit of nurses at a larger community health centre. The operations managers are non-nursing health managers in charge of certain functional units such as the pharmacy, social workers, rehabilitation unit and radiography.

Palliative Care[3]: Palliative Care is an approach that improves the quality of life of patients (adults and children) and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, spiritual and bereavement for the family.

Sub-Structure Management Teams: The senior and middle managers who are responsible for strategic decision-making, corporate governance, and leadership within a defined geographic area. There are 4 such structures within the Metro District.

Macro Level: The provincial level of management and functioning within the health system.

Meso: This is divided into 2 types: Strategic Meso and Operational Meso and refers to the district level of management of the health system.

Micro: The service delivery level of health care provision. This refers to the health facility such as a hospital or primary health care facility (community health centres, community day centres and clinics).

Primary health care (PHC): A whole-of-society approach to health that aims to maximize the level and distribution of health and well-being through three components: (i) primary care and essential public health functions as the core of integrated health services; (ii) multisectoral policy and action; and (iii) empowered people and communities.[2]

Universal health coverage (UHC): Ensured access for all people to needed promotive, preventive, resuscitative, curative, rehabilitative and palliative health services, of sufficient quality to be effective, while also ensuring that the use of these services does not expose any users to financial hardship.

Abstract: An Assessment of the Integration of Palliative Care, in the Health System of the Cape Metro District

Background

Palliative Care (PC) is a neglected yet core component of health care in the public sector. It embodies holistic, people-centred, compassionate care, focussing on vulnerable patients, and their families, with life threatening illness, to enhance their quality of life. Globally and in South Africa (SA), it has been delivered by non-governmental organisations (NGOs) such as hospices. However, in SA in 2017, the National Policy and Strategy for Palliative Care (NPSFPC) prescribed its integration into the public sector health care system. Following the NPFSPC, the Western Cape provincial health and wellness department initiated a PC service without additional resources prior to the COVID-19 pandemic.

Aim

The aim of the study is to investigate factors that influenced integration of PC into the Metro Health Services within the Cape Metro District (CMD).

Four complementary studies were conducted to assess integration of PC within the CMD public sector health system. Firstly, the state of PC service delivery was compared 24-months on from baseline. Then, perceptions of and identification of enablers and obstacles to PC among managers and external stakeholders at the beginning of the initiative were elicited, followed by the experiences of implementers, and finally the experiences of beneficiaries of the services.

Methods

Study methods were informed by a framework for analysing integration of targeted interventions into health systems, for both data collection and data analysis. A mixed methods approach was used – a document review, quantitative before and after implementation design, complemented by qualitative research that aimed to understand the underlying issues. These comprised a review of personnel and services in the public health sector, PC ICD 10 data codes and morphine utilisation data, and 16 individual interviews and 13 focus group discussions. It utilised the conceptual framework of Atun et al. for analysing integration of targeted interventions into health systems.

Findings

The project increased the availability of CMD PC services and resulted in a partial integration of PC into primary care services. There was clear commitment to improve the pattern and rate of adoption of PC, towards eventual assimilation into the health system functions.

The document analysis found that governance arrangements included PC in provincial priority setting and operational service planning, indicating the growing importance given to this

service. The COVID-19 pandemic had exposed the gaps in PC provision but had also highlighted the need and opportunities for PC as an essential service. The quantitative data analysis of morphine utilisation and PC attendance did increase, but this was not statistically significant.

Managers' and external stakeholders' commitment to a compassionate health system that is patient centred, enabled its integration. Additionally, a PC capacitated workforce, together with leadership and governance that supports PC integration is required.

Two years after policy implementation, managers' reflections indicate that a more inclusive policymaking process, together with creating awareness about PC among both staff and communities served, which focussed on reducing stigma, were important. Furthermore, to take PC integration forward requires pandemic planning that includes PC, strategic partnerships, and leading with care and compassion.

Front line health providers, the street level bureaucrats (SLBs) in health systems, need to be heard in service package policy making. They need visible managers and senior leadership to support PC service on the frontline. A multi-disciplinary team approach, facilitating inter-professional support, are essential to support integration of PC.

Patients and family receiving PC services needed support for family caregiver, and better pain and symptom control. They were frustrated by delayed referrals and service waiting times, and their inability to access other MDT members, particularly during the COVID-19 pandemic.

Conclusion and recommendations

The study demonstrates that robust well-consulted policymaking processes are required to ensure that policy is relevant and includes the voice of SLBs in clinical policy decision-making. They require leadership that is compassionate and visible together with clear guidance on service changes that facilitate inter-professional support and involves community health workers. Health system changes, such as standardised referral systems that include PC are required which allow flexibility when considering facility and patient context. Training was a gap, and capacity building for PC service provision should be included in undergraduate training for all health professionals, coupled with in-service training for employed health professionals. Furthermore, stakeholder engagements towards collaboratively creating public awareness about PC that drives the compassionate care agenda while addressing social determinants of health, is essential to embed and mainstream the service, support staff, patients and family caregivers. Finally in the light of the experience of the COVID-19 pandemic, planning for future pandemics needs to include ongoing care for PC patients as well as factoring in an increased demand.

An Assessment of the Integration of Palliative Care in the Health System of the Cape Metro District

A. Foreword

This thesis explores the question of whether and to what extent palliative care (PC) services can be integrated into the high-volume, resource constrained public sector health system in the Cape Metro Health District,[4] as guided by the National Policy Framework and Strategy on Palliative Care (NPFSPC), which proposes integration of PC into the public health system.[5]

By mid-2021, the population of the Western Cape (WC) province was 7 113 776 with 65,9% residing within the Cape Metro District (CMD).[4] This large urban city, Cape Town, known as the Cape Metro Health District is plagued by a quadruple burden of disease which includes chronic diseases, HIV/AIDS and TB, injuries and communicable diseases.[6] The health system in the Cape Metro forms part of the functional provincial health system and comprises 1) tertiary and central hospitals, 2) secondary/regional hospitals, 3) district hospitals, 4) specialised hospitals and 5) primary health care facilities, which includes City Health municipal health services – a network of primary health care (PHC) services largely providing child health and preventive health services in addition to environmental health services. Furthermore, established stakeholder relationships through formal governance arrangements, exist between the provincial health system and various NGOs, Higher Education Institutions (HEIs), City Health and the private health care sector.[4]

The NPFSPC acknowledges that "*palliative care has its roots in the hospice concept*"[5] and South Africa (SA) has been active in PC since 1979. However, PC as a component of universal health care (UHC) has not yet been integrated into the SA public sector health system as proposed by the NPFSPC released in 2017.[5, 7] The expectation sketched in the NPFSPC is that each province will develop implementation plans geared to integrating PC into the health system. The health system challenges that have been identified by the NPFSPC[5] included service delivery gaps regarding spiritual care; the lack of defined care pathways for PC patients (including inadequate communication and referral processes); inappropriately skilled personnel currently in the health system; a perceived lack of knowledge on the concept of PC by various actors; and, the community health worker (CHW) platform with gaps in their current training regarding PC.

The conceptual framework for analysing integration of targeted interventions into the health system was used to conduct an exploration of the combinations of factors that influence integration.[8] It draws on a range of health system characteristics and various actors within the health system, to assess the complexity of the intervention, the absorptive capacity of the health system for this new policy, the perception of adopters and actors, as well as prevailing cultural norms and social networks that may influence integration.

This study commenced in 2018, prior to the implementation of including PC into the health system, with the development of the proposal, ethics approval in 2019 and commencement of data collection which continued into early 2022. In 2020, the global COVID-19 pandemic not only influenced the methodology for this study, but it delayed the study and introduced factors that may have influenced the adoption of the NPFSPC.

In summary, this thesis tells a story, over a 24-month period, starting with where PC services were at in the CMD at baseline, compared to 24-months later. Next, views of various managers on what would be required to enable the integration of PC services and what could pose as obstacles were elicited before the pandemic as the integration project commenced. Then there was engagement with implementers on their experience with PC service provision following their training. Importantly an understanding of the patient and family's experience of the PC service compared to their expectations was determined. And finally, a follow-up with health system managers to explore what had changed, what lessons were learned and where to next was conducted.

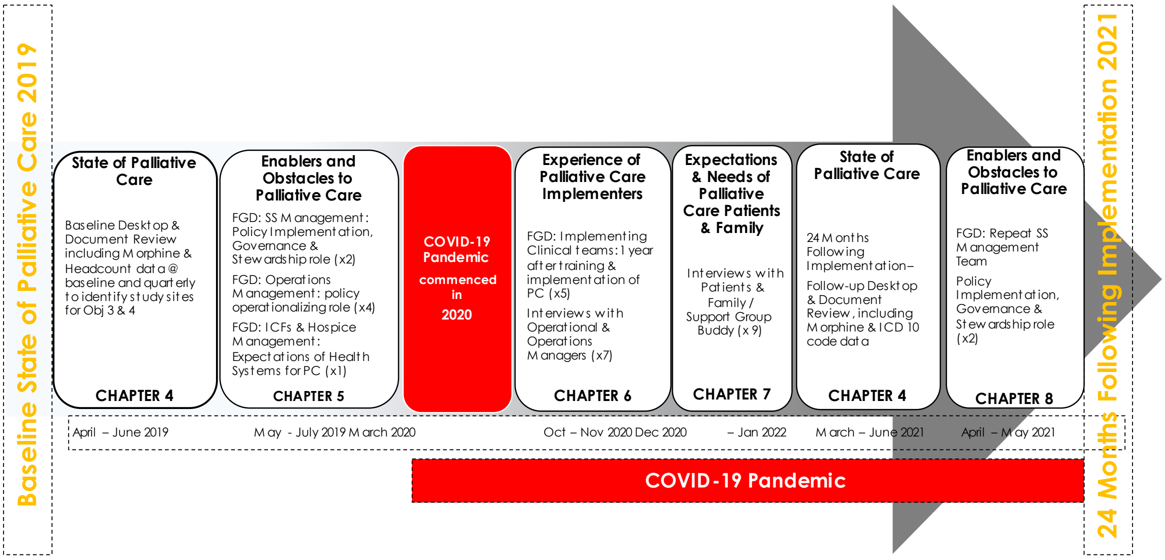

Figure 0.1 : Timeline for this study

Chapter 1 provides the background and overview to the thesis, the burden of disease and mortality data for the CMD. It defines what PC is and outlines the history of PC globally, in Africa and SA, leading to the development of the NPFSPC which suggested integration. Progress made within the local context for PC policy implementation support, the impact of the COVID-19 pandemic on the study and location and study context.

Chapter 2 is the literature review. It conceptualises PC as a component of Universal Health Coverage, reviews policy integration, health systems thinking, compassionate care and home-based PC. The chapter further explains the extent of the problem: that PC is neglected within the health care system in SA and in the WC and outlines the conceptual frameworks considered for this thesis and rationale for the selection of the conceptual framework for analysing integration of targeted interventions into health systems.

Chapter 3 presents the conceptual framework applied in the study, the research problem, aims, objectives and questions as well as an outline and summary of the methodology.

Chapter 4 details the baseline state of PC before the implementation of the NPFSPC in the Cape Metro District in the WC in relation to the health systems characteristics and compares the state of PC 24-months on, with a focus on the shift in the health system as adoption and diffusion occurred. A document analysis through a desktop review, was conducted at both points. In addition, quantitative data for morphine use and ICD-10 coding for PC were used to describe policy implementation and integration.

Chapter 5 provides insights into the perceptions of those who are in senior and middle management positions at the sub-structure and health facility levels in the metro health system, to identify obstacles and enablers to the implementation of the NSPFPC. The opinions and expectations of the hospice and intermediate care facility (ICF) stakeholders are also reported.

Chapter 6 describes how the implementers of PC perceived their training in PC as well as to what extent it was adequate for them to practice or implement. The implementers are all the different categories of clinical staff rendering PC at the point of care, and include doctors, nurses, pharmacists, social worker categories, administrative support staff and allied health cadres. This chapter reflects on their experiences when implementing a new intervention as it relates to support from operational management as well as system characteristics, eliciting what enabled them to integrate PC and what presented as an obstacle.

Chapter 7 provides insight into and describes the experiences of patients and their family caregivers of the PC services and whether they consider that their expectations and needs were met. The patient reported outcomes were assessed according to the African Palliative Care Association (APCA) Integrated Palliative Outcome Scale (IPOS) score.

Chapter 8 describes and analyses the reflections from the sub-structure management teams, 24 months following implementation, on the lessons learned about policy implementation and integration. This includes their perspectives on the COVID-19 pandemic and the many innovations that were introduced during that period.

Chapter 9 discusses how the findings from the four sub-studies align with the conceptual framework for analysing integration of targeted interventions into health systems and presents an outcome of this study, the ‘matrix tool for assessing the integration of policy’. This chapter highlights the extent, pattern and rate the integration of PC that has been possible, a summary of the matrix tool for assessing integration that was developed during this study, together with recommendations that will promote better policy decision-making with adequate consideration for the health system realities.

i) Rationale for and significance of this study

The research contributes to the body of knowledge on integration of new interventions into public health systems and provides information on enablers and barriers to the integration of PC specifically in low- and middle-income countries' (LMIC) health systems with comparable burdens of disease. The findings from the sub-studies, while maintaining a reflection on the elements of the conceptual framework on integration, have resulted in a recommendation that can be used for appraisal and implementation. This proposed tool, is a matrix that could be used to assess integration that can be applied to various policies within public health systems in LMICs.

Several articles in peer-reviewed journals are intended to disseminate findings such as:

- Comparing the state of PC in the CMD 24-months following implementation of the NPFSPC and the shift in the health system as adoption and diffusion occurred.
- The identified enablers and obstacles, as articulated by managers, to the integration of new complex interventions into the health system.
- Expectations of the health systems response to PC implementation, from experienced stakeholders, i.e., hospice and intermediate care facility managers.
- The implementers experiences of factors that influence the integration of new policy.
- Meeting the needs and expectations of patients and their families regarding PC.

Feedback will also be provided to the Western Cape Government Health and Wellness (WCGHW) and all informants who expressed an interest in the findings and recommendations.

Lastly, in support of substantive relevance for this study; there was significant high-level support from top provincial management for the introduction of PC into routine health services. The provincial health Chief of Operations, in 2017,[9] voiced concern that clinical and other personnel were inadequately equipped to have 'the difficult conversation' (break bad news and build hope), that would set the course for the patient and their family for PC which does not do more harm than good. This study considered this question within Chapter 6 and 7.

ii) The Person of the Researcher

I consider myself to be an insider researcher, having worked in the WCGHW for 34 years. This study was conducted at the University of Cape Town for a doctoral degree. As a health professional, I worked initially as a nurse practitioner, then in teaching and training, followed by 14 years in the health programmes arena, which required the management of staff and contract management of NGOs funded to provide services on behalf of the public sector health services.

For the last 13 years, I have been a senior manager in the WCGHW: responsible for the HIV and TB programmes (responsible for policy writing and various tools to facilitate policy implementation), followed by sub-structure (SS) management responsible for health service delivery at district level, and later transitioning to being responsible for five transversal functions within the WCGHW – Emergency Medical Services; Forensic Pathology Services; Medicine Management, Laboratory and Blood Services; Service Priorities Coordination (previously known as Health Programmes) and Clinical Service Improvement.

As an insider researcher, my initial assumptions regarding the major contributors to enabling or hindering PC integration, were tabled with both PhD supervisors and these have assumptions have been tested regularly.

Chapter 1 : Introduction

This chapter presents the background to this research into the integration of palliative care (PC) into the public sector health system. Firstly, PC is introduced as a key component of universal health care (UHC) and the complexity of the PC service interventions are discussed. This is followed by an overview of the global, African, South African (SA), and local context as it relates to PC and health policymaking considerations.

1.1. Background and overview

PC is a core component of health care[10] and is an approach that improves the quality of life of patients and their families who face life threatening illness.[3] The World Health Organisation (WHO) views PC as a crucial part of integrated, people-centred health services, which is needed at all levels of care, namely i) level 1 = primary health care and district hospital, ii) level 2 = regional hospital, and iii) level 3 = tertiary (central) hospital. PC aims to relieve suffering, offers a support system to patients and their families, enhances the quality of life and manages distressing clinical complications.[11]

Despite this, Gwyther (2002), a global leader in advocacy for PC, argued that PC in SA was not widely implemented as part of the comprehensive package of care. Since patients have traditionally been referred to hospice non-government organisations (NGO) for end-of-life care, PC has been viewed as end-of-life care. Furthermore, as funding from government for hospices had commenced as part of the response to the AIDS pandemic, hospice care could be regarded as end-of-life care, including for AIDS.[12] According to Drenth et al. (2018), funding for hospice NGOs in SA is limited and although some hospices had been partially funded by government, several hospices closed down during the period 2011–2016 because of insufficient funds. Furthermore, the challenges to PC service provision remained funding and the communities' perceptions of PC.[13]

Between 2016 and 2018 and in the light of an informed perspective of the benefits and nature of PC to the patient and the health system, the Metro Health Services (MHS) of the Western Cape Government Health and Wellness (WCGHW) department decided to implement the 2017 National Policy Framework and Strategy for Palliative Care (NPFSPC).[5] However, the NPFSPC would not be introduced with dedicated staff, governance and resources, but as defined in the NPFSPC, the policy was introduced into the health system within existing resources and governance responsibilities.[5] This approach aimed to encourage the integration of PC services into the public sector health system while intentionally moving away from offering PC as a separate service.

While this research focuses on the entire Cape Metro District (CMD), two sub-districts (out of eight) were selected as learning sites to gain insight into the factors that influence the integration of PC services into the comprehensive package of care rendered to patients attending the primary health care (PHC) and district hospital services. Through the utilisation of the conceptual framework to analyse the integration of targeted health interventions into health systems, developed by Atun et al.[8], this research analyses the extent, pattern and rate of integration and elicits the factors that influence integration.[8]

This approach was informed by the findings of a local study conducted at one of the community health centres in the CMD by Morgan (2014). The study participants considered the PC programme, which included support groups to be beneficial and strongly proposed that PC should be instituted at primary care level. Furthermore, a programme should include prompts to clinicians to refer patients timeously, PC training for facility staff, as well as present opportunities for staff to be more involved in future PC programmes within the health facilities.[14]

1.2. Palliative care

The WHO (2021) document that assesses worldwide development of PC stated that PC offers holistic care which is inclusive of medical, psychological, social, and spiritual care, when addressing the care needs of people who have pain and suffering because of severe illness. It further proposed that PC is applicable early in the course of illness alongside other therapies such as chemotherapy and irradiation which are implemented to prolong life.[2] Additionally, a case is made for the provision of PC services at all levels of care, based on the different needs of the patient (adult or child), ranging from primary to specialist services over the disease trajectory.[2]

According to the WHO (2002),[11] PC for adults is defined 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 by means early detection and impeccable assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual*".[2] Furthermore, PC aims to improve the quality of life of patients and their families to positively cope with the patients' illness until death and in the families' bereavement.[10]

The WHO (2021) defines PC for children as the "*active total care of the child's body, mind and spirit and also involves giving support to the family*". PC should commence on diagnoses and continue irrespective of whether the child receives any form of treatment for the disease. A broad multi-disciplinary team (MDT) approach that includes the child's family and the community-based service resources, is required. Together, the team would evaluate and provide relief for the child's physical, psychological, and social distress. This care can be provided at any level of care ranging from the tertiary hospital to the home.[2]

1.3. Global context of palliative care

The WHO (2021) assessment on global PC indicated that approximately 56,8 million people globally were in need of PC, of which 78% are in low- and middle-income countries (LMIC)[2] However, at that time only 14% of those in need of PC received it.[15] Lynch, Connor and Clark

(2013) reported that a regional analysis of PC conducted between 2006 and 2011 demonstrated that only 20 of the 234 countries included had PC well integrated into the health system, 42% had none and 32% had isolated services.[16] In 2021 the WHO reported that 39% of countries reported general availability of PC services for patients with non-communicable diseases.[2]

An extensive literature review conducted by Webster et al. (2007) demonstrated inequities in the provision of PC between developed and developing countries.[17] Brennan argued that while death is inevitable, based on international human rights law, access to PC is a human right. He elaborated that the goal of freedom from unnecessary suffering and care for a patient with PC needs, required attention to adequate housing, safe food and water, sanitation, and warmth, which are directly linked to the provision of good health care.[18] This was supported by Gwyther et al. (2009) who indicated that PC is an international human right and access to PC was integral in the preservation of human dignity.[19] This is reiterated in the WHO fact sheet[15] on PC which states that "*palliative care is explicitly recognized under the human right to health*" and that countries should ensure "*health system policies that integrate palliative care health services into the structure and financing of national health-care systems at all levels of care*".[15] Furthermore, PC is an ethical responsibility of heath care systems[2] and Gwyther et al. expressed concern regarding the global lack of PC provision, for those who are eligible.

Early PC helps the patient and family manage symptoms, better prepares them for end of life, and reduces unnecessary hospital admissions and utilisation of health services.[20],[15],[21],[3] Various global studies, systematic reviews and the WHO 2018 fact sheet on PC[15], agree and further argue that in order to address suffering, a team approach is required to support the patients and their caregivers regarding physical symptoms, practical needs and bereavement counselling. PC also offers the support system that the patient will require in order "*to live as actively as possible until death*".[15]

Although pain is a common moderate and severe symptom experienced by patients in need of PC, this is often a symptom experienced at the end of their lives. The WHO 2018 report clarified the conditions that require PC as follows:

> "*The majority of adults in need of palliative care have chronic diseases such as cardiovascular (38,5%), cancer (34%), chronic respiratory diseases (10,3%), AIDS (5,7%) and Diabetes (4,6%). Many other conditions may require palliative care including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, Rheumatoid Arthritis, Neurological disease, Dementia, congenital anomalies and drug resistant Tuberculosis*".[15]

By 2015, a 14 country, international, population-level study in 26 studies from 13 countries, demonstrated that many hospital deaths were preceded by invasive and inappropriate admissions and treatments shortly before death, which could compromise the provision of PC and the quality of end of life.[22]

1.3.1. History of global palliative care policy

The WHO, in 1990, pioneered the Public Health Strategy for the integration of PC into existing health systems that included guidelines about how to implement national PC programmes as well as national cancer control programmes which included PC as one of four pillars in comprehensive cancer care. An enhanced WHO Public Health Model (Figure 1.1) emerged to effectively integrate PC into society and includes four components, namely: "*1) appropriate policy, 2) adequate drug availability, 3) education of health care workers and the public, and 4) implementation*".[10]

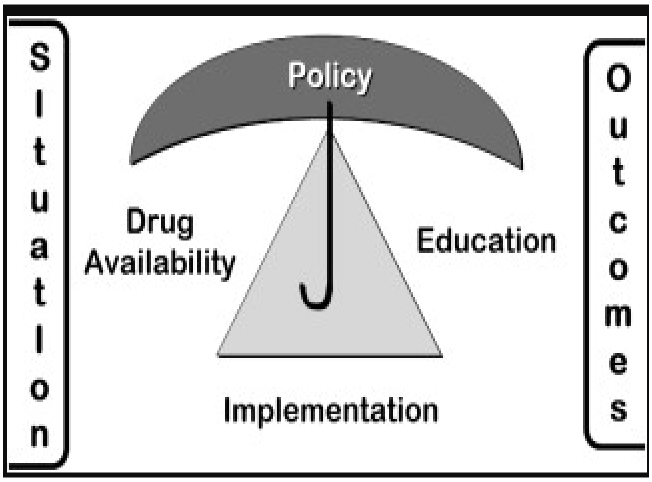

Figure 1.1: WHO Public Health Model

The WHO public health implementation steps (Figure 1.1, overleaf) articulates the steps that will ensure "*the best approach for translating new knowledge and skills into evidence based, cost effective interventions that can reach everyone in the population*".[23] This approach has been embraced and Stjernswärd et al. (2007) argued it demonstrated an effective strategy for integrating and establishing PC, into the health system and society at all levels within a given country.[23]

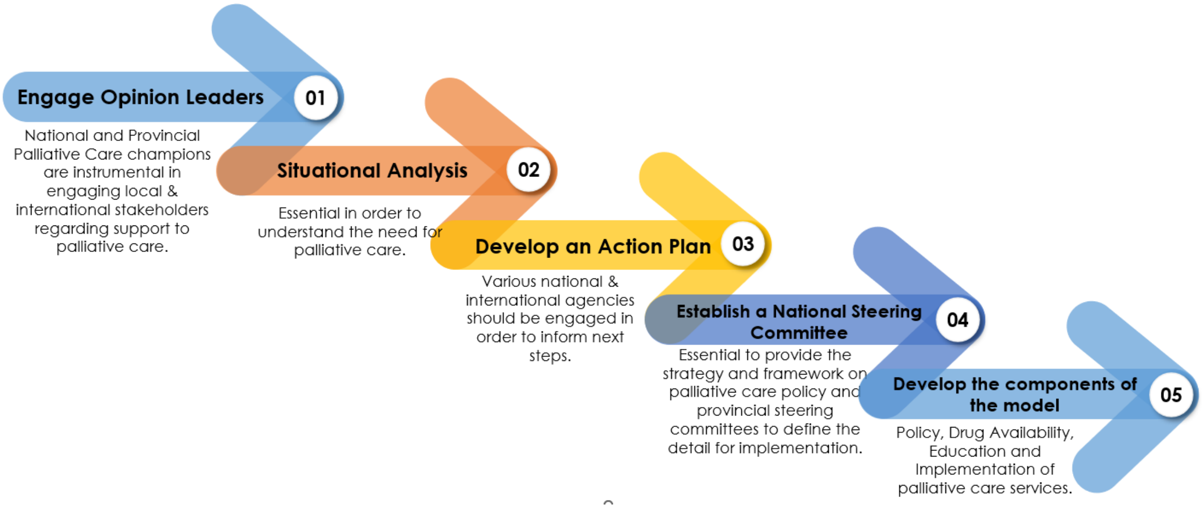

Figure 1.2: WHO Public Health Model Implementation Steps

These implementation steps (Figure 1.2) provide a systematic and structured approach that guides national and state/provincial health systems to establish an integrated public health model for PC within public sector health systems. This model has been used to describe progress on the PC implementation in various country studies.[23-26]

Stjernswärd et al. (2007), in a follow-on article, made a case for the integration of PC into national policies to ensure that PC programmes are provided to those in need of it, in an equitable and affordable manner. They outlined the steps towards incorporating PC into national policy in a systematic manner so that all the layers – advocacy, education, resource, and drug availability, are addressed. Furthermore, they argued for including PC within national health plans, as well as integrating into national and regional health care system as a whole, similar to what was achieved in Canada, Catalonia, Kerala, Georgia, Mongolia, Ontario, Uganda and the United States.[21]

A study conducted by Lohman et al. (2022) in five Eurasian countries between 2017 and 2021, found that three of the five countries implementing a PC strategy, focused firstly on training, technical support, and robust engagements; followed by advocacy and campaigning to demand roll-out of services, which resulted in more progress than in the other two countries. Furthermore, they found that post the COVID-19 pandemic, there was a sustainability risk to PC services following the withdrawal of external funding and the resultant impact on further progress.[27]

In 2021, the WHO proposed a PHC approach to the monitoring framework and set of indicators to measure improvement which evolved to the conceptual model for the development of PC. This conceptual model proposed that a national strategy of PC strengthening should be part of a country's commitment to strengthen PHC towards the achievement of universal health coverage (UHC).[7] This model positions people with PC needs at the centre of the development model and comprises six key components, namely (i) empowerment of people and communities, (ii) health policies, (iii) research, (iv) use of essential medicine, (v) education and training and (vi) provision of PC in integrated health service delivery platforms. Two of the six components are essential for optimal integrated service provision, namely the use of essential medicines to relieve pain and suffering, and the education of all health care providers involved in the provision of PC. These two components depend on appropriate relevant regulatory health policies and the empowerment of people and communities. The model rests on these foundations and subsequently informs evidence-based improvements in the use of medicines and professional education, which then enhances PC provision to patients in need.[2]

UHC is the United Nations (UN) Sustainable Development Goal 3 and UN member states committed to try to achieve UHC by 2030.[28] According to the WHO, with UHC, people should have equitable access to good quality health care services with no risk of financial hardship. UHC includes access to promotive, preventive, curative, rehabilitative and palliative health services. The WHO's guide to countries to measure progression towards UHC, identified three dimensions to address: who is covered; what services are covered; and, how much of the cost is covered? PC services need to be provided and assessed by these principles of UHC.[3]

Research conducted by Gomez-Batiste et al. (2005) has also shown that in high income countries, integrated PC was proven cost-effective over a 15-year period. Catalonia, the wealthiest region in Spain, is one such example.[29]

1.3.2. The World Health Assembly

The World Health Assembly (WHA) Resolution 67.19, adopted at the 67th WHA in 2014,[30] gave due consideration to "*Strengthening of palliative Care services as a Component of Integrated Treatment throughout the Life Course*". The resolution recognises that provision of PC is an ethical responsibility of health systems, worldwide. The WHA resolution[30] further stated that PC, when indicated, is fundamental to improve the quality of life of patients and their families who face life-threatening illnesses, by preventing and alleviating avoidable suffering of treatable symptoms. It advocated for services to be integrated within the continuum of care, across all levels of the health system, with a focus on primary care.[7]

The WHA[30] urged all member states to develop PC policies. These policies should ensure adequate resource allocation, provide basic support to families, partners, and stakeholders, and include PC in ongoing education to assess PC needs. The policies must ensure adequate supply of essential medicines, revisit controlled medicines policies in alignment to the WHO and UN policies, and monitor PC actions included in WHO's global action plan for the prevention and control of non-communicable diseases 2013-2020.[30] Table 1.1, overleaf, provides a summary of the WHA resolution 67.19.

Table 1.1: Summary of WHA resolution 67.19 recommendations30

"URGES Member States:

1. *to 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, with emphasis on primary care, community and home-based care, and universal coverage schemes,*
2. *to ensure adequate domestic funding and allocation of human resources, as appropriate, for palliative care initiatives,*
3. *to provide basic support, including through multisectoral partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals,*
4. *to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities:*
    a) *basic training on palliative care should be integrated as a routine element of all undergraduate medical and nursing professional education, and as part of in-service training of caregivers at the primary care level,*
    b) *intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses,*
    c) *specialist palliative care training*
5. *to assess domestic palliative care needs, including pain management medication requirements,*
6. *to review and, where appropriate, revise national and local legislation and policies for controlled medicines,*
7. *to update, as appropriate, national essential medicines list,*
8. *to foster partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care,*
9. *to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of noncommunicable diseases 2013–2020"*

1.4. African context of palliative care

PC services vary across countries in Africa, with NGOs predominantly being the source of provision. Major difficulties remain – related to access to opioids and skills development for health care providers in PC. Clark et al. (2007) conducted a multi-method review to assess the current state of PC services across 47 countries in Africa. To describe the various countries status regarding PC service provision, each was categorized into one of four groupings with the following outcomes: 1) no PC activity or hospice identified in 21 countries, 2) capacity building for PC commenced in 11 countries to promote PC delivery, 3) local provision of hospice and PC in place with donor funding support in 11 countries and 4) hospice and PC services approaching a measure of integration with mainstream service providers with broader policy recognition in four countries.[31] Evidence of the development of sustainable community-based hospice PC models existed in Uganda, Kenya, SA and Zimbabwe. However, they noted that sensitivity is required with adopting PC which is regarded as a western model of health care in African culture context countries.[31] Furthermore, the study found that PC services in SA are predominantly offered by NGO hospices and while care was fairly comprehensive in some areas, it was almost non-existent in others.[31]

Quality of life (QOL) is a core outcome of PC and in 2011, Selman et al. conducted a survey on quality of life amongst 285 patients receiving PC in SA and Uganda. The survey questionnaire included physical, social, psychological, spiritual domains and one global QOL item. The results showed that the patients valued feeling at peace, a sense of meaning in life and spiritual well-being, as more important than being physically comfortable or active. Following the application of a QOL score, the study concluded that the patients accessing PC in the two African countries had experienced poorer QOL since the psychological and spiritual support was not regarded as equally important as the provision of symptom and pain management, by the palliative health care providers.[32]

The 2013 global study, conducted by Lynch et al. that mapped levels of PC development, found that SA was one of 20 countries categorized as being in "*Preliminary Integration*".[16] SA remained at that stage along with 21 other countries in the recent global atlas for PC 2nd edition (2020).[33] Preliminary integration is defined as the existence of a "*critical mass of palliative care activism in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care on the part of health care professionals and local communities; the availability of morphine and some other pain-relieving drugs; limited impact of palliative care on policy; the provision of a substantial number of training and education initiatives by a range of organisations and the existence of a national palliative care association*".[16, 33] However, in 2018 Dr Liz Gwyther the CEO of Hospice Palliative Care Association noted that although PC in SA is categorized as being in preliminary integration, this varied between provinces (personal communication).[34] The following background and historical overview of PC services in SA describes this in more detail.

In summary, PC in Africa remains a challenge, with research clearly demonstrating the obvious demand for a holistic PC approach on the continent. As Ntzimira et al. (2014) argued, legislation and regulations are required to realise PC as an imperative for patients who need it. Furthermore, as the authors argue, the WHO public health model can assist countries in integrating PC into public sector health policy and public sector health facilities. However, as they confirmed, only two (Rwanda, Swaziland) out of 53 African countries have standalone policies on PC and four countries (Uganda, Kenya, Tanzania, SA) have demonstrated some integration of PC into the public health services.[26]

1.5. Historical overview of palliative care in South Africa

SA's PC services are rooted in the hospice movement which began in 1979.[5] Although PC had an initial focus on and was associated with cancer, the HIV pandemic in the 1990's mobilised hospice focussed NGOs to respond to the end-of-life care needs of those dying at the time. Notable is that this took place outside of the public sector health services and the Hospice Palliative Care Association (HPCA) of SA provided a range of local PC services for both adults and children through member hospices in many localities across SA. Hospices still provide PC services in communities through home-based care models (clinical assessments conducted by professional nurses), as well as some specialist inpatient services. Although the majority of referrals to hospices were from both public sector primary care facilities and hospitals, Ens et al. (2008) assessed that referrals to hospices were not standard; referring doctors lacked insight into what PC was; patients were fearful of hospice referrals; and, even when linkages between referring doctors and hospice doctors were in place, resistance to referral remained a challenge due to lack of patients understanding.[35]

The National Department of Health (NDOH) of SA responded to the 2014 WHA Resolution 67.19[30] and various SA PC practitioners have taken a leading role globally in advocacy for PC as a human right, for an integrated and holistic approach to PC services and have committed to implementing a national PC policy which reflects the spirit and intent of the WHA resolution.

1.5.1. The health system in South Africa

Inequities in health status, and access to health services were structured into the racist pre-apartheid and apartheid health systems. For many years the apartheid regime that governed SA, perpetuated inequality in access to health care, for all her people based on their racial classification.[36] Following the first democratic elections in 1994, the new government embarked on developing health policy based on the principle of healthcare for all.[37]

The Constitution of the Republic of SA 1996, being the highest law of the land, provides that everyone has the right to have access to health care services including reproductive health services and it requires that the State "*take reasonable legislative and other measures within its available resources to achieve the progressive realisation of that right*".[37] The Constitution also enshrines human dignity, and Section Ten [38] states that "*everyone has inherent dignity and the right to have their dignity respected and protected*". In Section 11, the Constitution further asserts that "*everyone has the right to life*" and this right is further elaborated on in Section 27 – the right to food and social security, water and access to health care. Recognising that many of these rights may not be actualised, the Constitution requires that the state should "*take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights*".[38] Furthermore, the Constitution prioritises children's right to health care, and Section 28 unequivocally states that all children have the right to access health care services.

The National Health Act 61 of 2003 soon followed, with a framework for a structured health system considering the obligations imposed by the Constitution and relevant laws on national, the nine provincial administrations and local authority governments regarding health services.[39] According to the Health Act, the roles of spheres of government are summarized in Table 1.2 below.

Table 1.2: Summary of roles of spheres of government according to the Health Act 61 of 2003[39]

Spheres of Government	Role and function
National health functions	The National Minister of Health has the responsibility for the following functions: • Ensure implementation of national health policy. • Identify national goals and priorities. • Develop norms and standards for the provision of health services.
Province health functions	The nine provincial executive councils lead by the MEC is responsible for ensuring the following: • Care for public and private hospitals. • Provide specialized hospital care. • Implement systems to maintain quality control. • Support districts in providing health services. • Ensure that the head of health consults communities on health matters.
District health structures	These structures are at the centre of health care service delivery and are lead by a district manager. Boundaries of a district are the same as municipal boundaries, but the provincial government has the autonomy to define and establish health sub-districts. The municipal health services are provided in these districts by the local authorities, and this includes water and sanitation services.

SA faces a quadruple burden of disease, namely maternal, neonatal and child health; HIV/AIDS and Tuberculosis (TB), non-communicable diseases; and violence and injury. Intentional injuries and mental health are major contributors to the burden of disease in the Western Cape (WC) and CMD.[40],[6] The World Bank has ranked SA as the most unequal country in the world[41] based on high levels of unemployment and unequal access to health services.[42]

The State provides health services to 86% of the country's population while only 14% are able to access health care through the private sector.[43]

The community oriented primary care (COPC) approach pioneered in Natal, SA in the 1940s, by Sydney and Emily Kark, combines determining the epidemiological profile of a community together with the provision of primary care services that address the health issues found. Implemented in many countries and a precursor to the PHC approach, COPC ensures seamless continuity of care that addresses health care needs delivered within a defined geographic area.[44]

SA was one of the member nations of the WHO that signed the Alma Ata declaration in 1978, putting forward the new PHC policy which not only meant the provision of health at a primary care level, but also included social, political, and economic causes of poor health. Essentially, the Alma Ata declaration proposed viewing health in a holistic manner to ensure equity, community participation and addressing the social determinants of health[i].[45] SA participated in the 5th Annual Primafamed Conference[46] in 2012 where it was acknowledged that COPC was the appropriate strategy to address upstream causes of ill-health including social, environmental and behavioural determinants of health. DeMiglio and Williams(2012) described local heath integrated networks in Canada which function on a model that is similar to COPC and offers PC at all levels of care which is geographically organised.[47]

SA is undergoing health sector reform that requires further restructuring of the health system. The recently tabled National Health Insurance (NHI),[48] legislation intends to address the inequities in health care provision and move SA towards UHC. The NHI makes clear provision for PC as part of a comprehensive set of health care services, to ensure comprehensive care along the care continuum.

1.5.2. National Policy Framework and Strategy on Palliative Care in South Africa

In the SA context, the implementation of the WHA Resolution is particularly relevant given the quadruple burden of disease. The provision of PC outlined is also aligned to the National Development Plan principles of overcoming inequity and poverty by ensuring access to PC at all levels of care within the public sector health system.[40]

In response to the WHA Resolution, the SA National Minister of Health convened a task team to identify service platform gaps and develop the NPFSPC 2017–2022, which proposed the integration of PC into the SA health system.[5] Using different methodologies, the NPFSPC estimated that between 45-50% of all deaths in SA during 2014 needed PC services. The

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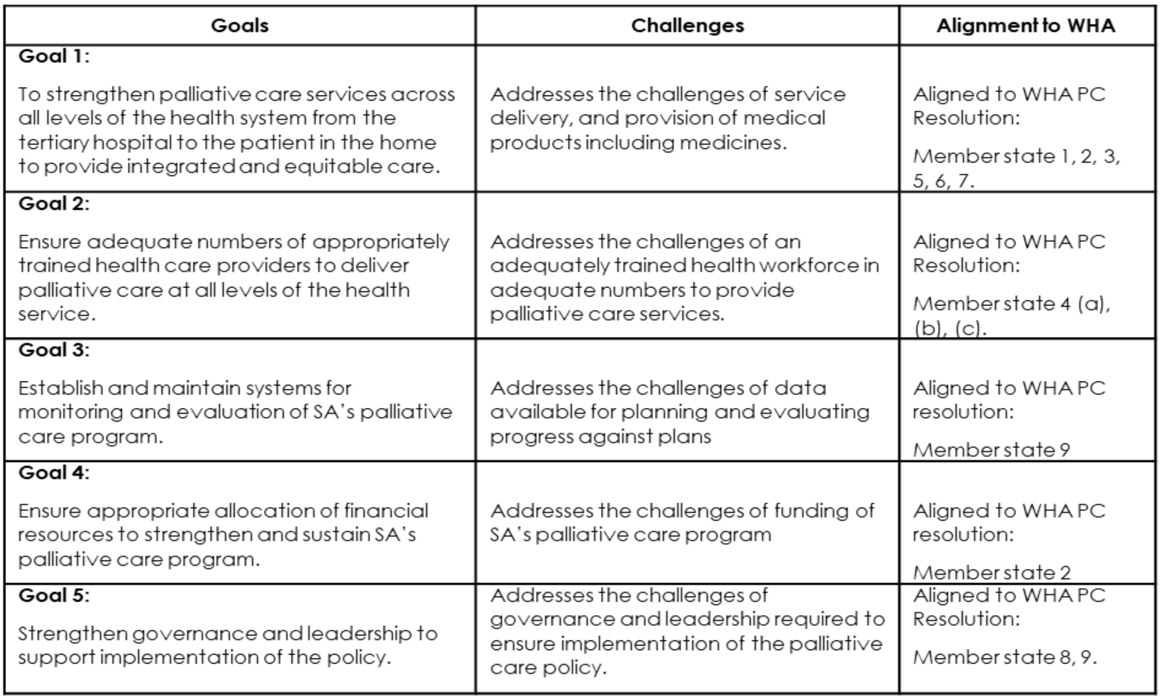
[i] Social determinants include access to proper nutrition, education, adequate supply of safe water, basic sanitation, maternal & child health care, preventative medicine such as family planning & immunisations.

NPFSPC proposed a guide to provinces to integrate PC services throughout SA's health system. The framework and strategy intend to:[5]

- Capitalise on existing services and existing policy priorities, most notably efforts to strengthen the district-based health system through primary health care re-engineering.
- Draw upon the strong national network of hospices and NGOs who have led the provision of care and support services to patients and their families and who have been instrumental in advancing education and training of health care providers.
- Enable the tertiary, secondary and primary levels of the health system to strengthen linkages with community-based services to provide a seamless, patient-centred service.
- Guide the implementation of PC services as part of the continuum of care for all life-threatening conditions which include condition specific clinical practical guidelines and tools to assist provinces to plan, implement and monitor PC services.[5]

The NPFSPC provides the tools for all levels of health care services, in the nine provinces of SA, in collaboration with other relevant departments, stakeholders and NGOs to address the gaps in the scope of services for public sector health care towards a holistic approach to patient care. The expectation sketched in the NPFSPC is that all nine provinces will develop implementation plans geared at integrating PC into the health system that align with the five national goals and objectives. Table 1.3 below identifies the challenges for each goal that aligns to the WHA PC resolution.[5]

Table 1.3: Five Goals as defined in the NPFSPC, their alignment with the WHA and challenges5:



Goals	Challenges	Alignment to WHA
Goal 1: To strengthen palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care.	Addresses the challenges of service delivery, and provision of medical products including medicines.	Aligned to WHA PC Resolution: Member state 1, 2, 3, 5, 6, 7.
Goal 2: Ensure adequate numbers of appropriately trained health care providers to deliver palliative care at all levels of the health service.	Addresses the challenges of an adequately trained health workforce in adequate numbers to provide palliative care services.	Aligned to WHA PC Resolution: Member state 4 (a), (b), (c).
Goal 3: Establish and maintain systems for monitoring and evaluation of SA's palliative care program.	Addresses the challenges of data available for planning and evaluating progress against plans	Aligned to WHA PC resolution: Member state 9
Goal 4: Ensure appropriate allocation of financial resources to strengthen and sustain SA's palliative care program.	Addresses the challenges of funding of SA's palliative care program	Aligned to WHA PC resolution: Member state 2
Goal 5: Strengthen governance and leadership to support implementation of the policy.	Addresses the challenges of governance and leadership required to ensure implementation of the palliative care policy.	Aligned to WHA PC Resolution: Member state 8, 9.

1.6. Background to the health system in the Western Cape Province

This background provides the context within which health service provision occurs in the province, the development of PC services within SA and within the CMD of the Western Cape Province (WCP). The WCP, one of SA's nine provinces, comprises six districts, of which the CMD is one district.

1.6.1. The District Health System, Comprehensive Service Plan and Healthcare 2030

A policy for the development of a District Health System (DHS) for SA was published for comment in December of 1995 with comments due on 29 February of 1996. The DHS development aimed to move towards a healthy nation. The DHS was implemented from 1995 onwards and a review conducted in 2001 found that although geographic areas were demarcated, the DHS was a long way off from being functional.[49] The WCGHW embarked on a process of developing and defining the DHS in the form of the Comprehensive Service Plan (CSP) which was released in May 2007, with a target date for implementation 2010.[50]

Following the implementation of the DHS according to the stipulations in the 2010 CSP, it was agreed that the "*overall configuration of the health service proposed by the CSP remained sound and that the major building blocks envisaged by the 2010 CSP have or are being implemented*". Healthcare 2030 plan reoriented the service to be intentional on increasing wellness through a whole of society approach, highlighting the agreed priority focus areas, person-centred care, integrated care provision by ensuring continuity of care across the life course.[51]

The service platform design for 2030, while maintaining the original configuration according to the 2010 CSP, is as follows:

- Primary Health Care Services comprise three inter-related care settings which collectively provide a comprehensive package of care aligned to UHC, namely, health promotion, disease prevention, curative services, rehabilitative and PC interventions:
    - ✓ Home and community-based care (HCBC)
    - ✓ Primary care
    - ✓ Intermediate care
- Acute Hospital according to the 3 levels of care:
    - ✓ District hospital – Level 1 (L1)
    - ✓ Regional hospital – Level 2 (L2)
    - ✓ Tertiary and Central hospital – Level 3 (L3)
- Specialised services that transversally support the service delivery platform:

- ✓ TB hospitals
- ✓ Psychiatric hospitals
- ✓ Rehabilitation hospitals
- ✓ Oral Health
- ✓ Emergency medical services (EMS) responsible for Emergency First Response (including Rescue), Disaster Risk Management (including Mass Events), Inter-facility Transfers, Non-emergency patient transport[51]

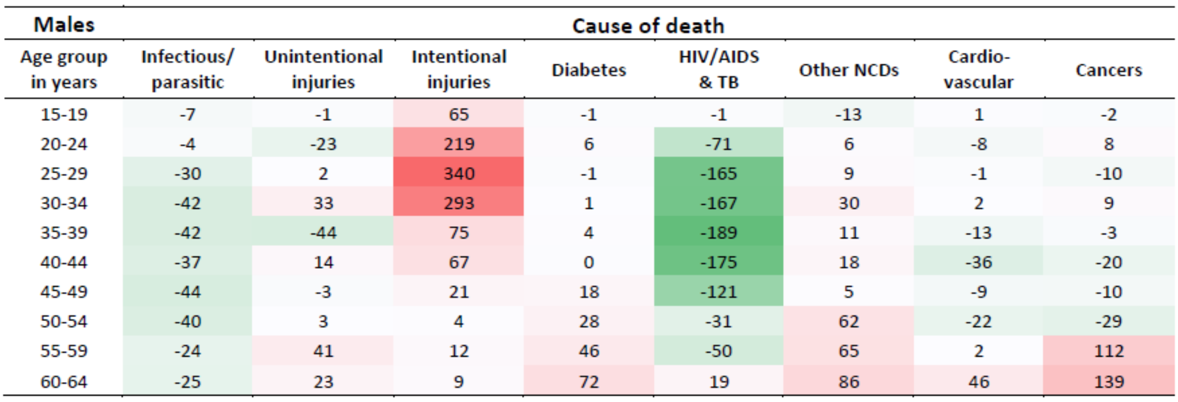
The continuum of care across the care pathway is aligned to the service platform design to ensure optimum care coordination for the patient.[51]

1.6.2. Health service delivery context

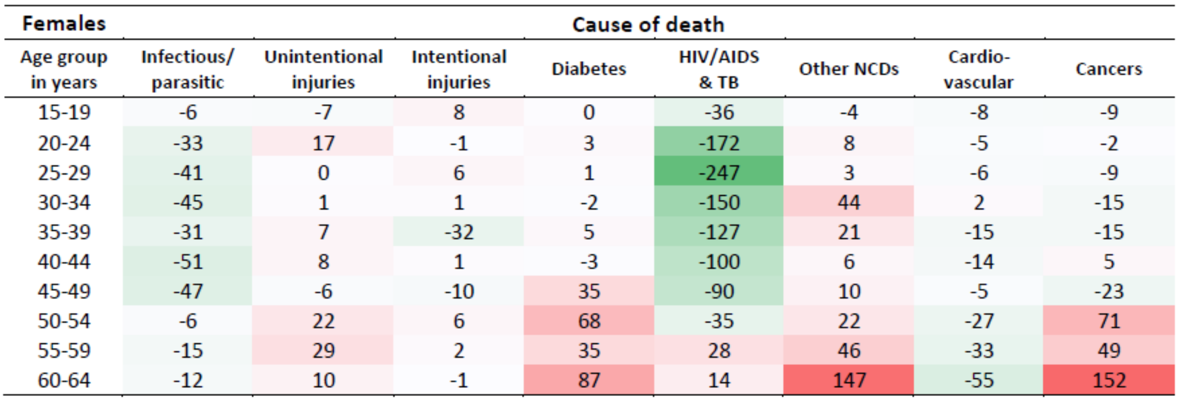
The WC burden of disease report released in 2020, indicated that by 2016, there had been an overall 17% decrease in early mortality, a 40% reduction in deaths in the age group <5 years mostly due to gains made in HIV care, diarrhoeal disease, and malnutrition. Furthermore, there has been a 40% increase in mortality due to intentional injuries among males aged 20–29 years, increases in non-communicable diseases due to increasing ageing population while HIV/AIDS and TB remain the leading causes of premature mortality.[6]

The Table 1.4, overleaf, illustrates the change in the number of deaths from 2009 to 2016 in the WC from leading causes by 5-year age groups and sex. Decreases in death rates (shades of green) are depicted as negative values and increases (shades of red) are depicted as positive values.[6]

Table 1.4: Changes in number of deaths from 2009 – 2016 in the Western Cape from leading causes of death by 5-year age group for males and females[6]



Males	**Cause of death**							
Age group in years	**Infectious/ parasitic**	**Unintentional injuries**	**Intentional injuries**	**Diabetes**	**HIV/AIDS & TB**	**Other NCDs**	**Cardio-vascular**	**Cancers**
15-19	-7	-1	65	-1	-1	-13	1	-2
20-24	-4	-23	219	6	-71	6	-8	8
25-29	-30	2	340	-1	-165	9	-1	-10
30-34	-42	33	293	1	-167	30	2	9
35-39	-42	-44	75	4	-189	11	-13	-3
40-44	-37	14	67	0	-175	18	-36	-20
45-49	-44	-3	21	18	-121	5	-9	-10
50-54	-40	3	4	28	-31	62	-22	-29
55-59	-24	41	12	46	-50	65	2	112
60-64	-25	23	9	72	19	86	46	139



Females	**Cause of death**							
Age group in years	**Infectious/ parasitic**	**Unintentional injuries**	**Intentional injuries**	**Diabetes**	**HIV/AIDS & TB**	**Other NCDs**	**Cardio-vascular**	**Cancers**
15-19	-6	-7	8	0	-36	-4	-8	-9
20-24	-33	17	-1	3	-172	8	-5	-2
25-29	-41	0	6	1	-247	3	-6	-9
30-34	-45	1	1	-2	-150	44	2	-15
35-39	-31	7	-32	5	-127	21	-15	-15
40-44	-51	8	1	-3	-100	6	-14	5
45-49	-47	-6	-10	35	-90	10	-5	-23
50-54	-6	22	6	68	-35	22	-27	71
55-59	-15	29	2	35	28	46	-33	49
60-64	-12	10	-1	87	14	147	-55	152

Notably increases in the causes of death from conditions that would most likely require PC are in the older age-groups and were due to unintentional injuries, diabetes, non-communicable diseases, and cancers.[6]

To make health care services more accessible and equitable, the senior managers[ii] of the CMD, working with local universities embarked on developing the COPC approach. The usual practice for PC is to extend care to the household,[52] therefore the fit with COPC approach using CHWs is well aligned.[44] The COPC approach furthermore advocates for and facilitates a multi-stakeholder (whole of government and whole of society) response to societal challenges that impact negatively on the health of the community.[53] which dovetails well with a PC approach.

1.6.3. Impact of the COVID-19 pandemic on the health system in the Western Cape

Pre-COVID-19, the country's health care system was under tremendous strain,[42] due to "*lack of human resources, poor governance and management, and unequal distribution of resources*".[54] The year 2020 marked the start of the global COVID-19 pandemic and

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[ii] Led by Chief Director Metro Health Services (MHS), Dr Giovanni Perez together with the four sub-structure managers.

challenged global health systems' response to health care needs. The pandemic exacerbated the need for PC since more patients required it, however the available PC services were at the pre-pandemic state, further highlighting global inequities.[55]

The WCGHW department had just embarked on implementing the NPFSPC. As deaths rates climbed due to COVID-19, the local COVID-19 pandemic highlighted the need for PC and access to the rapid provision of PC became more urgent.

The healthcare system in the WC, along with the rest of the world, responded with agility to address the biggest global pandemic it had yet to face.[56-58] As detailed in Table 1.5, to ensure the provision of and response to the growing urgent need for PC service provision, the WC PC task team (PCTT) along with other key stakeholders rapidly responded with a 'makeshift' plan that included healthcare worker training, the provision of additional PC beds and staff and formalised referral services for people needing PC and bereavement care.

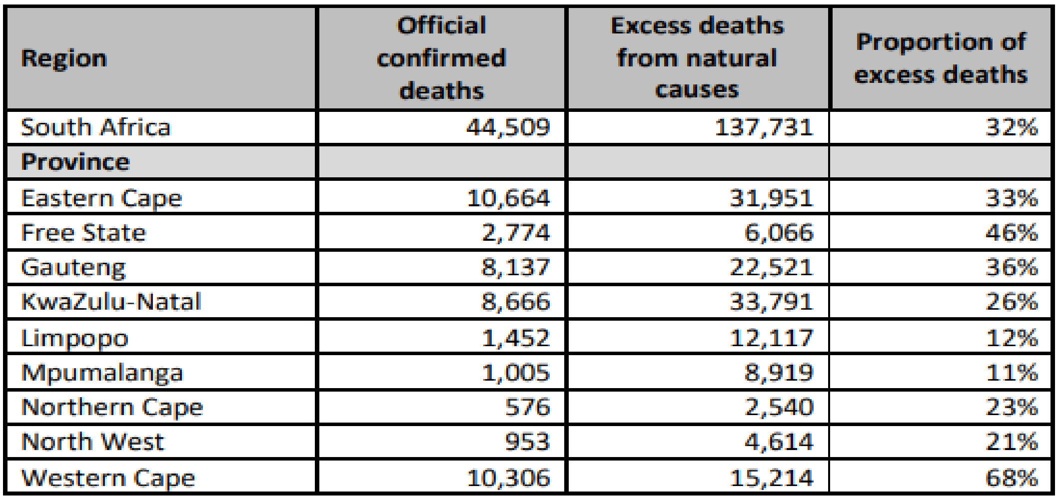
Table 1.5: Rapid agile 'makeshift' responses to rising palliative care needs during the COVID-19 pandemic in the WC

- **Five on-line training courses** were conducted, and five training videos were produced to ensure virtual access to- and rapid scale-up of palliative care training relevant for the COVID-19 pandemic (details in chapter 3).
- **Five new intermediate care facilities** were commissioned to increase the health system capacity to accommodate patients no longer requiring intensive medical care, but not ready to be discharged home, and patients requiring palliative care. An intermediate care facility specifically for palliative care patients, was commissioned at Lentegeur Hospital in the CMD to support the healthcare system and relieve some of the acute hospital bed pressure.
- **16 palliative care beds** were included in the 332 beds commissioned at the Brackengate Hospital of Hope in the CMD.
- Rapid **equipping of acute hospitals** to ensure integration of palliative care services for patients who would die within days of diagnosis.
- A **spiritual carer support database** was developed in each sub-structure (SS) and as part of the COVID-19 call centre, to provide bereavement support. Each SS identified a spiritual care coordinator and referrals were facilitated through an online referral application known as VULA.

The National State of Disaster regulations in SA defined the non-pharmaceutical interventions aimed at slowing the spread of COVID-19.[59] The unintended consequences of the regulations was the increase in unemployment due to the closure of many businesses. This resulted in increases in patients with mental health conditions due to isolation and bereavement without adequate support together with the decompensation of patients with various chronic conditions including mental health due reduced access to healthcare.[42]

The toll of unexpected deaths due to COVID-19 in the WC increased significantly from Wave One in mid-2020 to Wave Two at the end of 2020 into the first two months of 2021[60] and was followed by a prolonged Wave Three in the middle of 2021.[42] The correlation of excess natural deaths report published by the SA Medical Research Council (SAMRC)confirmed that 85-95% of excess deaths in SA over this time were due to COVID-19[60], as depicted in Table 1.6.

Table 1.6: Cumulative officially reported/confirmed COVID-19 deaths and proportion of excess deaths until end 6 Feb 2021, SA[60]



Region	Official confirmed deaths	Excess deaths from natural causes	Proportion of excess deaths
South Africa	44,509	137,731	32%
Province			
Eastern Cape	10,664	31,951	33%
Free State	2,774	6,066	46%
Gauteng	8,137	22,521	36%
KwaZulu-Natal	8,666	33,791	26%
Limpopo	1,452	12,117	12%
Mpumalanga	1,005	8,919	11%
Northern Cape	576	2,540	23%
North West	953	4,614	21%
Western Cape	10,306	15,214	68%

1.7. Location of this study

In the light of an informed perspective of the benefits and nature of PC, the CMD of the WCGHW department decided to roll out the new NPFSPC in 2018.[5] The NPFSPC was not introduced with additional dedicated staff and resources, but as given in the NPFSPC, the policy was introduced into the health system within existing resources and governance responsibilities.[5]

This study was located in the CMD of the WC. The CMD is divided into eight sub-districts: Northern, Tygerberg, Khayelitsha, Eastern, Klipfontein, Mitchells Plain, Southern and Western. The Metro Health Services (MHS) are responsible for the provision of L1 services, and comprise four SS offices that each manage two sub-districts:

- SS 1: Northern Tygerberg (NTSS)
- SS 2: Khayelitsha Eastern (KESS)
- SS 3: Klipfontein Mitchells Plain (KMPSS)
- SS 4: Southern Western (SWSS)

The four SSs belong to two geographic service areas (GSA), Metro East and Metro West. These GSAs, each have access to a central (tertiary level) hospital with specialist services within the referral care pathway. With the establishment of the four SS offices in the MHS, the number and type of health facilities, the dependent population size, and span of the geographic surface area were considered, to best align to the health service drainage areas and the approved management team structure, responsible for primary care services and district hospitals. Furthermore, the MHS has the management responsibility for four psychiatric, two specialized and two regional hospitals. Metro West has proportionately more in-patient beds and a favourable geographic location of specialised hospitals compared to Metro East, as illustrated in Table 1.7. along with the total health facilities in the CMD.

Table 1.7: Summary of hospitals in the Metro East and Metro West service area

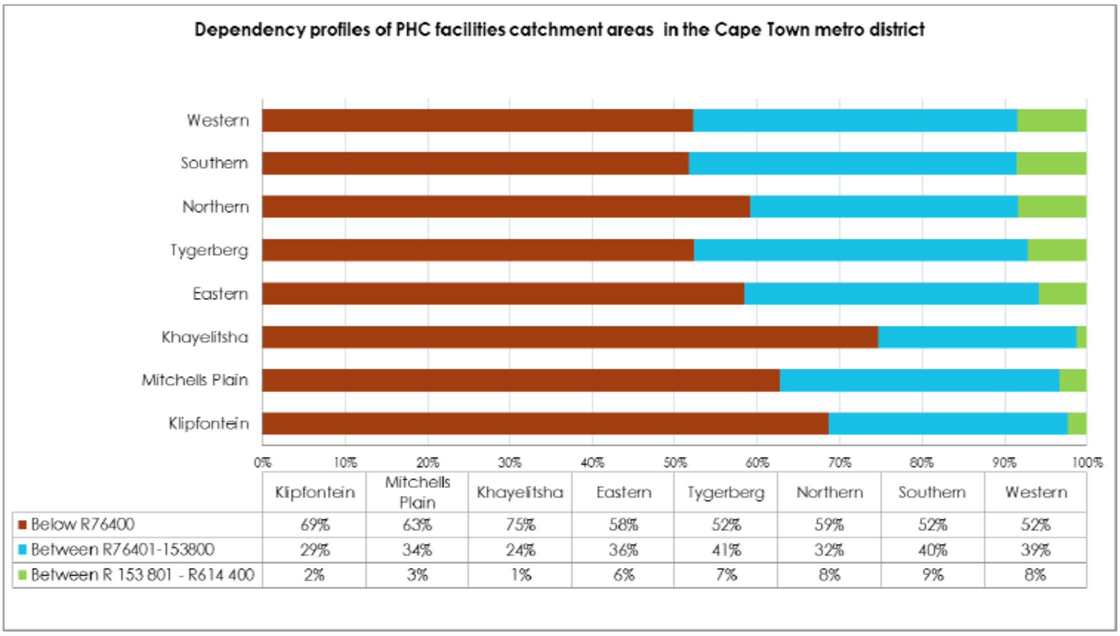
	Total Facilities	**Metro West**	**Metro East**
L3 Hospital	3	2	1
L2 Hospital	2	2	0
L1 Hospital	8	4	4
PHC Facilities	44	21	23
Psychiatric Hosp	4	3	1
TB Hospitals	2	2	0
Other	2	1	1
	65	**35**	**30**

The health services within the CMD are not only delivered by the MHS but also by various stakeholders such as the City Health, Private Providers and NGOs.[4] City Health provides mostly child health services, together with women's health and TB and HIV services through a network of primary care clinics. These services, which are subsidised by the province, are nurse based with medical officer support. The NGOs are funded by the WCGHW to provide HCBC services and post- and sub-acute in-patient services at intermediate care facilities (ICFs). Those with access to private insurance access general practitioner services, specialist, and hospital services through a fee-for-payment system. Once medical insurance cover is exhausted, people return to the public sector for care, which is free at the point of care.

Figure 1.3, overleaf, illustrates the functions of each organisational level within the WC provincial health system and the division of the Metro into four management SSs. The MHS senior management team comprise a chief director responsible for strategic direction and oversight, as well as four Directors (SS Managers) and their sub-structure management teams (SSMT) who hold the responsibility for operational governance and stewardship within the health care system of the Metro District.

Figure 1.3: Graphic representation of the Metro Health Services in alignment to the WCGHW

There are differing degrees of deprivation between the sub-districts, with some sub-districts having larger proportions of the population accessing private health care. Those without medical insurance are dependent on public sector health services. Income and dependency profiles on the public sector for primary health care (PHC) by sub-district are illustrated in Figure 1.4.[61] There are three income bands depicted and the lowest income band ranges from 52% in Western, Southern and Tygerberg sub-districts, to as high as 75% in Khayelitsha. When combining the two lower income bands, the overall dependent population ranges between 91% to 99%.[61]



	Klipfontein	Mitchells Plain	Khayelitsha	Eastern	Tygerberg	Northern	Southern	Western
■ Below R76400	69%	63%	75%	58%	52%	59%	52%	52%
■ Between R76401-153800	29%	34%	24%	36%	41%	32%	40%	39%
■ Between R 153 801 - R614 400	2%	3%	1%	6%	7%	8%	9%	8%

Figure 1.4: Proportion of dependent people per income band per sub-district in the CMD[61]

The PHC platform comprises 8-hour community day centres and clinics which are nurse driven and doctor supported, 24-hour community health facilities with access to a specialist family physician and district hospitals with differing acute bed capacities. These facilities are collectively referred to as PHC facilities. NGOs are contracted by the MHS to support patients in the home environment according to a defined basked of care[62] and deliver medication for chronic conditions to the patient's home.[62]

1.7.1. Leading up to this Study

A point prevalence survey was conducted by Van Niekerk and Raubenheimer among in-patients in eleven public hospitals in the CMD in 2012 to assess the need for PC. The case records of 1443 inpatients, with a mean age of 56 years, were reviewed and 16,6% were found to be eligible for PC. This study confirmed the need for PC services in the health system and that PC services were predominantly offered by the NGO sector. It highlighted that PC models varied significantly at the different health facilities and the absence of emergency PC services.[63]

The office of the MHS Chief Director initiated the first province-wide PC 'think-tank' in March of 2016, in response to the, then, draft NPFSPC. Stakeholders attending came from the following institutions and organisations:

- WCGHW: District Managers, Professional Support Services Managers, Comprehensive Health Programmes managers
- Hospitals: District Hospital (Victoria Hospital) and Tertiary Hospital (Groote Schuur Hospital) representation where some form of PC services were offered.
- HPCA: CEO of the HPCA, hospice representatives and friends of HPCA
- Academia: University of Cape Town's (UCT's) School of Public Health and Family Medicine.

At this high-level strategic meeting, it was recognised that in the WC, PC was not consistently and equitably provided across the health service platform and within all the health care facilities. The Southern-Western SS was the only one of four SSs within the CMD that had progressed regarding PC service delivery at the Victoria District Hospital and Groote Schuur Hospital (GSH). In addition to this, GSH serves as an academic teaching platform for UCT post graduate programmes in PC and had also established an agreement with the HPCA and a long-established hospice, St Luke's Hospice, to further enhance the training platform for PC. In the three remaining SSs within the Metro District, the provision of PC remained heavily dependent on the NGO sector hospices and ICFs.

The decisions taken at this meeting resulted in the following sequence of events:

- A mini review to understand the different models of PC being offered within the WCP.
- The establishment of task team that would drive the process of developing an implementation model for PC in the MHS. The researcher was delegated to lead this team in her capacity as a senior manager.

1.7.2. Findings of the palliative care mini review

The mini review was conducted between November 2016 and February 2017, before the PhD study, based on the elements[iii] contained in Annexure 1. It was developed with the support from NGO and senior Family Medicine physicians. Sites were sampled according to the service delivery model for PC, with a view to gain insight into the varying models of PC provision and how these were aligned to public sector services across the WCP.

The following factors were known and considered when selecting sites for inclusion:

- not all ICFs that were funded by the WCGHW, offered PC services.
- some ICFs were closely linked to a public sector hospital (on the same premises) while others were in close proximity but with no established or obvious link to public sector hospitals.
- some hospices focused more on outreach home-based PC services, while others were more focused on an in-patient model, and some had a dual focus.
- the CMD is mostly urban with shorter travel to access health care and the rural districts are mostly farming and peri-urban with further travel distance to access health care – these contextual differences were considered.
- some public sector facilities offered a model of PC while others offered no PC services at all.

Five hospice (NGO) organisations, one paediatric hospice organisation, three hospitals and one PHC facility (ten in total) were included in the mini review. Notably, each facility offered a different model of PC service provision and the review revealed inequities and opportunities for improving access to PC services. At one district hospital and one tertiary hospital, a small clinical team took responsibility for PC service provision for the entire health facility. Their experience and opinions on PC service delivery in the rest of the health facility and health system, were as follows:

[iii] Elements in Mini Review: functional beds; staffing cadres and their training; geographic location; package of care; relationship and proximity to other health care services; referral processes; challenges and financing.

- There is a lack of knowledge and experience among other health care professionals at their health facilities regarding PC who are unable to effect adequate pain and symptom control.
- Patients and their families are not fully informed regarding their conditions and need for PC. Other health care professionals are reluctant to break bad news to the patients and their families.
- Lack of administrative support to the PC teams, since the role they fulfil for the entire health facility is administratively heavy.
- Late referrals from colleagues within the health facilities to PC teams and lack of after-hour clinical support for the PC teams.
- Inadequate ongoing community support for patients who are referred out since there are no set referral mechanisms in place for PC patients. A gap exists in community-based services policy framework for patients eligible for PC. There is no clarity regarding access to in-patient beds at hospices and ICFs within community settings and the community-based nurses are perceived as being poorly trained and unable to attend to the patients being referred out.
- There is also no one-size-fits-all approach for paediatric PC, and it requires a different approach.

Since various NGO managed ICFs were included in this mini review, their perspectives on PC services offered by the public sector services were noted:

- Inappropriate timing of referrals for PC, such as late referrals only after all possible invasive interventions have been exhausted. Consequently, many patients die before the home assessments have been conducted by the hospice team, and many eligible patients are never referred.
- Poorly documented referrals which provide inadequate information to inform care and management plans for the patients.
- Inappropriate referrals for the management of conditions, such as complicated wounds, which hospices are not adequately equipped to manage.
- Patients arrive from the public sector facilities without the necessary medication or specific wound care products.
- Doctors at public sector health facilities are inaccessible when the hospices need clarity about referred patients.
- Patients often fear hospice care as they are ill-informed regarding what a hospice is, and very little effort is made by the referring clinician to clarify this.

- Delays in accessing stoma, tracheostomy and other specialised consumables for patients persist.
- Patients with no fixed home address are referred from public sector health facilities and this results in patients remaining in ICFs or hospices as social cases and not necessarily in need of PC.

These findings from the mini review helped to set the context for the PCTT, in preparation for to implementing the NPFSPC.

1.7.3. The Palliative Care Task Team

The PCTT was formally established after the findings of the mini review was tabled at the Chief Director's official management forum, namely the District Management Committee. The PCTT is chaired by the researcher in her capacity as a senior manager and the members included are outlined in Table 1.8, overleaf.

Table 1.8: Summary of Palliative Care Task Team Representatives[64]

Representative Categories	Members and their functions
Training and Teaching	• Provincial development centre trainer responsible for contracting training providers; liaison with higher education institutions regarding curriculum; communication with the health system regarding available training. • Academic institution lecturers and researchers in palliative care, family medicine and oncology from University of Cape Town and Stellenbosch University.
Programme Managers	• Comprehensive programme managers representing SSs and districts and responsible for management of priority programmes who provide operational support to clinical implementation teams on various service projects and priorities. • Community based services managers responsible for contract management of NGO sector providing HCBC and ICF services. • Provincial service priorities managers responsible for ensuring implementation support and stationery and tool development for the province.
Clinicians	Responsible for commissioning palliative care services, identifying patients in need of palliative care, supporting the clinical teams at facility level, providing in-house training, and ensuring referrals and continuity of care. These included: • Internal medicine specialists and oncologists at central and tertiary hospital level • Medical and clinical managers of district hospitals • Family physicians based at various PHC facilities, mostly 24-hour community health centres and larger 8-hour community day centres. • Palliative care nurse coordinator at central hospital level • Nurses and nurse managers at district hospitals • Social workers at central hospital level • Palliative care clinicians in the NGO sector
Finance Managers	A finance manager based at a SS wrote business cases for funding to the national treasury via the provincial treasury
Communications	The provincial communications director and a communications officer responsible for mass media and public awareness of and sensitisation to palliative care.
Registrars (internationally also known as Residents)	Public health medicine registrar on rotation support to the task team to support on various public health related aspects.

The first PCTT meeting convened in June 2017 and met on several occasions to define and design the elements of this project – the introduction and integration of the NPFSPC into the public sector health services.[64] These included defining:

- the institutional arrangements between the different levels of care including the alignment between the public sector services and NGOs.
- the care pathway for a PC patient within the public sector health facilities and the NGOs.
- the document that detailed the proposed model for the implementation of PC was developed.[65] Aligned with the NPFSPC, this document guides integration of PC in and has been tabled and accepted at the provincial management structures,[iv] chaired by the then Chief of Operations for the WCGHW, Dr Keith Cloete.

Table 1.9, overleaf, outlines the PCTT sub-task teams and the function and progress of each. There was no PC medicines sub-task team because the member of the WC PCTT was a national PC medicines task team member.

[iv] District Heath Services Executive Committee (DHS EXCO) and Operational Executive Committee (OPEXCO)

Table 1.9: Functions and Progress of the PCTT Sub-Task Teams[64]

Sub-Task Team	Function and Progress
Top management engagements in WCGHW	Tabled proposed model for the implementation of PC as well as plan of action to roll this out within the WC, with the provincial decision-making bodies for the district health services (DHS EXCO), operations that include all hospitals (OPEXCO) and the top management that included corporate governance and the head of department (TEXCO). To report on progress to the OPEXCO on a quarterly basis.
Communication strategy	To debunk the myths that exist amongst personnel and the greater public regarding PC. A video regarding PC has been produced and a communications strategy has been developed.
Stationery development	To standardise all stationery used for recording PC patient encounters at all levels of care. To ensure that this is part of the integrated clinical stationery process for the WCGHW in order to enable adequate record keeping. Adult and Paediatric assessment stationery has been developed as well as referral stationery for PC. Morphine booklets in the three official languages of the WC have been developed as information and education tools for patients and caregivers.
Proposed model for implementing palliative care	The proposed model of PC service delivery, aligned to existing WCG health service delivery model and the NPFSPC, has been developed. This model will be refined over time as lessons are learned.
Information management and monitoring and evaluation	To determine which indicators and data collection tools are appropriate and will link into the WCGHW information management systems to define the PC cascade indicators.
Family and carer support	To develop a support programme and define training needs.
Roadshow programme & content	To sensitise all comprehensive health programmes and clinical staff to PC and identify champion drivers that can form teams to drive PC going forward. To ensure that all information, education, and communication (IEC) materials are developed to facilitate this.
Research coordination	To coordinate all PC related research, a PC consortium comprising of service and academic units will be established and create research sharing platform.
Training and higher education engagements	To identify and negotiate the training programmes and models of training as well as develop a training plan for existing clinical staff and community level carers. To facilitate the supply chain management processes for the contracting of a service provider to develop and offer the Introduction to PC training course, both online and in-person. The inclusion of PC content into other existing clinical and related courses.
Twinning of learning sites	To develop a guide that would define the parameters for the twinning of PC-experienced facilities with PC-naïve facilities, to facilitate skills transfer.
Funding and business case development	A business plan for the funding of the PC policy has been developed and submitted to the National Treasury through the chief financial officer of the WCGHW.
Paediatric palliative care	Define detail on paediatric PC and support to health facilities
Emergency medical services	To define the detail for roles of emergency medical services personnel within PC. A document defining this has been developed.

At the WCP launch for the NPFSPC that took place on the 29 October 2018, during world PC month, people responsible for driving the integration of PC were identified by senior and middle managers. These drivers or champions took up the role of defining, coordinating, and supporting the policy roll-out in geographical areas or health facilities. These drivers would also be responsible for determining appropriate implementing teams at each level of care as well as their training needs. Guidance to all of this is contained in the proposed model for the Implementation of PC[65] document.

1.8. Study context and purpose

These initiatives and events form the background to this study, since both globally and locally, the importance of integrating PC into the health system has been recognised.

In the context of being the lead on the PC initiative, the researcher wanted to find out what factors assisted or impeded the integration of PC services into primary care services and hospitals. While the initiative included rural districts and hospitals, as well as tertiary and secondary hospitals, the researcher was based in the CMD, so the location for this study was the CMD with specific focus on two sub-districts, one in Metro East and one in Metro West. The following table reflects a summary of the status of PC service provision in the Metro District.

Table 1.10: Metro District divide synopsis and rationale for sub-district selections

Metro East		Metro West	
Northern and Tygerberg sub-districts	Researcher's area of responsibility as a Senior Manager.	**Southern and Western sub-districts**	Significant progress already made in PC within the public health sector.
Khayelitsha and Eastern sub-districts	Only NGO sector PC service provision.	**Klipfontein and Mitchells Plain sub-district**	Mostly NGO sector PC and at Gugulethu CHC.

Having considered the afore-mentioned information, the following influenced the selection for the two sub-districts:

- NTSS was eliminated since it was the researchers place of employment and area of responsibility.
- SWSS was not considered since it had made significant progress in PC provision beyond the other three SSs.
- The remainder SSs, KESS (Metro East) and the KMPSS (Metro West) were at a similar level regarding PC services. Furthermore, the burden of disease in as it relates to HIV/AIDS/TB, intentional injuries, non-communicable diseases and cancers are similar in these SSs.[6]
- The two SSs were further investigated regarding access to PC services, and it was concluded following discussion at the PCTT and with doctoral supervisors, that Eastern sub-district in the KESS and Mitchells Plain sub-district in the KMPSS, were similar at baseline.

The purpose of the study was to identify the factors (enablers and obstacles) that influence integration of PC into an already over-burdened district health system characterised by high patient loads and the quadruple burden of disease. This could provide insight into and contribute to discussions about integration that can enable policy makers to identify factors that make for robust options for policy development and implementation that may be generalizable to the broader context.

Chapter 1 has provided a background description of PC and painted the picture on global, African, South African, and local context, and furthermore provided the sequence of events leading up to this study. Chapter 2 presents the literature review to this study.

Chapter 2 : Literature Review

Chapter 1 outlined the focus of palliative care (PC) services and described the global, African, South African (SA), and local picture for the provision of PC services, with specific focus on the Cape Metro District (CMD). Furthermore, it described the purpose and context for this study.

Chapter 2 reviews additional literature relevant to the overall study and focuses on pertinent systems that are required for the inclusion of a new package of care into health systems. The key components are i) health systems, ii) systems thinking and PC, iii) complexity and complex adaptive systems, iv) compassionate health systems, v) health policy, vi) policy integration, vii) the integration of PC as a new service into existing services, viii) the impact of COVID-19 pandemic on PC globally, and ix) the conceptual frameworks for integration and the selected framework that was used to assess integration in this thesis.

Further literature relevant to the various sub-studies are reported in Chapters 4, 5, 6, 7 and 8, and although there will be more reflection on key literature such as compassionate care and policy integration, it is relevant to the findings in each chapter.

2.1. Introduction

PC is not only a clinical service rendered by certain health care providers with specific skills for patients nearing end of life. They are dependent on clear policy and buy-in from the entire health care work force that functions within a functional compassionate health system. Referral pathways are required to ensure continuity of care. Indicators are needed to monitor quality of care and progress towards integration at all levels within the health system.

The principles of health care systems are to ensure the right management of the right patient at the right level of care, according to the Comprehensive Service Plan (2007) of the Western Cape Government Health and Wellness (WCGHW).[50] It is therefore important to have systems for referral that can accommodate the patients' diverse need.

Introducing a new service into a functional health system that is over-burdened is not easy, and the scale or complexity of the new service or intervention should meticulously be considered according to the World Health Organisation (WHO) (2007) building blocks of the health system.[66] PC forms part of the management of a range of life-threatening conditions, and the life-limiting stages in the natural course of a diverse set of chronic disease conditions. It is therefore important to understand enablers and barriers to its integration into the health system and determine the degree of integration of PC as a new service, to address a service gap.

2.2. Literature Search

Literature searches were conducted throughout the timeline of the study – proposal writing, data collection, analysis and report writing – between August 2017 and June 2023. Various online databases – CINAHL via EBSCOHOST, Medline via PubMed, and Google Scholar – were accessed. Keywords were used to guide the literature searches which identified relevant articles. The references from these articles were reviewed leading to further searches using Google Scholar. Furthermore, relevant articles that were sent by supervisors, colleagues, and PC network partners, were added to the bibliography. Table 2.1 below provides the keywords for the literature search for each chapter.

Table 2.1: Keywords used for literature search for each chapter

Chapter 1	Palliative Care Global, SA, Integration, Health Policy
Chapter 2	Policy Integration; Health Systems; Systems thinking; Palliative Care; COVID-19 pandemic; Compassionate Care; Compassionate Health Systems; Integration Lessons
Chapter 3	Palliative care needs; End-of-life needs; Palliative care myths; Conceptual framework analysing integration
Chapter 4	Governance; Stewardship; Leadership; Health Systems; Palliative Care; Cost effectiveness; Planning; Integration; Referral care pathways; Barriers AND Enablers to Palliative Care integration
Chapter 5	Adoption System; Power relationships; Leading change; Policy Consultation; Compassionate Health Systems; Continuity of Palliative Care; Geographic access to Hospice; Palliative Care patient feedback; Holistic care; Palliative Peer Support; Value Family Room End-of-life in-patient
Chapter 6	Role operational managers; Street level bureaucrats; Policy making; Multidisciplinary teams; Interprofessional Support; Partnerships, Stakeholders; Palliative Care; Home-Based Palliative Care; End-of-life Care; Time, Capacity for Palliative Care; Leadership; Palliative Care integration; Patient centred care
Chapter 7	Patient AND Family caregiver expectations; Spiritual Care; Palliative care teams; Family Caregivers; COVID-19 impact on Palliative Care; Pain control; Burden Family Caregivers; Experience of Health Care System
Chapter 8	COVID-19 AND Compassion; Policymaking for Palliative Care; Educating Communities AND Palliative Care; Leading Health Systems AND Systems for Health;

2.3. Health systems

When introducing a new service into an existing basket of health services, it is important to understand the components of health systems and its functioning. In the WHO (2013) reader on health policy and systems research (HPSR), health systems are defined by the elements and characteristics that they are comprised of or what they seek to achieve. Furthermore, the general goal of health systems is to improve the health status of the population, through equitable distribution of health services without financial burden to the user, responsiveness to population needs, and respect for the dignity of persons. The WHO (2013) also articulates that health systems are critical contributors to addressing social determinants of health and related health inequities, through service provision and influence over societal relations.[67]

The WHO (2013) further identified the elements which health systems comprise. This includes:

- the population that the heath system serves,
- six key functions or building blocks: outlined by the WHO (2007), as illustrated in Figure 2.1, as service delivery, health workforce, information, medical products, financing, and leadership and governance,
- the service delivery functions which includes the service packages rendered.[67]

Furthermore, the WHO building blocks alone do not constitute a system but includes the multiple interactions and relationships between these building blocks and how they affect each other, that converts the building blocks into a system. These relationships are shaped by both the health system hardware (organisational, policy, legal and financing frameworks, clinical and service delivery requirements) and software (values, traditional, organisational culture, norms, roles and procedures), which in turn influence levels of system performance.[67] Whyle and Olivier (2020) make the case that "*health systems are conceptualized as social systems, embedded in social contexts and shaped by human agency*".[68]

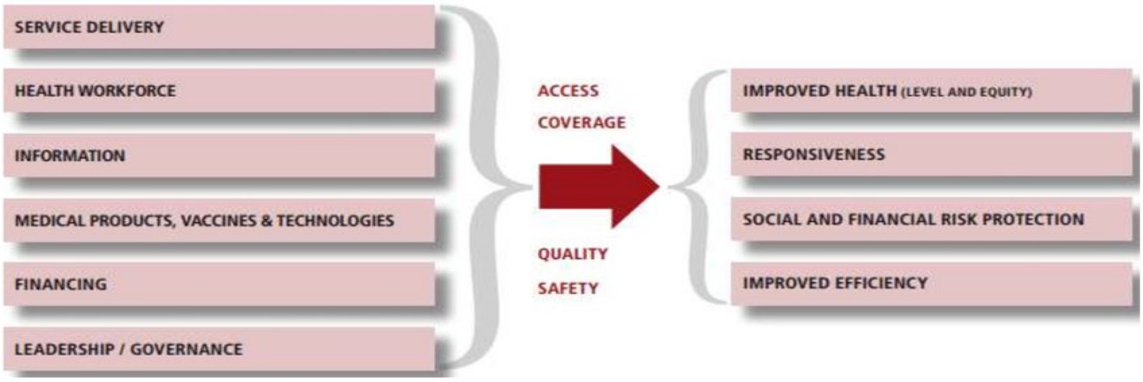


Figure 2.1: The WHO health system building blocks framework. Source: WHO 2007[66]

The WHO (2013) HPSR reader indicates that in a government-based bureaucratic system governed by laws and regulations, useful notions in analyses focusing on the multi-level operational architecture include the macro, meso and micro levels within health systems.[67] They provide a framework that clarifies the function and responsibility of each level of the health system, and in SA are aligned to the National Health Act No.61 of 2003.[39] The macro level refers to the national or provincial level, the meso level is the district health system and the micro refers to the health establishments or individual health care workers (HCW). Their functions are:[67]

Macro: setting the strategic direction; balancing and developing policies and regulations; overall corporate governance and allocating resources; designing and defining health worker performance reward systems; engaging with health system actors and the general public/citizens; interacting with national and international agencies; coordination across service delivery activities.

Meso: managing the health services, activities, and health care providers; coordination of local actors; supervision and training of service and health care providers; adaptation of national and/or provincial policy to local circumstances; responding to local health service needs.

Micro: providing health care in compliance with broader health behaviours; developing innovative provider-patient interactions; managerial decision-making and leadership. Individuals in the health system includes the healthcare providers, health promoters, users of the health system, managers, and their interactions.[67]

Schroff et al. (2022) in a WHO position paper, argue that health systems should be reimagined as 'systems for health' that secure health and create healthy populations, while supporting the achievement of universal health coverage (UHC).[69] This is due to the expansion of the boundaries of health systems to include preparedness for known and unknown risks and threats. This means going beyond the building blocks to include addressing social, environmental, economic, and commercial drivers and determinants for health, and being intentional about intersectoral collaboration to address matters beyond the health sector, such as climate crisis.[69]

Understanding that health systems are complex adaptive systems,[68] de Savigny and Adam (2009), in a WHO publication, considered thinking about health systems beyond just the health systems building blocks. Health systems are constantly changing, not linear, and function as a network of connected systems. De Savigny and Adam presented the "*ten steps to systems thinking*" to guide "*systems thinking and applying a systems perspective to design and evaluate health systems interventions*".[70] This has given rise to a growing body of literature that investigates various theories, models, frames and tools for systems thinking.[71] Peters (2014) explored these in health systems, and concludes that the use of models in systems thinking provides opportunities to "*test and revise our understanding of the nature of things*", that strengthens the health system to improve population health.[72] Thus the literature on systems thinking presents an important approach to health systems strengthening. It considers events and the patterns, trends, social paradigms, views and influences, that give effect to those events. [72]

2.4. Systems thinking and palliative care policy

When introducing PC into the public health system, it is important to consider the degree of complexity of these services. Recognising that PC requires consideration of the building blocks of health systems, 13 studies of ten countries, were reviewed by Abu-Odah et al. (2022) to investigate the implementation of PC services within country health systems that explicitly included PC in their national strategies and policies.[73] They found that despite different strategies for implementing PC, poor access to PC remained. They identified that challenges impeding PC implementation included knowledge and training deficits of HCWs about PC, misunderstanding of PC amongst the general public, inadequate infrastructure, and lack of comprehensive PC national plans.[73]

Rhee et al. (2017)[74] conducted a scoping review on peer reviewed articles on the national development of PC from 2005–2016 for each African country, using the WHO public health model for PC. The focus of the review was on education, national policy, drug availability and implementation of services. However, information on only 26 of the 54 African countries were found and included. Although this scoping review is not as rigorous and exhaustive as a systematic review, PC services were mostly concentrated in Kenya, SA, and Uganda, while 14 countries showed some increase in the provision of PC services during the scoping review period. The post-graduate diploma in PC is only offered in these three countries and Tanzania. They concluded that in most African countries, there remains little to no growth in PC services, education and research, and improved health policy that includes PC.[74] Furthermore, opioid access, low morphine use and prescriber restriction laws remain challenges,[74] and the Lancet (2017) article on access to opioids – recognising the balance of harms – confirmed that 80% of people in need of analgesia still do not have access.[75]

According to a critical review conducted in UK and USA by Seymour and Cassel (2017), providing optimal and equitable models of PC remains a global challenge. For patients with serious illness, early access to care through to end-of-life, is the intent of NPFSPC.[76] They used the WHO public health model to measure PC development, and found that some patients could access excellent end-of-life care, while significant deficiencies in care remain for the majority. The authors argued that achieving a public health approach in PC will require international consensus about what PC means and who the target population is. Furthermore, prognosis-based eligibility to PC will need to be replaced with a needs-based approach, so that the timing of death is regarded as less important than the need for care to address conditions that are causing distress for the patient. A case is made for closing the generalist-specialist divide based on evidence for cost-effective partnerships and the provision of care at the most appropriate level.[76] Luckett et al. (2014) conducted a rapid review on electronic databases and grey literature to investigate evidence-based models of PC to inform Australian policy reform. This included nine randomised control trials, 23 systematic reviews, and 34 non-randomised comparative studies, which support the closing of the generalist-specialist divide and argue that models for PC should integrate specialist expertise into primary and community-based services, including old age care homes, based on increasing complexity of disease and related care needs.[77]

It is important to consider lessons learned from countries that have included PC in their national policies and strategies. In a review conducted on approaches to PC implementation into health systems by Abu-Odah et al. (2022), a modification to the WHO public health PC approach is proposed. They suggested key priority areas that are linked to successful service implementation of PC into the health system. These include enhancing public awareness about PC to understand of the end-of-life processes; healthcare providers knowledge and training in PC to build capacity for PC service provision; and identifying and securing financial budgets for expansion of PC service provision.[73]

2.5. Complexity and complex adaptive systems

Health system complexity is referred to by McDaniel et al. (2009) as complex adaptive systems that are unpredictable and dynamic. The authors warn that health care systems/organisations cannot be treated mechanistically.[78] de Savigny and Adam (2009), in a WHO publication, confirm this, and add that health systems are not linear, constantly changing, and function as a network of connected systems.[71] Gilson et al. (2012), in a study conducted in the CMD focusing on the complexities and possibilities of sub-district management, highlighted the mindfulness that middle managers need to navigate the relational and organisation complexities daily. Failure to consider these could render efforts for improvement, futile.[79]

2.6. Compassionate Health System

PC requires a display of compassionate care that is empathetic, preserves patient dignity, is non-judgemental, and "*an empowering concept of quality of healthcare*", according to Mohammed and Edae (2021). The challenge is how to instil compassionate care into the health system. The authors conducted a hospital-based study in three public hospitals in Ethiopia with 423 patients on compassionate health care and reported that overall disrespect and abuse was common at 71% of these patients. They reported that the firm commitment from the Ministry of Health advocating for a compassionate caring health workforce had followed and resulted in the development of implementation tools for measurement and training.[80]

Tehranineshat et al. (2019) conducted a systematic review of 46 studies investigating factors that influence compassionate care in health systems and interventions designed to promote it. Fourteen of the studies consider compassion to be the first ethical principle when providing high quality care. Compassionate care requires attention, understanding and empathy towards the pain and suffering of another individual. This leads to resilient healthcare professionals, as well as hope for the patients and a sense of control over their own health.[81] As detailed in Table 2.2 below, a summary of the findings from this systematic review indicate that, in addition to being ethical, compassionate care is a multi-dimensional concept that involves professionalism, communication, responsiveness, spiritual and being patient centred.

Table 2.2: Summary of findings from a systematic review on the dimensions that make for a compassionate care[81]

i. "*Ethical dimension*": Respecting and protecting the patient's dignity through ensuring respect and time for patient and family caregivers to make informed decisions regarding their care options.

ii. "*Professionalism dimension*": This refers to good professional communication that includes a conscious awareness of the patients' needs and the expression of acts of kindness.

iii. "*Efficient communication dimension comprises both clinical and informational communication*": With clinical communication, the verbal and non-verbal communication plays a major role in compassion, and these include gestures such as placing a chair for the patient or family to sit. Informational communication refers to the clarification of medical information so that the patient and family caregiver understand and are responded to in the manner that makes them feel heard or listened to.

iv. "*Human-related dimension*": Humanistic behaviour refers to the evident, urgent and appropriate behaviour that confirms sensitivity to unique patient needs.

v. "*Religious spiritual dimension*": Compassion forms the basis of many religious beliefs and various studies confirm that spiritual beliefs are a foundational motivation for compassion.

vi. "*Involving patient dimension*": the health professional is involved in the patient's care process and both the patient and health professional share the care decision-making.[81]

A global scoping review that included 20 studies, was conducted by Nigusie et al. (2022). The authors reported that the status of compassionate respectful care was concerning, and that patients were often treated as a disease, and suffered abuse and disrespect. This was particularly high in maternity patients across most of the studies. The high staff turnover made efforts to drive compassionate care, futile, and therefore efforts should be made to educate new staff on compassionate, respectful care, before employing them.[82]

2.7. Health policy

To instil a compassionate health system into a large complex system requires policy making. According to the WHO (2013), health policies are formal written documents that provide guidelines, standards or rules that presents the views or decisions of policy makers regarding the actions that are legitimately intended to improve health and strengthen the health system.[67]

May et al. (2009), in a study in Denmark investigating the influence of politicians, managers and SLBs on policy implementation, found that policy implementation is not as straightforward as the written policy intent because they are translated into action by decisions made by these role-players.[83] The resultant practices, which may vary from the formal policy document intent, then becomes the lived reality of the policy. Therefore, according to the WHO (2013), health policy should be regarded as both the formal documents and the translated practices and reality.[67] According to Ansari et al. (2018), when conducting a PC policy analysis in Iran, Nilsen et al. (2015) in an implementation science study on making sense of theories, models and frameworks, and other authors, the implementation frameworks and proposed operational models for implementation that align policy to practice are required to reduce misinterpretation of policy.[65, 84, 85]

According to the WHO (2023) health policy actors assume varying roles, such as those who develop formal policy, those who influence how policy is translated (middle managers, health workers, patients and citizens) and those actors who seek to influence formal policy (civil society and interest groups).[67] The health policy triangle (Figure 2.2 overleaf), developed by Walt et al., depicts a simplified representation of a complex set of interrelationships that holds the actors in the centre.[86] These actors are influenced by the context within which they live and work (influenced by politics, history, culture), the policy processes that gets the policy onto the agenda (influenced by power structures and their own values), and the content of the policy (possibly all of the aforementioned).[87]

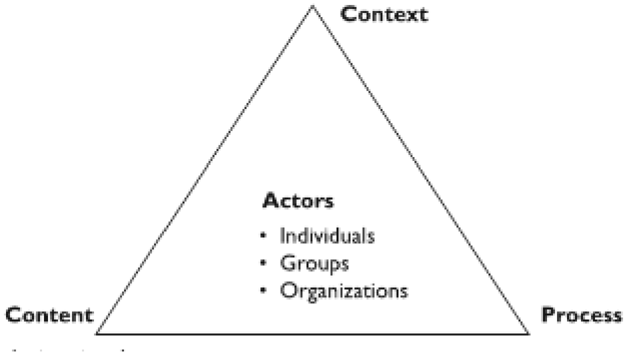


Figure 2.2: Health Policy Triangle[87]

2.8. Policy Integration

Briassoulis (2004), in an article on policy integration for complex policy problems, described that to integrate can mean to "*blend into a functioning or unified whole*" or "*to unite with something else*" or "*to incorporate into a larger unit*".[88] Furthermore, she asserted that policy is not a single stand-alone element, but rather a "*series of decisions*",[88] that do not stop at what is proposed or intended in a document but extends to what is ultimately actioned. Consequently, what is actioned is dependent on the characteristics of the problem, the interests and goals of involved actors, and the structures and instruments available to reach the set goals.[88]

As Walt and Gilson (1994) argued, health policymaking and implementation commonly focus on the content. If the actors involved in policy reform, the processes necessary to develop and implement change, and the context where the policy is implemented, are all neglected, policymaking will fail to bring about its intended outcomes. They maintained that this "*explains why the desired policy outcomes fail to emerge*". This argument resulted in the model for health policy analysis, developed by Walt and Gilson in 1994, (Figure 2.2 above) and makes a case for due consideration for the policy content, the dynamic context, processes and all actors involved.[87]

Briassoulis (2004) argued that actors are central to policy formation and implementation and play a crucial role from the time of identifying the problem that requires an intervention (policy), the consultation and development of the policy, and the implementation and related measures for implementation.[88]

While actors are central, other factors are also important. De Jongh et al.'s systematic review consisting of 46 studies, investigating the barriers and enablers of successful integration of various programmes into women's health services, found that the rationale for integration included improved access for health service users. This would reduce loss to follow-up, increase user uptake and utilisation of essential services, and reduce service cost through a "*more synergistic use of human and financial resources*".[89]

The WHO publication (2021) on assessing the development of PC worldwide: a set of actionable indicators, describes health policy (PC policy) as a foundational element for the integration of PC into the health system.[2]

2.9. Integration of palliative care at health facility level

de Jongh et al. (2016) define integration of service provision at the health facility level to "*include co-location of services, using a single point of access; collaboration between different service providers involved in a woman's care (e.g. in integrated care teams) or a well-organised referral system, with follow up and feedback among different service providers*".[89] In practice, this can mean that while services are co-located in the facility, they may be delivered by a single provider in a single consultation, or by two HCWs working in parallel, referring to each other. Service integration can thus be an imprecise term, which makes it important to understand the evidence for integration of PC at the health facility level.

In SA's recent past, there have been experiences of integrating new service components into the existing service platform. In the Western Cape (WC), the HIV antiretroviral treatment (ART) programme was largely funded through earmarked funds – national conditional grants or donor funding. Stein et al. (2008) in a qualitative study conducted in 15 clinics in the Free State province, asserted that these services were offered as stand-alone vertical programmes with the appointment and specific training of dedicated staff to render these services.[90] This may have been appropriate at the time, due to national government AIDS denialism (Nattrass, 2007),[91] and the need to prove that ART indeed reduced mortality. It occurred at a time where actors did not all agree with emerging policy, driven by civil society and clinician advocates. However, while ART services were funded and resourced, at the same time other services were under resourced. Consequently, a strong case was made for the integration of vertical programmes within the public sector to benefit and add value to the already overburdened and fragile health service that was in urgent need of additional resources.[90]

Morgan (2014) conducted a study at a PHC facility in the CMD to evaluate the PC patients' reported outcomes before and after a PC intervention was integrated into the comprehensive package of care. Poor integration of PC services in the public sector made the case for this study. The study found that HCWs and patients welcomed this comprehensive package of care that included the identification of patients in need of PC, providing them with care that included spiritual care and a monthly support group for patients and family caregivers. Morgan makes the case that integration of PC is possible, and although the evaluation after a six-month period was shown to be acceptable to both patients and HCWs, more studies are required to determine impact and find simple processes for integration of PC at PHC facility level.[14]

2.10. Impact of the COVID-19 pandemic on palliative care

The importance of PC has been highlighted in the international literature about the impact of COVID-19 on societies globally and was referred to in Chapter 1. Radbruch et al. (2020) in a Lancet editorial, indicated that the tsunami of suffering and death brought on by the COVID-19 pandemic has focused attention on the key role of PC and its management. They added that there have been calls for the immediate extended provision of PC during and after the pandemic.[92]

Rodin et al. (2020) highlighted that the COVID-19 pandemic exposed the global lack of integration between public health approaches, such as oncology (cancer care) with palliative and end-of-life care, as well as the inequities in access to PC. Many individuals in impoverished or population-dense settings with weak health systems were less likely to access essential end-of-life care.[55]

The Lancet editorial (2020) on PC and the COVID-19 pandemic, summarised existing inequities regarding access to inexpensive treatment, and maintained that "*a pandemic is a cause and powerful amplifier of suffering, through physical illness and death, through stresses and anxieties, and through financial and social instability*" and the "*alleviation of that suffering, in all its forms, needs to be a key part of the response*". The editorial reminds readers that PC has historically been under-resourced. The added burden placed on global health systems due to the COVID-19 pandemic made the provision of effective PC even more vital and yet more difficult. Some doctors had to decide who had access to critical care and who did not, and for the patients who were unlikely to survive, they had to ensure rapid access to high quality PC interventions.[93]

The Republic of South Africa issued the national state of disaster regulations in 2020, which limited visitor access to patients who were hospitalised. Given that these patients deteriorated rapidly, they often died alone.[59] The Lancet (2020) reported that during the pandemic, in community settings, PC provision was restricted or even stopped due to the increased risk of exposure from the community health workers to the already compromised PC patient.[93] Mitchinson et al. (2021) conducted a rapid review of HCW experience delivering care during the pandemic in the United Kingdom, and reported that the pandemic limited the provision of usual PC due to restrictions that prevented families from being with patients during end-of-life. This missing human connection was experienced by health care providers as a significant barrier to providing PC.[94] Highlighting the lack of PC, the Lancet editorial (2020) further noted that the WHO neglected to include PC in its issued guidelines on the maintenance of essential health services during the pandemic, which included immunisation programmes, maternal care, emergency care, and chronic disease management.[93]

Fadul et al. (2021) conducted a review on the integration of PC into COVID-19 pandemic planning and found that during the pandemic health care providers required standard operating procedures to manage the overwhelming surge of critically ill patients. This placed them in the unusual position of rationing of health care based on the availability of critical resources such as ventilators and ICU beds, withholding and withdrawing non-beneficial treatment, and having end-of-life discussions. Multiple PC guidelines, algorithms, and training videos and tools were provided, but in a reactive manner.[95] PC in SA should have been integrated into COVID-19 pandemic planning, as early reports from Wuhan and Washington,[95] indicated the likelihood of high mortality due to SARS-CoV-2. As Fadul et al. (2021) argued, the pandemic burden surpassed global health systems' capacity to provide intensive care to all patients in need, making integration of PC into COVID-19 pandemic planning essential. This includes the provision of treatment algorithms to guide decision-making on the rationing of care, rapid training on effective symptom control, PC interventions and principles, as well as other forms of providing care such as telemedicine (Allen-Watts et al., 2021), death and bereavement support to surviving family members (Mayers et al., 2022).[95,42, 96]

Efforts to reduce the pandemic's load on the health care system were required and Borasio et al. (2020) in an article on COVID-19 decision-making and PC, suggested that clarifying key conditions to healthcare providers, would reduce the decision-making and PC burden. They proposed 1) that all PC patients who were already in care with PC teams should be excluded from intensive care for COVID-19 infection, 2) the documentation of the care preferences of all patients with decision-making capacity, 3) palliative decisions should include a PC specialist as part of patient triage, and 4) that all dying patients should have access to PC. Furthermore, they highlighted that psychosocial and spiritual support is crucial for patients, their family, and healthcare providers.[97]

In summary, COVID-19 has highlighted the importance of investing in emergency and disaster preparedness and response.[69] Borasio et al. (2020),[97] Rodin et al. (2020)[55] and Fadul, Elsayem and Bruera (2020)[95] argue for the integration of PC in pandemic planning so that health systems are better prepared to provide the full continuum of health services to all who require it in an equitable manner during a pandemic.

2.11. Conceptual Frameworks for Integration

As part of the literature review, various theories, models and frameworks relating to implementation science, integration theory and conceptual frameworks relating to health systems relevant to this study, were reviewed. These frameworks provided constructs and elements that were considered for conceptualising this study and analysing findings.

Bauer et al. define implementation science as "*the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and hence, to improve the quality and effectiveness of health services*".[98] While various existing implementation theories overlap in constructs, all intend promoting effective implementation.[99] This resulted in Damschroder et al. developing a Consolidated Framework for Implementation Research (CFIR) which "*provides a pragmatic structure for approaching complex, interacting, multi-level, and transient states of constructs in the real world by embracing, consolidating and unifying key constructs from published implementation theories*".[99]

The CFIR comprises five domains which affect the implementation of an intervention, namely: intervention characteristics (implementation climate, relevant stakeholder perceptions); inner setting (leadership engagement, readiness for implementation); outer setting (external context or environment, external policy); characteristics of individuals (knowledge and beliefs about the intervention, by individuals with influence); and implementation processes (strategies and tactic, engaging the right people, reflecting, and evaluating). These allow for a degree of flexibility in application since they are not prescriptive. According to Keith et al.,[100] the CFIR can thus be used to guide formative evaluations and systematic assessments of multilevel implementation contexts, by identifying factors that could influence intervention implementation and effectiveness. Since this study is investigating integration, certain constructs within the CFIR were considered in a complementary manner, for example the readiness (of the health system) for implementation and the characteristics of individuals.

Greenhalgh et al.'s[101] systematic review discusses a set of processes for the successful implementation of innovations in health systems. Drawing on reviewed articles, it emphasises areas to consider in implementation, and these are included in the conceptual model/framework which makes provision for the determinants of diffusion (passive spread), dissemination (planned efforts to persuade a target group to adopt an intervention), implementation (planned efforts to mainstream an intervention in an organisation) and sustainability (making an intervention routine) of innovations in health service delivery.[101] This extensive systematic review provides a wide and rich conceptual model that takes into account the elements and constructs in each of the articles that were reviewed. They argue [101] that the conceptual model should be seen as "*illuminating the problem and raising areas to consider, rather than providing definitive answers*".[101]

Mayhew et al. (2017)[102] argue that while most evaluations of services and health systems integration focus on structural factors - such as resources, trained staff, physical infrastructure and service statistics - these will not necessarily lead to integrated service delivery. These structural factors, even when adequately in place, can be overridden by interactions and relationships between the staff themselves. Furthermore, implementing change in the health system is strongly influenced by the approach of managers at all levels, as well as amongst their team members. Depending on how these interactions play out, the factors that can enable or hinder integration include the following: frequency of supervisory support, occupational stress, manager consultation before decision-making and team support.[102]

Conceptual frameworks for diffusion of innovation (Rogers et al., 2007)[103] and for health programmes integration into health systems (Coker et al., 2010)[104] were also considered for this study. Rogers[103] provides a model of five-stages in the innovation decision process which focuses on the variables that determine the rate of adoption of innovation: 1) knowledge of context and history, 2) persuasion based on perceived characteristics of the innovation 3) decision to adopt or reject 4) implementation and 5) confirmation.[103]

Coker et al.[104] also provide conceptual frameworks for health programmes integration into the health system with a specific focus on HIV and TB, based on the theoretical frameworks on integration by Atun et al. These frameworks include a stronger focus on the epidemiological problem and the measurement of output and outcome.

Each of these frameworks were carefully considered, by unpacking each of the elements to determine its relevance against the research questions. It was found that some elements between the frameworks overlapped, and that some refer back to the framework for analysing integration of new interventions into health systems by Atun et al.[8] Since the National Policy Framework and Strategy for Palliative Care (NPFSPC) calls for the integration of PC into the public sector health services, and following due consideration of each conceptual and theoretical frameworks, the framework by Atun et al.[8] was identified as being most appropriate for this research and this will be clarified in the following section. Atun et al.'s framework focuses on the problem at hand, each of the key health system elements that should be considered when integrating any new health intervention, and the adoption system with its key role-players and stakeholders. Annexure 11 provides a comparison of the elements for each conceptual framework that was considered.

The framework for analysing integration of targeted health interventions into health systems

An analytical framework was developed by Atun et al.[8] in 2010, based on studies that reviewed health systems' adoption of innovations and interventions. This framework, illustrated in Figure 2.3, overleaf, for analysing integration of targeted interventions into health systems, considers all the elements that critically affect the adoption, diffusion, and assimilation of a health intervention. This enables a structured approach to exploring the nature and extent to which an innovation or intervention is integrated into a particular setting, as well as the different factors that influences the integration process, which ultimately provides reasons for variation.[8]

Atun et al.[8] argue that there was no one commonly accepted definition for integration since this "*term is loosely used to describe a variety of organisational arrangements for a range of programmes in different settings*". The literature on integration of Women's and HIV services (Loveday and Zweigenthal, 2011) concurs with this statement.[105]

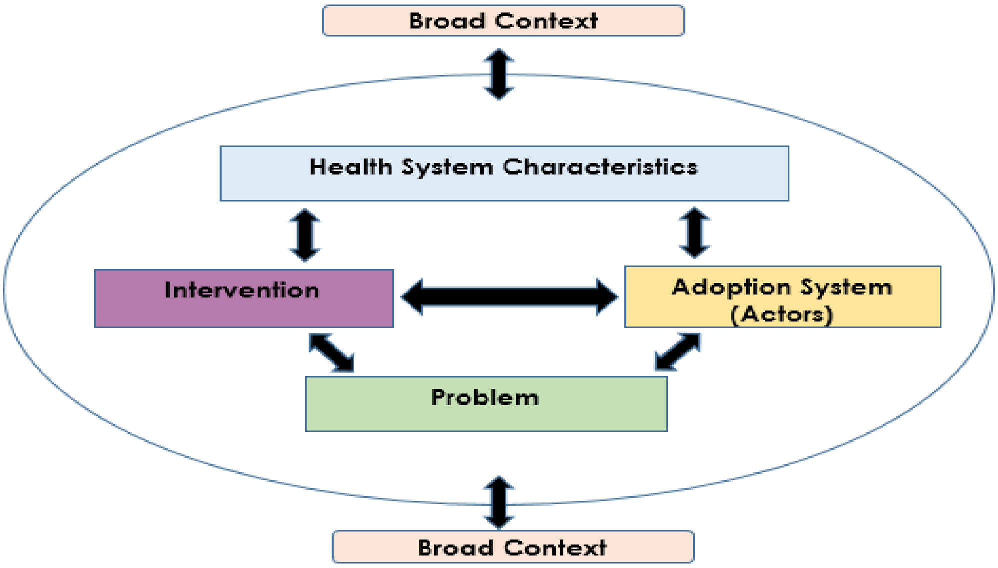


Figure 2.3: Atun et al.[8] Framework for Analysing Integration of Targeted Health Interventions into Health Systems

Consequently, Atun et al.[8] defined integration as "*the extent, pattern and rate of adoption and eventual assimilation of health interventions into each of the critical functions of a health system*"[8]. The critical functions of the health system for integration, identified by Atun et al. in 2009,[106,8] were governance, finance, planning, service delivery, monitoring and evaluation, and demand generation, and were mostly aligned to the WHO building blocks.[66]

Atun et al.[8] argue that the extent to which a new health intervention is adopted and diffused into the health system is influenced by the nature of the problem that is being addressed, the degree of complexity of the intervention, the adoption system dynamics which includes the cultural norms, beliefs and values of the actors within the adoption system, the characteristics of the health system, and the broader context within which it all exists.

Innovative health interventions are often introduced into unpredictable complex adaptive health systems. As McDaniel et al.[78] argue, these then change and adapt in response to internal and external influences such as actions, disturbances and triggers.[8] In dynamic complex systems, as Atun et al. point out, the consequences - the effects of decisions or system responses - are not always immediately visible or are not accurately predictable, since these are affected by the cultural norms, values and beliefs of actors within the system, which could lead to unintended consequences.[8] The extent to which an intervention is integrated into the general health system can be assessed as full integration, partial integration or no integration.[106] This framework does not make provision for finite definitions of all these levels of integration, but enables deconstruction of the term ‘integration’ into elements that align with the critical health system characteristics and aids in determining the extent of integration. ‘No integration’ refers to no evidence of any form of integration according to the elements contained in the framework. ‘Partial’ and ‘full integration’ are determined with due consideration for the elements contained in the framework, and are triangulated with qualitative information gained through interviews.[8]

Atun et al.(2008) maintained that as the broader context and the health system are intricately linked, changes in the health system can affect the broader context and similarly changes within the broader context can influence the health system[107]. Consequently, adoption and assimilation of health interventions, as well as its sustainability are dependent on contextual factors, hence all the double-sided arrows for all the elements in Figure 2.3.[8]

The COVID-19 pandemic is a recent example of the impact of a global disaster that directly influenced health systems in both positive and negative manners. On a positive note, as Atun et al. maintained, critical events and technological changes can facilitate more rapid absorption and assimilation of interventions into the health system. Such opportunities are created particularly when integration achieves synergies and demonstrable benefits.[8]

Conversely, as Atun et al. argue, socio-economic circumstances and the political environment could negatively influence the desirability for adoption and assimilation of an intervention, even when sufficient evidence for the benefit to the patient of an intervention exists.[8] Integration can also be hindered by fiscal relationship complexities between levels of government, whereby lower levels of the health system may have no incentive to implement interventions without earmarked funding.[8]

2.12. Conclusion

Chapter 2 explored the literature describing key components relevant to this study, such as health systems and systems thinking for PC policy, complexity and complex adaptive systems, compassionate health system, health policy and policy integration, integration of PC at health facility level and the impact of COVID-19 on PC.

Various theories, models and frameworks were reviewed, and since the NPFSPC calls for integration of PC, the rationale for using the Atun et al.’s conceptual framework, was presented. Atun et al.’s framework considers the problem that needs to be addressed, the contextual complexities of the intervention, examines the health system characteristics and the adoption system, while considering all relevant actors and their relationships.

The COVID-19 pandemic increased the PC burden globally and this calls for an inclusion of PC in pandemic planning. A PC service and approach requires a compassionate health system.

However, this health system is complex, does not exist in isolation, is dynamic, influenced by its broader context, does not operate in a linear fashion, and considers complexity when initiating new interventions. Furthermore, a health system that is compassionate and engaging can influence the broader context.

As the results from the various sub-studies unfold, further literature will be reviewed and included in subsequent chapters. The study offered an opportunity to identify the enablers that operate when critical events arise, and on the other hand, the impact on the broader context when the health system presents itself as a compassionate and engaging health system.

Chapter 3 provides the methodology for this study and the application for the conceptual framework of analysing the integration of a new intervention in the health system.

2.13. Motivation for this study

Given the deliberate strategy to include PC into the CMD health system and the NPFSPC's expectation to integrated PC into existing health services, the intention of this study is to examine its integration through the lens of assessing the building blocks needed, and through the roles of various actors. The health service is under pressure with resource constraints, and it is opportune to learn how a complex service package that challenges the usual way of offering a discrete service, can be integrated into the existing services. Furthermore, this took place in the time of the COVID-19 pandemic. Consequently, there are lessons to learn regarding opportunities and threats that are useful for SA and other health systems, which aim to address the health needs of the people served, in an accessible, equitable, and appropriate way.

Chapter 3 : Conceptual Framework and Outline of Methodology

Chapter 2 presented the literature review for this study and Chapter 3 presents the conceptual framework for this study and an outline of the methodology, which is further detailed in the sub-study chapters – Chapters 4 to 8.

The study utilises Atun et al.'s[8] (2010) conceptual framework that assesses the nature and extent of integration of health interventions into existing health systems. It is used in the design of the study, both in data collection and data analysis. Atun et al. through various studies have applied this framework in different contexts.[8, 89, 104, 106, 108] This framework is further elaborated, where relevant, in each chapter.

3.1. Application of the conceptual framework for analysing integration interventions

The conceptual framework developed by Atun et al.[8] was used as the framework for this study, the definitions for each component of the framework were unpacked in relation to the National Policy Framework and Strategy on Palliative Care (NPFSPC) implementation and the health system of the Cape Metro District (CMD).

Figure 3.1 illustrates how this framework was applied for this study and how each objective intended to unpack integration according to the components of the framework.

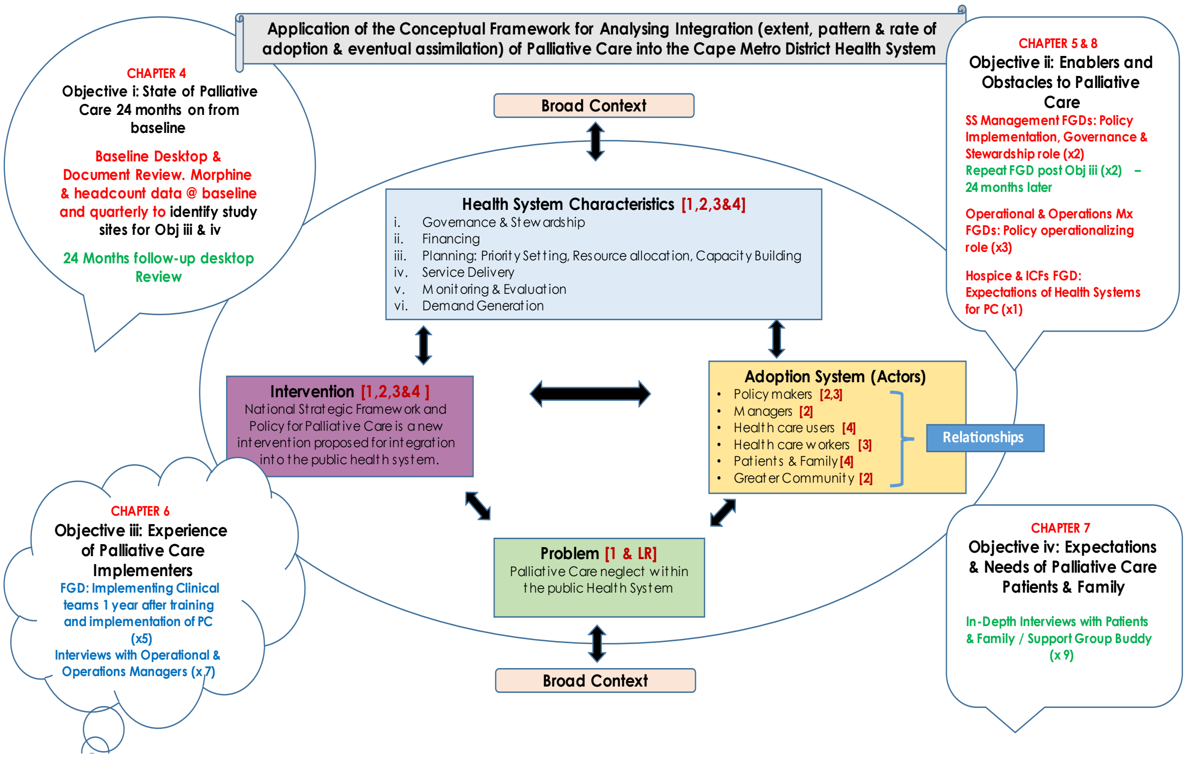


Figure 3.1: The application of the framework by Atun et al., [8] to this study

3.1.1. The problem addressed by the research

Each health problem has its unique characteristics and degree of complexity, which influences the rate at which the intervention that is designed to address it, is integrated into the general health system[8]. Atun et al.[8] argue that the extent of the socio-economic impact arising from the problem and the urgency with which the intervention is required to address the problem, will determine the speed with which the intervention is integrated into the health system. However, a rapid response and speedy introduction of an intervention may limit integration initially, but would then gradually be adopted and eventually be assimilated into the health system[8].

In the case of this study, PC is a neglected area in the current health system. The NPFSPC)[5] and the Western Cape Government Health and Wellness (WCGHW) proposed model for implementation of PC[65] was developed to address this problem. The provincial model contains the elements that need to be integrated into the health system in the CMD and the WC to address this problem.

Until the launch of the NPFSPC, there had been four dedicated PC programmes out of 51 public sector hospitals in the WC. In addition to advanced cancer, DesRosiers et al.[109] (2014) articulated the growing end-of-life care needs of patients suffering from advanced organ failure. Furthermore, the lack of PC services for this patient group had negative consequences for the quality of care for patients as well as on the already strained health care system in SA.[109]

A recent assessment of PC needs in SA, by Gwyther et al. (2018) revealed that only 17,8% of clients that required PC at the end of their lives, accessed it.[110] The NGO traditional providers of PC were unable to meet the total need for PC in the country and the authors furthermore maintained that PC remains a government obligation and the NGO sector should not be viewed as a substitute for this.[110]

3.1.2. The intervention

According to Atun et al. (2010), an intervention refers to a combination of technologies, decision making modifications, organisational changes, service delivery amendments and changes in planning processes.[8] In the study context, the interventions for PC were innovative since various new practices, training, care pathways and new ideas of work processes will be required by individuals or units of adoption.[103] Less complex interventions lend themselves more towards standardization and replication and are more readily scalable than interventions that are more complex.[8]

Since the PC services affect various platforms of service delivery (both in acute hospital and primary care settings), as well as various actors (involving both managers and a range of health providers), the involvement of a range of stakeholders is necessary. The PC intervention, with its range of interrelated and interdependent systems could be considered a complex intervention. It also accords with Atun et al.'s intervention complexity framework[8] where the NPFSPC, consisting of multiple elements and episodes of intervention that will need to be implemented at multiple levels of the health system, and involving and affecting multiple stakeholders, is therefore considered to be a complex intervention. Complex interventions also require greater stakeholder involvement and this extends beyond just implementers and also includes a high degree of user engagement.[8]

Various interventions intended to alter behaviour may be required, such as the media and WCGHW health communication, since PC is not currently considered standard practice within the health system in the CMD. As articulated by Drenth et al.,[13] this is important for both providers and potential users of the service, since PC is still widely misunderstood, with various myths still existing in SA regarding PC. It is seen to be only about death and dying, which could consequently deter uptake of the service.

The perception of the actors of any new intervention determines the level of caution with which they view it and according to Atun et al.[8] this will influence the rate, pattern and extent of the adoption of the intervention. Notably there are early and late adopters, and the desire is to have the entire adoption system onboard and included.

3.1.3. The adoption system

The adoption system, in Atun et al.'s conceptual framework, refers to key actors and institutions within the health system as well as in the broader context, with their varied interests, values and their institutional power in relation to the introduction of PC services.[8] Such key actors include policy makers and translators, managers within the health system, implementers of the policy (health care workers), health care users (patients and their families) and the broader affected communities and civil society organisations. Notable is that each of these stakeholders may have a different perception of the risks and benefits of PC. Atun et al. argues that the combination of "*the perceptions and positions of these actors (will) determine the receptivity of the adoption system to these interventions*."[8]

3.1.4. Health system characteristics

The health system characteristics that can improve individuals' and population health are a set of elements connected, forming a whole. These are governance and stewardship, financing, planning, (priority setting, resource planning and allocation and capacity planning), service delivery (care pathways, referral processes and levels of care), monitoring and evaluation and demand generation[8] (PC headcounts and access to morphine). The activities within a health system are the result of the influence (feedback) of one element on another and as has been seen, it can be either positive or negative in nature. Systems can be closed (autonomous and independent) or open (interact with environment). Atun and Menabde[107] further elaborated that health systems contain three drivers of dynamic complexity: "*the presence of a feedback loop, variable time lags between the cause and effect of an action and existence of non-linear relationships among the systems elements*".

The NPFSPC makes a case for integration of PC into the health system[5] and that integration of a new intervention can occur at any level/s of the health system (local, district, regional or national) in relation to critical health system functions.[8]

The intervention recommended by the NPFSPC is one of integrating PC into the existing health system[5] and when aligning this to the health system characteristics proposed in Atun et al.'s[8] framework, the functions are identified as follows:

- **Governance** – the NPFSPC[5] links governance with leadership with the expectation of supporting policy implementation, drive collaboration with partners that support service provision, and coordination within the existing accountability framework, implementation of a M&E strategy to measure progress within the existing performance management system.
- **Finance** – the NPFSPC[5] expects the appropriate allocation of existing financial resources to strengthen and sustain SA's PC programme, mobilise adequate financial and other resources for policy and strategy implementation, define the minimum standards for PC service delivery by NGO implementers and align service level agreements with NGO PC service providers to the national standards. There is no costing model in place for funding PHC and hospital based PC, however the NPFSPC does include the objective to "i*ncrementally increase the funding for palliative care to ensure a phased implementation of this policy*".[5]
- **Planning Function** – within the NPFSPC[5] the first goal of "*strengthening palliative care services across all levels of the health system from the tertiary hospital to the patient in the home to provide integrated and equitable care*", ties in with the provision of equitable and, the second goal of, sustainable access to appropriate medication and related consumables, the provision of adequate facilities, needs assessment, priority setting and resource allocation, ensuring adequate numbers of PC trained health care workers (HCW) and specialists across the continuum of care.
- **Monitoring and Evaluation** – the third goal in the NPFSPC[5] states that each province must establish and maintain systems for monitoring and evaluation of the PC programme and integrate PC into the provincial information data sets.
- **Demand generation** – Atun et al.[8] clarify that as a health system functions, demand generation, although critically important, is often overlooked. The integration of demand generation activities includes individual- and population-level health

education and promotion interventions to increase the uptake of services and address any myths (including stigma and denial) that exists within the communities and various actors.

Atun et al.[106] proposed that the elements outlined above and given in Table 3.1 below should be assessed when determining the extent of integration of an intervention into the general health system.

Table 3.1: Health System Characteristics and Elements of Integration

Health System Characteristic/Function	Elements of Integration
Stewardship and Governance	• Accountability functions • Reporting • Performance Management
Financing	• Pooling of funds • Provider payment methods
Planning	• Needs assessment • Priority Setting • Resource Allocation
Service Delivery	• Structural • Human Resources • Shared Infrastructure • Operational Integration • Referral and Counter-referral systems • Guidelines for care pathways • Procurement • Supply Chain Management
Monitoring and Evaluation	• Information technology infrastructure • Data collection and analysis
Demand Generation	• Financial incentives, e.g., conditional cash transfers, insurance • Population interventions, e.g., education and promotion

3.1.5. Context

The broader context and the health system are intricately linked, changes in the health system can affect the broader context and similarly changes within the broader context can influence the health system.[107] According to Atun et al. (2010), contextual factors range from critical events, technological changes, new drugs and even changes in prevention mechanisms.[8]

The COVID-19 pandemic was an example of a global critical event that influences the rate at which the health system characteristics and the adoption system assimilates and integrates a new intervention.

3.2. Research problem

To summarize, the problem that the study addressed is that PC within the public health system in the Cape Metro District (CMD) was a neglected area and was not integrated into the current health system. The National Policy Framework and Strategy for PC (NPFSPC)[5] developed by the national department of health was intended to address this problem by providing a policy that outlined the importance of PC, and provided the elements that need to be in place to integrate PC into the public health system.

Since this was a new policy, it is not known what combination of factors would influence integration (extent, rate and pattern of adoption and eventual assimilation) of PC into the health system.

The purpose of the study was to identify the factors, both enablers and obstacles, that influence integration of PC into CMD health system. This would provide insight into and contribute to discussions about integration that could enable policy makers to identify factors that make for robust options for policy development and implementation that could be generalizable to the broader context.

3.2.1. Research aim, questions and objectives

This study aimed to describe, explore, and explain the factors that influence integration of PC within the district health service platform in the Metro District.

The research questions were:

i. To what extent was PC integrated into the health system.

ii. How do different perceptions, knowledge, and skills of PC amongst multiple actors in the health system and their relationships influence the extent, rate, and pattern of integration of PC into the health system?

iii. What are the experiences of the implementers of the NPFSPC in terms of enablers and obstacles?

iv. Are the eligible patients and their families' expectations and needs met regarding access to quality PC?

v. Does the NPFSPC proposed package for PC facilitate integration of PC into the existing public health system?

Consequently, the objectives of the study were to:

I. Describe the PC services at baseline and then assess the integration in the Metro District, 24-months following implementation of the NPFSPC.

II. Assess perceptions of PC and identify enablers and obstacles to the introduction of the PC approach and set of services, among managers and external stakeholders.
III. Identify the factors influencing the implementation of the NPFSPC amongst implementers.
IV. Determine the perceptions and expectations of PC services amongst clients and their families enrolled into care and whether their care needs have been met.
V. Determine if NPFSPC was sufficient to enable integration into the health system.

There are four parts to the overall study that respond to the four objectives and the methodology for each part is briefly described in Table 3.3 below.

3.2.2. Summary of sub-studies

The study will facilitate learning more about the enabling factors and obstacles towards integration, which is discussed in Chapter 9.

Sub-studies investigate the following objectives as presented in Chapters 4 to 8. As was noted in the Foreword, Chapter 4 focuses on objective i) comparing the state of PC 24 months on from baseline; Chapter 5 focuses on objective ii) the perceptions of middle and senior managers and hospice and intermediate care facility (ICF) managers on the enablers and obstacles to the implementation of PC; Chapter 6 focuses on objective iii) the implementing teams and operational managers and their experience of providing PC services one year after being trained; Chapter 7 focuses on objective iv) the expectations and experiences of the patients and their family caregivers of the PC services and whether their needs have been met; Chapter 8 focuses on objective ii) the follow up engagement with sub-structure management teams (SSMT), 24 months following PC implementation, to explore lessons learned on integration. Table 3.2 overleaf provides a summary of the overall study research questions, objectives, and sub-study objectives.

Table 3.2 : Summary of research questions, objectives, and sub-study questions

Research question	Objective	Chapter, sub-study and sub-study objectives
To what extent was PC integrated into the health system	Describe the PC services at baseline and then assess the integration in the Metro District, 24-months following implementation of the NPFSPC.	**Chapter 4: Sub-study 1** Determine any changes in PC service provision over time and identify changes in policy and guiding documents.
How do different perceptions, knowledge, and skills of PC amongst multiple actors in the health system and their relationships influence the extent, rate, and pattern of integration of PC into the health system?	Assess perceptions of PC and identify enablers and obstacles to the introduction of the PC approach and set of services, among managers and external stakeholders.	**Chapter 5: Sub-study 2** • Determine the perceptions of the public sector senior and middle managers about PC. • Identify enablers and obstacles to the introduction of the PC approach and set of services, among managers and external stakeholders. • Explore the perceptions of the hospice and intermediate care facility (ICF) managers on the public sector's ability to implement PC. **Chapter 8: Sub-study 2** Identify enablers and obstacles to the introduction of the PC approach and set of services, among senior management teams for the two study sites and to learn lessons to embed it further.
What are the experiences of the implementers of the NPFSPC in terms of enablers and obstacles?	Identify the factors influencing the implementation of the NPFSPC amongst implementers	**Chapter 6: Sub-study 3** • To determine the experience of PC implementers at least one year after training • To explore their level of confidence in breaking bad news and building hope • To understand the approaches to PC integration at the identified sites • To identify the need for support from management in terms of enablers and obstacles

CONTINUED: Summary of research questions, objectives, and sub-study questions

Research question	Objective	Chapter, sub-study and sub-study objectives
Are the eligible patients and their families' expectations and needs met regarding access to quality PC?	Determine the perceptions and expectations of PC services amongst clients and their families enrolled into care and whether their care needs have been met.	**Chapter 7: Sub-study 4** • Assess whether the care needs of the patients and their family caregivers or 'buddies' who were enrolled into PC, have been met. • Determine their experience of the service. • Identify areas for improvement that are suggested and proposed by them. Determine their symptom control using the African Palliative Care Association Integrated Palliative Outcome Scale (APCA IPOS).
Does the NPFSPC proposed package for PC facilitate integration of PC into the existing public health system?	Determine if NPFSPC was sufficient to enable integration into the health system.	**Chapter 9: Discussion, conclusion and recommendations**

3.3. Methodology

This presents a summary of the methodology that is detailed in each sub-study chapter.

3.3.1. Study Design

The design of the overall study comprises a mixed methods approach including a document review, a quantitative before and after implementation design complemented with qualitative research aimed to understand the underlying issues. The quantitative elements are historical analyses, desktop reviews of personnel and service provision in the public health sector – PC ICD-10 data and morphine usage data. The qualitative elements include individual interviews and focus group discussions (FGD).

The study design was different for each sub-study and is detailed in each sub-study chapter.

3.3.2. Study Sites

The CMD served as the overall study site for the desktop and document review at baseline and 24 months following NPFSPC implementation, as well as for the NGO sector actors that contribute to the health system.

The Eastern sub-district in Metro East and Mitchell's Plain sub-district in Metro West were the sub-study sites for engaging of public sector actors. Three higher morphine usage sites and two low morphine usage sites were identified in Mitchells Plain and Eastern sub-districts to engage implementers and patients and their family caregivers. Details on the sub-study sites are included in the relevant sub-study chapters.

3.3.3. Study participants

Participants included sub-structure management teams, operational management teams, and hospice and ICF managers, implementing teams and their operational managers, and patients and their family caregivers.

The study participants that were included and the selection criteria for each of the sub-studies is detailed in each of the sub-study chapters.

3.3.4. Introduction of the study to the study sites

Once ethical approval had been received, due process was followed through the provincial health research centre to request access to the health facilities identified as study sites, in the CMD. Once written permissions were received, the researcher made initial contact with each of the research entities as indicated on the approval letters, to introduce the relevant sub-studies.

3.3.5. Recruitment of research assistant

The researcher was accompanied by one of two research assistants for each FGD. The two researcher assistants were social workers with research experience in conducting FGDs and in-depth interviews. They were recruited and trained in effective notetaking, research ethics and were familiarized with the study protocol. One research assistant attended two focus groups and the second accompanied the researcher for the remaining nine FGDs.

3.3.6. Recruitment of participants

The recruitment for each of the sub-studies is detailed in each of the sub-study chapters. A summary of these are as follows: the relevant manager was contacted and requested to identify potential participants that the researcher could contact. These managers were not expected to identify participants for focus groups and were not informed regarding who had participated. Each potential participant was then contacted by email and provided with the information sheet and consent form.

3.3.7. Data collection process

The qualitative data collection tools were developed considering Atun et al.'s elements for integration and the data extraction templates for the quantitative data sets were developed according to the type of data. Table 3.3 overleaf provides a summary of this.

Table 3.3: Summary of data collection methods and tools for the four sub-studies

Sub-study	Data collection method	Data collection tool
SUB-STUDY 1: State of palliative care 24-months on from baseline.	All WCGHW internal documents that pertain to PC	Template developed in MS Word based on foundation documents collected
	Morphine Data	Template developed in Excel based on the variables in the aggregated data. One sheet was created for each sub-district and one summary sheet for the CMD.
	Evaluation of the Introduction to PC training course.	Excel template to capture the elements included in the course evaluations. One sheet was created for each course and one summary sheet for the CMD.
	Pre-workshop surveys of 28 middle and senior health managers' knowledge of PC	Elements that were included in the survey document was used as the basis to develop the Excel template.
	Desktop review elements of integration	Excel template was developed around the elements of integration according to Atun et al.[8]
SUB-STUDY 2: Enablers and Obstacles to Palliative Care.	Three sets of FGDs with various management groups	Semi-structured discussion guides with open-ended questions
SUB-STUDY 3: Experiences of Palliative Care Implementers.	FGDs with implementers In-depth interviews	Semi-structured discussion guides with open-ended questions
SUB-STUDY 4: Expectations and Needs of Palliative Care Patients and Family or Buddy	In-depth interviews	Semi-structured discussion guides with open-ended questions

The researcher collected the data, except for the FGDs in sub-study three where the researcher was in attendance, but the research assistant conducted the FGDs.

The most significant impact on the planned fieldwork for this study, was the COVID-19 pandemic. Data collection commenced in 2019 (2nd year of this PhD) and all the interviews and FGDs were in-person until 2020. After approval from UCT's Human Research Ethics Committee in August of 2020, the remaining interviews and FGDs were conducted through online platforms and telephonically. Table 3.4, overleaf, presents a summary of sub-study objectives and data collection methods.

Table 3.4: Summary of sub-study objectives and methods

Study Aligned to Objective	Methods	Study Population/Focus Area
SUB-STUDY 1: State of Palliative Care 24-months on from baseline.	Desktop and Document Review conducted at **Baseline** in 2019 and repeated at **24 months following palliative care policy implementation, in 2021**	**Governance and Stewardship Structure:** • Project data collected from reports on surveys conducted managers – Baseline only. • WCGHW management structure • Annual performance plans for the WCGHW **Financing:** Budget allocation to NGOs that offer PC (HCBC and ICFs) PC business case/plan **Planning: Priority Setting, Resource Allocation, Capacity Building:** Capacity building: PC training. Evaluation Report on PC training for the first batch of individuals trained across the Cape Metro District – Baseline only. **Service Delivery:** • Referral pathway for identified PC patients. • Staffing complements trained in PC, • Levels of care at which PC is offered. • Spiritual carer and social worker access at all levels of care. • Functional MDTs across the service platform **Documents: alignment to PC** • NGO funding service package • ICF policy • Home and Community Based Care (HCBC) Draft Policy **Data from Provincial Health Data Centre** – tracked quarterly throughout study: • Morphine • ICD 10 code for PC
SUB-STUDY 2: Enablers and Obstacles to Palliative Care.	Sub-Structure Management Team (SSMT) FGDs • **Two FGDs:** One with Khayelitsha Eastern and one with Klipfontein Mitchells Plain SSMTs • **Two follow-up virtual FGDs** with the same SSMTs, 24 months later	SSMT responsible for the sub-districts that served as study sites: • Director • District Hospital CEOs • District Hospital Clinical Managers • Deputy Director: Programmes • Deputy Director: Professional Support Services • Deputy Director: Primary Health Care Manager • Deputy Director: Pharmacy Manager • Deputy Director: People Management • Community Based Services Manager • Community Based Services Coordinator The researcher recruited participants to the four FGs.
	Operational and Operations Managers FGDs • **Three FGDs** One with Eastern Sub-District and Two with Mitchells Plain Sub-District Operations managers	Operational and Operations Managers: • 24-hour Community Health Centre Facility Managers • 8-hour Community Day Centre Operational Managers. • Assistant Managers Nursing • Operations managers: Pharmacy, Medical • Family Physicians • Social Workers The researcher recruited participants to the three FGs.
	Hospice and ICF Management - **One FGD**	Managers of ten Hospices and ICFs in the CMD. The researcher recruited participants to these FGDs.

CONTINUED: Summary of sub-study objectives and methods

Study Aligned to Objective	Methods	Study Population/Focus Area
SUB-STUDY 3: Experiences of Palliative Care Implementers.	Implementation Team Virtual FGDs • **Five virtual FGDs** Virtual Interviews with Operations managers • **Seven virtual interviews**	At the same facilities identified in Objective iii, the NPFSPC implementers and support staff at these facilities were invited to participate in virtual FGDs one year after being trained in PC and policy implementation. In-depth virtual individual interviews were conducted with the operational and operations managers for each of these facilities.
SUB-STUDY 4: Expectations and Needs of Palliative Care Patients and Family or Buddy	Virtual Interviews **Nine telephonic Interviews** until no new information emerged	The telephonic interviews were conducted with patients and their family or support buddy, who met the inclusion criteria were invited to participate. These patients were selected from the facilities identified as being low and higher morphine usage facilities in Eastern and Mitchells Plain sub-districts,

Abbreviations: WCGHW = Western Cape Government Health and Wellness; FGD = focus group discussion; HCBC = home and community-based care; ICF = intermediate care facility; NGO = non-government organisation; CEO = chief executive officer; CMD = Cape Metro District.

3.3.8. Data analysis

The detail of the data analysis for each sub-study is included in each chapter and Table 3.5 below contains the summary for all four sub-studies. The researcher conducted the qualitative data analysis and obtained statistical assistance to determine changes over time for quantitative data for morphine and ICD-10 coding. The qualitative data was inductively analysed and not according to the element of integration according to Atun et al.[8] Furthermore, the quantitative data was analysed using Excel and STATA, and a narrative description was provided to describe the data between 2019 and 2021.

Table 3.5: Summary of the Data Analysis for the four sub-studies

Sub-study	Research Method	Type of Analysis
SUB-STUDY 1: State of Palliative Care 24-months on from baseline.	Quantitative analysis Qualitative analysis	Descriptive analysis to summarize the quantitative data trends over time. Documents were systematically reviewed using the READ approach. Sections of pertinent information were retrieved, organized and written up. Content analysis was used to organize information into categories that related to the research question.
SUB-STUDY 2: Enablers and Obstacles to Palliative Care.	Qualitative analysis	Thematic analysis
SUB-STUDY 3: Experiences of Palliative Care Implementers.	Qualitative analysis	Thematic analysis
SUB-STUDY 4: Expectations and Needs of Palliative Care Patients and Family or Buddy	Qualitative analysis	Thematic analysis

3.3.9. Data management and confidentiality

Hard copies of all completed questionnaires, transcripts and identifying materials were securely stored in a lockable cupboard accessible only to the researcher. This will remain in place for a period of five years and this material will then be destroyed. Similarly, all electronic versions were secured through password protection and saved using an archival number, onto a hard drive, making it accessible to the researcher only and will be destroyed five years after completion of the project. These processes should protect both informants and facility anonymity and confidentiality.

In summary, through examining the critical health system functions, the data collected should enable a macro-analysis of integration of PC in the overall health system of the CMD.

3.3.10. Ethical considerations

Beneficence and justice as ethical principles were considered throughout all interactions with the staff and patients to ensure non-maleficence and that participants were treated in a fair and impartial manner. This is detailed below.

Ethical Approval and Study Permissions

Ethics approval was obtained from the UCT FHS HREC (Annexure 2 – HREC REF: 058/2019) and permission was given by the structures and health facilities within Western Cape Government Health and Wellness (WCGHW) to conduct field work amongst staff and patients at the study sites: to obtain data related to morphine drug prescribing; the PC cascade indicators; and, the NGO data sets related to PC in the CMD.

The WC Provincial Health Data Centre then provided the various datasets and information required at baseline and again 24 months after the NPFSPC was implemented. They provided deidentified aggregated information related to ICD10 codes for diseases for PC at all health facilities, as well as morphine prescribing, supply, and health facility access points.

Protecting Participants

The rights of study participants were upheld in all sub-studies. Attention was given to protecting their confidentiality as well as ensuring their anonymity and autonomy. Consequently, protecting the identity of the patients underlay the quantitative data collected, stored, and analysed. Data was aggregated and consequently deidentified and stored in password protected files. The researcher worked with the Provincial Health Data Centre to ensure data security along each step of the process.

A range of informants participated in in-depth individual interviews or FGDs. For public sector and NGO staff, power differentials were considered, and the various categories of staff were separated as indicated in the methodology sections of each sub-study. Since the researcher was a senior manager, issues of overt or subtle coercion were addressed by reiterating that participation was not compulsory in the information sheets and at the start of the FGDs and in-depth interviews, and by appointing an experienced research assistant, to promote good practice and reduce discomfort. All transcripts as well as survey data were anonymised, and all identifiers removed. Informed written consent was obtained from all participants and their identity, as well as the record of discussions, was kept confidential, known only the researcher and assistant researcher.

PC patients are considered a vulnerable population. Engaging them in research is often neglected. Not giving them the opportunity to be heard, is an injustice, as they deserve equal opportunity to take part in research and to benefit from research. A distress protocol[34] (Annexure 3) was in place to mitigate emotional or physical distress that became evident to the researcher. Voluntary informed consent was obtained, and patients were asked to explain to the researcher what the sub-study was about, to demonstrate understanding. They were assured that participation or reasons for non-participation would not be disclosed to their health care provider. Patients and their family or support buddy were invited to ask questions and were reassured that choosing not to participate would not affect their care plans in any way. Patients disclosed symptoms that were poorly managed and to mitigate the risk of expectation that the interview would result in a change in their care plans, they were encouraged to raise these with their health care providers and advised that the interviews formed part of a study that would contribute towards improved understanding of the health care service delivery platform and practices.

The identity of all study participants is known only to the researcher and to the research assistant for the groups she was involved in. The names of health facilities are known only to the researcher, the research assistant and PhD supervisors. Furthermore, participants in all FGDs undertook to preserve the confidentiality of the contents of the group and not disclose participants and the discussions.

Dissemination of research findings is an ethical responsibility and findings from this study will be presented at various forums and conferences, and articles will be published. This will add to the broader scientific body of knowledge, should enable transformation, and impact the health system by providing insights into the factors that influence integration.

3.4. Conclusion

Chapter 3 has provided a summary of the mixed methods study and the conceptual framework for this study. The chapter for each of the four sub-studies will present further details on its methodology and articulate the link to the conceptual framework for analysing integration of targeted interventions into health systems, by Atun et al.[8]

Chapter 9 will present the discussion, conclusion, and recommendations for the overall study. The conceptual framework for analysing integration of targeted interventions into health systems by Atun[8] will be used to frame the discussions from the various sub-studies.

Chapter 4 describes the state of PC 24-months following implementation of the NPFSPC in the CMD.

Chapter 4 : Comparing the state of palliative care 24-months on from baseline

4.1 Introduction

Chapter 4 describes the state of palliative care (PC) services offered in the Cape Metro District (CMD) at the onset of the implementation of the National Policy Framework and Strategy on Palliative Care (NPFSPC) in early 2019 and compares it at 24-months following implementation of PC services, in 2021. The CMD consists of eight sub-districts which make up four sub-structures (SS), which will be referred to as SS1, SS2, SS3, and SS4.

The focus is on the health system characteristics of governance and stewardship, financing, planning (priority setting, resource planning and allocation and capacity planning), service delivery (care pathways, referral process and levels of care), monitoring and evaluation and demand generation (PC cascade, headcounts, and access to morphine). These are drawn from Atun et al.'s conceptual framework for analysing integration of targeted health interventions into health systems.[8]

The literature reviewed in this chapter aligns with the health system characteristics identified in the conceptual framework for analysing integration of targeted heath interventions into health systems. It includes considerations related to governance for health systems, the cost-effectiveness of PC integration, seamless continuum of care and barriers and enablers to PC integration.

4.2. Literature Review

4.2.1. Governance and stewardship for health systems

The World Health Organisation (WHO) publication (2021), assessing the development of PC worldwide: a set of actionable indicators, considers governance and leadership as being critical for ensuring the development of an appropriate national policy for PC.[2] Atun et al.'s also considers governance and stewardship as the first component of the health system characteristics,[8] as these are essential to provide the necessary elements for service provision. However, as Atun et al. indicated, standards of governance vary[107] by country and even by government department within the same country or geographic area and they call for global health governance to provide international health regulations that all countries should adhere to, as with tobacco laws.[107] Notably problems are compounded due to weak public infrastructure. Consequently, the private sector and civil society can make important contributions to health governance.[107] When measuring integration, Atun et al. (2010) indicated that full integration is achieved when the governance arrangements for an intervention are the same as for the general health system. These include accountability functions, reporting and performance management.[8] Non-integration of an intervention means a specialist team or entity outside of the general governance arrangements, are accountable for an intervention.[106]

4.2.2. Cost effectiveness and financing for palliative care

Although information in low- and middle-income countries (LMIC) on cost effectiveness of PC is scant, according to Krakauer et al. (2021), the return on investment on the initial cost for policy development, essential medicine procurement, education and training and additional staff, yields return with time. This comes from the reduction in unnecessary admissions and invasive interventions, improving the quality of life of the patient without shortening it, protecting the patient and family from impoverishment as well as improving the satisfaction of the family caregivers.[111]

PC services proposed in the NPFSPC and the proposed model within the Western Cape (WC), includes offering home-based care and support services to patients and their families.[5, 65] This is based on the surmised preferred place of death being at home and using the opportunity to build support around families in preparation for a home death. Hongoro and Dinat (2011)[43] argued that a hospital-based outreach programme in South Africa (SA) is more cost effective than repetitive admissions to already burden overcrowded hospitals, and improves the quality of life of the patient and family in the home setting. The cost of an outreach visit amounted to 50% of the cost of one patient day equivalent in a district hospital bed.[43] Daviaud et al. (2018) found that in SA the cost of home-based PC offered by CHWs, was 10% of the cost of in-patient PC over a two-week period.[112] Furthermore, DesRosiers et al. (2013) confirmed that offering support to patients and their families in the form of outpatient hospital-based services reduces admissions and increases the rate of home deaths, offering a feasible and cost-effective model.[109]

4.2.3. Planning for palliative care integration

Planning is one of the critical health systems functions. According to Atun et al.,[8] conducting capacity planning (including education and training in PC), resource and service planning as part of the general health service planning for any new intervention or policy, is considered as being full integration. The WHO has developed a guide for programme managers regarding the planning for and implementation of PC services.[113] Furthermore, Fadul et al. (2021) raised the importance of the inclusion of PC in pandemic planning.[95]

According to Hosking, morphine is the opioid drug of choice since it is affordable, versatile and readily available. Opioids are primarily used to relieve symptoms of pain, dyspnoea, distressing cough, and diarrhoea. It is important to ensure that drug supply is planned for and maintained to prevent suffering. Being the gold standard for the management of PC patients, makes its utilisation a useful indicator to track. It could be a useful measure of both the integration and provision of PC in LMICs.[114]

4.2.4. Care pathway and referral

National health systems are responsible for ensuring that PC is included in the continuum of care for patients with serious life-limiting and life-threatening conditions.[113] In addition, providing PC is an ethical obligation of all health professionals and such care should be accessible across the care pathway.[113] Continuity of care is dependent on defined care pathways and referral processes. A case is made by O'Connor et al. (2016), for a nurse practitioner model that ensures linkage to care between in-patient and community settings in Melbourne, Australia. While continuity of care for the patients is ensured, the nurse practitioner can facilitate inter-professional liaison between the different levels of care.[115]

A local WC study by Ens et al. (2008), found that PC providers contributed to the development of a framework for the now standardised ideal patient referral system in SA for PC patients. In this framework a case is made for adequate referral pathways to ensure seamless continuity of care. However, the framework is limited to PC patients and was informed only by hospice clinicians.[35]

Morey et al. (2021) conducted a study exploring PC patients' and their caregivers' understanding of continuity of care when transitioning from in-patient to home-based care. They found that continuity of care was firstly, consistency in the exchange of information between care providers across the care pathway and secondly, consistency of treatment while adapting care plans to patients' needs. Furthermore, the authors found that relational continuity between patient and provider at the level of care is fundamental and even more important near the end of life. While there are many definitions for continuity of care based on healthcare location and provider, these authors argued that the 2 main elements are "*care of the individual patient, and care delivered over time*".[116]

Furthermore, the Morey et al. study reported that nurse led continuous support while transitioning from hospital to home, reduced hospital readmissions for those with life-limiting conditions.[116] O'Connor (2016) conducted a study where permanent nurse practitioners were appointed to ensure continuity of care of PC patients from the hospitals to the home. These nurse practitioners worked hand in hand with non-governmental organisation (NGO) partners and following a 12-month period the findings indicated improved collaboration across the care continuum as the nurse provided an enabling role for continuity of care and patient support. This facilitated timely support and symptom control, as the nurse was accessible to the hospital team and the community-based team which resulted in decreased unplanned and preventable hospital admissions. Furthermore, there was reduction in hospital discharge delays, since the nurse was linked to the community setting and available to support the in-patient team, and the nurses expertise enabled improved knowledge on PC for all hospital staff, including improved knowledge on discharge planning.[115]

It is important to have a functional feedback mechanism for referrals, to ensure continuity of care and holistic patient care. To facilitate this, a standardised electronic system that is available at all levels of care, including the hospice and intermediate care facilities (ICFs) is required. The SA public sector health system does not use electronic health records (EHR) in patient care. However, the Western Cape Government Health and Wellness (WCGHW) department piloted and is rolling out the electronic continuity of care records (eCCR), which is an electronic hospital discharge summary, accessible to any clinician registered to use it. In 2019 the process of including PC discharges had commenced.[117]

Esquivel et al. (2012) commented that although EHRs are increasingly being used to facilitate referral communication, referral and feedback communication between primary care providers and specialists is often unsatisfactory as different practices or health care facilities do not have access to the same EHR. Consequently, these records do not necessarily eliminate care delays. They concluded that information and communication technology must fit the social environment of health care and this will require a multifaceted "*socio-technical*" approach.[118]

4.2.5. Barriers to palliative care Integration

Barriers to PC integration include access to analgesia, health policy gaps, limited training in PC, stigma associated with the term 'palliative care' and terminology such as 'do not resuscitate'. Additionally, many family caregivers cannot quit their jobs or take time off work to support the patient and offer home-based PC.

The Lancet Commission on palliative care and pain relief in 2017, concluded that PC and pain relief are some of the most neglected dimensions in contemporary global health.[119] Appropriate and adequate use of pain-relieving medication is a human right. However, it is neglected and has been overshadowed by the focus on the prevention of non-medical use of internationally controlled substances, such as opioids commonly used for pain control in PC.[119] A Lancet editorial[75] on access to opioids, confirmed that in 2017, approximately 80% of the global population did not have adequate access to analgesia for pain relief. Horton et al. (2017) report that a global call has been made to take seriously the alleviation of pain and suffering.[120]

One study included in this review found that when the name was changed from 'palliative care' to 'supportive care', medical oncologists and mid-level health care providers agreed that they were more likely to refer patients for supportive care, but not PC.[121]

The WHO in its 20 December 2013 session, indicated that there are significant barriers to the provision of PC that need to be overcome. These include the gap in health policy to meet the needs of those requiring PC, limited training in PC, challenges in accessing opioid analgesics and research. The WHO, Graham-Wisener et al., and Ahmed et al. identified other barriers that include lack of community awareness about PC, gaps in finance and care pathway networks, as well as a skills gaps amongst health care provider.[3,122,123] Provider skills and perspectives, particularly that PC was end-of-life care, were found to be the most significant barriers to early access to PC in a systematic review conducted by Aldridge et al. (2016).

The demand for PC is likely to increase and this was a conclusion of the "*palliative care and beyond*" workshop in Turkey in 2020, which brought together 80 global PC experts, reported by Ahmed et al. This could be a constraint for health services operating in resource constrained systems, since it means that patients need to participate in decision making about their care and it is incumbent on the care team to discuss eventualities with patients, which they are not comfortable or trained to do. Furthermore, barriers to compassionate PC such as 'Do Not Resuscitate (DNR)' orders require attention within each country's law-making terrain.[123]

In SA, the NPFSPC[5] identified a number of implementation constraints and challenges which require further exploration. These included inequitable access to PC, inappropriate use of PC services by patients, family caregivers and health care providers due to gaps in understanding about illness trajectories and the socio-economic cost burden that caring for family members in need of PC places on families. These result in patients being left home alone or hospitalised inappropriately as family caregivers must work. The health system challenges identified by the NPFSPC[5] include PC service gaps in spiritual care, ill-defined care pathways and referrals processes, inadequately skilled health care providers and CHWs, and the lack of knowledge about the concept of PC.[5]

4.2.6. Enablers to palliative care integration

A key enabler to PC integration in SA is the National Department of Health's (NDOH's) adoption of the WHO public health model.[23] This articulated the implementation steps to ensure "*the best approach for translating new knowledge and skills into evidence based, cost effective interventions that can reach everyone in the population*". This model has been used in many countries and extensive literature describes the use of this model to determine PC development.[23, 27]

Although the enhanced WHO Public Health Model emerged to effectively integrate PC into society and includes four components, namely: "*1) appropriate policy, 2) adequate drug availability, 3) education of health care workers and the public, and 4) implementation*".[10] Additionally, the WHO publication (2021) on assessing PC development contained a set of indicators (Table 4.1, overleaf) that can be used by any country, considering the diversity of each setting, to monitor and assess the development of PC at a country level.[2] The 2021 publication provides a conceptual model of PC development. It contains a set of indicators and two sub-sets of indicators that can be used to assess country level development.[2] Furthermore, it provides guidance on the process for implementing the indicators.

Table 4.1: WHO set of indicators to assess PC development at country level[2]

	Indicators
1	*"Number of specialised palliative care programmes in the country per population",*
2	*"Number of specialised palliative care programmes for children in the country per population"*
3	*"Existence of a current national palliative care plan, programme, policy or strategy with defined implementation framework"*
4	*"Inclusion of palliative care in the list of health services provided at the primary care level in the national health system"*
5	*"Existence of national coordinating authority for palliative care in the Ministry of Health responsible for palliative care"*
6	*Reported annual opioid consumption – excluding methadone – in oral morphine equivalence (OME) per capita"*
7	*"Availability of essential medicines for pain and palliative care in the country"*
8	*"General availability of immediate-release oral morphine (liquid or tablet) at the primary care level"*
9	*"Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula"*
10	*"Specialisation in palliative medicine for physicians"*
11	*"Existence of congresses or scientific meetings at the national level specifically related to palliative care"*
12	*"Palliative care research on the country estimated by peer reviewed articles"*
13	*"Existence of groups dedicated to promote the rights of patients in need of palliative care, their caregivers, and disease survivors"*
14	*"Existence of national policy or guideline addressing advance care planning of medical decisions for use of life-sustaining treatment or end-of-life care"*

Collaborative formal and informal productive relations between providers and patients, and within teams, were identified as key enablers in a systematic review conducted by Watt et al. (2016). They added that adequate education and training with appropriate expertise, supportive structures and dedicated resources and leadership with effective management oversight, while holding holistic patient centre care at the centre of service delivery decisions, are facilitators towards integration.[124] Mayhew et al. (2017)[102] argue that actors in the health system and their relationships of power may influence the health systems performance and enable the adoption and implementation of a new service focus. According to Walt et al.[86] the importance of power, which is fundamental to policy analysis, is a highly contested notion. It is unclear if this could be an enabler or obstacle to the integration of PC.

National PC policies that can inform provincial and local level policies, are critical enablers for PC service integration. Luyirika et al. (2016) argue that robust policy development should include an assessment of the state of PC, the use of evidence and adequate consultation.[25]

The CMD, comprising the City of Cape Town, is a district in the WCP of SA which is a LMIC country, with a projected population of 4,686 million.[4] It is consequently relevant and important to determine the success of integration of a new intervention. For the CMD health system it would be important to identify the factors that enable integration of PC in this setting.

4.2.7. COVID-19 pandemic, palliative care and service delivery

The COVID-19 pandemic commenced in SA in March 2020 and the first recorded SA patient death was in the WC. The COVID-19 pandemic locally exposed the gap in PC within the public sector as many patients were dying and required rapid access to PC, but inadequate numbers of staff had been trained in PC by March of 2020. The PC task team (PCTT) drafted the WCGHW provincial PC position statement and plan for COVID-19 response, which was officially communicated via Circular H67-2020.[1]

Provincial palliative care position statement and plan for COVID-19 response

The document emphasised that PC is not only end-of-life care and that PC included patients and families. It acknowledged that PC was not part of the normal working day for many of our employees and not everyone (even when trained) was able to break bad news and build hope.

The plan (Figure 4.1) identified the following categories of patients in need of PC:

- Known PC patients who are COVID-19 negative and usually cared for by family in their homes.
- Known PC patients who are diagnosed with COVID-19.
- COVID-19 diagnosed patients who required rapid access to PC. These patients were those with a poor chance of survival, were poorly responsive to ventilation or not eligible for ventilation.[1]

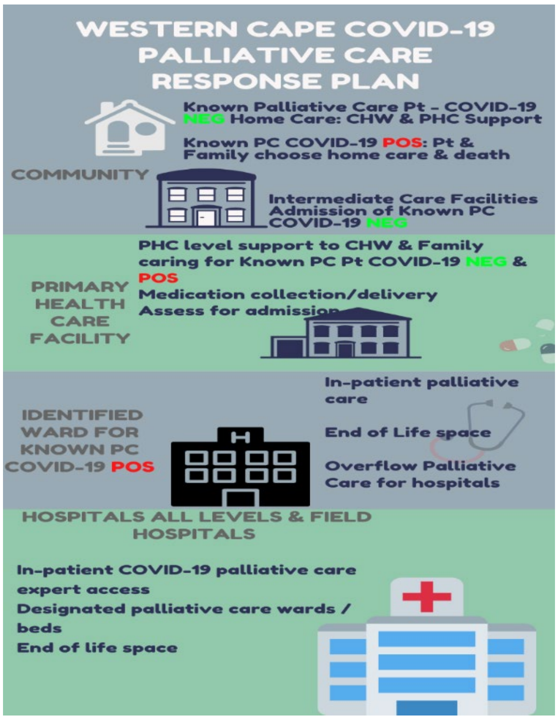


Figure 4.1: WC COVID-19 Palliative Care Response Plan Infographic

An initial bed planning exercise was conducted by the WCGHW provincial health data centre and PCTT members to determine the number of beds required for palliative and end-of-life care at all acute hospitals and stand-alone in-patient PC facilities across the province.

The plan proposed that:

Each facility had to develop and agree upon a signed COVID-19 PC plan as a part the SOP for the flow of COVID-19 patients. These plans were tabled at the weekly COVID-19 check-ins.

Identified PC experts were linked to each acute hospital, that did not have access to in-house PC expertise, to offer advice on daily individual patient decision-making, training for clinical teams and provide onsite support when needed.[125]

Furthermore, an ethics committee was established by the WCGHW, and a PC expert was identified to support this committee for PC related matters, since it was not clear how much PC awareness this committee possessed for PC.[126]

Spiritual care and bereavement counsellor volunteers were recruited at each sub-structures in the MHS from NGOs, faith-based organisations, community structures and retired staff. A database was established, a coordinator identified, and access to the spiritual counsellors was facilitated using a mobile application and telephonically.

The national state of disaster regulations placed various limitations to movement and human contact. The acute hospital space placed a moratorium on visitors, and this impacted on the emotional support to patients from their loved ones. Tablets were provided to each hospital to facilitate video calls with loved ones, spiritual carers and grief counsellors.

For PC patients, SSs had to procure sub-cutaneous syringe drivers, ripple mattresses, incontinence consumables to facilitate home administration of pain and other medication and keep patients at home and out of hospital/ICF.

The referral path for the known PC patient was different from that of the COVID-19 patient requiring PC. To protect the already compromised PC patients and to preserve the ICFs for COVID-19 negative patients, alternative facilities were opened for COVID-19 positive patients.

The following diagram (Figure 4.2) reflects the flow of the known PC patient vs the COVID-19 patients that require PC.

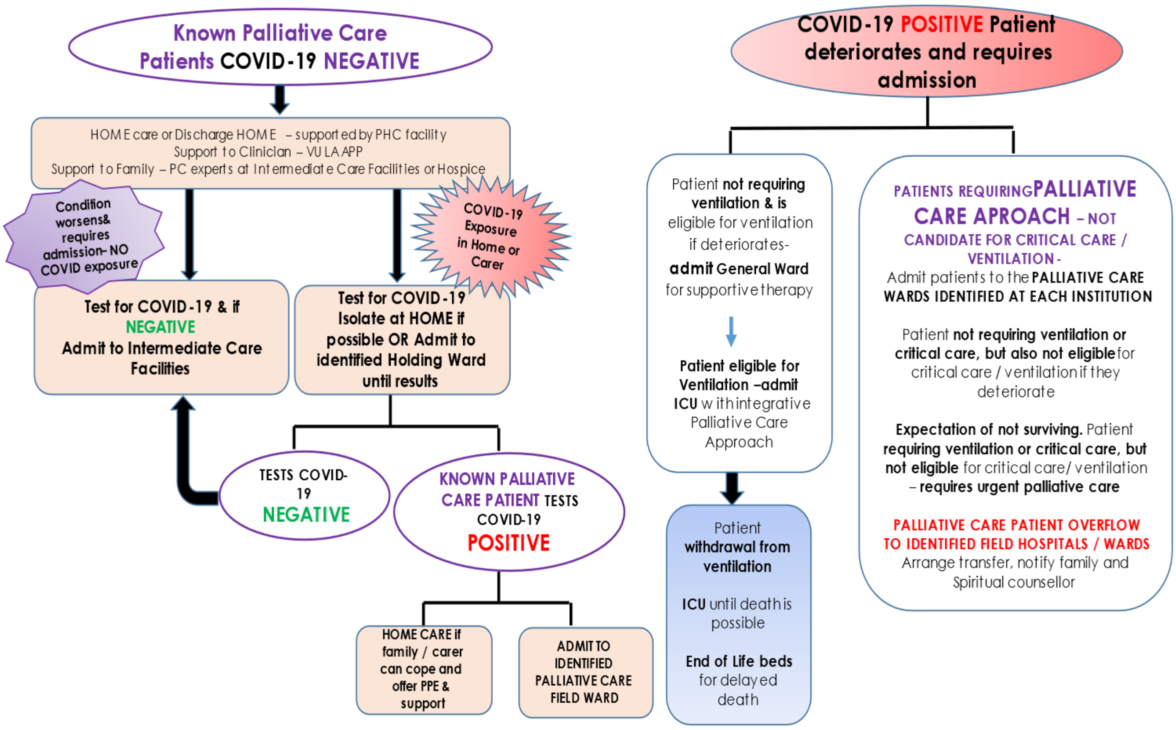


Figure 4.2: Flow of the Known palliative care patient vs the COVID-19 patient requiring palliative care

This demonstrates that considerations of governance, financing, planning, care pathways and its related systems, as well as good understanding of factors that influence the health system, were critical for the implementation of this new intervention over COVID-19, and indeed for new programmes or policies.

4.3. Aims and objectives

The aim of the overall study is to describe, explore and explain the factors that influence integration of PC within the district health service platform in the CMD. This sub-study explored and described the state of PC services 24-months on from baseline in the CMD.

The objective of this sub-study was to determine any changes in PC service provision over time and identify changes in policy and guiding documents, as indicated in Table 4.2.

4.4. Methodology

A desktop review and document analysis were conducted at baseline and repeated 24 months following implementation of the policy. It focused on the elements of integration (captured in Table 3.1 in Chapter 3), to assess the extent of integration of the NPFSPC into the health system. A mixed methods approach: a quantitative before and after implementation design complemented with qualitative research that aimed to understand the underlying issues, was used for this sub-study.

4.4.1. Sub-study design

A cross-sectional descriptive sub-study of the baseline (March-June 2019) PC services across all the health system characteristics[v] of the conceptual framework for integration[8] was compared to 24 months following implementation (March-June 2021) in the CMD. The reason for the range in time and not an instant in time, is based on data cleaning, finalisation of budgets, and governance documents that correspond to the WCGHW financial year.

A review of quantitative changes in morphine prescribing and access and PC service availability based on ICD 10 coding, was conducted.

The desktop review included a review of all relevant documents and data sources applicable to PC. The analysis of documents is a recognised qualitative analysis method to examine the response to policy.[127],[128]

4.4.2. Selection criteria

The document selection process specifically looked for WCGHW internal documents that aligned to the elements of integration of a new intervention in Atun et al.'s conceptual framework[8] and the NPFSPC,[5] focusing on the PC policy. Policy-related documents, documents focusing on PC service provision and all guiding and strategic documents that referred to PC, available in the WCGHW were reviewed.

The researcher works within the WCGHW and was familiar with how to access the various documents. Some documents were used as part of her role and function in the WCGHW, others were part of the documents used and developed by the PCTT. Documents were accessible on the Western Cape Government website or obtained from various colleagues. Engagements with key informants within the researcher's work environment, with PCTT members, and with PhD supervisors, ensured that all relevant documents were included.

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[v] Health system characteristics include governance and stewardship, financing, planning, service delivery, monitoring and evaluation and demand generation.

Primary data that were available from projects that had been conducted, prior to this research study, by the WC PCTT were selected to paint a richer picture of the governance and stewardship health system characteristic. These included the following:

- post-course evaluations conducted on 133 participants who attended the initial PC training courses that formed part of the WCGHW mini contract for the 40-hour training course in PC. This data was used to provide context to baseline information on PC amongst the clinical staff within the multi-disciplinary teams in the CMD.
- a survey conducted among 28 middle and senior managers to gain insight into their baseline knowledge on PC before being exposed to an information session introducing them to the NPFSPC.

Data on the funding mechanisms, type of services funded and funding norms for NGOs performing ICF services for the WCGHW in the community-based setting, was included. PC training, spiritual carers and social worker capacity data at baseline and 24 months following implementation were included as data sources.

Data selected, included morphine utilisation and ICD 10 coding for PC and these were used to determine referral systems, PC headcounts, morphine dispensing patterns, patterns of interruption in morphine supply and client access points within the health system. The selection criteria for the data on morphine sulphate and mist morphine included all available data on the medicine management system (JAC) and the Chronic Dispensing Unit (CDU) system within the WCGHW. Morphine usage was determined through morphine dispensed per subdistrict in the CMD through the pharmacy health information system. The morphine data are divided into morphine unspecified, assumed to be mist morphine usually prescribed at primary health care (PHC) level, and morphine sulphate, the injectable version usually prescribed and administered for inpatients either admitted to or being referred to hospital level care. A comparison was made between morphine usage before implementation of the policy and morphine usage after implementation for the entire CMD.

A summary of the focus areas and relevant data sets and documents included at baseline and 24-months following PC policy implementation, are included in Table 4.2, overleaf.

Table 4.2: Summary of focus areas, data sets and documents

Focus Area, Data Sources and Documents
Governance and Stewardship Structure: - Project data collected from reports on surveys conducted with 28 middle and senior managers before being exposed to an information session on PC – Baseline only. - WCGHW management structure - Annual performance plans for the WCGHW
Financing: Budget allocation to NGOs that manage ICF and home and community-based care (HCBC) workers PC business case/plan
Planning: Priority Setting, Resource Allocation, Capacity Building: Capacity building – Training staff in PC and skills budget expenditure on PC training courses. Evaluation report on PC training will be conducted on the first 133 individuals trained across the Cape Metro District – Baseline only.
Service Delivery: - Referral pathway for identified PC patients. - Staffing complements trained in PC, - Levels of care at which PC is offered. - Spiritual carer and social worker access at all levels of care. - Functional MDTs across the service platform
Documents: alignment to Palliative Care - NGO funding service package - ICF Policy - HCBC Draft Policy
Data from Provincial Health Data Centre – tracked quarterly throughout study: - Morphine sulphate and mist morphine - Output indicators: head count based on PC ICD10 coding – tracked quarterly throughout the study.

Table 4.3, overleaf, summarises the data sources that were included in the desktop review and document analysis. The red font depicts the data sources, and the blue refers to the documents that were reviewed for each of the health system characteristics.

Table 4.3: Summary of data sources reviewed in the before and after sub-study

Health System Characteristic	**Data Sources and Documents**	**Reason and Purpose**
Governance and Stewardship	WCGHW Top Executive Structure (Organogram) and Governance Arrangements	Accountability function (Policy Structure, responsibility, and roles), Reporting and Performance Management for WCGHW.
	Survey conducted in 2018 - Managers knowledge in PC	
	Performance management within the WCGHW	
Financing	Finance Instructions for transfer payments	Used the WCGHW finance instruction as the bases of developing the Governance arrangement for NGO funding. Funding guidelines and funding norms for NGOs including HCBC and ICFs.
	NGO Service Package	
	PC funding business case/plan	
Planning	People development: matrix approach to workplace skills planning	Needs assessments, priority setting, resource allocation and capacity building. Including COVID-19 pandemic increased demand for rapid training in PC.
	Training evaluations: Before and After training in 40hr Introduction to PC course	
	Capacity Building in PC – Training data;	
	Accessing 5 x training videos in COVID-19 pandemic	
Service Delivery	WCGHW packages of care and referral pathways; District Health Plan: Comprehensive Plan 2010; Healthcare 2030	To describe service delivery at each level of care, the referral processes, care pathway and operational integration of PC. Describe the package of care at ICF level with focus on PC provision and shared infrastructure. Describe the policy response to PC within HCBC. To understand and contextualise the UWC recommendations for HCBC. Procurement and Supply Chain Management consideration of PC.
	ICF Policy Framework	
	ICF Data	
	Policy on HCBC	
	Policy review of HCBC[129]	
	Provincial PC Position Statement and Plan for COVID-19 Response	
	Spiritual carer database Social worker appointments in the CMD	
Monitoring and Evaluation	WCGHW Indicator Data Set booklet	Identify and describe PC indicators and cascades, i.e., all forms of cancers, TB care, ICD 10 code for PC and conditions requiring PC. Indicator of morphine Usage at each level of care.
	PC cascade Identifiers and ICD 10 code headcounts	
	Morphine data	
Demand Generation	Ideal Clinic document (Signage)	Financial incentives, e.g., conditional cash transfers, insurance. Population interventions, e.g., education and promotion

4 .4.3. Data extraction and management

Various templates were created for all relevant data extracted, except for the ICD 10 coding, for the PC dataset, as it was provided by the Provincial Health Data Centre (PHDC) in a usable Excel format.

A template (Appendix 1a) was created in MS Word to capture the extracted data from each document that pertained to PC and the literature on the elements for integration.[8]

The following Excel templates were created to capture the relevant extracted data:

- Aggregated morphine data (Appendix 1b) that was received annually and then quarterly from the PHDC.
- Post course care training evaluations.
- Results of the pre-workshop survey for the health managers.
- Desktop review elements for integration that included spiritual carer access, training of health professionals in PC, functional multi-disciplinary teams at the different levels of care in the health system, ICF beds and related infrastructure.
- All categories of social worker capacity in the health system
- NGO funding

Table 4.4, overleaf, presents the development and utilisation of each template for data extraction. All templates were discussed with relevant role players, such as the finance manager in the metro health services (MHS), community-based services (CBS) coordinators and comprehensive health managers in two of the MHS sub-structures (SS), the PCTT members, or PhD supervisors.

Table 4.4: Templates for data extraction

Data included	Template development	Utilisation of data in template
All WCGHW internal documents that pertain to PC	This was developed based on foundation documents collected – see Table 4.2.	Title and date of document, summary of the section of the document that pertains to PC. The list of documents included are in Annexure 5 The annually reviewed WCGHW documents were captured in 2019 and 2021
Morphine Data	The template was developed based on the variables in the aggregated data received from the PHDC. One sheet was created for each sub-district and one summary sheet for the Cape Metro District.	Aggregated data for morphine dispensing, per facility in subdistricts annually (2013-2018) and quarterly (2019-mid 2021) was captured in Excel. Each of the eight sub-districts were captured on a sheet that linked to a summary sheet to provide a Cape Metro summary. Excel was used to create graphs to determine trends
Evaluation of the Introduction to PC training course.	Elements that were included in the course evaluations were used as the basis to develop the template. One sheet was created for each course and one summary sheet for the Cape Metro District.	The sum of each (10) staff category was captured for each SS and central hospitals. 133 post course evaluations were captured. Each course run was captured on a separated sheet which is linked into a summary sheet that was developed to provide a Cape Metro District summary.
Pre-workshop surveys of 28 middle and senior health managers' knowledge of PC	Elements that were included in the survey document was used as the basis to develop the template.	Anonymised data extracted from survey sheets and captured in template to inform the baseline assessment and the capacity building aspects. Aggregate data for each question and response was captured, i.e., 'true' or 'false'. The proportion correct vs incorrect responses for each question were calculated.
Desktop review elements of integration	The template was developed around the elements of integration according to Atun et al.[8]	Aggregated training data for health professionals in PC in 2019 and 2021 were captured. ICF funded, and operational beds and infrastructure were captured in 2019 and 2021. Functional MDTs that include PC at all levels of care, were captured in 2019 and 2021. Spiritual carer access database was captured 2019 and 2021.
Social workers capacity	The template was informed by the data variables as received from the MHS People Management sub-directorate.	Existing aggregated social work staff categories by level of care was captured by 2019 and 2021.
NGO Funding	The template was informed by funding norms for both the HCBC and ICF projects as provided by the Finance office of the MHS.	Funding norms for HCBC and ICF across the Cape Metro District was captured for 2019 and 2021.

The information, documents and datasets accessed for the desktop review and document analysis were captured and saved in password protected files on the researcher's laptop and backed up on an external hard drive that were placed in a lockable cupboard, accessible only to the researcher.

4.4.4. Data analysis

Documents were systematically reviewed using the READ[vi] approach to document analysis.[128] The first step was to read the materials according to the topic 'palliative care' and all documents available within WCGHW that included or made mention of PC for the period 2011 until 2021, were included. This was followed by data extraction as indicated in Table 4.3 and the documents were captured along a timeline to paint a picture of PC processes over time, allowing for comparison between baseline and 24 months following implementation of the PC policy. Data analysis was iterative, because the data was analysed as it was extracted with decision-making about which documents to include until a full picture emerged. The document review ended when saturation occurred and the researcher was satisfied that answers to the research question were found.[128] Content analysis was used to organize information pertaining to PC into categories that were related to the research question,[127] the policy content, contextual factors related to the health system characteristics and the adoption system. Furthermore, any process data that helped to paint the picture over time, was considered.

The post course evaluation from the 133 participants was descriptively analysed using Excel. This determined the proportions of each category of staff trained in the 40 hours introduction course to PC. Furthermore, the data was analysed to determine the proportions of participants who found that the course matched the learning outcomes and whether the teaching and engagement methods that were used, were deemed appropriate by the participants.

The pre-workshop survey for health managers comprised closed ended true and false questions and the data from this survey was entered into Excel and the proportions for each correct and incorrect answer was calculated to paint a picture of the baseline knowledge of the 28 middle and senior managers for each question included in this survey. The survey was designed to understand their perceptions of PC as end-of-life care, pain as an inevitable part of death and dying, and various truths and myths related to PC.

Morphine data was descriptively analysed by sub-district comparing the period 2019 to 2021, using Excel. A two-sample z-test was performed to compare whether the increase in the proportion of morphine use for the sub-structures (SS) significantly changed. The central hospitals located in the of the four sub-structures were removed so that only the PHC facilities, and the district and regional hospitals were compared across the four SSs.

Descriptive analysis of the ICD 10 code, Z51.5 for Encounter for PC, was performed to determine the baseline compared to the period 2019 to 2021.

[vi] READ steps: i. ready your materials, ii. extract data, ii. analyse data, and iv. distil the findings.128. Dalglish SL, Khalid H, McMahon SA. Document analysis in health policy research: the READ approach. Journal of Health Policy & Planning. 2020;35(10):1424-31, 128. Ibid.

To determine if the proportion of staff trained at baseline was different to the proportion of staff trained 24 months following implementation, McNemar's test was conducted with df=1 as the staff employed before and afterwards were largely the same. While some may have exited employment and others commenced employment, the majority would be the same. This population was tested at two moments in time stratified by staff category. The proportions of the ten staff categories trained in the 40-hour Introduction to PC course over time were calculated using Excel, and McNemar's test was conducted using STATA 13.1.

The data on numbers of spiritual carer volunteers, the appointment of social worker categories and proportion of functional MDTs were analysed using data at baseline in 2019 compared to 24 months later, in 2021. The proportions were calculated in Excel and McNemar's or Fisher's exact test were conducted using STATA 13.1 to determine if these proportions had significantly changed.

4.4.5. Ethical considerations

Beneficence and respect for persons as ethical principles were considered throughout all interactions with the staff who furnished the documents and data. The reason for the collection of the data was explained and where necessary the sub-study proposal and Ethics Approval was supplied.

Ethics approval was obtained from the UCT FHS HREC (Annexure 2 – HREC REF: 058/2019) and permission was given by the structures and health facilities within Western Cape Government Health and Wellness (WCGHW) to obtain data related to morphine drug prescribing; the PC cascade indicators; access to WCGHW documents that were not in the public domain, and the NGO data sets which included funding related to PC in the CMD. Attention was given to protecting confidentiality and ensuring anonymity of all NGOs and their staff.

The WC PHDC provided the various datasets and information required at baseline and again 24 months after the NPFSPC was implemented. The researcher worked with the PHDC to capture health service encounters relevant to PC in Metro Health Services and diagnoses where PC was required and to ensure data security along each step of the process. To protect patient privacy, only deidentified aggregated information related to ICD10 codes for PC at all health facilities, as well as morphine prescribing, supply, and health facility access points was provided. These were derived from individual patient records that contained patient identifiers. All stored data was password protected and individual level data was anonymised by the data centre before transfer to the researcher for analysis.

4.5. Results

The desktop and document review were conducted at baseline and compared to 24 months following implementation. A situational analysis of PC service provision was conducted between March and June 2019 to provide a baseline for comparison during the situational analysis conducted between March to June 2021.

The results are reported according to the health system characteristics as indicated in Table 4.2. For each characteristic, the documents reviewed is presented, followed by the data sources.

4.5.1. Governance and leadership

Document review was conducted on the approved WCGHW provincial management structure and the WCGHW annual performance plan documents.

Data source: the pre-workshop health managers' survey results were conducted at baseline only.

WCGHW management structure

In 2019 the departmental management efficiency and alignment project (MEAP) was underway, and the PCTT was resident in, driven from, and accountable to the office of the chief director MHS.

By 2021, MEAP had been concluded which resulted in significant changes to the organisational structure at a provincial level. This resulted in the establishment of the component Emergency and Clinical Services Support Chief Directorate, with governance responsibility for the transversal services of Emergency Medical and Forensic Pathology Services, and three clinical service support directorates (Medicine Management, Clinical Service Improvement and Service Priorities Coordination).[129] These changes repositioned the PCTT at a provincial level. The establishment of the Service Priorities Coordination directorate would now project manage all departmental priorities until they reach implementation and eventual integration. PC as a component of UHC, was well positioned in this new directorate. The researcher, as chair of the PCTT moved from the MHS level to the Provincial level, affording PC a seat at the operational executive structure for the WCGHW.

Annual performance plan for the WCGHW

In 2019, the Healthcare 2030 (HC 2030): The Road to Wellness, which was formally released in 2014, referenced UHC and the inclusion of PC at all levels of service delivery.[51] However, by March 2019, the annual performance plan of the department had not included or made mention of PC.[130]

By 2021 the WCGHW annual performance plan highlighted PC as a key component of UHC and reference was made to the United Nations General Assembly's adoption of UHC. Subsequently the most recent annual performance plan 2021-2022 mentions local demographic changes with increases in ageing population along with the increasing prevalence of non-communicable diseases, indicating the need to significantly expand rehabilitation and PC services.[131]

Surveying managers knowledge in palliative care

In 2019, 28 managers completed the pre-workshop questionnaire which was used by the PCTT to assess the baseline knowledge of the managers about PC. Figure 4.3 presents the proportion of managers in the CMD who scored incorrectly in the survey, which provided insight into the knowledge gap and focus areas for PC training workshop.

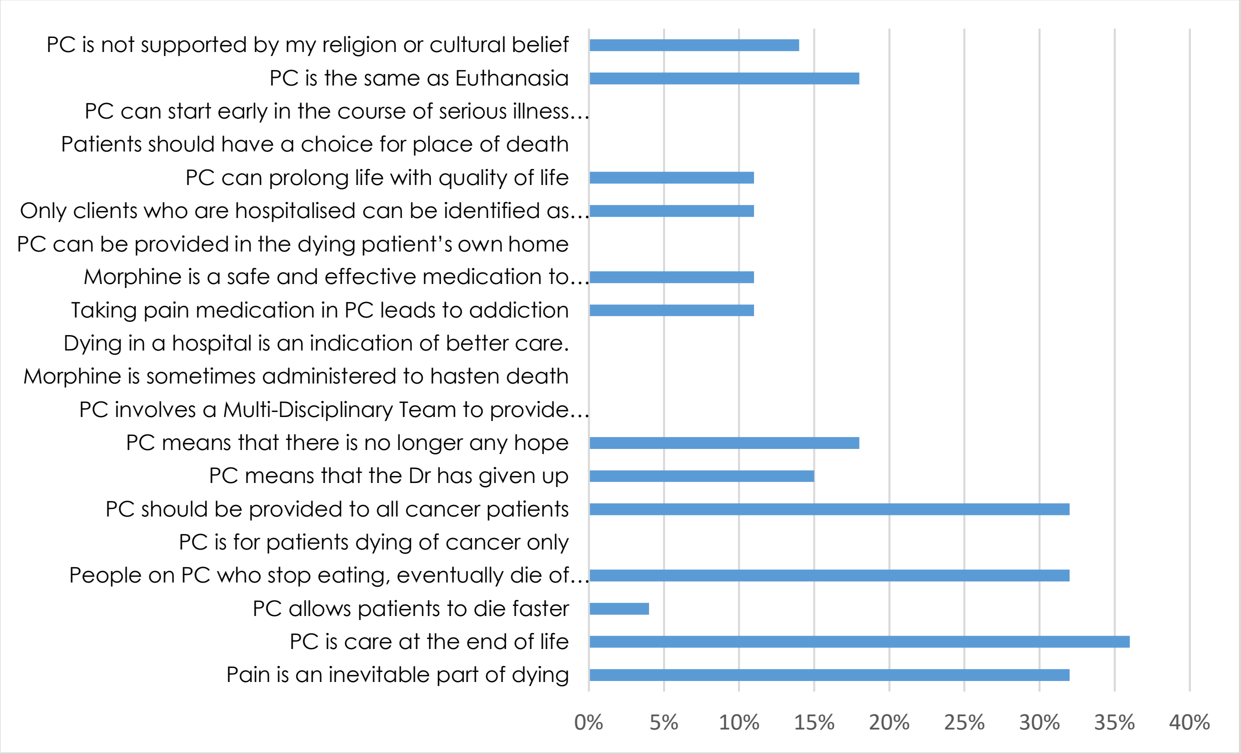


Figure 4.3: Baseline knowledge gaps of managers in the Metro (n=28)

The report on this survey revealed that 36% of managers regarded PC as end-of-life care only and saw PC as commencing when a life-limiting or life-threatening diagnosis is made. Pain management and control is critical to improve quality of life, including end-of-life care, and yet 32% of managers considered pain as an inevitable part of dying. Additionally, some misperceptions were that 32% of the managers believed that the PC patient who stops eating, eventually dies of starvation and only 32% agreed that all cancer patients should receive PC. Close on one fifth (18%) of the managers regarded PC as euthanasia, as an indication that there is no longer hope and that the clinical team have given up on the patient. Although 14% of the managers stated that PC is not supported by their religion, none gave reasons.

4.5.2. Finance

A document review was conducted on the annually amended NGO funding service packages that defines packages of care for various projects that NGOs are funded for, the PC funding business plan submissions, and ICF bed funding.

The data sources were the funding, in Rands, of all NGOs that provide home and community-based care (HCBC) and ICF projects, irrespective of whether PC is included, which increases year on year according to the WCGHW determined inflator.

NGO funding

In 2019, the NGO service package of care included "*users requiring palliative care for symptom and pain control*" as an admission criterion to ICFs.

By 2021, in the NGO service package, PC was further elaborated for HCBC projects and the intention to move towards UHC was articulated in this area of service delivery. This NGO funding service package was not amended at the provincial level, but at the district level. The MHS released an internal memorandum to define data flow and data collection methods for contracted NGOs, which included the home delivery of chronic medicines that included but was not limited to PC medicines, a need that arose during the COVID-19 pandemic.[132] Within 6 months, 760 812 chronic medicine parcels were successfully delivered to patients' homes by community health workers (CHWs).[133]

Palliative care funding business case

By 2019, the NDOH had not allocated a budget for the NPFSPC despite formal funding requests by means of business plan submissions by the WCGHW to the NDOH in 2017, 2018 and 2019. These submissions were acknowledged, but not funded.

In 2020, funding was allocated to PC, as part of the COVID-19 emergency response budget. This was the first budget allocation to the health services, to support the increased PC burden as part of the COVID-19 pandemic response. Vacant wards were identified at one Cape Town hospital and a dedicated 50 bed PC unit was funded and commissioned.

By 2021 the finance manager who serves on the PCTT proposed a different mechanism to request funding through the Provincial Treasury. This business case, aligned to progress in the NPFSPC implementation in the WC, was developed and submitted to the Provincial Treasury. The funding envelope request for R38m was provisionally and partially approved for R12m with effect 1 April 2022. A summary of this provisionally approved envelope is contained in the discussion chapter, Chapter 9.

Intermediate care facilities and funded beds

In 2019, the nine funded ICFs in the CMD were funded at different funding norms, ranging from R471 to R680 per bed per day. This is due to variations in the range of rehabilitation services offered at each ICF and a considerable difference in the number of beds per geographic area.

By 2021 this disparity remained and the funding norm per bed per day increased between 11,5% and 17%, thus ranging from R 525 to R 793 per bed per day. The number of beds in the ICF in SS3 increased from 187 beds to 237 beds for a period of 8 months to accommodate the COVID-19 pandemic in-patient PC needs.

Table 4.5 below, provides a snapshot of the funded ICF's in the CMD in 2019, compared to 2021 and indicates the disparity in the funding norms and types of services rendered.

Table 4.5: Funding and services framework governing ICF at baseline and 24 months later

Funding for ICFs and Types of Services

Metro SS	ICF	Type of Beds	Number of Beds		Funding Norm/bed/day		Types of Service Rendered	
			2019	2021	2019	2021	2019	2021
SS1	1	Adult	40	40	R527	R599	PAC; RC; Rehab; SW; SLT	PAC; RC; Rehab; SW; SLT and **PC**
	2	Paediatric	168	168	R527	R599	PC; PAC; RC; Rehab; SW; D; SLT	PC; PAC; RC; Rehab; SW; D; SLT
SS2	3	Adult	6	6	R476	R540	PC; RC; SW; D	PC; RC; SW; D
	4	Adult	10	10	R593	R674	PC; PAC	PC; PAC
	5	Adult	22	32	R471	R535	PAC; RC; Rehab	PAC; RC; Rehab and **PC Bed expansion based on geographic need**
	6	Adult	5	25	R471	R525	PAC; RC; Rehab; D; SLT	PAC; RC; Rehab; D; SLT and **SW**
SS3	7	Adult	187	237 (187)	R680	R728	PC; PAC; RC; Rehab; D; SLT	**Bed expansion PC COVID-19 x 50 bed unit**
SS4	8	Adult	20	20	R522	R593	PC; PAC; RC; Rehab	PC; PAC; RC; Rehab
	9	Adult	106	106	R680	R793	PC; PAC; RC; Rehab; SLT	PC; PAC; RC; Rehab; SLT

Abbreviations: **PC**: Palliative Care; **PAC**: Post-Acute Care; **RC**: Respite Care; **Rehab**: Rehabilitative Care (includes either of the following: Occupational Therapist, Physiotherapist or Rehabilitation Care Worker) ; **SW**: Social Worker; **D**: Dietician; **SLT** - Speech and Language Therapy

The total number of ICF beds had expanded by 17% from 564 in 2019 to 644 in 2020 (to accommodate the COVID-19 pandemic) and although this reduced to 594 in 2021, it remained 5,9% higher than baseline in 2019. The expansion in service package at each of the

ICFs and the expansion in bed number is indicated in red font. Since 2019, capacity for in patient care for PC expanded in three of the four SSs in the MHS's (SS1-3), increasing by between 5,85 and 17%.

4.5.3. Planning, priority setting, resource allocation, capacity building

Data Sources: PC training data – the number of staff per category trained against the short-term contract and the subsequent formal contract, formed the numerators and the same category staff in employ in the WCGHW formed the denominator. The scale-up training during the COVID-19 pandemic is also presented.

Planning, priority setting, resource allocation and capacity building is one of the terms used in Atun et al.'s framework within the heath system characteristics, and this includes training.

Short-term contract training in palliative care

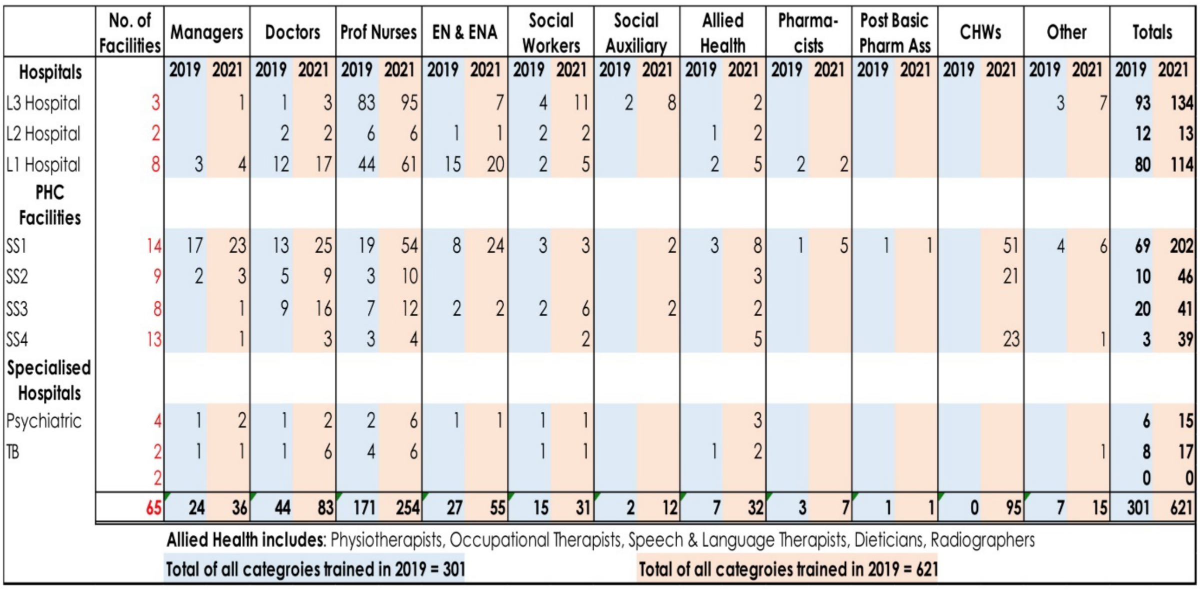
In 2019, PC training commenced and was driven by the PCTT. This was enabled by a short-term contract with the Hospice Palliative Care Association of SA (HPCA). In parallel, the supply chain management component within the WCGHW commenced the process for a formal 3-year contract for training.

As part of the short-term contract for the 40-hour in-person Introduction to PC course, 133 health professionals were trained in seven courses. Of these, 16% were (various) managers, 14% medical officers, 62% nurses, and 9% were social workers, pharmacists, and allied health professionals. At the end of each course, course participants were encouraged to complete the course evaluation and 91,7% of participants agreed that the content matched learning outcomes while 96,2% of participants agreed that the teaching and engagement methods used were appropriate.

Formal contract for palliative care training

In 2019, the training in the 40-hour in-person Introduction to Palliative Care course against the 3-year formal contract commenced but was halted in March 2020 with the onset of the COVID-19 pandemic. Table 4.6, overleaf, shows the progress made in PC training from 2019 to 2021.

Table 4.6: Palliative Care Training at baseline vs 24 months following implementation of the NPFSPC



	No. of Facilities	Managers		Doctors		Prof Nurses		EN & ENA		Social Workers		Social Auxiliary		Allied Health		Pharma-cists		Post Basic Pharm Ass		CHWs		Other		Totals	
Hospitals		2019	2021	2019	2021	2019	2021	2019	2021	2019	2021	2019	2021	2019	2021	2019	2021	2019	2021	2019	2021	2019	2021	2019	2021
L3 Hospital	3		1	1	3	83	95		7	4	11	2	8		2							3	7	**93**	**134**
L2 Hospital	2			2	2	6	6	1	1	2	2			1	2									**12**	**13**
L1 Hospital	8	3	4	12	17	44	61	15	20	2	5			2	5	2	2							**80**	**114**
PHC Facilities																									
SS1	14	17	23	13	25	19	54	8	24	3	3		2	3	8	1	5	1	1		51	4	6	**69**	**202**
SS2	9	2	3	5	9	3	10								3						21			**10**	**46**
SS3	8		1	9	16	7	12	2	2	2	6		2		2									**20**	**41**
SS4	13		1		3	3	4				2				5						23		1	**3**	**39**
Specialised Hospitals																									
Psychiatric	4	1	2	1	2	2	6	1	1	1	1				3									**6**	**15**
TB	2	1	1	1	6	4	6			1	1			1	2								1	**8**	**17**
	2																							**0**	**0**
	65	**24**	**36**	**44**	**83**	**171**	**254**	**27**	**55**	**15**	**31**	**2**	**12**	**7**	**32**	**3**	**7**	**1**	**1**	**0**	**95**	**7**	**15**	**301**	**621**

Allied Health includes: Physiotherapists, Occupational Therapists, Speech & Language Therapists, Dieticians, Radiographers

Total of all categroies trained in 2019 = 301

Total of all categroies trained in 2019 = 621

Training in SS1 had increased by 192%, compared to the other three SSs. The steady increase in managers accessing the training is noted, since the survey results for managers knowledge on PC (Figure 4.1), confirmed a knowledge gap. Despite the interruption in training due to the COVID-19 pandemic, 301 (1,5%) of 20 691 health professionals in the CMD were trained by 2019. By 2021 this had increased to 621 (2,9%) of the 21 382 employed health professionals. This is a statistically significant increase ($\chi2=18\ 600$; $p=0.00$), an increase of 106,3% trained health professionals overall, with 48,5% more professional nurses, 103,7% more enrolled nurses, 88,6% more doctors, and 153% more social workers having completed the training. The allied health professional baseline was low at 7 individuals, resulting in a 357% increase. Training for CHWs only commenced after the baseline was determined in 2019, resulting in an increase from 0 to 95 CHWs trained by 2021.

The proportions of various health professional categories employed in the CMD, trained in PC in 2019 and 2021 were compared using paired McNemar's tests. All increases in proportions were statistically significant ($p<0.05$), as is shown in Table 4.7, overleaf.

Table 4.7: Proportion of Various Health Categories trained in palliative care in the Cape Metro District

	2019		**2021**		**McNemar's Chi-sq statistic** (χ2)	**p-value**
	Total employed and trained in PC	Proportion trained	Total employed vs trained in PC	Proportion trained		
Doctors	44 / 2715	1,62%	83 / 2871	2,89%	**2432**	**<0.01**
Professional Nurses	171 / 4213	4,05%	254 / 4473	5,67%	**3340**	**<0.01**
ENs and ENAs [vii]	27 / 5039	0,53%	55 / 5318	1,03%	**4850**	**<0.01**
Allied Health [viii]	7 / 1168	0,59%	32 / 1186	2,69%	**1068**	**<0.01**

Need for rapid scale-up of palliative care training due to the COVID-19 pandemic

In 2020, during the COVID-19 pandemic face-to-face training was prohibited, yet the need for urgent PC training had significantly increased. The PCTT took on the responsibility of developing the 'Provincial PC Position Statement and Plan for COVID-19 Response' (see 4.2.7) which included the rapid production of five training videos based on the COVID-19 clinical guidelines for providing PC. The target audience were frontline doctors and professional nurses, and the intent was to equip clinical teams to provide the spectrum of care for in-patient PC, appropriate compassionate communication, symptom management and the skills to assess when the COVID-19 positive patients became eligible for PC. These five training videos were initially provided in the form of five 1-hour interactive webinars, that were recorded, edited, and uploaded onto YouTube to access at convenient times. Between 60 to 140 attendees attended these interactive online webinars. Although Table 4.8, overleaf, provides the number of views visible on YouTube, it is unclear how many health care providers watched to the end, so these views are regarded as the potential reach by the end of 2021. Notably, COVID-19 was a stimulus for many people to learn about PC. All training videos are easily accessible on https://coronavirus.westerncape.gov.za/health-workers. At some of the acute hospitals, the staff were overwhelmed to the extent that they found it difficult to make use of the resources at their disposal.[125]

Table 4.8: Palliative Care training video title, summary, and total views on YouTube as at end of 2021

Training Video Title	Summary	Total Views
Transitioning from critical care to PC	Focuses on deciding eligibility for PC, to withdrawal from ventilation to end-of-life care and approporuate compassionate communication.	2014
Protecting, caring and supporting PC patients during COVID-19	Focuses on decreasing the risk for known PC patients and explaores symptom management if a PC patient does develop COVID-19.	1258
Navigating grief in healthcare in the face of COVID-19	Focuses on equipping healthcare professionals, faith leaders and lay counsellors with key skills to support themselves and others through loss and grief in response to the pandemic.	1075
Engaging spirituality in healthcare in the face of COVID-19	Focuses on providing healthcare professionals, faith leaders and lay counsellors with essential skills for engaging spiritual matters in the response to the pandemic.	1001
Communication in COVID-19: Breaking Bad News	Focuses on the basic skills you will need to ease the breaking of bad news for your patients and for yourself and more importantly help you to build hope in the time of COVID-19.	1315

4.5.4. Service Delivery

Documents reviewed: policy framework for ICFs, HCBC service design framework, eCCR reports, SOP for requesting, issuing, returning, maintenance and control of PC equipment loan store.

Data sources: The use of the VULA application – used for patient referrals and specialist consultations, social worker category appointments, situational analysis desktop information on health services for PC,

Policy framework for intermediate care facilities

In 2019, the intermediate care policy framework document that was in place in the Western Cape[134] was signed and launched in 2012. In this policy document, intermediate care is referred to as the integration of inpatient services for post-acute-, palliative-, and respite care, as well as rehabilitation services.[134] The service has been provided by NGOs that received funding from the WCGHW. This policy refers to PC as passive care and to intermediate care as active and rehabilitative care.[134] By 2021, this policy document had not been reviewed and updated.

Home and community-based care service design framework

In 2019, the WCGHW's community-based care (HCBC) service design framework document was aligned to the HC 2030. Although the framework did not refer to PC, the patients that were cared for in the home environment by the HCBC teams were mostly bed bound, with or without pressure sores and incontinence. The HCBC package included the provision of full body wash, dressing changes and catheter care.

By 2021, the HCBC services had changed significantly even though the framework had not been reviewed and this was mostly due to the impact of the COVID-19 pandemic and the national state of disaster regulations. Many services offered in 2019 which included support to PC patients, had been reduced to accommodate the pressing need of home delivery of chronic medication parcels in order to reduce risk by decongesting heath facilities.[135] Furthermore, the MHS released a standard operating procedure (SOP) document, (internal memorandum: MHS 09 of 2020) addressing the data flow process for NGOs rendering HCBC services in the CMD. This outlined the key steps towards aligning data collation, capturing, submission, sign off and reporting processes at the SS level. The SOP positioned the NGO data within the SS Information Management units to improve accountability and ensure inclusion into SINJANI – the primary electronic information management system for the WCGHW to capture data.[132]

Structural, referral and counter referral systems

In 2019, the WCGHW did not have one standardised official referral system policy in place. Patients were down referred for further care to PHC services and the process varied based on whether liaison had been established between the referring health facilities and was dependent on the patient presenting at the referral facility. Down referral processes from L3 hospitals were further complicated by patient admissions from various sub-districts across the province.

The WCGHW does not have a standard referral policy in place and adequate referrals are dependent on the eCCR, the provincially developed electronic clinical discharge summary. Although not yet compulsory for referrals, it is used in many outpatient and in-patient units and has variable uptake.[117]

To facilitate the identification of the PC patient, a butterfly stamp to mark the folder of the patient in need of PC was implemented in the CMD.[65] In addition, referral stationery branded with the butterfly logo was developed to facilitate identification and referral of PC patients.[65] Hospitals are further complicated since patients are admitted to this level of care from various many sub-districts within the WC province.[65]

By 2021, the referral pathways for patients in need of PC had improved in the CMD due to the liaisons established and need for PC that was highlighted during the COVID-19 pandemic.[4]

The eCCR is in the final stages of development and with the built-in geo-locating capabilities, the hospital ward administrators can locate the appropriate referring PHC facility based on proximity to patients' home address. Furthermore, should patients not present at the PHC facility with referral letters, eCCR will allow the referral health facility electronic access to patients' details. The eCCR does not make provision for direct referral to ICFs and HCBC NGOs, and all patients are referred to these services from the in-patient or PHC facility, via the WCGHW community-based services coordinators in each SS.[117]

VULA application for consultations and referrals

In 2019, the use of the mobile phone referral application (VULA) had been in place for several years, at no cost, across the WCGHW, and enabled consultation with specialists and up referral of patients for certain disciplines. This application was one of the referral processes in place and had not yet been used for PC consultations or patient referrals.

By 2021, because of the COVID-19 pandemic, the PC champions in Mitchells Plain sub-district piloted the use of VULA for the consultation and up referral of PC patients. This was subsequently piloted in the Eastern sub-district at Helderberg Hospital. VULA referral data from July 2019 until Jan 2022 for the Mitchells Plain district hospital (MPDH) and from October 2020 until Jan 2022 for Helderberg Hospital is indicated in Table 4.9.

Table 4.9: VULA APP referrals for palliative care

	2019 (6 months)	**2020**	**2021**	**TOTAL**
Mitchells Plain District Hospital (MPDH)	34	304	497	**835**
Helderberg District Hospital	0	7	3	**10**

At MPDH there was steady increase in patient consultations and referrals using VULA, which was not the case at Helderberg Hospital. Year on year increase at MPDH was 794% in 2020 and a further 63% in 2021. Figure 4.4 (overleaf) illustrates referral details, provided by the VULA management team, for MPDH.

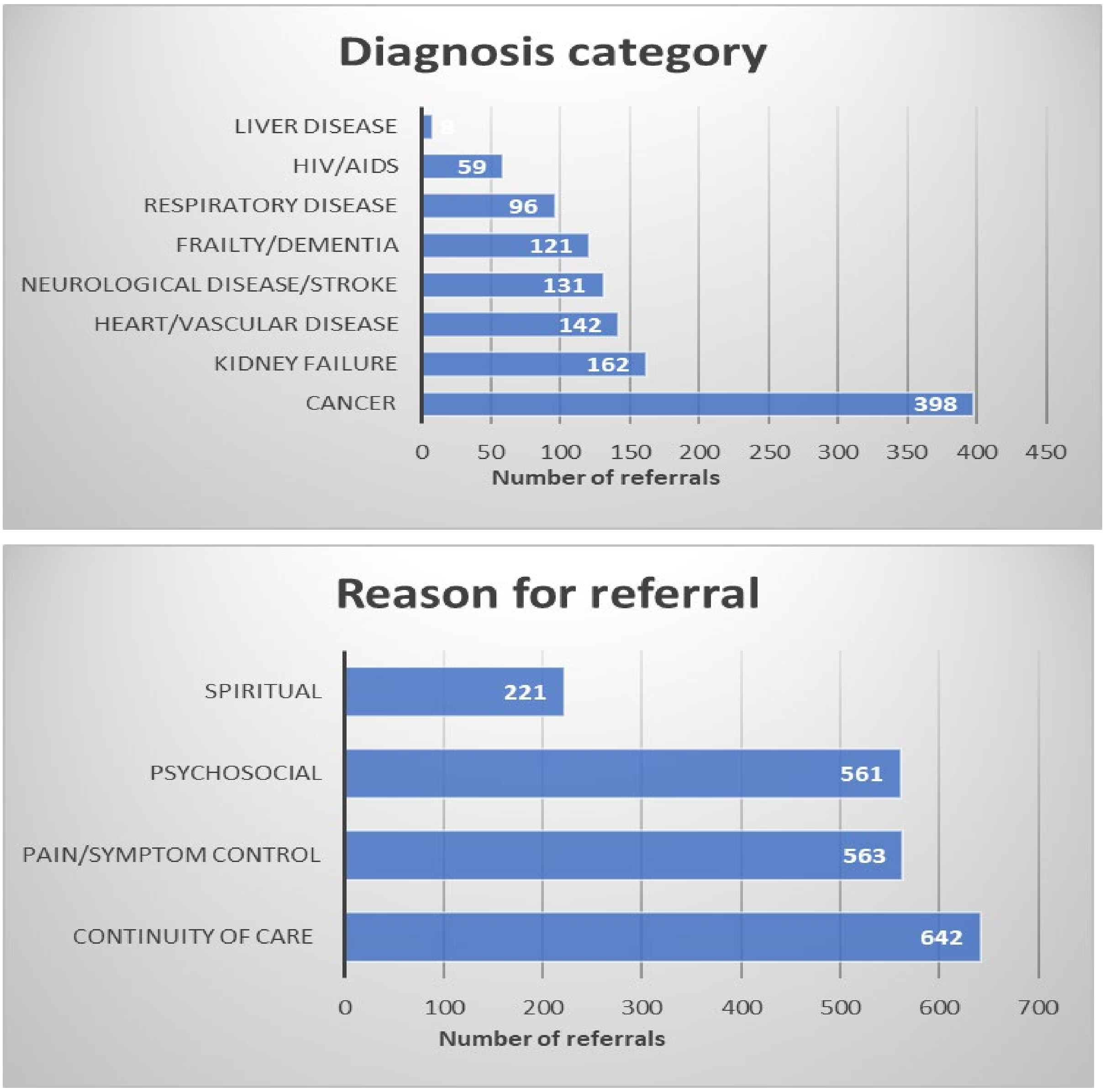


Figure 4.4: Reasons for referral and diagnosis categories at MPDH (n=835)

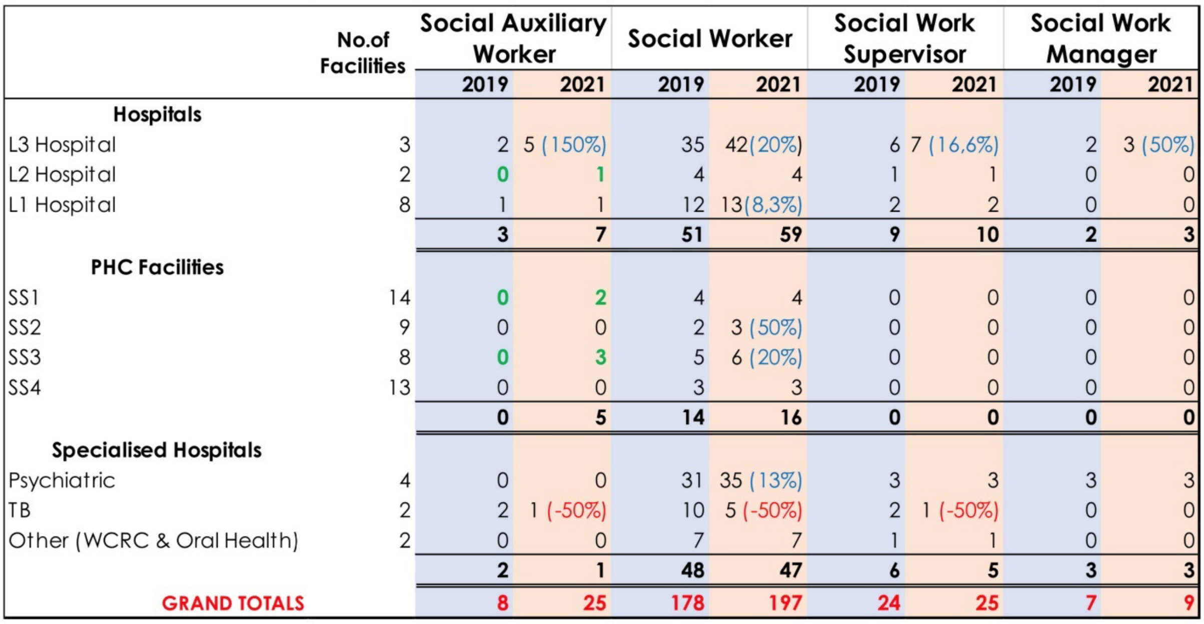
Patients were often referred for more than one reason, with 77% of patients requiring referral for continuity of care, while 67% required pain and symptom control as well as psychosocial support, and 26% required spiritual care. Considering that many patients presented with more than one diagnosis, the lead presenting diagnosis was cancer (35,6%), followed by kidney failure (14,5%), heart disease (12,7%), cerebrovascular accidents (11,7%), and dementia (10,8%).

Human resources: social workers

In 2019, various categories of clinical staff commenced training in PC from health facilities across the CMD and no additional dedicated posts were created for PC provision or coordination.

By 2021, a minimal upward trend in the various funded social work posts in the CMD was found, as indicated in Table 4.10, below. When comparing 2019 to 2021, three of the four SS (SS1, SS2 and SS3) had increased the recruitment of social auxiliary workers and social workers; the acute hospital platform and the central hospitals reflected the most significant increase in recruitment across all categories of social work; and the specialised TB hospital indicated a significant decrease in these posts.

Table 4.10: Social workers categories employed across the Cape Metro District at baseline and 24 months later



	No.of Facilities	Social Auxiliary Worker		Social Worker		Social Work Supervisor		Social Work Manager	
		2019	2021	2019	2021	2019	2021	2019	2021
Hospitals									
L3 Hospital	3	2	5 (150%)	35	42(20%)	6	7 (16,6%)	2	3 (50%)
L2 Hospital	2	0	1	4	4	1	1	0	0
L1 Hospital	8	1	1	12	13(8,3%)	2	2	0	0
		3	**7**	**51**	**59**	**9**	**10**	**2**	**3**
PHC Facilities									
SS1	14	0	2	4	4	0	0	0	0
SS2	9	0	0	2	3 (50%)	0	0	0	0
SS3	8	0	3	5	6 (20%)	0	0	0	0
SS4	13	0	0	3	3	0	0	0	0
		0	**5**	**14**	**16**	**0**	**0**	**0**	**0**
Specialised Hospitals									
Psychiatric	4	0	0	31	35 (13%)	3	3	3	3
TB	2	2	1 (-50%)	10	5 (-50%)	2	1 (-50%)	0	0
Other (WCRC & Oral Health)	2	0	0	7	7	1	1	0	0
		2	**1**	**48**	**47**	**6**	**5**	**3**	**3**
GRAND TOTALS		**8**	**25**	**178**	**197**	**24**	**25**	**7**	**9**

Table 4.11 below, shows the proportion of social workers and social auxiliary workers trained in PC in the CMD in 2019 compared to 2021. The categories of social workers, social work supervisors and social work managers were combined into one category, namely social workers. The proportion of total employed social workers trained in PC statistically significantly increased from 7,2% in 2019 to 13,4% in 2021 (χ2=39,2; p<0,0001) and the proportion of social auxiliary workers trained from 25% to 48%, which is not statistically different.

Table 4.11: Proportion of Social Workers and Social Auxiliary trained in palliative care in the Cape Metro District

	2019		**2021**		**p-value**
	Total employed and trained in PC	Proportion trained	Total employed vs trained in PC	Proportion trained	
Social Workers*	209 / 15	7,2%	231 / 31	13,4%	**<0,01**
Social Auxiliary Workers**	8 / 2	25%	25 / 12	48%	**0.41**

* McNemar's test   ** Fisher's exact test

Human resources: spiritual care and bereavement counsellor volunteers

In 2019, the four SSs did not have a spiritual counsellor database in place. One organisation offered spiritual support to the three L3 hospitals and some hospitals had access to pastoral care on a case-by-case basis.

By 2021, and because of the increased need for grief and bereavement support brought on by the COVID-19 pandemic, the SSs in the MHS had actively recruited volunteers from NGOs, faith-based organisations, community structures, and retired staff, to provide spiritual support. A coordinator, in each SS, was responsible for establishing the database for these volunteers, linking them to training, facilitating referrals to them, and ensuring their access to supervision. These SS spiritual care coordinators were linked to VULA to facilitate referrals via this platform. A volunteer team based at the provincial call centre, also provided spiritual support to patients and families.[42] Table 4.12 below shows the number of spiritual carers and referrals for spiritual care.

Table 4.12: Sub-structure reports[136] and VULA APP data set on spiritual carer access from mid-2020 to mid-2021

	Number of spiritual carers on database			**Number of referrals for spiritual care 2021**		
	2019	2020	2021	# of manual referrals	# of VULA referrals	Total recorded referrals
SS1	0	79	33	110	12	122
SS2	0	19	19	Data not on record	15	15
SS3	0	39	16		221	221
SS4	0	23	23		1	1
	0	**160**	**91**	**110**	**249**	**359**

Operational integration of palliative care

By 2019, one L3 and one district (L1) hospital had already achieved some operational integration for PC. In both hospitals, established core teams assessed PC eligibility and developed care plans for identified PC patients. At the L1 hospital, patients' folders were marked to indicate that the patient had PC needs. Care plans were developed, and patients were placed into support groups with the NGO that functioned as part of the PC team at the hospital. Furthermore, these patients were directly linked to the HCBC NGO to provide ongoing support in the home.

PHC facilities have established multidisciplinary teams (MDT) as part of the standard of clinical practice to discuss and manage certain patient groups. In 2019, 11% of the PHC facility MDTs had commenced the process of actively assessing patients for PC eligibility, developed care plans and ongoing care. These teams are referred to as functional PC teams.

By 2021, the two remaining L3 hospitals, one regional (L2) hospital and four additional L1 hospitals had progressed significantly towards operationally integrating PC with clear referral pathways to the HCBC NGOs for ongoing care and support and access for spiritual care. However, one L2 and three L1 hospitals have not responded to the request for providing feedback on their progress regarding PC.[125]

The functional MDT PC teams at PHC facilities had increased to 36%. Table 4.13 below reflects the comparison between 2019 and 2021.

Table 4.13: Functional Palliative Care teams at baseline vs 24 months later in the Cape Metro District

	No. of Facilities	Functional MDT Palliative Care Teams	
Hospitals		**Mar - June 2019**	**Mar - June 2021**
L3 Hospital	3	2	3
L2 Hospital	2	0	1
L1 Hospital	8	5	5
PHC Facilities			
SS1	14	3	4
SS2	9	0	1
SS3	8	2	3
SS4	13	0	8
Specialised Hospitals			
Psychiatric	4	0	0
TB	2	0	2
Other	2	0	0
	65	**12**	**27**

Although there has been a statistically significant increase – 56% (χ2=8,2; p=0,0042) in the number of functional PC teams, there is still a gap of 58% of facilities that do not have functional PC MDTs.

Each SS made provision for PC and end-of-life care beds, during the COVID-19 pandemic. In SS1 the ICF beds were preserved for known or newly diagnosed PC patients who were COVID-19 negative. In July 2020, an additional 336-bed transitional care in-patient facility was commissioned for the provision of care to COVID-19 patients. This facility was managed by the WCGHW and included 16 beds dedicated for palliative and end-of-life care.

SS2: The ICF beds in this SS increased by 30 beds across four NGOs and all beds were preserved for COVID-19 negative patients in need of PC.

SS3: In Sep 2020, during the COVID-19 pandemic this SS worked with the NGO that provided intermediate care to expand its service and commission a stand-alone 50-bed unit for the provision of PC to COVID-19 positive patients from the whole CMD. In Nov 2020, a 200-bed transitional care COVID-19 field hospital was commissioned, and at the end of March 2021, the 50-bed stand-alone PC unit was decommissioned and incorporated into the field hospital (temporary hospital set up to provide emergency care).[58] To facilitate referrals, information about the service, including admission criteria was communicated to all health facilities and to the community-based services platform across the Metro.[137] .[58] To facilitate referrals, information about the service, including admission criteria was communicated to all health facilities and to the community-based services platform across the Metro.[137]

SS4: The ICF beds were preserved for known or newly diagnosed PC patients who were COVID-19 negative. An 800-bed transitional care field hospital was commissioned and operated for 5 months and included beds for patients with PC needs and end-of-life care.

Procurement and supply chain management

In 2019, all processes for acquiring PC consumables and equipment were part of the usual procurement processes which often took up to three months. This resulted in many patients dying before accessing the necessary commodities.

By 2021, one of the SSs within the CMD had implemented a SOP for establishing a loan store (Annexure 6) so that CHWs could readily access equipment for the patient with PC needs and any patient who is cared for within the HCBC environment. This SOP clarifies the procedure that the CHW must follow to access, return, maintain, and control the equipment. This loan store is located on the premises of the district hospital in the SS and is managed by the two CBS coordinators for the SS.

4.5.5. Monitoring and evaluation

Data sources: Morphine usage data and ICD 10 code (Z51. 5 - encounter for PC)

Indicators that are specific, measurable, achievable, realistic and time-bound are important when monitoring progress of any health programme or policy from input, to activities, outputs, outcomes and impact.[138] As numbers of patients accessing PC were not collected, the tracer indicators, morphine dispensing was identified as a proxy for provision of PC and ICD10 code (Z51. 5 - encounter for PC) was utilised.

Morphine use

Figure 4.5, overleaf, shows that the morphine usage among patients presenting at PHC facilities and district hospitals in the CMD decreased by 3% overall when comparing 2019 (n=5848) to 2021 (n=5646). There was huge variation by sub-district – four sub-districts decreased between 3% and 35%, while four sub-districts increased between 9% and 19%.

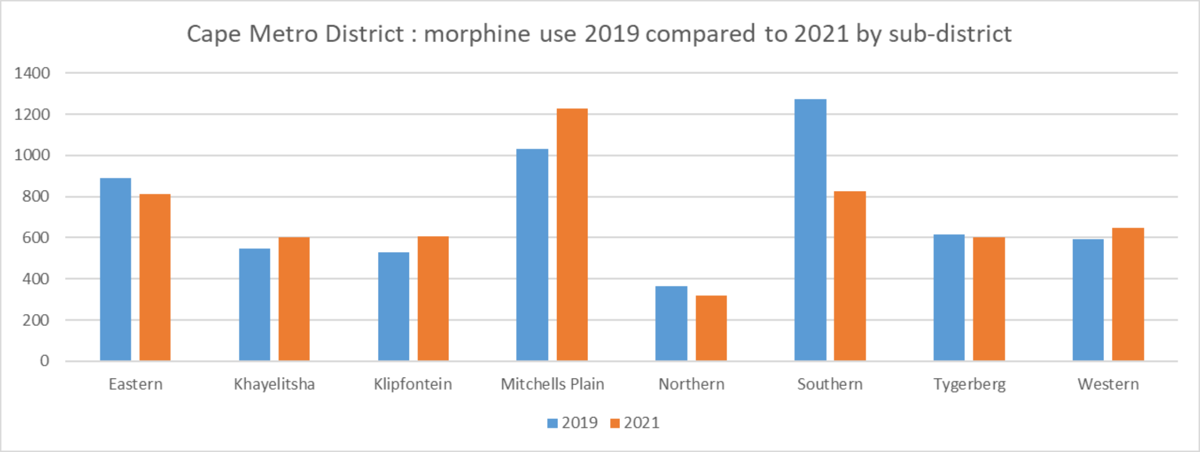


Figure 4.5: Morphine Usage per Sub-District - 2019 compared to 2021

Table 4.14 below shows the highest percent increases in overall morphine usage were within the Mitchells Plain and Klipfontein subdistricts with increases of 19% and 15% respectively, followed by Khayelitsha and Western sub-districts with 10% and 9%. A two-sample t-test was performed to compare the proportions increase of morphine use at the four sub-districts in 2019 and 2021. Using the z-test, these increases were statistically significant (p- <0.05).

Table 4.14: Comparing morphine usage in 2019 to 2021 - sub-districts that increased

Sub-district	**2019** **n = 5848**		**2021** **n = 5646**		**p-value**
	Morphine usage for sub-district	Proportion morphine use (of total prescriptions)	Morphine usage for sub-district	Proportion morphine use (of total prescriptions)	
Mitchells Plain	1030	17,61%	1228	21,74%	**<0.01**
Klipfontein	531	9,08%	608	10,76%	**0.0026**
Khayelitsha	548	9,08%	604	10,69%	**0.0038**
Western	595	10,17%	648	11,47%	**0,0248**

One of the four psychiatric hospitals reported one morphine use in 2019 and one of the two TB hospitals reported on a small number of patients to whom morphine was administered in both 2019 and 2021.

Episodes and Cascades

In 2019, the PC ICD10 coding which can be viewed on the WCGHW web-based dashboard known as the Single Patient Viewer (SPV), reflected 98 encounters when excluding central hospitals and 148 when including these facilities.

By 2021 and as indicated in Figure 4.6, overleaf, the ICD 10 code has notably increased when compared to 2019.

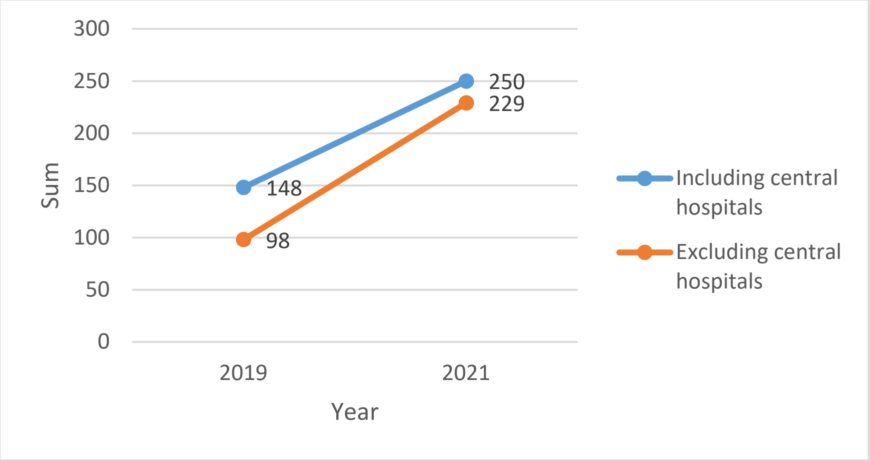


Figure 4.6: Annual totals of ICD 10 (Z51.5) for Palliative Care in the Cape Metro District between 2019 and 2021

National Indicator Data Set

In 2019, the NPFSPC included a set of indicators to monitor progress towards implementing PC. Indicators for the availability of essential medication, facility implementation, teaching and training, finance, governance, and community engagement, were included. However, these indicators have not been added to the national indicators data set (NIDS).

By 2021, the proposed indicators (Annexure 7) in the NPFSPC have been further refined through a national PC platform and has been submitted for consideration to the NIDS for both adult and paediatric PC.

4.5.6. Demand generation

The demand for PC is enhanced when awareness is increased. None of the documents reviewed provided an indication of efforts to increase awareness of PC. However, the COVID-19 pandemic brought an awareness regarding what PC is, the need for the provision of this service and the gaps at the time in providing PC within the public sector services.

4.6. Discussion

When comparing PC in the health system of the CMD at baseline, following the implementation of the NPFSPC, to 24 months later, it appears that some of the high-level structural changes as well as the critical event – COVID-19 pandemic – had impacted the context and the process of PC integration into the services. The underlying reason for the movement from no integration to partial integration are discussed.

The actionable indicators for countries to use to monitor progress for PC programmes, the conceptual model for PC development at country level, provided by the 2021 WHO report,[2] provides a model and indicators that focus on specialized PC programmes at country level. These include the presence of PC in health policy, availability of essential medicines, undergraduate and specialist PC education and training, empowerment of people and communities, and research.[2] Atun et al. (2010) on the other hand provides a conceptual framework to assess and determine the extent of integration of an intervention, in this instance PC policy and related services, into the health system.[106]

4.6.1. Context

According to Atun et al. the broader context and the health system are intricately linked, and therefore changes in the health system can affect the broader context and similarly changes within the broader context can influence the health system.[107] While this sub-study reviewed the implementation and integration of PC into the routine health services in the CMD, it was hugely impacted by the COVID-19 pandemic which highlighted the need for PC.

Impact of COVID-19 on palliative care

COVID-19 facilitated increased resources - financial, infrastructural, and human resources. It enabled the rapid development of training material, in-situ support for clinicians and the development of patient referral mechanisms. It affected the perspectives of all personnel – from top managers to health care workers (HCW) working with patients on the frontline in health service delivery. Over 2020-2022, many people experienced the loss of a family member or friend. For health workers this has foregrounded the importance of PC.

There is no clear answer to the question as to whether the NPFSPC alone could have resulted in PC integration. The experience of starting up such services over this time was heavily influenced by the global COVID-19 pandemic. It occurred between the baseline and follow-up assessment on the extent of integration of the NPFSPC. COVID-19 highlighted the need for rapid access to PC and has flagged PC in the minds of many HCWs who faced many patients who were dying alone and without support and access to PC. However, without an intentional focused implementation plan, many of the gains during COVID-19 could have fallen by the wayside, in view of the realisation, post COVID-19, of the many services had been neglected and deserved attention.

Globally, according to Bausewein et al. (2022), the COVID-19 pandemic has highlighted the need for pandemic preparedness to include the provision of PC at all levels of care including the home environment, for severely ill and dying patients and their relatives.[139] Furthermore, as seen in the referral data in this sub-study and as confirmed by Ferrell et al. (2020), there is the need for spiritual care generalists and specialists to respond to spiritual suffering as a result of unexpected death, loneliness and isolation that came with this pandemic.[140] Although the SSs had each put mechanisms in place to identify the spiritual care coordinator for the geographic area to coordinate rapid access to spiritual care, the data shows that spiritual care was not equally prioritised across the health care platform within the CMD.

4.6.2. Governance and leadership

WCGHW management structure

The restructuring of the WCGHW provincial management structure over the 2019-2021 period brought about a more strategic, integrated whole system organisational design, and did away with silos that managed components separately. This enabled the integration of people, processes, performance, and culture for the whole system. This sub-study has found that these changes to the organisational design has not only demonstrated intentional integration between operations and corporate governance but relocated PC policy and service priority policies at the Operational Executive Committee level. Furthermore, this restructuring exercise has positioned the leadership as a collective to agree that it is important to support people through change and with change comes the natural consequence of continuous improvement.[129] The PCTT primarily operated as a CMD entity[64] and changes to the provincial structure has located the PCTT function at a provincial level. This brought the entire province into strategic alignment with the NPFSPC.[5] PC is now tabled at the appropriate provincial platform as it relates to the functional and accountability arrangements within the WCGHW.

Value of managers knowledge on palliative care

The survey conducted with managers to determine their baseline knowledge on PC before attending the roadshow on PC information session, highlighted various gaps. These managers, as leaders, play a vital role in the MHS and consequently it was imperative that investment is made in improving their knowledge and understanding of PC policy, the need for integration, and the support that the operational teams require. The WHO guides for programme managers(2016)[113] and planners, implementers and managers (2021)[7] confirms this, and Dahlin et al. (2019) in a study focusing on interdisciplinary palliative leadership, reports that PC leadership is essential to promote the focus on patient-centred quality care and navigate the change in service delivery.[141]

WCGHW Annual Performance Plan

The WCGHW annual performance plan (2021/2022) has incorporated PC service delivery, which is aligned to the relevant legislative and policy mandates as well as to the HC 2030 strategy towards UHC. However, PC performance indicators have not been included in this plan,[131] since the national indicator data set that guides and requires alignment of the provincial indicator data sets, had not yet included these.

4.6.3. Finance

This sub-study showed that while the NDOH has not responded to formal submissions for seed funding for PC policy integration, in view of the COVID-19 pandemic the WC Provincial

Treasury provided funding for PC services to address this rapidly growing service need. An initial investment was required for PC integration, which should kick-start implementation. However, it is too early to discern if uptake of these services is sustained. These services were funded from the provincial budget signifying the confidence that government, with competing demands, had in the work of the WCGHW. During the local COVID-19 epidemic, there were daily updates with the provincial Premier, ongoing liaison with other departments, which may have resulted in the trust that such allocations signify.

The importance of initial funding for PC policy development, education and training, and increased staff, is raised in a study conducted by Krakauer et al. (2021) on essential PC needs of women with cervical cancer in LMICs. They argued that such funding would yield a huge return on investment and that required medication and equipment is inexpensive and basic training is effective.[111] This was also found by Byock et al. (2006) where 22 projects using innovative models of palliative and end-of-life care across various population settings and groups in North America demonstrated that the cost of care provision was either unchanged or decreased.[142]

This sub-study showed that the WCGHW funded NGO service package, that is included in the service level agreements, has seen a considerable change with the inclusion of PC in the package of care for home and community-based services. Modelling the capacity for home medicine delivery, Brey et.al. (2020) estimated that 200 000 chronic medication parcels could be delivered by the 2500 CHWs within the CMD and this translates into 4 parcels per CHW and allows for adequate time in the day to perform other agreed duties.[143] Notably medication for patients who were eligible for PC, were included and Brey et al. confirms no additional cost was incurred to the health system.[143]

The sub-study also showed that the intermediate care beds in the CMD have increased by 30 beds in total and the service packages offered at ICFs in three of the four SSs had expanded since the baseline situational analysis. There was an increased need for more beds since the COVID-19 pandemic as confirmed by Peters (2022).[58]

4.6.4. Planning: capacity building

This sub-study showed that significant progress has been made in training health care professionals in the 40-hour introduction to PC course, and more than double the number of healthcare providers were trained when comparing 2019 to 2021. Furthermore, the virtual training platforms for the rapid scale-up of training to accommodate clinician needs for decision-making related to PC during the COVID-19 pandemic, was well attended and accessed.

Despite the uptake in basic training, local training needs analyses have been skewed and difficult to project in absence of a skills framework or matrix approach. These training matrices are mostly multi-dimensional, meaning that certain job functions require specific training and employees should be assessed accordingly to determine their training needs. Pereira et al. (2021) showed that large scale training in PC requires much consideration for the methods, learner location and circumstances, class size, course length, content, and teaching method options, to accommodate the needs of the PC clinical teams. This Canadian study demonstrated that interprofessional learning approaches to PC course design are essential to effect large scale training in PC.[144]

4.6.5. Service Delivery

As mentioned, COVID-19 highlighted the need for PC across the whole health system. This set the stage to review the service platform to ensure access to PC services at each level of care to address the burden of disease for the population.

Intermediate Care Facility (ICF)

This sub-study showed that appropriately sized ICFs that are aligned to a population-based approach to planning of ICF services, are required in each sub-district.[134] A review of the policy framework for intermediate or transitional care is needed that includes the training requirements for ancillary health workers (National Qualifications Framework Level 1-4), defines the role of the SS management teams to foster strong collaborative working relationships between the ICFs, the HCBC services and acute hospitals. This study differentiates between the terms PC and end-of-life care, which are used interchangeably in current ICF policy documents. The national policy proposes indicators that have evolved over time through extensive consultation. These include indicators regarding essential medicines, facility level implementation, teaching and training, finance, governance, and community engagement (Annexure 7).

The sub-study showed the ICF bed expansions in 2020 because of the COVID-19 pandemic, with a decision to continue with 50 additional ICF beds beyond the first three waves of the pandemic. This indicates a commitment to continued provision of in-patient care for PC patients. Furthermore, a pamphlet detailing admission criteria for PC referrals was designed and implemented.[137] Zimmerman et al. in a Canadian study (2006) with cancer patients, supports the importance of clear admission criteria to ensure acceptable length of in-patient stay and deaths.[145]

Home and Community Based Care Services

This sub-study showed an important shift at 24 months post PC policy implementation, with the inclusion of HCBC NGO data within the SS information management system. This addition makes for a complete data set for the PHC platform activities and services in an integrated report that supports the COPC approach and related decision-making for all services including

PC. Although this is seen as progressive, a study conducted by Mueller-Hirth (2012) with 40 NGO managers in SA, found that while funding for NGOs is becoming more scarce, the monitoring and evaluation expectations have increased and NGOs are not able to express the complexity that they face when international and local donors are only interested in outputs.[146]

Referral mechanisms

This sub-study showed that while there is no standard referral mechanism in place in the WCGHW, various context specific mechanisms have been explored, such as VULA and eCCR. VULA data shows that active consultation, patient referral, and the PC service provision that spans the hospital, CHCs and HCBC with this seamless direct referral, is in place at some health facilities. The WHO, in a guide for programme managers[113] on implementing PC, indicates that it is the responsibility of the national health system to ensure that referral mechanisms are in place and this includes the PC patient across the care continuum.[113] This however, is not in place in the WC and requires attention.

Human Resources

In view of Gwyther et al.'s,[147] report that social workers are uniquely positioned and qualified to work as a crucial component of the interdisciplinary team in the provision of PC, making for integration of PC across the CMD, an assessment of appointment and training of this staff cadre was undertaken. There was a significant increase in the recruitment and appointment of all social work categories. The concerning area is the TB hospital setting where the numbers of social workers had reduced. Social workers roles often extend beyond the functioning of the team within the health care setting, into the larger community setting.[147] However, in SA, PC was not included in the undergraduate training of social workers[147] and in addition a spiritual counsellor, albeit volunteer, database in each SS was established.

Operational integration of palliative care

This sub-study showed an increase in operational integration of PC through improved referrals to HCBC for eligible patients and a significant increase in the public sector health facilities that have functional MDTs that include PC.

4.6.6. Monitoring and Evaluation

In view of no data routinely collected for patients accessing PC services out of hospital, the proxy indicator of morphine usage was selected as it is a recognised indicator for the availability of PC services. This data can be used to determine levels of morphine use and changes post policy implementation. It provides useful information to determine where to focus resources, training, and efforts with regards to PC service planning and prioritisation.

This sub-study shows that in the CMD, SS3 (both the Klipfontein and Mitchells Plain subdistricts) significantly increased morphine dispensing compared to the other six Metro subdistricts. This shows how actively the policy is being implemented and benefitting the patients in these subdistricts. The lower morphine utilisation areas can learn from the higher-performing facilities, comparing their practices and explore how these successes can be implemented within their context. Both subdistricts had started looking at ways to improve PC services before the policy was being implemented. They had initiated focused PC clinics at a PHC level run by the family physician or a medical officer. The smallest increase was found in the Tygerberg subdistrict at 4% of the overall morphine use. This subdistrict's challenges with implementation of the policy can be partially explained by the resignation of the PC champion at the facility with the largest PC headcount before the end of 2020.

The 3% decrease in overall morphine use between 2019 and 2021 may be a direct result of the COVID-19 pandemic, as services and resources were redistributed and de-escalated due to the overwhelming platform response required to treat patients with COVID-19. As a result, existing/known PC patients were negatively impacted in certain geographic areas regarding access to medication for pain control. It is anticipated that morphine use will increase with resumption of usual services, post pandemic.

An analysis conducted by Hofmeyr (2021) on the oral use of morphine at primary healthcare facilities within the CMD, indicates a lack of confidence in prescribing at the lower levels of care. Morphine was prescribed at L3 at a higher rate per 100 000 outpatient visits than at the district hospital or primary care level.[148] The morphine consumptions data for SA has increased since 2013, particularly between 2018 and 2020 when it increased four-fold (from 7mg/person to 28 mg/person). Although this has been a significant increase in morphine consumption, SA compares poorly to UK Britain's consumption which was as at 55 mg/person in 2020. However, SA is part of the AFRO region (according to the United Nations), where the average consumption is 1,75 mg/person and the global average consumption is 6,1 mg/person.[149] This re-iterates that SA together with other African and LMIC countries have an inadequate use of morphine.[149] Disparities in pain management is not unique to LMICs, according to Nguyen et al. (2023). In the US racial and ethnic disparities persist, and disparities amongst vulnerable populations, the elderly and rural communities persist in pain management.[150]

ICD10 codes for diseases that indicate PC disease consultations or admissions ('episodes') which will later feed into the PC cascade, are still in development. These would include the ICD10 codes for TB, HIV, cancers, mental health, cardiovascular disease, chronic kidney disease, and some paediatric codes. The current non-disease specific PC eligible cascade used in this sub-study includes co-morbidities of episodes that have been created/defined in the PHDC together with morphine use. By 2021 and as indicated in Figure 4.6 the ICD 10 code has notably increased when compared to 2019. However, based on PC need this may be under-reported as these numbers hardly changed when central hospitals were included or excluded. This is not unique to the CMD, as a study in Thailand hospital conducted by Fumaneeshoat (2018) between 2012 and 2016, found that even though patients had access to good PC, the use of ICD 10 codes was low.[151]

The PHDC continues to work on the 'PC eligible' cascade based on the episodes of three non-disease-specific evidence that can initiate an episode. These are ICD10 codes (weak-moderate evidence), morphine dispensing for 1-2 months (weak-moderate evidence) and morphine dispensing for more than two months (higher confidence). While progress has been made with PC eligibility criteria for cancers and renal disease, these have not yet been validated.

Atun et al.'s conceptual framework has formed the basis for a matrix tool for assessing policy integration (Annexure 4). Based on a scoring, it was designed to assess the extent (full, partial, or no integration) of integration of PC in health systems. It is discussed further in Chapter 9.

4.6.7. Strengths and Limitations

The baseline for this sub-study took place before the COVID-19 pandemic and the 24 months following implementation occurred at the time of the 3rd wave of the pandemic. The pandemic presented an unnatural event and highlighted the need for PC, which catalysed the introduction of PC into the health system.

Limitations include the assumption that no staff attrition had taken place in the CMD, and that the workforce was stable. This assumption may affect the proportions of staff trained in PC, and consequently the validity of the statistical tests used to determine whether these had changed. In addition, it is too early to tell if PC initiatives are sustainable and to determine the exact extent of integration. Finally, the matrix tool for policy integration, a product of this study, will require a further validation process.[152]

4.7. Conclusion

This sub-study investigated the integration of PC services within the public sector health system of the CMD between 2019 and 2021. While it has highlighted some gaps and opportunities, it shows that there has been a significant shift towards integrating PC into the health system. The CMD has moved from no integration in many of the health system characteristics analysed to partial integration.

PC has been positioned within the provincial structure of the WCGHW. The WCGHW has progressed in including PC in important policy and strategic documents, but implementation plans are required to guide next steps to line and programme managers. PC indicators are required to adequately monitor progress towards integration, yet available indictors such as morphine data and ICD-10 coding was used to provide an indication of PC services.

Training staff in PC is essential and significant progress has been made amongst various health professional categories. Further scale up is required as part of catch-up training for already qualified health professionals, such as the contracted 40-hour introduction to PC course. A motivation for the inclusion of PC training in appropriate health professionals, including social workers, health science undergraduate training programmes at higher education institutions is required, as well as consideration for training in and access to PC specialists. Training in PC for CHWs providing HCBC will need to be prioritised, as they are critical role-players in providing PC in the home and supporting family caregivers. Maintaining the spiritual counsellor volunteer support is important and will require sustained efforts. The need for social worker categories to support PC within TB hospitals and across the health platform, must remain on the SSMT agenda and receive attention in human resources planning. Disparities in the service scope, location, and funding envelope for ICFs must be reviewed to ensure equity in packages of care and geographic access to ICFs within every sub-district. The matrix tool for assessing policy integration was developed during this study. Although it will require further validation, it is a tool that can be modified and applied to policies other than PC.

In summary within the WC province, three factors have been identified that could be viewed as enablers for PC policy integration into the health care system. Firstly, a top management structure that is supportive and has bought into the PC policy content and proposal for integration in the health system. Secondly, HC 2030 The Road to Wellness[51] – the long-term vision that guides the WCGHW mandate and shifts the departmental approach towards a person-centred health system approach, focused on wellness and the need for UHC. Finally, the COVID-19 pandemic exposed the gap in the provision of PC and required a rapid response.[1]

The next chapter, Chapter 5, focuses on the enablers and obstacles to PC service provision as highlighted by various management teams, actors that form part of the adoption system, in the CMD.

Chapter 5 : Enablers and Obstacles to Palliative Care

Chapter 4 provided an overview of the state of palliative care (PC) 24 months on from baseline, after implementation of the National Policy Framework and Strategy on Palliative Care (NPFSPC) in the Cape Metro District (CMD). This chapter focuses on relevant actors' perceptions of PC at baseline, within the adoption system. By nature of their role, relationships and management support to the service delivery teams, they may influence the extent of integration of the NPFSPC or any intervention into the health system.[153] Furthermore, power skill sets and training of the various actors in the health system, as well as attitudes and skills of providers of health care, were considered.

5.1. Introduction

First, the application of the Atun et al. framework for analysing integration of targeted health interventions into the health system with specific reference to the adoption system is unpacked.[8] Then, the influence that various actors could have on the adoption of the PC policy is outlined, including their perceptions regarding PC and their relationships.[102]

Actors within the health system include policy translators, health managers at various levels, doctors, nurses, social workers, lay health workers, patients and family, and the greater community.[8] The relevant actors included in this chapter are the sub-structure management teams (SSMT) led by a director (senior manager), the operational and operations manager of the various primary healthcare facilities, the chief executive officers and clinical managers at the district hospitals, and managers of the non-governmental organisations (NGOs) that provide hospice and intermediate care services.

The SSMTs are responsible for ensuring that service priorities are identified in their geographic area, that relevant and appropriate services are delivered that respond to the needs of the dependent population and that the broader departmental priorities are included in operational planning and execution. These are ensured through leadership, governance and stewardship, as well as policy decision-making for the community-based services (CBS) platform which comprises home and community-based care (HCBC) and intermediate care facilities (ICF); primary health care (PHC) facilities which comprise 24-hour community health centres (CHC) and 8-hour community day centres (CDC); and the district hospitals in the SSs' geographical area. The managers in the district hospitals and PHC clinical settings are responsible for operationalising policy and providing implementation support to the implementers.

The NGO managers work for the ICFs that are funded by the Western Cape Government Health and Wellness department (WCGHW), and for the hospices that are members of the Hospice Palliative Care Association (HPCA). Most of these NGOs are funded by the WCGHW in the CMD. These hospices and ICFs have the historical advantage of providing PC since 1979[5] and are experienced in providing in-patient and community-based PC services. The reliance on the NGO sector alone, for the provision of PC does place sustainability at risk, particularly in this constrained fiscal environment. This is confirmed in a qualitative study conducted by Rhee et al. (2018), interviewing 16 PC experts in 7 African countries.[154]

5.2. Literature Review

5.2.1. Integration of palliative care

Globally, the integration of PC into the public sector health system has taken on various forms. This ranges from inclusion in national policy documents to integration into public hospital and primary healthcare settings, to inclusion in various disciplines and training programmes.

A review of the local and international literature about integrating PC into public sector health systems highlights enabling and obstructing factors. A study focusing on five European countries has emphasised the importance of "*diplomacy*" (skilful, kind communication) and compassionate care, and the importance of attitude to ensure trust for deepened relationships between health care provider (HCP) and the patient and family caregiver.[155] In Croatia (Počanec et al., 2022), the integration of PC into the health system commenced in 2014 and enablers included changes to organisational structure, stakeholder empowerment, staff education, and a bottom-up model for PC.[156] This is supported by studies conducted on palliative care integration in the PHC platform, in Kyrgyzstan (Mukambetov, 2018) and Iran (Barasteh, 2021), which further indicate that the inclusion of PC in national policy and law, and in undergraduate nurse and medical training, access to essential opioids, nation-wide advocacy to gain civil support, and the support from other government and non-government sectors were enablers to PC integration.[157, 158] The multi-country review conducted by Abu-Odah et al. (2022) concurred with these enablers and added that identification and securing of financial budgets to enhance PC services is required.[73]

The solution advocated by Luyirika et al. (2016) to meet the need for PC in five African countries is to integrate this into existing healthcare systems. They make a case for prioritising national PC policy, confirm the lack of critical mass of PC health professionals, and add that documented shared practice will aid policy development in low- and middle- income countries (LMIC).[25] Kamonyo (2018) focused on the PC journey in Kenya and Uganda and reported that obstacles to PC integration in these two countries included policy and regulatory limitations, failure to integrate PC services into public and private sector services, inadequate numbers of PC trained health care providers, dwindling budgets, and general lack of awareness amongst the public and government officials.[159] Luyirika et al. (2022) reported progress in PC across five African countries[vii] up to 2020, and found that Kenya and Rwanda

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[vii] Kenya, Rwanda, Uganda, South Africa and Tanzania

had made significant progress in scaling PC services within their public sector services. In the case of Uganda, the government had instructed public hospitals to provide PC services, whilst South Africa (SA) and Tanzania had not yet committed to public funded PC services, [160] despite the NPFSPC being launched in SA in 2017.[5]

Many studies have been conducted globally, including in SA, focusing on the benefit of integration of PC with various disciplines and training programmes, including emergency medical services, oncology, emergency departments, family medicine, pandemics, and undergraduate medicine training.[24, 95, 111, 161-163,164, 165,166-169] In separate studies on integration of PC into emergency departments, Lamba et al. (2014) and Basol (2015) focused on the value of early detection and integration of PC principles into emergency medicine and daily practices in emergency centres for patients who suffer from severe chronic conditions and who were imminently dying, together with the various models that can be explored based on context.[161, 162] Models highlighted were that, i) the PC patient is referred by the emergency centre clinician to the PC specialist ii) referral is to a medical officer who is trained in PC; iii) emergency care and PC specialists work together on achieving patient goals and objectives; and iv) the emergency centre clinical team fully integrate PC into their package of care.[162]

5.2.2. Applying the Framework for Analysing integration of targeted health interventions into the health system for this sub-study

The conceptual framework for integration is unpacked in relation to the adoption system and its actors. Figure 5.1 shows the relevant objective in the overall thesis in relation to the adoption system of this framework.

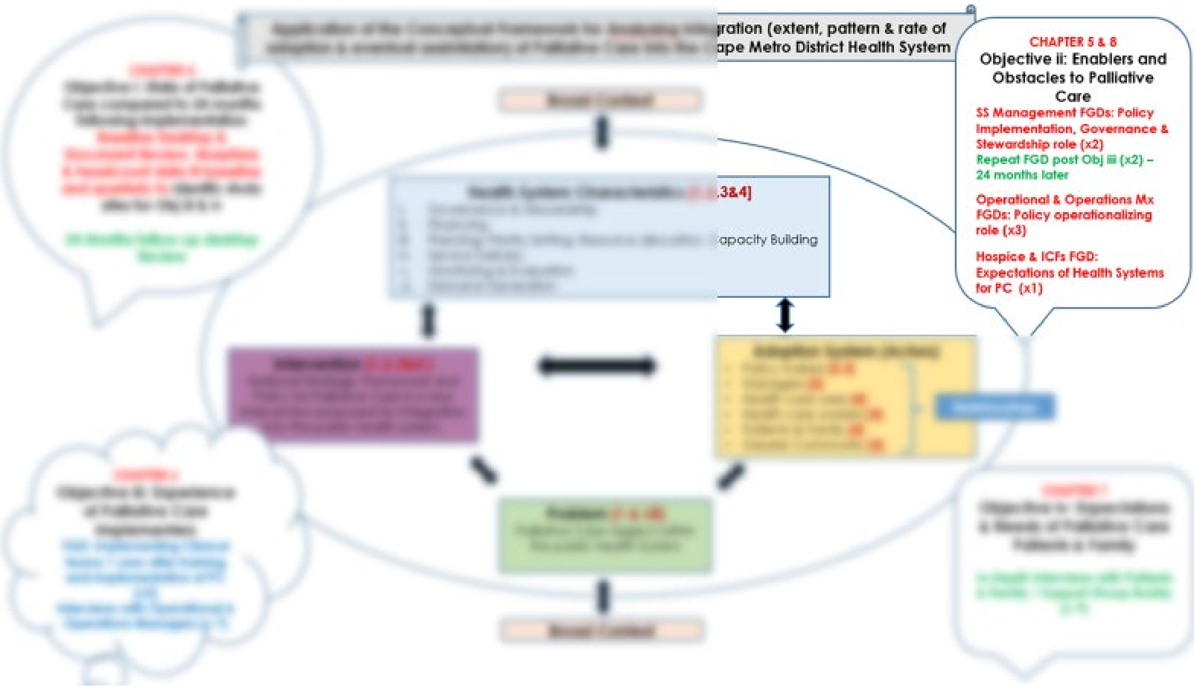

Figure 5.1: The application of the framework by Atun et al.,[8] for this sub-study objection – The Adoption System

Atun et al. (2010) argue that the extent to which a new health intervention is adopted and diffused into the health system is influenced by the nature of the problem that is being addressed, the degree of complexity of the intervention, the adoption system dynamics which include the cultural norms, beliefs and values of the actors within the system, the characteristics of the health system and the broader context within which it all exists.[8]

The Adoption System

As indicated in Chapter 3, the adoption system, in Atun et al.'s (2010) conceptual framework, refers to key actors and institutions within the health system as well as in the broader context, with their varied interests, values and their institutional power in relation to the introduction of PC services. These actors include the policy makers and translators, managers within the health system, implementers of the policy (health care workers), health care users (patients and their families) and the broader affected communities and civil society organisations.[8] Relationships within the adoption system, as suggested by Mayhew et al. (2017) are critical, and structural factors, even when adequately in place, can be overridden by relationships between the staff themselves. Mayhew et al. (2017) suggest that implementing change in the health system is strongly influenced by the approach of managers at all levels, as well as amongst team players. Interactions, such as frequency of supervisory support, occupational stress, manager consultation before decision-making and team support, can enable or hinder integration.[102]

Power, relationships, and the adoption system

In a study conducted on power in health policy in LMIC, Sriram et al. (2018) describe that power manifests at all levels and in all actor interactions, and can therefore shape all actions, processes, and outcomes. Power is the capacity to do something or influence the behaviour of others or direct a course of events, and it is important to engage and understand power to better understand underlying causes of inequity and better promote fairness.[169] The authors further propose that sources of power could be derived from technical expertise, bureaucratic power, political affiliations, financial power, networks or connections and personal attributes.[169] Walt et al. (2008) concur that actors in the health system and their relationships of power may influence the health systems performance and extent of adoption and implementation of a new service focus. It is unclear whether this will be an enabler or obstacle to the integration of PC in a health systems.[86] This sub-study explores this issue in the MHS context.

The adoption system comprises various actors functioning at different levels in the health care system. The hypothesis is that relationships of power and support they offer to their teams, influence the nature of integration of PC or any intervention. Additionally, actors' perceptions of the importance of the issue could be an enabling or obstructing factor in the provision of PC service to the eligible patients and their families.

5.2.3. Holistic approach to patient-centred care

According to Greer et al. (2015), while the biomedical model is necessary to manage PC patients, it is not sufficient, and a holistic biopsychosocial approach is appropriate.[170] There is extensive literature about the importance of language associated with care and caring and the notion of person-centred care evolved in response to patient-sensitive healthcare service, individualized care, and holistic care. This form of care moves away from a medical model, and according to Price (2006), it is centred around the patient. It allows the patient to be fully involved in the care decision-making and considers the patient holistically.[171] Abiodun (1991) articulated that a holistic approach to patient-centred care acknowledges that psychological and physical disorders often co-exist, and found that patients' social environment contribute to their susceptibility of physical and mental disorders.[172]

According to Mayers et al. (2022), when reflecting on virtual health seeking behaviour of patients and the public during the COVID-19 pandemic, clients' needs in Cape Town included socio-economic matters, grief responses and support in dealing with circumstances of death. This suggests that the patients and the public in the Cape Town context, where this study is located, do not just access support for physical conditions and the health system needs to be geared to support patients holistically.

5.2.4. Palliative Care training and skills development

The location of care services is important, as well as the capacity of the health care team to provide the right care, at the right time and the right location. Krakauer et al. (2021) proposed that for cancer patients, PC teams should be available at places of diagnosis in order to ensure initial assessment regarding psychological, physical, social and spiritual suffering and needs.[111] This facilitates early initiation of PC, the development of appropriate treatment plans – integrated into disease modifying plans – and early linkage to continued home-based or out-patient PC. Furthermore, the authors proposed that district level hospitals should have one or two doctors and nurses trained in at least the basic introductory course in PC and PHCs should have at least one doctor and one other clinician trained at this level.[111]

Most clinicians will care for patients with cancer and therefore require an understanding of the principles of PC and furthermore, oncologists should integrate PC into their service package. Following the World Health Organisation (WHO) endorsement of interprofessional practice and education, there were successful examples of interdisciplinary teaching.[173] These included one reported by Head et al. (2016), which evaluated the interdisciplinary teaching of a multi-modular team-based PC programme integrated into oncology for undergraduate medicine, nursing, social work and chaplaincy students at one university. They found that this not only exposed the student to the PC team approach, their knowledge and skills base regarding PC also grew.[164] The Lancet commission (2018) on the integration of oncology (*"tumour-directed"*) and PC (“*host-directed*”) approaches to care, asserted the benefits of integrating these approaches to the provision of care and integrated training for improved health gains. The commission further found that there is better survival and symptom control, less anxiety, depression and improved quality of life for the patient, increased family satisfaction, appropriate use of health care resources and reduced use of futile chemotherapy at the end of life.[174] In a study conducted in selected hospitals in Addis Ababa in Ethiopia when PC was new and little known about it, Kassa et al. (2014) made a case for the inclusion of PC in the curriculum of nurses based on their favourable attitude towards PC even though their knowledge and skills in PC were found to be poor.[175]

The evidence presented in the literature review conducted by Fernando and Hughes (2019), found that PC is optimally delivered through the multidisciplinary team (MDT) approach. Although the dynamics within the MDT can adversely or favourably influence team members, it is important to note that a supportive milieu with adequate leadership, mutual respect and effective communication will determine the team’s performance towards achieving the common goal of holistic patient care for the patient and family.[176] Furthermore, this confirms what DeMiglio et al. (2012) found, that the complexity of managing patients with PC needs and those at the end-of-life stage requires a variety of health professionals to provide holistic PC as a team.[47]

All healthcare professionals require training in PC to effectively communicate poor prognosis to patients and families, as was found by Ganca et al. (2016) in a study on communication skills. Furthermore, communication on grief and loss should form part of the undergraduate curriculum of all health disciplines.[177]

There was no literature found in peer-reviewed journals on providing onsite PC skills transfer in the workplace, in the absence of it being part of a formal training programme. However, according to Gwyther and Rawlinson (2007), trainers at one SA university, in a post graduate programme in PC, provided support to course participants for a six month period to facilitate the transfer of skills in PC.[178]

5.2.5. Compassionate care and difficult conversations

The WCGHW department in its overarching policy framework, Healthcare 2030 the Road to Wellness (2014), advocated for a move to a patient-centred compassionate health system.[51] Compassion is essential to PC provision and PC is an essential component of universal health care[179] Indeed, following a systematic review conducted on compassionate health care, Tehranineshat et al. (2019) considers compassion to be the first ethical principle when providing high quality care. Furthermore, the factors that influence compassionate care include the health care workers (HCW) personal experience of suffering and the strong leadership that model compassion and efficient support to subordinates.[81]

Navigating difficult conversations and breaking bad news is challenging and there are pitfalls which require education, otherwise adverse events may result. Johnston and Beckman (2019) found in a review article, that patients prefer to understand their diagnosis and prognosis, so that they can make informed decisions with their clinical care teams. However, clinicians may fear that patients will blame them or lash out at them for being messengers of bad news, anxious that they may themselves show emotion when breaking news and feel awkward that they do not have all the answers for the patients and the family at that point in time.[180]

5.2.6. Leading the change

Quality improvement for PC requires buy-in from the level of clinician to top leaders. Giannitrapani (2021) reported that this is essential, since committed leadership offering support to the frontline, is enabling.[181] Proactive middle managers, who are committed, positively influence implementation of innovation. According to Birken et al. (2013), middle managers can be change-agents since they are strategically located between senior management and the implementers and, thus close the gap required for innovation implementation. They do this by changing their own practice and reporting requirements, and often stifle their own opinions and emotions for the sake of the frontline.[182]

5.2.7. Policy consultation

Walker et al. (2004) found that policy consultation that includes the policy implementers is important to aid buy-in from these implementers.[183] A good example of the need for adequate policy consultation, is the national and provincial consultation processes on the Mental Health policy in SA, where non-substantive changes were made to the draft policy – two appendices were added, and the eight-point plan was developed – following a top-down nation-wide consultation process. According to Marais et al. (2011), these extensive national and provincial consultative processes were not adequate and they commented that in future consultations, every effort should be made to ensure the inclusion and adequate engagement of experienced implementers and users of the healthcare service for better commitment.[184]

Nurses are key influencers of practice at the frontline (Loyens, 2010)[185] and have been dubbed as 'street level bureaucrats' (SLBs), or gate keepers of implementation in SA's health system, according to Walker and Gilson (2004). The authors conclude that "*nurses' views and values inform their implementation of health policy*" and that "*nurses feel excluded from the process of policy change*". Furthermore, financial, and human resources are insufficiently allocated and incorporated into the policy implementation process. Consequently, those providing the service, the SLBs, have the discretion to make suggestions and decisions based on the knowledge of the needs of those that they serve, which signifies the relevance of bottom-up theories of policy implementation. They recommend that policymaking should be viewed through the lens of these SLBs and that engaging nurses is essential when planning and managing resource requirements and processes for implementing new policy.[183]

5.3. Aims and Objectives

The aim of the overall study was to describe, explore and explain the factors that influence the integration of PC within the district health service platform in the CMD.

This sub-study identified from actors, the enablers, and obstacles to the introduction of this approach and elements of the health system at the beginning of the NPFSPC implementation.

The objectives of this sub-study were to:

i) Determine the perceptions of the public sector senior and middle managers about PC.

ii) Identify enablers and obstacles to the introduction of the PC approach and set of services, among managers and external stakeholders.

iii) Explore the perceptions of the hospice and intermediate care facility (ICF) managers on the public sector's ability to implement PC.

5.4. Methodology

5.4.1. Sub-study Design

An exploratory qualitative sub-study was designed to gain insight into the perspectives about PC of managers and stakeholders at the onset of the implementation of the PC policy.

A set of focus group discussions (FGDs) for each of the three groups of actors within the adoption system, were conducted as follows:

1) SSMTs with two of the four SSMTs in the Metro Health Services of the CMD, one in Metro-East and one in Metro-West.
2) Operational and operations managers: managers in one sub-district from each of the two SSs.
3) NGO sector hospice and ICF managers from all WCGHW funded and unfunded hospices and ICFs.

The public-sector actors worked in the Eastern sub-district, in Metro East; and the Mitchells Plain sub-district, in Metro West. These are managed by the Khayelitsha Eastern SS (KESS) and the Klipfontein-Mitchells Plain SS (KMPSS), respectively. In contrast, the NGO sector actors delivering PC services in the health system operate throughout the CMD, as indicated in Table 5.1 overleaf.

Table 5.1: Sub-study Population for the FGDs

Group	Study Site	Number of groups	Selection criteria	Number of informants
Sub-Structure Management FGDs **Code – SSMT 1 and SSMT 2**	KESS in Metro East and KMPSS in Metro West	2	Managers and clinical managers that form the executive team for the SS of each of the two sub-study sites. They are responsible for governance, stewardship and strategic policy decision making.	16
Operational and Operations Managers FGDs **Code – OMT 1, OMT 2 and OMT 3**	Eastern sub-district and Mitchells Plain sub-district	3	Managers based at various clinical settings who are responsible for the operationalizing of policy and implementation support to implementers in the Eastern and Mitchells Plain sub-districts	43
Hospice and ICF Management FGD **Code - HIMT**	Cape Metro District	1	NGO sector managers of HPCA member hospices and ICFs across the Cape Metro District, who were experienced and historically responsible for providing in-patient and community-based PC.	10
TOTAL		**6**		**69**

According to Gibbs, informants' attitudes, feelings, beliefs, experiences and reactions are more likely to be revealed via the social interaction in a focus group.[186] FGDs are a suitable data collection method for informants with a common experience and offer the added benefits of building morale, self-worth, and experience being listened to.[187] Since the objective of the sub-study focussed on managers who function in a similar environment and explores the issues in depth or beyond the content theme, FGDs were chosen to create that space.[188]

Purposive sampling was used to select information rich informants for the FGDs. Informants for each group were selected according to roles and responsibilities, while avoiding power differentials and to gain insight into their specific area of performance and expertise.[189] All informants were provided with an information sheet (Appendix 7a, 8 and 9) about this sub-study. They had the opportunity to ask questions for clarity, signed consent and were assured of anonymity, before the FGDs were conducted. The request to maintain confidentiality was re-iterated at the start of each focus group.

5.4.2. Participant Recruitment

The sub-structure management teams (**SSMT)** for KMPSS and KESS were engaged after being informed about the sub-study. Initial emails were sent to both directors, together with information sheets and consent forms. After the directors agreed to participate in the sub-study, they were asked to identify relevant executive management team members, who could be approached, and provide their two preferred dates for the engagement, with a lead time of approximately two weeks.

The identified executive management team members were then individually contacted by email, requesting their participation in the FGD, and provided with the information sheet and consent form. They were invited to pose questions for clarity and to indicate their preferred date based on the two dates indicated by the directors. The researcher identified a time and place that was convenient to all participants.

The Operational and Operations Managers (OMT) for Mitchells Plain and Eastern sub-districts were engaged by making initial email contact with each of the SS PHC managers. The PHC manager is part of the SSMT and the line manager of the CHCs[viii] facility manager and CDCs[ix] operational manager. They were asked to identify and provide the contact details of the relevant facility, operational and operations[x] managers who the researcher could approach. These individuals were then individually contacted via email, provided with information sheets and consent forms, and requested to participate in the FGD. They were invited to pose questions for clarity and provided with two dates with a two-week lead time to choose from. All venues were confirmed once informants had agreed on the most suitable date.

Hospice and ICF Managers (HIMT) were approached by contacting member hospices within the CMD from the database furnished by the Hospice Palliative Care Association (HPCA) and a list made available by the MHS of all funded ICFs[xi]. The CEOs or Managers of each NGO were approached via email, provided with information sheets and consent forms, and requested to participate in the FGD. They were invited to pose questions for clarity and provided with two dates a lead time of approximately two weeks. The FGD took place on the premises of one of the ICFs.

5.4.3. Data Collection

Data Collection Tools

Discussion guides (Appendix 2a, Appendix 3, Appendix 4) were developed for each of the three targeted informant FGDs and consisted of a set of open-ended questions to guide the discussion. All probed their perceptions of PC and their knowledge of the new policy, their role regarding the integration of this policy into the health system, any changes that they

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[viii] CHC is a community health centre which operates for 24 hours and is managed by a Facility Manager

[ix] CDC is a community day centre which operates Monday to Friday for eight hours per day and is managed by an Operational Manager who is a Professional Nurse

[x] Operations managers are managers of sections within a CHC or CDC, i.e., pharmacy manager, rehab manager, social worker manager, etc.

[xi] WCGH funded Intermediate Care Facilities (ICF's) is a combination of member hospices with the HPCA and independent ICFs that are not members of the HPCA.

anticipated that were required within the health system and by stakeholders, as well as anticipated enablers or barriers to integration.

Data Collection Procedure

Between six and 12 informants participated in each FGD. Each had an opportunity to ask clarifying questions which were immediately addressed. They were advised that they could withdraw from the session at any point. The consent forms (Appendix 7a, Appendix 8, Appendix 9) were completed before the FGD took place. The contact details of all participants who requested a copy of the research report, were captured onto a database for that purpose only.

The researcher was accompanied by one of two research assistants for each FGD, who recorded detailed notes[190] and observed participant non-verbal and interpersonal dynamics. The two researcher assistants were social workers with research experience in conducting FGDs and in-depth interviews. They were recruited and trained in effective notetaking, research ethics and were familiarized with the sub-study protocol. The FGDs were moderated by the researcher who led the discussion. One research assistant attended two focus groups and the second accompanied the researcher for the remaining four FGDs.

Data Management and Confidentiality

The FGDs were audio recorded and brief notes were taken by the researcher, while detailed notes were taken by the research assistants. At the end of each FGD, a de-briefing session took place between the researcher and the research assistant to expand notes and generate de-briefing notes. All notes were transcribed verbatim by a professional transcriber and were checked by the moderator and note taker before analysis. Each transcript was saved using the archival number as the computer file name and this Indicated the site name (Khayelitsha (K) or Eastern (E)), method of data collection (FGD (F) or In-depth interview (I)), participant category (SSMT (S), OMT (O) or HIMT (H)), and sequential number (1-n). Each transcript was password protected and only accessible to the researcher, the PhD supervisors and the WITS university professor who reviewed the transcripts for confirmability. All written notes were placed in a marked envelope, using the same allocated archival number, and placed in a lockable cupboard that was dedicated for this sub-study. All audio-recording will be deleted from all devices and computers, 3 years after the study is concluded.

Table 5.2, overleaf, contains the data variables that were captured from the consent sheets and includes the data variables gender, median age, and years of experience of two of the three categories of informants, namely the sub-structure management teams (SSMT) and operational or operations managers (OMT). A code was allocated for each focus group category, which is used when extracting quotes from these FGDs, for the thematic results section below.

Table 5.2: Demographic characteristics of the Public Sector Actors

Group	**Gender**	**Median Age**	**Years of Experience in Current Capacity**				
			<1 year	1-3 years	4-5years	6-10 years	11-15 years
2 FGDs for Sub-Structure Management Teams (n=16) **SSMT**	Female	49,6	1	1	3	6	
	Male	54			1	3	1
3 FGDs for Operational and Operations Management Teams (n=43) **OMT**	Female	49	3	5	5	6	10
	Male	43	1	6	4	2	1

Table 5.3 below provides the job title and years of experience of the PC experienced informants from the NGO sector. These informants represent the hospice and ICF managers (HIMT). The years of experience ranged from less than one year to more than 20 years.

Table 5.3: Hospice and ICF managers: 10 NGO sector managers experienced in palliative care

Group	**Job Title**	**Average Years of Exp**	**Years of Experience in Current Capacity**				
			<1 year	1-5 years	6-10 years	11-20 years	20 + years
1 FGD for Hospice and ICF Managers (n=10) **HIMT**	General Manager	7,5	1	1	1	1	
	Nurse Manager	18		2	1		3

5.4.4. Thematic Analysis

The transcribed data was checked against the original audio recording for accuracy. To explore the narrative from the focus groups, the researcher approached the analysis using an approach to thematic analysis as described by Braun and Clark (2006)[191]. During this process the researcher remained mindful and reflective of biases. Data from the focus groups were analysed in search of key themes and concepts regarding their perceptions about PC as well as enablers and obstacles that influenced the execution of their governance and stewardship role, which may influence the extent, pattern, and rate of integration of PC into the health system.

First the researcher became familiar with the narrative by repeated reading of the transcripts and immersion in the data in search of meanings and patterns.[191] An initial list of ideas were coded into meaningful groups by using the NVIVO data management software program. The entire data set was worked through in order to ensure equal attention to each data item.[191] Extracted data included data that was coded many times, coded once and even un-coded, which was then further explored to identify sub-themes and then main themes. Each sub and main theme were defined, named and captured in a code book and in NVIVO. A thematic map was also developed and was written up in the results section 4.3 below.[191]

5.4.5. Trustworthiness and rigor of this sub-study

In this sub-study credibility, transferability, dependability, confirmability, and a reflexive approach as identified by Cresswell (2018) were used to establish rigor and trustworthiness of the reported findings.[192] To assure trustworthiness and credibility, the researcher, being a senior manager in the WCGHW, worked closely with the supervisors to identify any pre-existing beliefs regarding possible enablers and obstacles, which were assessed at regular intervals. An intentional reflective process was agreed upon to ensure that the researcher's assumptions were not embedded in the sub-study findings. Credibility about sub-study tools is assured as the open-ended interview guides, developed by the researcher, were carefully reviewed, and were aligned to the sub-study's aim and objectives.

To ensure credibility, a detailed description of the sub-study sites, sub-study population and processes of data collection was captured. The participants recruited had many years of experience and had worked in a variety of health care settings. Based on this, transferability may be possible in settings outside of the CMD.

In recognising research bias and to ensure confirmability, the code book, access to the data set, as well as the transcripts were shared with both PhD supervisors and an external qualitative research professor. All discrepancies were discussed and resolved by consensus. Dependability of this sub-study can be assured by the provision of the detailed description of the methodology and rigor, by adherence to the recruitment and data analysis plan. The six transcripts were coded by the researcher and three were randomly selected and shared with the two PhD supervisors and a professor at WITS to ensure confirmability. In reporting this sub-study, all the relevant criteria for reporting qualitative studies (COREQ) according to Tong et al. (2007) were utilised.[193]

5.4.6. Ethical considerations

Beneficence and justice as ethical principles were considered throughout all interactions with the public sector and NGO staff to ensure non-maleficence, and that participants were treated in a fair and impartial manner.

In protecting participants, the rights of the sub-study participants were upheld, and attention was given to protecting their confidentiality as well as ensuring their anonymity and autonomy.

A range of informants participated in the FGDs and for the public sector and NGO staff, power differentials were considered, and the various categories of staff were separated as indicated in the methodology sections of this sub-study. Since the researcher was a senior manager, issues of overt or subtle coercion were addressed by reiterating that participation was not compulsory in the information sheets and at the start of the FGDs, and by appointing an experienced research assistant, to promote good practice and reduce discomfort. All transcripts as well as survey data were anonymised, and all identifiers removed. Informed written consent was obtained from all participants and their identity, as well as the record of discussions, was kept confidential, known only to the researcher and assistant researcher.

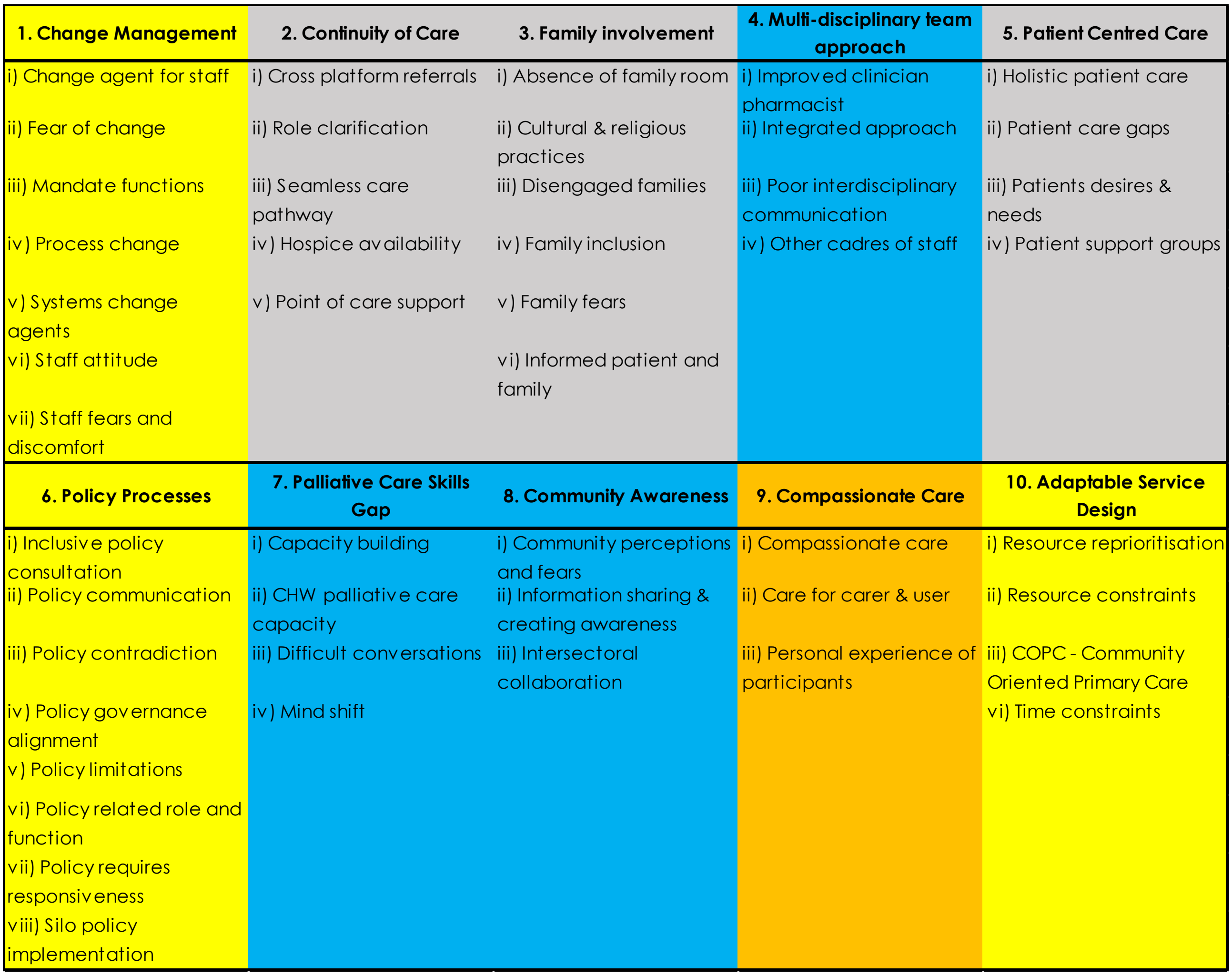
5.5. Results

Six FGDs comprising three categories of informants from two SSs were held. These were three operational manager FGDs, two SSMT FGDs and one NGO FGD, totalling 69 participants.

Informants from all six FGDs raised the need for service design to be more adaptable, accommodating of change and inclusive of the voices of informed family and community members, while remaining part of the culture of doing business in the WCGHW. They delved deeply into obstacles, reflecting on their resolution, and identifying enablers. Likewise, obstacles to these enablers were identified. Consequently, many codes were both enablers and obstacles.

From the six FGDs, 56 initial codes were generated and of these, 48 were categorised into ten sub-themes, while eight initial codes were hard to classify. The ten sub-themes were further grouped and categorised to generate four major themes. The initial codes generated from the data and the sub-themes are given in Table 5.4 overleaf.

Table 5.4: Ten sub-themes and initial codes generated from the six focus groups



1. Change Management	2. Continuity of Care	3. Family involvement	4. Multi-disciplinary team approach	5. Patient Centred Care
i) Change agent for staff	i) Cross platform referrals	i) Absence of family room	i) Improved clinician pharmacist	i) Holistic patient care
ii) Fear of change	ii) Role clarification	ii) Cultural & religious practices	ii) Integrated approach	ii) Patient care gaps
iii) Mandate functions	iii) Seamless care pathway	iii) Disengaged families	iii) Poor interdisciplinary communication	iii) Patients desires & needs
iv) Process change	iv) Hospice availability	iv) Family inclusion	iv) Other cadres of staff	iv) Patient support groups
v) Systems change agents	v) Point of care support	v) Family fears		
vi) Staff attitude		vi) Informed patient and family		
vii) Staff fears and discomfort				

6. Policy Processes	7. Palliative Care Skills Gap	8. Community Awareness	9. Compassionate Care	10. Adaptable Service Design
i) Inclusive policy consultation	i) Capacity building	i) Community perceptions and fears	i) Compassionate care	i) Resource reprioritisation
ii) Policy communication	ii) CHW palliative care capacity	ii) Information sharing & creating awareness	ii) Care for carer & user	ii) Resource constraints
iii) Policy contradiction	iii) Difficult conversations	iii) Intersectoral collaboration	iii) Personal experience of participants	iii) COPC - Community Oriented Primary Care
iv) Policy governance alignment	iv) Mind shift			vi) Time constraints
v) Policy limitations				
vi) Policy related role and function				
vii) Policy requires responsiveness				
viii) Silo policy implementation				

Four main themes were subsequently generated from the ten sub-themes as indicated Figure 5.2 overleaf. The main themes, colour-coded and incorporating the initial ten sub-themes using the same colour, are discussed below.

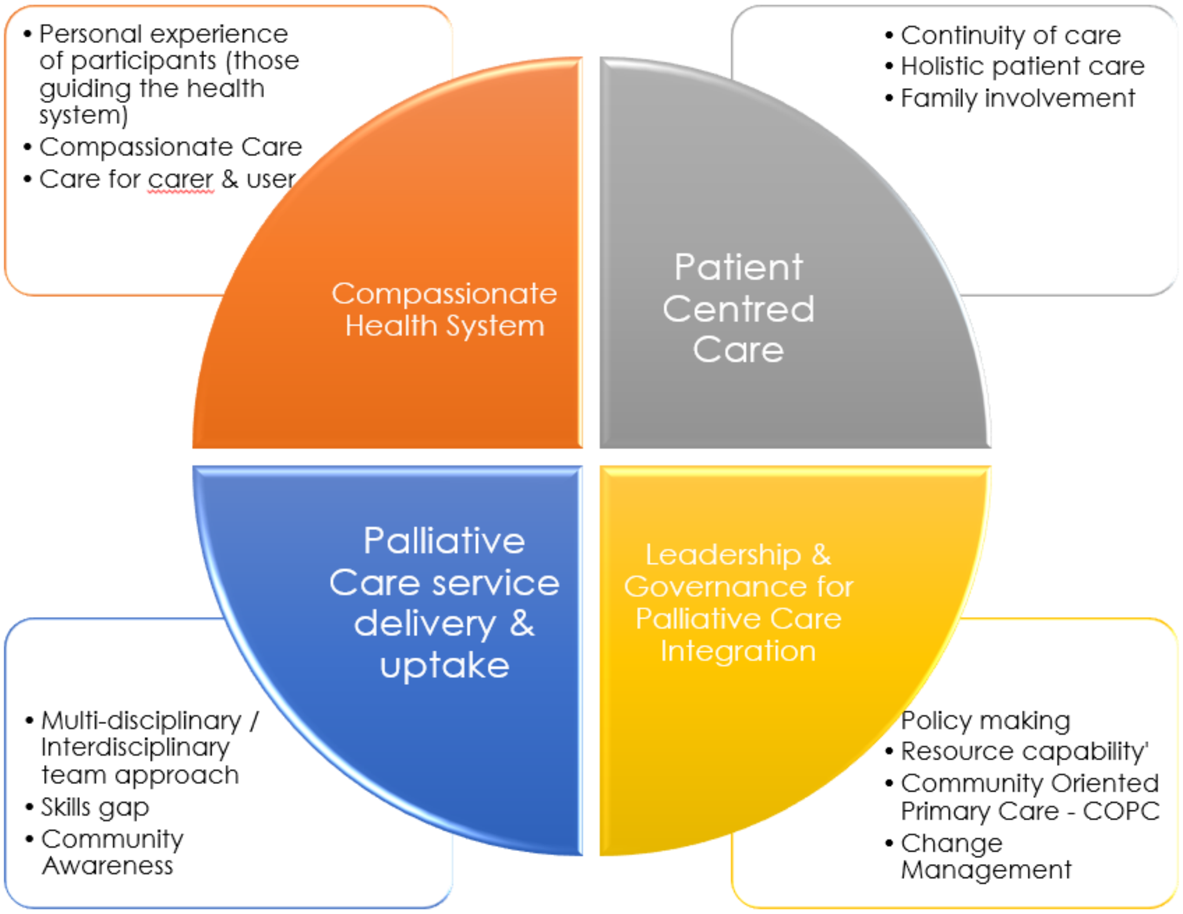


Figure 5.2: Map of the sub-themes and main themes generated from the six focus groups.

5.5.1. Compassionate health system

Throughout most focus groups, statements were made that a compassionate health system was required to offer quality PC and the HIMT informants were not convinced that either the public sector system or the private sector were able to provide compassionate PC. Concerns regarding the public sector staff attitudes were raised. While informants believed that a change towards a compassionate health system would take time, the provision of PC as part of universal health care was pressing. New ways of thinking are required that can result in a new way of service provision and a new way of providing care. The informants in the HIMT group expressed concerns that the public sector clinical staff view their professions as merely a job with a salary and changing this would require a mind shift to get back to a place of compassionate care for the patient.

> "Health department needs to change their mindset over…how patients need to be cared for... It's just become a job...because they need to have a salary but there's no compassion there's no enthusiasm there's no loyalty there's no dignity…and I mean if you look at all the complaints that is coming from the different hospitals, how people are treated." HIMT

In the same vein the SSMT informants raised that the WC Healthcare (HC) 2030 strategy's approach towards a person-centred health system which considers the shift to wellness and the need for universal health coverage, as essential to achieving person-centredness. Furthermore, they indicated that perpetuating vertical and siloed discussions and policy decisions within the WCGHW result in contradictions that do not aid attitude or behaviour change. There was unanimous agreement among both SSMT groups that the process of operationalising the HC 2030 strategy, that commenced in 2014, was shifting the public health system towards being, becoming and promoting a caring health system.[51]

Informants in the HIMT group extended their concerns about the public and private sector health system and services regarding compassionate care. They maintained that it takes time to rid a system of bad staff attitudes and much effort is required to build a compassionate health system.

> "Yet the premise of 2030 is about compassion and caring in a holistic manner and so I think sometimes the department is their own worst enemy when they want to give the standalone discussions or policies and expect that behaviour and attitudes is going to change."
>
> SSMT 1

Personal experiences of life-limiting illness

Participants from all the FGDs shared their perspectives, perceptions, and personal experiences of PC. Experiences with family and friends with critical life limiting illness is ubiquitous and so this was close to everyone's heart. Some had positive encounters and expressed excellent support from clinicians and fellow patients, that met their needs as family members of patients. Notably one informant was an oncology patient and received PC as part of the cancer journey. Some informants had negative experiences, in both the private and public sector health services, with loved ones who had PC needs. While some informants expressed a renewed passion to take on PC within the public sector system and to support its development, others expressed that their own pain would make it difficult to offer PC and that they rather viewed curing and life-giving as part of their role.

> "I'm an operation manager at [XXX] and palliative care is a reality. But I can't help it, I don't like palliative care and not because of what you can do for the client but it's because it's morbid and I've chosen to work at the CHC [be]cause I want to work with people that are going to be alive and well…" OMT 2

> "I've had personal experience...to last me a lifetime with regards to palliative care...If I, myself as the leadership don't get peoples' head to understand that everybody that walks through the door is possible palliative care then we going to miss it...because...someone is going to have an unexpected death." SSMT 1

Compassionate care and difficult conversations

Compassionate care was articulated by informants in all FGDs as a one-on-one kind and caring encounter between the HCW (or any public sector employee) and the PC patient/family or any patient. The SSMT informants grappled with the concern that a HCW's inability to express compassion, could impact on patients' perception of the quality of care and ultimately their experience of the health services.

Informants from both OMT groups were concerned that many staff may not be able to provide compassionate care when the patient is actively dying. They also reflected on the HCWs' ability or inability to have difficult conversations with patients and/or families, which involved breaking bad news while building hope, and that this could be an enabler or obstacle to the provision of compassionate care.

Informants from all six groups believed that sharing difficult information with the patient did not come easily to everyone, and that the choice of words was critical. Many believed that clinicians would require training in appropriate communication.

> "The most difficult part is the language we use, how we talk to the patients. For instance, not saying, "We can do nothing for you anymore." That's just the wrong sentence. But you must be taught ... what to say and to say it in a correct way, else… you are just creating panic and unhappiness. And I think our best mentor at our area for palliative care is [XXX]. Just listening to him and hearing how he talks to patient is…you just stand there and say next time I must do it like him. And the next time comes, and you can't do it … because you … must train to do it like him, that's a process… it doesn't happen overnight." OMT 1
>
> "I think palliative care is a personality thing as well. You can't push palliative care on all clinicians, it's not a flowchart you can follow, it can't [just] be in a PACK flowchart[xii] that you follow, and it will be fine (group agrees). You need a personal touch for this, you need a love for this, and you need a certain personality. And you don't always have that, in all the doctors or in all the CNPs in the clinic. So, you can do harm as well. This is going to be in my opinion, a person-driven thing. And it's going to be difficult to have this all over." OMT 1

In all groups, there were concerns regarding the attitudes of staff working in the public sector, which was expressed as being rude, curt, not making eye contact, being dismissive and showing irritation when approached. Informants from the SSMT group raised that this behaviour is often due to personal problems or staff feeling uncared for within the health system. The HIMT group reflected on their perception of the culture of public sector health care services, and they considered this a barrier to the provision of PC, which requires caring work environments. Furthermore, they voiced that many complaints could be avoided if compassion in care was evident.

[xii] PACK Flowchart: This is an algorithm type of practical application to managing health conditions & is used in the PHC arena

> "a lot of our complaints that come through it's because a bad nurse was rude… but it's actually… I have a need and its unmet and I'm thrown to the wolves" SSMT 1

> "So, patients are not being nursed. So I don't know how you [are] going to implement … additional palliative care … if they still [have] got this thing that they [are] doing you a favour when they [are] working in hospitals and looking after patients." HIMT

Informants in SSMT and OMT FGDs had a persistent perception that PC was only end-of-life care and that compassionate quality care only commenced at that point in the care continuum.

> "With palliation you've reached the end of what you can effectively do apart from giving, you know, pain [medication] and so you have to then respond in terms of compassion and quality of life" SSMT 1

Care for the carer and care for the user

Informants in the SSMT and OMT FGDs, regarded care for the carer as being their responsibility as managers and supervisors. It was not only the responsibility of the company that is contracted to provide employee and wellness services to public sector employees. They added that caring for the carer is important and creating a culture of caring for one another is needed. Informants from the OMT group realised that PC would place a larger caring burden on carers. Furthermore, this expectation is layered on top of the abuse inflicted on some carers by the patient's family members or loved ones.

> "Out there is our carers who are victims and targets. Just one week ago … the Friday [the carer] washed the mother … and then she asked on the Monday when she came, but why is she [the patient] still in the same clothes and in the same position [since the] Friday. And the one daughter went ballistic, and she [scolded] skelled her [the nurse] and [swore] swear at her … we should look at that aspect also of the carers who are vulnerable [when] … treating that type of patients." OMT 1

5.5.2. Patient-centred care

The theme, patient-centred care, refers to the patient being placed in the centre of the health care system, addressing their healthcare needs in a holistic manner, with their ability to access care at the appropriate level of care across the care continuum. While patients' acuity, care needs and support are considered, families are also involved.

Continuity of Care

Informants in all FGDs indicated that patient-centred continuity of care must be facilitated. Consequently, access to PC at all levels of care, including intermediate care must be ensured. This requires a seamless interconnected care pathway with clearly defined roles, proximity to the local ICF that is optimally utilised and a feedback loop for all patient referrals.

They elaborated that a seamless interconnected care pathway should be established for the patient and the family that ranges across the entire health service platform, from the home to tertiary level (L3). Informants in all groups reflected on the importance of communication to ensure a seamless care pathway, the need for a point person in the hospital to facilitate linkage to the primary healthcare platform including community-based services and clarification of roles of HCWs along the care pathway.

> "We would like to have a dedicated palliative care coordinator at [XXX] hospital … it must come with a post … because there's no point in me being more nice to my patients … if I don't have anybody to be that link to the primary care facility, it's going to fail…" OMT 2

Informants in the SSMT and OMT groups indicated that each geographic area should have access to a hospice or ICF that is located within the same geographic boundaries. These hospices and ICFs should form part of the PC patient's care pathway and would be in close proximity for family visitation. Furthermore, this would facilitate rapport and partnerships, and PC support to the public sector services. The HIMT informants indicated that it is essential that hospices or ICFs offer PC as part of their packages of care.

> "it's kind of having the conversation in a geographical area and knowing that these are the palliative care patients in our neck of the woods. Like CBS [community-based services] for example and what are the conversation that is happening, around those clients across the platform" SSMT 2

Informants in the SSMT and OMT FGDs reflected on the need for a departmental standardised cross-platform referral process to be develop, that includes the PC patient. The HIMT informants discussed the poor utilisation of the services they provide, that doctors in the public sector do not seem to know about their role in providing PC and that they can assist in care and that HCWs may not be familiar with the patient referral forms and processes.

> "Seriously I don't [think] they know about the existence of intermediate care and how to ... refer.... We have this referral of [XXX] CHC the other day … and they did not know the process … They asked me for the forms. I sent them the forms a week ago and still I didn't hear any feedback. ...Where is this patient now? The poor family must now [go] backwards and forwards with the patient…The communication of how to complete the referral form, even if they don't come back to you and say "please help", so we don't know what is going on in our facilities."
>
> HIMT

Informants in all groups also raised and explored obstacles such as no feedback about referred patients or clear feedback loops. Some maintained that these could be facilitated through an electronic patient information or patient referral system between the different levels of care and with partner NGOs and hospices. The consequence of no links between levels of care results in patients being lost in the system. Since the family do not feel held by the health system, they use the emergency centres as the access to care point.

> "What has been a bit of our problem is that we never get feedback. We refer out and refer out and there is never feedback on how well is that patient doing … the technology does not help us NGOs. We are not on the government systems we can't follow a patient."
>
> HIMT

> "So that is actually the linkage that I was referring to. You've got a proper discharge plan, that is the continuum of care. But you lost the patient somewhere [in] the system. And because nobody is there for the family, the family starts [to] panic and they come to this [emergency centre] EC."
>
> OMT 1

Holistic patient care

Informants in all FGDs discussed holistic patient care, noting that it meant that whole patient care – body, soul and spirit – needed to be centre stage of the care decision-making space. They noted that it had formed part of undergraduate training for nurses and medical doctors but somehow got lost along the way.

Interestingly, the HIMT group argued that the word 'PC' could place a limitation on the provision of holistic patient care. They indicated that the patient could present with other conditions that required rehabilitation or cure. When patients are regarded as having PC needs, these other aspects of care provision may be disregarded.

> "… when you enter the profession no matter which profession [in] the medical sector they start with looking at holistic care … physically, emotionally, spiritually, socially so what are we saying? Let us implement a culture of holistic care which … we are calling it palliative care… So let us change our mindset out there in the community… When I introduce palliative care to people and patients, I would say palliative care is holistic care and then people would receive it."
>
> HIMT

To ensure holistic patient care, it is important that the health care team understand the needs, preferences and desires of patients and families. Informants in all groups discussed the importance of patients' need to understand what PC means, knowing what patients' preferences are regarding where their care is offered, their need for support and their preferred place of death and dying.

> "The person is so shocked and also doesn't really know at that time what [this means]. But it will be the family [that we engage]. And so, our strategy is inviting those people to articulate … what kind of support do they need? Do they need it in the hospital? Do they need it at home?"
>
> HIMT

The informants in the HIMT discussed care costs. L3 care for PC patients was seen mostly as inappropriate when compared with care at home. The cost saving of providing support to patients and families at home should be considered. Similarly, OMT informants discussed the appropriate place of support and care for the patient and the importance of considering the patient and families' wishes.

> "So, if you [are] at your own home [it is more] cost effective compared to being in a hospital. … The expense is major compared to you just being at home and the registered nurse coming into your home, where your family members [are] being supported. … Bringing in the social worker, bringing in the spiritual carer and whatever other needs that you've got. So, it will be then holistic at the same time" HIMT

> "When I'm a palliative patient the last place I want to be [is to] spend the whole day at a clinic. (group agrees) … I want to be at home. And it depends on my home situation... I'd much rather have somebody come and support me at my house. [It] obviously depends on your level of functionality," OMT 1

Public sector informants in the OMT group described historical nursing practices and nurses' roles and argued that there should be consideration for revisiting those. These included the district nurse being an extension of the PHC facility providing care in the home. They could then assess patients, make decisions about appropriate linkage to care, conduct point of care testing (blood glucose, blood pressure) and consult the doctor and the multidisciplinary team (MDT) telephonically. These patients could then be further discussed at the MDT meetings at the PHC facility.

> "… this is also reminding me of the time when I was still in my early years in my nursing, I worked as a district nurse. As a district nurse it was very easy for us to pick up a lot of patients that were in the community with the problems and were able to link them directly to the to the facility. And for those patients who needed ... a blood testing, be able to draw some blood. And patient would only go when you see this patient really need[ed] a doctor. But at least you were there as a nurse to assess the condition of the patients. So, when that thing was phased away, I was thinking of the gap that was left now" OMT 2

When reflecting on the WHO definition of PC, informants in all groups discussed gaps in patient management which negatively impacted the provision of holistic care. The OMT group particularly reflected on PC patients who have an acute illness that requires care. The current service gaps raised included access to PHC, due to the inflexible health services appointment system. Patients with acute conditions, requiring care within a day or two, cannot wait for 2 to 3 weeks for an appointment. Bed-ridden patients who do not have appropriate transport, then present to ECs.

> "The group of patients we often meet in the emergency centre at the hospital side; because they aren't necessarily brought to the CHC because they're bed bound… On a stretcher the EMS brings them to hospital. [These are] the patients that have been bed bound for many years, … [with] advanced dementia, gradually deteriorate[ing]. They got to the point where they could no longer attend the CHC for their appointments. So, the families get re-boards of medication … the patient only ever meets any sort of healthcare worker in the emergency centre … Sometimes we discharge them sometimes they get admitted, but … they'll never see primary healthcare." OMT 2

Some OMT informants discussed what could be regarded as appropriate support groups for the patients and the family. They were not confident that organised and structured support groups that were facilitated by health care providers, including community health workers (CHWs), addressed patients' needs. Some believed that support groups were in vogue but may not be needed or appropriate, and that peer support was of greater value. They explained that HCWs should rather create spaces for patients and families to connect but should not actively facilitate the support group sessions.

> "I went through the whole thing. So, I had chemo, I had radiotherapy. And what you find is, when you are sitting in the chemo room, and everyone is sitting on their chairs, you form your own support group there, it's the same people that you see in your six months or however long journey. So, some leave (laugh) some new ones join. But there's a conversation that happens in that group that you cannot prescribe or teach because it's something that flows from your experience. And you find that patients share silly things like side effects that the doctors will tell you doesn't exist. But yet, we all experience them. I kept dropping things because I lost sensation in my fingers … Oh I mentioned that to the doctor, but the doctor said it doesn't happen. It happens! And that kind of support group was absolutely incredible! It meant more than any conversation that I could have with the clinician who looked after me" OMT 1

Family Involvement

Family involvement was raised in all groups, and informants discussed the health systems ability to accommodate families in hospitals when patients are dying. They highlighted different cultural and religious practices; disengaged versus engaged families; dealing with the fears of family members and the value of an informed family.

Most public sector facilities have not been designed to include family rooms. The informants in the SSMT group raised this gap as a potential barrier to integrating PC in the in-patient setting.

> "… provision has never been made in the state hospital sector, so in private you can come and go, basically like you want to, as family members. But in the state … it's because there's … no space for family …" SSMT 1

Different cultures and religions each have different traditional and religious practices when it comes to death and dying. The informants in the SSMT and OMT FGDs described differences in practice in a multi-cultural society and the due consideration and attention that should be given to that, particularly when integrating PC and when developing health care policies in general.

> "The family said, "We want to take the spirit of our father and take it home." Our team did not know the process of allowing the family to go through that process. So, when we do integration, we need to have some understanding. We need to train our staff regarding how do we deal with processes to meet the patient and the family holistically" SSMT 1

Some families intentionally disengage from the patients' PC journey and cannot cope with ongoing care. Informants in the SSMT and OMT FGDs discussed current challenges with families and how the patients become the hospitals' 'burden'. They reflected that this becomes an obstacle to PC provision, since PC integration relies on and includes patients' families.

> "We've had several cases in the emergency unit to where the patient is going to be dumped by the family and the patient need[s] palliative care and the family cannot take care of the patient anymore. Several cases like that, [you want to] take the patient to the family's house, [and] the family say[s] no." OMT 2

> "We have a project here at the hospital that… needed us to track down a whole bunch of families … And you'd be shocked [at] people that have been, ... in hospital for many, many years, and you find a family and they go, WHAT?! … maybe they were too young [to remember the family member]" OMT 3

Some OMT informants indicated that families' fears and anxieties, due to knowledge gaps about PC, were obstacles to PC integration, as some families preferred to hospitalise patients. Having families adequately informed about what to expect, the care required and access points for support, reduced anxieties about their concerns of how to deal with the actively dying patient and when to seek health care.

> "… from my side I can say, with palliative care, we actually deal more with fears from the family members… As soon as you mention that the person must be under any kind of palliative care whether it's at home or must be taken off to ... hospice, they are already thinking, that person is about to die now very soon." OMT 1

> "The minute that we become more open, and we communicate, we might not have people running to the hospital for each and everything. They understand, they know exactly what to expect." SSMT 2

5.5.3. Palliative care service delivery and uptake

The theme, PC service delivery and uptake, included the need for integrated care requiring functional multidisciplinary teams, with a clear focus on patients within the context of families. The service delivery platform will need to consider new cadres of staff, training of existing staff and re-orientate the community through appropriate advocacy efforts.

Multidisciplinary or Interdisciplinary Teams

A multidisciplinary team (MDT) usually represents a range of health professionals working together to deliver comprehensive patient care. Informants in one OMT group discussed that MDT meetings presented the opportunity to flatten hierarchies so that all contributors in the provision of health services could work together in the interest of patients and families. All role players together form the complementary team.

Some initial codes arose from specific informants' contributions to improve clinician to pharmacist communication, the repercussions of poor MDT communication and the value and limitations of MDTs at the coalface. These were incorporated into the sub-theme – MDTs, which are important for the provision of PC services.

Informants, furthermore, discussed their understanding of an integrated approach. Most indicated that it was a missing element as they were accustomed to working in silos over many years. They shared that a new programme, intervention, or policy was usually accompanied by additional financial resources. Furthermore, they described how many health professionals work across facilities. This made it difficult to set up MDTs at facilities, with expectations that these shared human resources would be available at all meetings.

> "That is difficult in a facility such as mine, because the physio is full for the next three months; ... you can't involve the OT as she is away at three or four different facilities. So, it's difficult to take a half day to discuss things. We don't have a social worker at all in the area. So, the [MDT] group is now the doctor … so, we need enough people to come to the table to help the patient. It's not only the doctors signing the morphine script …" OMT 2
>
> "I've had multiple discussions about palliative care with different people on different levels, since the awareness has been stepped up in the department… And the question that keeps on popping up is how do you integrate it? Do you create a separate silo system? … Some people want dedicated or designated beds for a specific clinic. Or do you see it as an essential unavoidable part of primary health care which starts even before the diagnosis?"
>
> OMT 2

There was also robust discussion on staff cadres that could be of value in the provision of PC. Personnel that are not currently part of the health department's establishment were regarded as important to enable to provision of PC within the public sector services. Informants agreed that consideration should be given to staff categories, such as sessional chaplains or spiritual counsellors, who could support the integration of PC,

> "Maybe [we] need to look at our staff compliment. Like social workers maybe a part time, or a session-based chaplaincy services …maybe some categories like … your carers to be assigned to that ward, when they can do the touch and hold hands and talk to them and just listen to them" SSMT 2

Skills gap

Informants in all FGDs discussed the need for training in PC and the skills sets that would be required to implement the PC policy in an integrated manner. These included communication skills – communicating with sensitivity and empathy, providing compassionate care and breaking bad news while building hope. The HIMT and OMT groups raised the importance of skills transfer from experienced PC nurses to shape newly trained staff in conducting a PC assessment with the right attitude and compassion.

> "… we need to have the expertise, like for example, people that are retired as well – palliative sisters. Those people can come on board and be able to teach because that is also a transition of their skills to the very people that attended the course … Training here on the ground and they can be used as champions to come back and teach us and tell us what we don't know."
>
> OMT 3

The SSMT and OMT FGD informants raised concerns about the training gap that will need to be closed to build the PC capacity of the entire staffing platform in the public sector. These informants also expressed that formal training is not necessarily needed for new policy implementation as clinicians are experienced, could read the policy and commence services. HIMT informants raised concerns that generally clinicians are trained to render curative services and save lives. Consequently, they are reluctant to offer PC as this is viewed as giving up on the patient. There are few nurses trained to assess and decide, but nurses are rather trained to follow and execute care plans.

Furthermore, informants in both HIMT and OMT groups expressed the urgent need for training CHWs, since the health department depends on their role in the extension of healthcare service provision into the home environment. CHWs would also require the support of more experienced trained PC HCWs to offer support in the home.

> "I always tell people, "Do not expect [the] community health worker to think like a nurse". They've got no background training. You teach them. They will do what you are teaching them."
>
> HIMT

> "CBS [community-based services] needs [the] backup of people that have got advanced palliative care training. So, you can't expect the CBS care worker [CHW] to be able to do all things and wear all the hats and be able to do COPC [Community Oriented Primary Care] … So ideally, ... CBS should be able to have backup of your substructure-wide palliative care team, to give input and also, to be able to send someone more advanced to the house when [the] CBS care worker is not sure, [or] wants help, advice." OMT 2

Various proposals were offered in all FGDs on how to close the skills gap. These include the introduction of PC into basic nurse, social work and medical officer training and that undergraduate training shifts from curative to holistic care which would include PC. Furthermore, they proposed that the health department commit to ensuring that at least one PC trained person was based in every facility; that the psychiatric trained nurses and social workers be considered for psycho-social support, grief and bereavement for PC patients and their families; and psychiatrists for complicated grief.

Community advocacy for palliative care

Informants in all groups raised that communities perceived PC as end-of-life care and was stigmatised. Consequently, when participating in PC services, they feared that they were committing their family member to a likely death. These perceptions were significant obstacles for the mainstreaming of PC into health services. They advocated that the inclusion of stakeholders, such as trusted CHWs, who contributed to the care of the patient and family, would improve awareness and subsequent perception of PC. The CHWs and religious leaders have built rapport in the communities they serve, and informants articulated that if these stakeholders are well informed and buy in to PC as quality patient care, they would advocate for this in the areas that they operate and are trusted in.

> "From my perspective being in a hospice, palliative care is a stigma that is linked to death.... This is very problematic within the health system because when you use the word palliative care, people link it to dying. The same goes for morphine. So, patients would prefer to go on tramadol instead of using morphine. I think for the health system [challenges are] the stigma around palliative care" HIMT

Some informants regarded information sharing, and creating awareness amongst all staff categories, patients, their family members, and the greater community on what PC is, as important. This would reduce the stigma that often accompanies death and dying. Proposals from the informants in the OMT and HIMT FGDs included radio talk shows and leveraging social media platforms to sensitize communities.

> "I think we need to get the message out there, that palliative care is more than just end of life. So, the end-of-life is a small part of it, and ... there's always something we can do. And we have to drive that as clinicians, as nursing staff. We engage with patients and with NGOs and obviously as managers also. But it's something that we have to practice and let people see in action" OMT 1

There is a need for intersectoral collaboration – including all of government and non-government sectors acting in a collaborative manner to address PC. Informants discussed the value of having agreements with other key government departments, such as education and social services, regarding what PC means and what their role in this space could be. They agreed that all stakeholders within government and society, can add value to breaking stigma and clarifying PC.

> "I think the department is very much inter-sectorial. So, to provide a holistic service we need [the department of] education on board. [The department of] social development its crucial and I think for the others too. Because so often to provide a holistic integrated approach, these people need to be on board, so I don't know if social development even knows the word palliative care or understands the policy or anything." HIMT

> "…intersectoral collaboration. So, you want to empower people. But if they don't have proper homes to live in, you can counsel and you can link to spiritual care. But if somebody was dying, then not having a home isn't actually comfortable you know. So those [entities] addressing the social determinants of health is an aspect that is really lacking in terms of the whole system" SSMT 1

5.5.4. Leadership and governance for palliative care integration

The leadership and governance theme includes policymaking processes from formulation to adoption, implementation and integration, resource considerations, health service design and change management.

Informants in the SSMT groups raised a concern that clinical policy in the health department is dynamic and always changing. Since the same clinical teams see the same patients and need to stay abreast of changes, leadership must strategically direct them towards integration and holistic patient care.

> "If I [XXX] as the leadership don't get people's head to understand that everybody that walks through the door ... possibly [needs] palliative care, then we going to miss the point. Because then someone is going to have an unexpected death and then we not even going to be there because our focus is not on that" SSMT 1

Policy making

Informants in the SSMT and OMT groups raised that the policymaking process should be more consultative and inclusive. The operations managers expressed concern about policy that has not been adequately consulted with them and with the representativity of implementers, stakeholders, corporate services, and other affected groups. Furthermore, they believed that adequate policy consultation aids buy-in to new policies from implementation teams and can also facilitate change management processes. In addition, these informants discussed how poor or inadequate consultation often led to contradicting statements or instructions with other policies or even broader departmental strategic directions.

Some of the informants from the OMT groups admitted to never having read the PC policy that was officially circulated nine months prior to the FGDs and had not attended any of the roadshows. They raised concerns regarding other policies that did not filter down to operational levels and inappropriate and irrelevant circulars that do reach them. Furthermore, these informants expressed the need for onsite support when it came to policy implementation and raised the concern that emailing circulars was not adequate.

> "I think staff input is very important when it comes to drawing up of policies. That is the best way to get staff buy in to implementing your policies. Lots of staff, they are not keen on change. And when new policies come in then it is normally change that has to take place and they become resistant immediately. So, if they do have some input into policies that is being implemented it will help with implementing it also." OMT 2

> "Loved ones that want to stand next to the patients who are dying. Then it's our very own policies. We've got visiting time policies that's so bizarre that doesn't even speak [to the 2030 vision] but now we have a palliative care policy." SSMT 1

All FGD informants raised concerns about the expectation to implement new email-sent policy without the necessary onsite support, financing and alignment to the departmental budgeting processes.

> "The people on top cannot really send down the papers. If they can come support us when we are introducing those [new policies or interventions] … So, if at times they pay visit around the facilities not just sending the documents. … And when you have a conversation with the staff, it [is] much better." OMT 3

When reflecting on potential policy enablers, SSMT FGD informants reflected on the entire health system and the need to reduce a siloed approach to the provision of care. On the other hand, the OMT FGD informants discussed the need for responsiveness from the corporate governance teams within the health system, to meet the needs of the implementing teams and operational managers that are expected to implement new policy.

> "I often think that the department gets very focused on standalone things. So, then the flavour of the month would be, "we are now gonna talk about palliative care". And then we just talk about palliative care. Then we don't talk about chronic disease. And so that doesn't come together. And therefore ... the approach to any of these things is fragmented".
>
> SSMT 1

> "So, we do need sort of support from the supply chain because one of [the] things that we've had is we want to send somebody on the introduction to palliative care the online training, 40-hour course. But to go through the process of the paperwork... Then from substructure level, then it falls flat and that doesn't happen, … And nobody can explain to you what went wrong, and you just have to go through the process again. So, there's those things that can be discouraging to starting something." OMT 2

Resource capability

SSMT informants highlighted that new policy often came their way without additional funding and this could be an obstacle to ensure implementation. They referred to this as an 'unfunded mandate'. The OMT groups described how they shift the resources at their disposal to an area of greater output, outcome, impact, or need, to ensure that they can provide adequate care to patients.

> "there's this thing that's called the unfunded mandate. If you said it was introduced without extra and only with what you have. But you need resources, you need beds, you need space, you need things, sitting area" SSMT 2

HIMT Informants stated that they had the expertise to offer in-service training and onsite support to public sector staff, but that the funding for this would need to be prioritised.

> "But also, to provide support. That phone call that one needs to make to give advice on what is the next step that is needed. … This pool of experts [is] available … Not only for them to be

> trainers or for them to be used for that telephonic support or that first assessment support and to lead the team who is not palliative trained into understanding … I'm speaking about day to day on the ground understanding of what palliative care is. So, they could come in as consultants maybe or mentors" HIMT

The informants in the OMT group suggested that resources be reprioritised between the levels of care since most patients are managed at the PHC level. If adequately resourced, the PHC platform could do more to keep patients well and out of hospital. In one OMT FGD there was a strong argument that patients in long-stay specialised hospitals should be transferred out to a hospice or appropriate facility, once they are deemed eligible for PC.

> "Another change that I think would help is equity around finances and the resources. So, a lot of the resources are sitting at the tertiary hospitals... A lot more can happen outside of those tertiary settings, if the resources perhaps were more equitable" OMT 2

Providing PC takes time, including the time it takes to engage the patient and the family meaningfully and adequately. Informants in the HIMT group raised concerns of the overburdened health system and the additional human resources that will be required to complete the necessary forms, to ensure that adequate PC can be provided to the patient and the family.

> "Now to add to it all the department has added to that doctor who is overburdened in that hospital who has been on call for over 18 hours... He has to complete two palliative forms as well. It is never going to happen; it is not a practical expectation to be putting on those individuals; it's not. So, you [are] never going to get a palliative care form completed unless this doctor has a spare hour to sit and complete this form." HIMT

> "And the biggest challenge for me there is actually a time factor, because for me to sit with this lady I was talking about earlier, which is 15 minutes. But I probably need another 15 minutes to talk to her and her husband again to reinforce this. And I probably need to do the same again in two weeks' time to say, "Hey have you actually got this?" So, the time (group agrees), it's not just staffing. A good palliative care discussion is not something that is seven minutes per visit., it's about half an hour." OMT 2

Community Oriented Primary Care (COPC)[52]

Informants in the SSMT FGDs proposed changes in service design that will be required to give effect to the integration of PC into the public health system. They articulated that COPC is a model that is being rolled out in demarcated communities across the CMD in preparation for NHI. It calls for various government sectors and stakeholders to collaborate to address community-specific health or social determinants of health issues. The operational managers gave similar inputs into what health system changes were required and the value of COPC in facilitating these changes, based on their experiences with having piloted COPC.

> "Because in a lot of cases even our palliative care clients go home without the necessary resources that they need to have ... for support purposes at home. So, then we really need to look at the whole systems approach and service redesign, [such] as how do we plan on admission then to meet the need of the client. Because that might be a potential palliative care client." SSMT 1

> "And we have a COPC. You know, that is … well operating. So, there are certain things that we can immediately tap into that is already available to us and a methodology that we that we follow to reach people, to make things more accessible. And the MDT … kind of approach and home visits; I think they do home visits, and the clinicians do home visits,"
>
> OMT 1

Change Management

The theme 'change management' was regarded as an essential enabler for the integration of PC in the public health system. It surfaced in the discussions in the SSMT FGDs and was also raised by OMT groups. The groups raised the need for change agents, while acknowledging that fear of change is real which needs managing.

Informants in the SSMT groups highlighted the importance and shared their experiences of being change agents and how this could enable staff in their journey of change. This included ensuring resources were available. They recognised that it was their role to guide staff through the change process. Informants in the SSMT and OMT groups raised and acknowledged that staff fears, discomfort and perceptions must be considered in the change management process.

Informants in all groups further expressed their concern that if a function was not mandated and made part of a performance management process, that it might be regarded as not important by implementers and role-players. Informants in the SSMT FGDs reported that if governance processes, such as medicine access, did not change or align, then a new policy will not be implemented as intended.

> "How I can influence [is] to change the coding status [of morphine], make a life easier for the patient …Influencing the decision makers to change the policies with regards to medications. … My role is to support it; my role is to allocate resources; my role is to sell it; my role is to make sure that the people buy in; and, my role is that all the managers have the same common understanding this is necessary for the hospital." SSMT 2

> "I think for me it was an eye opener. Now the other day when I attended one of the MandM's [morbidity and mortality meetings] of one of our facilities and they started to incorporate, the perceptions of palliative care in discussing the case. And it was an eye-opener to hear the discomfort that many of the clinicians have with regard to that. But just the family physician, creating the space for that to be articulated, … the doctor actually asked a question, "Am I supposed to have a conversation with a patient? Am I supposed to tell the patient he is dying?"

> … And so, it was interesting to see that the doctors are avoidant of that conversation…"
>
> SSMT 1

Informants across all six focus groups raised the need for the service design to be more adaptable and accommodating of changes that are necessary for the inclusion of families at every level of care, in all discussions and decision-making regarding patients.

5.6. Discussion

This sub-study investigated the perceptions of PC by relevant actors within the adoption system, namely managers and NGO stakeholders, at the onset of the implementation of the NPFSPC. The intention was to identify factors that would enable the provision of PC within public sector services and obstacles that would prevent the integration of this approach and set of services.

FGDs were conducted early in the overall study and informants were made up of a range of stakeholders with deep insight into the health system and the hospice environment. They were able to identify complexities, caution against obstacles and propose enablers.

The informants in the SSMT and OMT groups represented people who guide the health system, are strong drivers towards integration and "*manage an intricate network of role-players*" in their stewardship role within their geographic areas.[79] The HIMT informants were experienced managers and providers of PC in hospices and ICFs and provided insight into what the public sector health system would need in order to integrate PC.

Participants in all FGDs were in favour of the integration of PC into the public sector and the concerns were more about how to achieve this. In many instances the identified enablers, if reversed would be obstacles and vice versa. Consequently, the themes identified were not categorised as enablers or obstacles.

The four themes that were generated, are interrelated and Figure 5.3, overleaf, illustrates this: i) leadership and governance, ii) PC service delivery and uptake, iii) a compassionate health system, and iv) patient centred. Leadership and governance that supports capacity building for the PC service delivery and drives the agendas of its integration towards a compassionate health system, makes for holistic patient-centred care, which is the end goal for the provision of PC. This in turn requires that continuity of care, family involvement, compassionate care, and MDT approach to care are essential.

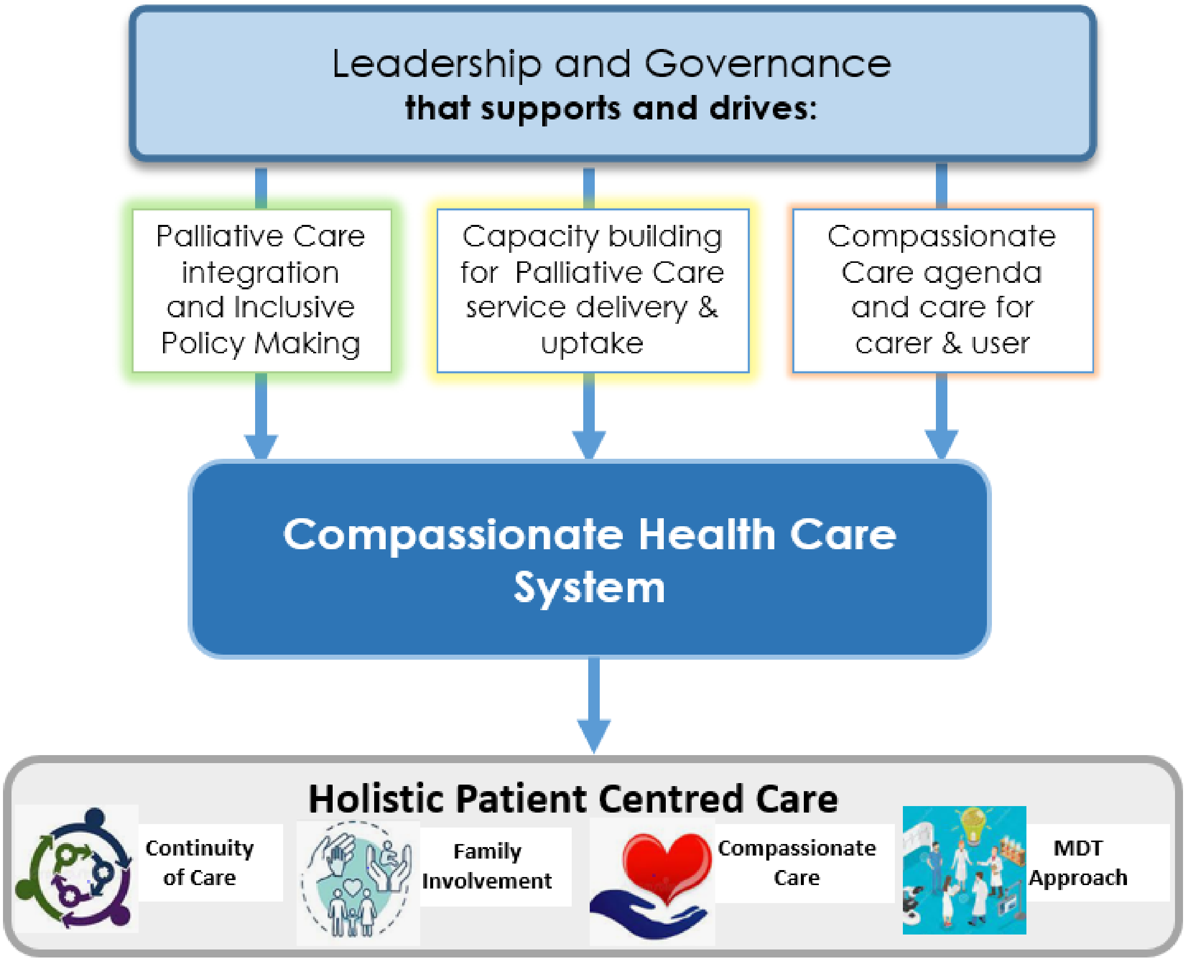


Figure 5.3: Link between the four Main Themes

5.6.1. Leadership and governance for palliative care integration

This sub-study found that the move towards policy implementation and eventual integration requires leadership that ensures the alignment of the local health services to the burden of disease of the community that it serves, while remaining aligned to departmental strategy through maintaining the focus on the transversal priorities and service design reform. This does not mean that operational changes will not need to be made, but leadership must actively make decisions about policy, related resource allocation, the service design changes and resultant change management.

Inclusive policymaking

This sub-study raised considerations that will require attention to give effect to policy implementation. These include the policymaking process which should be consultative and aligned to departmental short-, medium- and long-term goals. Inclusive policymaking creates platforms for bottom-up engagement with policy implementers, makes for buy-in from these implementers and operational management teams. Non-conflicting policy that is adequately communicated and comes with the necessary support and resources, enables policy integration. Policy that is not developed in an inclusive manner, is conflicting and poorly communicated, will not receive the same buy-in and support at the frontline and this could hinder or block integration.

Resource consideration

Although the NPFSPC advocates for integration into existing resources, the current sub-study found that inadequate resources are regarded as an obstacle to the adequate provision of PC. The need for additional resources for the NPFSPC, its additional services, and the time it takes to perform activities related to PC, translates into the need for more staff, access to opioids, an easy-to-use referral system, together with PC commodities[xiii]. The NPFSPC was regarded as an unfunded mandate. Furthermore, the informants advocated for reconsidering departmental funding allocations, as most patients are seen on the PHC platform and not in hospitals. The District Health Services policy framework and strategy (2014) acknowledges that the health system will remain unresponsive to the needs of the community in the absence of the required financial and management delegations.[194]

Driving the COPC approach

The COPC approach is being rolled out in the CMD. It utilises a multi-stakeholder approach within a defined geographic area to address health and social determinants of health matters.[44] This approach is an enabler for the integration of PC based on the support of other government departments, NGOs, faith-based entities, private sector and various stakeholders coming around the same table.

This sub-study found that the SS managers and the operational managers considered change management processes as being critical and regarded themselves as agents of change for the implementation and integration of any new policy or intervention. This includes PC policy which advocates for the inclusion of patients' families. There was an agreement that implementation is enabled when functions or roles are mandated through a formal process such as performance agreements. Birken et al. (2013), found that proactive middle managers and their commitment positively influences implementation. Furthermore, as middle managers are strategically located between senior management and the implementers, they form that bridge and close the gap necessary for innovation implementation. They do this by changing their own practice, reporting requirements and often stifle their own opinions and emotions for the sake of the frontline.[182] Committed leadership that offers support to the frontline, is essential to enable policy implementation and integration.[181]

[xiii] Palliative Care Commodities refer to wheelchairs, adult diapers, commodes, urinals, linen savers, dressing packs, syringe drivers.

5.6.2. Palliative care service delivery and uptake

Providing PC services and ensuring uptake, requires a multidisciplinary team (MDT) approach, closing the public sector PC skills gap, as well as a change in the communities' perceptions of PC. These three focus areas are grouped together because they require special effort in capacity building.

Optimising the MDTs

According to DeMiglio and Williams (2012) the complexity of managing patients with PC needs and those at the end-of-life stage requires a variety of health professionals to provide holistic PC as a team.[47] Furthermore Fernando and Hughes (2019), found that PC is optimally delivered through the MDT approach. This sub-study acknowledged that MDTs have not been optimally utilised in the primary care space for PC patients. Yet they valued and argued their transformative value as they flatten hierarchies within the public sector since all attendees are equal contributors to the team. However, personnel that are shared by multiple facilities hinder participation.

Although the dynamics within the MDT can adversely or favourably influence team members, a supportive milieu with adequate leadership, mutual respect and effective communication are important. These will determine the team's performance towards achieving the common goal of holistic patient care for the patient and family.[176]

Informants also believed that other cadres of staff including CHWs, and rehabilitation care workers (RCW) should be considered to form part of MDTs. These are new cadres of CHWs that were trained as rehabilitation care workers (RCW). A 2012 WC study conducted by Gamiet (2015) found that health professionals at the primary care level welcomed rehabilitation care workers as part of the PHC team.[195]

Closing the skills gap

This sub-study found that PC training in the public sector is a glaring skills gap, and this was raised by all informants. This includes communication skills that convey information compassionately. Proposals from this sub-study to address gaps included the use of experienced and qualified PC nurses to provide onsite skills transfer, training of CHWs in PC and the inclusion of PC training in undergraduate programmes for nurses, doctors, and other health professionals. These findings mirror that of Ganca et al. (2016) conducted in a hospital based qualitative study in the Cape Metro.[177]

Although literature on providing onsite PC skills transfer in the workplace was not found, other than being part of a formal training programme, there is literature about on-site mentorship for skills transfer in other domains, such as HIV care and lung health.[196, 197] Since there are precedents of this working for other illness domains, coupled with enthusiastic experts make for likely success.

Advocacy and community awareness for palliative care

In this sub-study it was proposed that advocacy for PC should be conducted in community settings. Engaging and teaching trusted community health workers, religious leaders, and local level NGO leaders in PC would reduce community stigma that PC is merely end-of-life care and sensitize communities about its value. In a study conducted in Kerala State in India during the COVID-19 pandemic, where PC is integrated into community structures and the healthcare system, Daniel et al. (2020) found that through an e-learning PC toolkit, community agencies, individual community activists, NGOs, faith/religious centres, educational institutions, and volunteers each could play a specific role and provide support to patients and families in need of PC. The study found that community networks of PC, "*turned out to be a strong force for advocacy*", according to Daniel et al. (2020). Furthermore, the authors concluded that communities are important environments to address stigma and every effort to empower, mobilize, and hear their voices must continue.[198]

5.6.3. Compassionate health system

A compassionate health system is built on the display of compassion to users of services as part of holistic patient-centred care. It depends on leadership driving the compassionate care agenda, personnel's ability to navigate difficult conversations, while ensuring that carers themselves feel cared for.

All groups in this sub-study were sceptical that both managers and clinicians in the public sector were positioned to offer compassionate care to people with life limiting illnesses. This was due to inexperience, inadequate training, poor communications skills, staff attitudes and organisational culture.

This, however, is not unique to the public sector health system in the CMD. A systematic review[81] that included 14 studies from six western countries showed unmerciful and non-compassionate care from health care providers to vulnerable patient groups. In a study conducted in five European countries, Van Gurp et al. (2020) that careful and sensitive communication, which the authors term "*diplomacy*" (skilful and kind communication), is essential for PC providers and that an investment in building this capacity is required.[155]

Caring for the carer

Compassion extends to caring for the carers as well as the users and is regarded by SSMT and OMT informants as being their responsibility. There was an agreement on being intentional about caring so that implementers feel supported when facing constant pressure and even abuse from some service users. The literature supports strong leadership that models compassion and efficient support to subordinates.[81], [199]

5.6.4. Holistic patient-centred care

Ensuring continuity of care through functional referral mechanisms

To ensure continuity of care for PC patients, informants believed that a seamless and interconnected care pathway with the necessary electronic communication network that facilitates referrals and feedback, was essential to hold the patient at the centre of health care system. This would require all health disciplines and role-players to purposefully engage and communicate in the best interest of quality patient-centred care.

Furthermore, role player communication must give attention to communication between attending clinicians and patients. As was found by Morey et al. (2021) who explored continuity of care for PC patients transitioning across care settings, longitudinal relationships between clinicians and patients can reduce challenges when transitioning and reduce emergency department visits at the end of life.[116] This was a concern raised by OMT informants.

Strengthening in-patient capacity

The WHO (2016) guide to programme managers suggests that an in-patient PC consultation service be established and accessible to all departments within the hospital. This can build capacity among other staff about pain management and facilitate district-wide referral pathways.[113] A case was made, in this sub-study, for the appointment of a hospital based PC nurse. These nurses would serve as the point person to ensure that patients are assessed according to a tool that assesses eligibility for PC, Supportive and Palliative Care Indicator Tool – South Africa (SPICT-SA),[200] to determine eligibility for PC, develop care plans in consultation with the MDT, and then link patients to the PHC platform to continue their care.

This sub-study found that clarifying roles of the various role-players within the sub-district is essential so that connectedness is established and communication regarding client care is enabled. These findings support recommendations of the WHO (2016), in that it is essential to connect hospitals, clinics and NGOs to ensure integration and continuity of care for patients.[113]

Access to local hospice or ICF

This sub-study found that access to a hospice or ICF, located in the vicinity of public sector facilities could enable easy referral and clinical expertise. With the move towards a sub-district model in the WC, the provision of ICF access with these boundaries would add great value. Increasing geographic access for patient care has been a focus in health systems such as in the United States of America (US). Whereas in 2000, only 40% of the PC patients had reasonable geographic access, in 2008 this had expanded to 98% (Carlson et al., 2010) due to the rapid growth in hospices, reducing the mean travel time to a hospice to 15 mins.[201]

However, in this sub-study, the HIMT informants argued that there was poor utilisation of hospices and ICF services which was likely due to the unwieldy systems and not the availability and accessibility of the services. This poor utilisation contributed to gaps in continuity of care in the CMD. This was also found in an earlier study conducted in the WC by Ens et al. (2008) who reported poor utilisation of hospices because of different referral mechanisms and processes for different disease profiles.[35]

Holistic patient-centred care

According to Price (2006), person-centred care has developed as a response to patient-sensitive healthcare service, individualized care, and holistic care. This form of care moves away from a medical model, is centred around the patient and allows the patient to be fully involved in the care decision-making, considering the patient holistically.[171] In line with this approach, informants agreed that the essence of care is holistic patient care of the body, soul and spirit. They regarded this as ‘going back to the basics’ of what they had been taught during their undergraduate training. Furthermore, they maintained that caregivers within the health system must understand and respond to patients’ and the families’ needs, preferences, and desires.

Support groups

The need for support groups in its historic format, being facilitated by a HCW for specific disease conditions, was heavily disputed as being beneficial to the PC patient. According to the informants, it did not add any value to patient outcomes and was not an efficient use of available human capital within the health care system. However, they proposed that spaces for patients and family members to connect with and support each other on their journey may add more value. Peer support has been advocated by PC practitioners, and a systematic scoping review, conducted by Kowitt et al. (2019) demonstrated the benefits of peer support. This included the attention that group members (patients and families) pay to the end-of-life issues that otherwise may be avoided, as well as support for family members who are coming to terms with loved ones’ worsening health and in-so-doing addressing families’ fears and anxieties.[202] Issues that can be positively addressed include distress regarding death and dying, pain and symptom management, and emotional support for patients and families.

Family involvement

Family involvement, beyond peer support groups, was raised as an enabler to the provision of PC, hence inadequate family’s involvement could be a barrier. Informants made proposals regarding the importance of at least one private family room at public sector hospitals to accommodate families who need to be close by when patients reach the end-of-life and to facilitate discussions between the clinical team and the family. The value of access to a private room to support the bereaved family was found in two hospitals in an Irish study by Donnelly et al. (2018), where bereaved families expressed their gratitude of being able to have access to a private room to support the dying patient. Families indicated that it was hard to listen to machine noises and other people laughing while facing death and dying. The privacy in those last hours made it a dignified experience.[203]

5.6.5. Strengths and limitations of the sub-study

Although this sub-study took place very early in the policy implementation period and before the COVID-19 pandemic, there was a unanimous agreement from all informants that PC was an essential component of the care package to eligible patients.

A strength in this sub-study was the willingness of a broad spectrum of experienced informants to participate in the sub-study with very little declines to participate.

Limitations include the fact that the researcher is a senior manager in the WCGHW, and this may have limited the responses of certain informants even when advised that sub-study content would be kept confidential. To mitigate this, the researcher was accompanied by a researcher assistant who recorded detailed notes and observed informant non-verbal and interpersonal dynamics, which were included in the results.

5.7. Conclusion

PC is needed and there was no counter argument that it was a neglected area in the public sector health system. Although the NPFSPC has been officially launched and it was expected that the public sector health system would integrate it, according to middle and senior managers within the WCGHW and partner HIMT managers, successful integration, will require careful attention to certain elements.

Committed leadership and appropriate governance arrangements that support implementers at the frontline, drives PC integration. Reprioritisation of resources according to local context, is essential. Change management with middle managers – intentional proactive change agents, the alignment of governance arrangements, and visible changes to agendas and reports, are all required.

The introduction of new policies requires that policy makers ensure robust consultative and inclusive policymaking processes with implementers. At the start of the policymaking process, appropriate platforms should be provided for policy discussions with the relevant implementers to ensure buy-in.

Capacity building in PC is essential. All HCWs require knowledge of PC. In-service health care practitioners require training that includes communication skills, a critical steppingstone in the pathway to offer compassionate care. In addition, PC knowledge and skills training must be included in all health care professional undergraduate programmes.

PC service delivery and uptake requires an MDT approach at all levels of care to close the service gap, efforts to close the PC skills gap, and effective community advocacy. Trusted community leaders can partner with the health services to debunk myths regarding PC among community members.

The WCGHW system is functional and clear about its intention about service design reform that uses the COPC approach. Consequently, PC should be provided within a defined geography and bring area-based stakeholders around the table to, in teams, address individual patients, families, and population needs, cognisant of social determinants of health.

A compassionate care agenda needs articulation. Caring for the carer and user/patient is central to elicit compassion from various role-players. A compassionate health system prioritises critical health issues faced by patients and considers the whole patient at its centre. It requires commitment from all role-players including political commitment. Breaking bad news and building hope is dependent on the display of compassion which does not come naturally to all clinicians, particularly inexperienced busy clinicians who are focused on seeing their quota of patients. They require training and encouragement to have these difficult conversations. Further research on where the responsibility for caring for the carer resides, would be beneficial as many managers regard it as layers of responsibility and not only within the responsibility of occupational health services or an external contracted employee health and wellness service entity.

Placing the patient at the centre of the care continuum, while offering holistic patient care and ensuring that the family is involved in the care pathway is not a standard practice within the public sector at PHC level. Changing this culture will require a change management process.

Chapter 6 focuses on the experience of the implementing teams and the frontline operational and operations managers on implementing the PC policy, which occurred during the COVID-19 pandemic, approximately 18 months after the findings reported in this chapter.

Chapter 6 : The Experience of the Implementing Stakeholders in Operationalising Palliative Care Integration

Chapter 6 highlights the experiences of the implementing teams who provide care and form part of the adoption system in the conceptual framework for analysing integration of targeted interventions into a health system.[8]

6.1. Introduction

At the health facility level, the doctors, nurses, allied health professionals, pharmacy staff, social workers, and lay health workers (including NGO staff) form part of the providers within this adoption system. Furthermore, the operations managers at the health facility level provide direct support to implementing teams, are responsible for supervision of the clinical and non-clinical teams, administrative duties and general management of PHC facilities[199] and in hospital wards.

In this sub-study the experience of the implementing teams and the operational and operations managers will be explored to gain insight into their perspectives on the factors that influence the integration of the palliative care (PC) services at selected higher and low morphine usage sites.

6.1.1. Implementation Studies and Science

The importance of understanding and studying implementation helps to inform policy makers and health system managers about the variables that must be considered when implementing new interventions. The need for research focused on implementation has grown over time in order to close the research to practice gap and determine whether research does impact on public health practice and subsequently whether evidence-based practice leads to quality improvement.[98]

In the framework developed by Damschroder et al.(2009) implementation can occur in a passive manner, as planned efforts to persuade the target groups to adopt and mainstream the intervention or routinise the intervention for sustainability within an organisation.[99]

Bauer et al. indicate that implementation studies assess natural diffusion of a new intervention or measures change based on planned interventions that aim to mainstream evidence-based practices. These studies often employ mixed quantitative-qualitative design methods to identify factors that influence uptake across the adoption system, the organisation, community and policy space, making it relevant to this study.[98]

It is interesting to note that implementation studies target transdisciplinary research teams such as frontline clinicians, administrators, patients, operations managers. Bauer et al., assert that implementation studies and quality improvement share a common goal of improving quality of healthcare.[98]

6.1.2. The conceptual framework for analysing integration of targeted interventions into the health system

As indicated in Chapter 2, the conceptual framework by Atun et al., for analysing integration of targeted health interventions into the health system, is the framework for this study as it enables a structured approach to exploring the nature and extent to which an innovation or intervention is integrated into a particular setting as well as the different factors that influences the integration process, which then ultimately provides reasons for variation.[8] The conceptual framework considers the World Health Organisation (WHO) building blocks for health systems and in this chapter, this will be unpacked in relation to the adoption system and its actors. Atun et al. argue that the extent to which a new health intervention is adopted and diffused into the health system is influenced by the nature of the problem that is being addressed, the degree of complexity of the intervention, the adoption system dynamics which includes the cultural norms, beliefs and values of the actors within the adoption system, the characteristics of the health system and the broader context within which it all exists.[8]

6.2. Literature Review

6.2.1. Role of operational managers

Operational managers at primary health care (PHC) facilities in South Africa are nurses and the literature indicates a challenge in developing countries of ineffective supervision from these managers. They are responsible for ensuring that their teams provide quality care to healthcare users and facilitate implementation of new interventions. However, Gilson in a study conducted in the Cape Metro District (CMD) (2012) reflects on the nurse operational managers' reluctance to take on this role in its entirety.[79]

A number of studies conducted in developing countries indicate that work overload resulting in absenteeism, poor technical knowledge, inadequate time to ensure adherence to treatment and clinical guidelines together with inadequate leadership, supervision and management skills as reasons for ineffective supervision at PHC facilities.[79, 199, 204] Furthermore, shortage of nursing staff contributes to poor delegation and limited time available for supervision and essential administrative work.[199] Consequently, Serapelwane and Manyedi (2021) reported that supervision by operational managers in developed countries was effective since they have the time to reflect and create safe environments for staff and patients, as well as strategize to meet various priority targets.[199]

6.2.2. Street level bureaucrats

The notion of street level bureaucrats (SLB) was coined to describe the role of frontline public sector workers who work at the frontline, engage the public in the line of duty and have significant discretion in performing their work.[205] They are considered to be "*policy reformers rather than implementers*" according to Hupe and Hill,[206] and citizen agents who possess great influence in the implementation processes.[185] Loyens et al. refer to them as street level leaders who, due to the complexity of their work environment, "*develop routines to avoid making endless individual choices*". Notably this involves using their discretion while considering the client and the organisation characteristics. However, they tend to consider the client and peers more than the organisation while maintaining positive professional relationships.[185]

In the context of nurses as SLBs and policy change, a study conducted by Walker and Gilson (2004)[183] indicated that the views and value of the nurses influenced health policy implementation, that nurses feel excluded from decision-making regarding policy change and that policy change often comes without due consideration for the financial, social and resource implications. One of the recommendations from this study was that planning and management should be improved in ways that reflect trust and respect for nurses.[183]

6.2.3. Multi-disciplinary Teams (MDTs) and interprofessional support

PC that is integrated into regular healthcare relies on functional multi-disciplinary teams (MDTs) and according to Fernando et al. (2019), many experts regard teamwork as a crucial functionality of PC teams.[176] The MDT health care professional involved in PC at the PHC facilities should ideally include doctors, nurses, allied health professionals, psychologists, registered counsellors, social workers, spiritual counsellors and volunteers, with access to physicians and other specialists and PC experts.[176] The value of having an integrated team with varying expertise, caring for the patient and family caregiver, enables a more holistic approach to care, improves the degree of vigilance over the patient[176] and addresses the complex needs of patients, particularly at end of life.[47] Furthermore, MDT effectiveness is dependent on good communication between team members regarding patient and family caregiver care plans and support. [203,176]

However, MDTs are not widely established and maintained and embedding them into the health system will require time and effort if PC is not integrated in undergraduate education, health system referral pathways, relevant policy and policy maker practices.[207] Furthermore, MDT core team members may vary from one PHC facility to the next,[47] since certain categories of allied health professionals' are often shared among facilities across the service platform in the Western Cape (WC) and therefore form part of the extended professional network.[207] The wider professional community includes access to specialist support from hospices and higher levels of care. Notably, den Herder-van der Eerden, et al., articulate that the MDT is not only the core team based at each health facility, but also include the health care professionals that they have access to in the extended professional network and the wider professional community.[207]

6.2.4. Capitalising on partnerships in providing palliative care

The community-based PC teams comprise community health workers (CHWs) and Professional Nurses employed by NGOs that are considered collaborative partners to the health care system. These NGOs are important for the provision of PC[47] and are often contracted to support the health services in the provision of care including PC.[208] This model is strengthened when the community based services team is included as part of the MDT.

This mechanism establishes a shared care model through interprofessional collaboration since these health care workers (HCW) take co-responsibility for patients and family caregivers, providing PC services within the defined geographic area[47] through a Community Oriented Primary Care (COPC) approach.[52] The involvement of external parties is not without risk. As DeMiglio (2012) points out, facility teams in Canada often feel threatened by community based PC service providers[47] and in rural Western Cape (2022), changes in the role of the CHW to focus on health promotion and disease prevention, resulted in role confusion when it came to their place in providing community-based PC.[167] Furthermore the success of a shared care model, is dependent on buy-in from the lead clinician, the family physician or clinical team at the local PHC facility.[47]

6.3. Aims and objectives

While the aim of the overall study was to describe, explore and explain the factors that influence integration of PC within the district health service platform in the CMD, this sub-study determined the factors influencing the implementation of the PC policy amongst implementers at selected CMD higher and low morphine usage facilities. Higher usage may signify more patients and more embedding of PC in service functioning, compared to low usage facilities where the PC services are less established and less functional.

Objective of this sub-study:

i) To determine the experience of PC implementers at least one year after training

ii) To explore their level of confidence in breaking bad news and building hope

iii) To understand the approaches to PC integration at the identified sites

iv) To identify the need for support from management in terms of enablers and obstacles

6.4. Methodology

This sub-study explored the implementers' experience of the National Policy Framework and Strategy on Palliative Care (NPFSPC) implementation and integration into the health care system one year after formal or informal training in PC, at low and higher morphine usage facilities in two sub-districts in the CMD.

6.4.1. Sub-study Design

A qualitative exploratory, descriptive study design was applicable and appropriate for this sub-study,[209] as it focused on the experiences of implementers and operations managers at the identified health facilities and sought to obtain perceptions and experiences from information rich participants.

Sub-study Population

The sub-study population comprised two different groups, namely the implementers and operations managers.

The implementers were the clinical staff categories involved in providing PC services, facility support staff as well as clinical staff not implementing PC but who identify and refer potential patients within the identified higher and low morphine usage health facilities. They were engaged through focus group discussions (FGDs), as described in Table 6.1 below.

First implementers participated in five FGDs followed by 1-1 interviews with the operational and operations managers for the selected sites.

Table 6.1: Summary of Sub-study Population

	Sub-study Population	**Study Method**
Implementers	Doctors Nurses Pharmacy staff, post basic pharmacy assistants. Social workers, social auxiliary workers Allied health professionals Support staff (non-clinical)	Focus Groups x 1 per selected health facility. Total: 5 focus groups
Operations Managers	Nurse Operational manager Facility Manager	In-depth interviews: two of the higher morphine usage sites proposed that two of their operations managers participate. Total: 7 interviews

Site Selection

The sub-study site selection criteria and process to determine the low and higher morphine usage health facilities was based on the quantitative morphine usage data, as an indicator of PC service utilisation, as described in Chapter 4. Mist morphine and morphine sulphate usage data was requested from the Provincial Health Data Centre (PHDC). The morphine data are divided into morphine Unspecified, which was assumed to be mist morphine usually prescribed at PHC level, and morphine sulphate, the injectable version usually prescribed and administered for inpatients either admitted to or being referred to hospital level care. It was not possible to determine whether any of the morphine sulphate data was misclassified and captured under the morphine unspecified data and vice versa. The two datasets were combined and analyzed to determine the total morphine used. The data set reflected morphine 'dispensing'. This is morphine that is both prescribed and dispensed to patients.

The data was captured in Excel by facility and sub-district as annual data from 2013 until 2018 and then quarterly for six quarters from January 2019 until June 2020. The quarterly data reflected the period following the NPFSPC launch.

The proportion increase year on year until 2019 and projected for 2020 was calculated and provided a clearer picture of the trends at facilities with smaller numbers. The cut off threshold for being designated as a low usage facility was an increase of ≤15% of morphine use. The three sites in the sub-district one (SD1) were found to be low morphine usage sites while all the sites in sub-district two (SD2) increased by ≥38% on average. SD1 has two district hospitals and six community day centres. SD2 has one district hospital, one 24-hour community health centre and two community day centres. Since no low morphine usage sites could be determined in SD2, three higher morphine usage sites were selected. In SD1, three low morphine usage sites were selected and one higher morphine usage site, which was a district hospital. These facilities would serve as the sub-study sites for research among implementers reported in this chapter and research on the patient experience, reported in Chapter 7.

The PC champions who serve on the PCTT and worked in the two sub-study sub-districts, were consulted to gain insight into any possible initiatives that would influence the sub-study findings and to determine if the data analysis was in keeping with their experience. Initiatives such as change in management or clinical lead, significant change in facility operations and personnel who span more than one facility, were considered. After this, one facility in SD1 was removed from the site identification process, since it was a newer site with very low numbers of patients for whom morphine was dispensed. In SD2, one site was removed since it was one of two sites that was clinically led by the same family physician since 2015. Although two of the low morphine usage sites in SD1 were managed by the same facility manager, the operational and clinical managers were not the same and for this reason both sites were included. Table

6.2, below, provides the location in the CMD of the higher (blue shade) and low (peach shade) morphine usage sites.

Table 6.2: Summary of higher and low morphine usage sites selected for this sub-study and sub-study three and four.

	SD1 (Metro East)	**SD2 (Metro West)**
Higher morphine usage site CDC: 8-hour facility – HMUS 1		▨
Higher morphine usage site CHC: 24-hour facility – HMUS 2		▨
Higher morphine usage site: District Hospital – HMUS 3	▨	
Low morphine usage site CDC: 8-hour facility – LMUS 1	▨	
Low morphine usage site CDC: 8-hour facility – LMUS 2	▨	

6.4.2. Participant recruitment

The sub-structure management teams were provided with the selection criteria (Appendix 10) that were used to identify potential individuals that the researcher would approach, which were PC implementers, included those who fulfil at least one of the following:

- Implementers who assess patients for PC eligibility according to the Supportive and Palliative Care Indicator Tool (SPICT)[210]
- Implementers using referral documents and enrolling patients into support groups.
- Implementers convening/conducting support groups and/or telephonic support for PC patients and their family caregiver/support buddy.
- Implementers who draft PC care-plans.
- Facility support staff involved in patient folder management.
- Personnel responsible for the dispensing of medication and
- Clinical staff responsible for the identification for referral to PC.

The target audience for selection included the following staff categories:

- Professional Nurses
- Clinical Nurse Practitioners
- Medical Officers
- Family Physicians
- Social workers
- Support staff – administrative and pharmacy

Sampling and inclusion

Purposive sampling was conducted from the range of potential implementers who met the selection criteria from the low and higher morphine usage facilities.

The multidisciplinary teams responsible for the implementation of the NPFSPC, facility support staff and other clinical staff were included. To recruit as many participants as possible to represent all clinical staff categories and support staff, all identified members of implementing teams from the identified sub-study sites were invited to participate. Notably not all of them had been formally trained in PC but all had been exposed to a briefing session on PC. These teams are referred to as the implementers.

The operational and operations managers at the identified facilities were invited to participate in virtual 1-1 in-depth interviews to gain further insight into some of the reasons for higher and low morphine usage facilities and to further explore the findings from the implementers FGDs.

6.4.3. Data Collection

Data Collection Tools

A FGD guide was developed (Appendix 11) to ensure that the narrative data required to achieve the research objectives, were generated. This semi-structured interview guide with open ended questions was designed to gain specific insights into implementers' level of confidence in breaking bad news, building hope and identifying needs and access to on-going care with patients and families. Additionally, the guide sought to determine the influence of their cultural values and faith orientation on providing PC; to understand the support from management; to identify enablers and barriers to the provision of PC; to elicit referral processes to HCBC services and to identify what is needed to enable integration going forward.

An interview guide was drafted (Appendix 12) for the virtual 1-1 in-depth interviews with the operational and operations managers. This open-ended guide sought to determine their role in PC policy implementation, the support they offered to implementing teams and received from the sub-structure management teams, and what changes within the health system had been observed. The guide was further refined after the FGDs had provided more information that required further exploration and has the potential to provide for triangulation of data.

Data Collection Methods

A researcher assistant, a social worker with field work experience and who had conducted FGDs and 1-1 in-depth interviews for research, was recruited to facilitate these virtual FGDs and interviews because the implementers and operations managers may not have felt comfortable stating their anxieties, fears, concerns, and challenges, knowing that the researcher was a senior manager in the Western Cape Government Health and Wellness department (WCGHW). For this reason, the virtual focus groups and interviews were moderated by the research assistant and accompanied by the researcher who performed the function of note taker to record detailed notes[190] and observed participants' non-verbal and interpersonal dynamics on Microsoft Teams. Notably this was not easy as some participants switched their cameras off during the group discussion. The research assistant was trained in how to moderate virtual focus groups, appraised about the study and the ethical issues surrounding the research.

Emails were set to the PHC manager for each of the two SSs, providing them with the information that supported the site selection and the criteria for participant selection. The PHC managers were requested to identify and provide the contact details of the relevant implementers and operational managers at these selected sites.

Most of the implementers were approached by email, provided with an information sheet and consent form (Appendix 13) for the sub-study and asked to participate in a FGD. They were invited to pose any questions for clarity and those who agreed to participate in the virtual FGDs, were asked to print, sign, and return consent forms via email or fax to the research assistant before the date that the FGDs were to take place. Some implementers did not have access to email, and telephonic contact was made by the research assistant to describe the research and obtain consent. Two possible dates were provided to each implementer who had agreed to participate with a lead time of at least two weeks. One FGD was held separately for each health facility. Table 6.3, overleaf, provides participant information, challenges, and mitigation, and is stratified by higher and low morphine usage facilities.

Table 6.3: Virtual Focus Group participant recruitment and challenges

Site	Challenges and Mitigation	Participants/Informants
Higher morphine usage site CDC: 8-hour facility – HMUS 1	The team that agreed to be interviewed, were faced with a significant challenge since five of the eight clinical staff members had not arrived for work on that day. As a result, three consenting clinical staff could not attend the FGD.	Family physician Social worker Pharmacist Admin clerk: reception Admin clerk: admissions Admin clerk: infectious diseases
Higher morphine usage site CHC: 24-hour facility – HMUS 2	No challenges encountered	Family physician 2 x Doctors 2 x Clinical Nurse Practitioners Social worker Admin Officer: reception Pharmacist
Higher morphine usage site: District Hospital – HMUS 3	No challenges encountered	Family physician Social worker 2 x Allied Health Pharmacist Admin: reception
Low morphine usage site CDC: 8-hour facility – LMUS 1	Numerous attempts made to secure an appointment with the implementers. Six confirmed and provided consent, yet only three arrived for the FGD	Doctor Pharmacist Admin clerk: reception
Low morphine usage site CDC: 8-hour facility – LMUS 2	Numerous attempts made to secure an appointment with the implementers. Five participants confirmed and provided consent, only one arrived for the FGD. The doctor was willing to proceed.	Doctor

The FGDs were followed by virtual 1-1 in-depth interviews with the operational and operations managers at the selected sub-study sites. These managers were contacted via email, their participation was requested, and they were provided with the information sheet and consent form (Appendix 14) for this sub-study in order to make an informed decision regarding participation. The health facility managers were copied into the emails sent to the operational managers, as requested by the PHC manager for the SSs. The operational managers were also advised that they could pose questions of clarity and opt out of the research at any time. Once the operations managers had confirmed their participation, they were asked to submit their completed consent forms, and provided with two alternative dates for the interviews. All completed consent forms were received via email. Table 6.4 provides a summary of the participants recruited for the virtual interviews for each HUMS and LMUS.

Table 6.4: Virtual in-depth interview participant recruitment process and considerations

Site	Considerations prior the virtual in-depth interviews	Participants/Informants
Higher morphine usage site CDC: 8-hour facility – HMUS 1	The operational manager resigned three weeks prior, and the Assistant Manager Nursing agreed to replace her since she was familiar with all operations at this site.	1 x Assistant Manager Nursing was interviewed.
Higher morphine usage site CHC: 24-hour facility – HMUS 2	The facility manager requested that the operational managers for both the PHC and Infectious Diseases (ID) units should be interviewed, because a significant proportion of the ID patients were referred for PC.	2 x Operational Managers were interviewed. Both the interviews were conducted telephonically since the internet at the facility was down.
Higher morphine usage site: District Hospital – HMUS 3	The Clinical Manager and the Family Physician assume the operations manager roles at the district hospital and the PHC manager for the SS requested consideration for both to be interviewed.	1 x Clinical Manager 1 x Family physician
Low morphine usage site CDC: 8-hour facility – LMUS 1	The facility manager suggested that the Assistant Manager Nursing should be interviewed.	1 x Assistant Manager Nursing was interviewed
Low morphine usage site CDC: 8-hour facility – LMUS 2	Numerous attempts made to engage the implementers. While five confirmed and provided consent, only one arrived for the discussion	1 x Operational manager was interviewed.

Data Management and Confidentiality

The virtual FGDs and the 1-1 in-depth interviews were audio recorded and brief notes were taken by the research assistant/moderator, while detailed notes were taken by the researcher. At the start of the FGDs and in-depth interviews, the implementers were reminded that the proceedings were confidential, that they should not talk about what was discussed with others as this could violate other participants right to privacy and that they would opt out at any stage during this research. Names of participants were not captured. At the end of the virtual FGD and in-depth interview, the moderator and researcher engaged in a de-briefing session to allow for note expansion and the generation of de-briefing notes. The audio-recordings were transcribed verbatim by a professional transcriber and checked by the researcher before analysis. Each transcript was saved using the archival number as the computer file name which indicated the site name (Mitchells Plain (MP) or Eastern (E)), method of data collection (FGD (F) or In-depth interview (IDI)), participant category (higher morphine usage sites (HMUS) or low morphine usage site (LMUS)), and sequential number (1-n).[127] All written notes and printed transcripts were placed in a marked envelope, using the same allocated archival number, and placed in a lockable cupboard, dedicated for this sub-study. All audio-recordings will remain on record and deleted from all devices and computers once analysis is complete and captured in the thesis, to maintain confidentiality.

Data on demographic variables, educational information, professional work, and skill sets, were also captured as part of the completed consent. Contact details of all participants who requested a copy of the research report, have been captured for that purpose only. In total 29 participants were recruited: 22 implementers for the five FGDs and seven operations managers for 1-1 in-depth interviews. These implementers and operations managers were from the three higher and two low morphine usage facilities as illustrated in Table 6.5.

Table 6.5: Summary of participants in the FGDs and interviews at the higher and low morphine usage sites.

	Implementers: Focus Group Participants	**Operations and Operational Managers: In-Depth Interview Participants**
Higher morphine usage Site 1 (HMUS1)	5	1
Higher morphine usage Site 2 (HMUS2)	8	2
Higher morphine usage Site 3 (HMUS3)	5	2
Low morphine usage Site 1 (LMUS1)	3	1
Low morphine usage Site 2 (LMUS2)	1	1
	22	**7**

Table 6.6 provides a summary of the work experience of the virtual focus group participants and Table 6.7 (overleaf) provides this for the operations managers who participated in the in-depth interviews.

Table 6.6: Summary of the virtual FGD participants at higher and low morphine usage sites.

Focus Group	**Job Title**	**Years of Work Experience**					**Total**
		<1 year	1-5 years	6-10 years	11 - 20 years	20 + years	
Implementing Teams at higher morphine usage sites PHC Facilities (n = 2)	Doctors				2	1	3
	Nurses			1			1
	Social Workers		1		1		2
	Allied Health						
	Pharmacy			1	1		2
	Admin		2		2		4
	TOTAL	**0**	**3**	**2**	**6**	**1**	**12**
Implementing Teams at low morphine usage sites PHC Facilities (n= 2)	Doctors				2		2
	Nurses						
	Social Workers						
	Allied Health						
	Pharmacy				1		1
	Admin				1		1
	TOTAL	**0**	**0**	**0**	**4**	**0**	**4**

Focus Group	**Job Title**	**Years of Work Experience**					**Total**
		<1 year	1-5 years	6-10 years	11-20 years	20 + years	
Implementing Teams at higher morphine usage site Hospital (n = 1)	Doctors			1			1
	Nurses						
	Social Workers					1	1
	Allied Health	1		1			2
	Pharmacy				1		1
	Admin			1			1
	TOTAL	**1**	**0**	**3**	**1**	**1**	**6**

All HCW categories that form part of the multi-disciplinary teams at PHC facility level and at district hospital level, were represented in the three FGDs from the HMUSs. The years of work experience of the participants from the HMUSs ranged between less than one year to more than 20 years. The mean work experience was 11,2 years (SD = 6,69), suggesting moderate variability. Between five and seven informants participated in each FGDs at the HMUSs. Participation ranged from one participant to three at the two FGDs from the LMUSs and no nurses, allied health and social work staff attended. Informants work experience ranged from 11 - >20 years, with a median of 12,75 years (SD = 1,5) suggesting that the work experience in years is relatively close to the mean.

Table 6.7: Demographics of operational and operations manager participants

In-Depth Interviews		**Job Title**	**Age**	**Years of Experience**	**Gender**
Operational or Operations Managers	Higher morphine usage site 1	Assistant Nursing Manager PHC	51	5	Female
	Higher morphine usage site 2	Operational Nurse Manager PHC	46	3	Female
	Higher morphine usage site 2	Operational Nurse Manager PHC	44	13	Female
	Higher morphine usage site 3	Clinical Manager	50	11	Male
	Higher morphine usage site 3	Family Physician	45	9	Female
	Low morphine usage site 1	Assistant Nursing Manager PHC	45	8	Female
	Low morphine usage site 2	Operational Nurse Manager PHC	48	4	Male

Seven operations managers participated and six of the seven took the time to engage meaningfully, while one manager's tone was that of irritation and arrogance with each response. This manager was advised by the moderator that he could exit the interview at any point. The managers ranged in age between 44 and 51 years old, five were female and two males. The mean age of the managers was 47 years (SD = 2,71), suggesting that the ages are clustered close to the mean. Their years of experience as an operations manager however significantly varied, ranging between 3 – 13 years, the mean years of experience is 7,5 years (SD = 3,73) suggesting moderate variability.

Table 6.8: Total number of HCW's trained in palliative care at the selected sites

	Total Staff Trained in PC at the Facility
Higher morphine usage site 1 (HMUS1)	2
Higher morphine usage site 2 (HMUS2)	4
Higher morphine usage site 3 (HMUS3)	5
Low morphine usage site 1 (LMUS1)	1
Low morphine usage site 2 (LMUS2)	0
TOTAL TRAINED	12

Although Table 6.8 shows that fewer PC trained implementers (12 of the 29 informants) were part of the implementer teams and operations managers who supported these teams, the qualitative data provided detail of their experience in offering PC since the launch of the NPFSPC in the WC at the end of 2018.

6.4.4. Thematic Analysis

An approach to inductive thematic analysis as described by Braun and Clark[191] was used to explore the narrative from the focus groups and in-depth interviews. First the researcher became familiar with the narrative by repeated reading and immersion in the data in search of meanings and patterns,[191] and key themes and concepts[211] regarding the factors that influence the implementation of the NPFSPC amongst the implementers, in order to determine how these may affect the extent, pattern and rate of adoption and eventual assimilation of PC provision into the health system. An initial list of ideas was coded into meaningful groups using the NVIVO software program. The entire data set was worked through in order to ensure equal attention to each data item.[191] Extracted data included data that was coded many times, coded once and even un-coded, which was then further explored to identify sub-themes and then main themes. Each sub and main theme were defined and named and captured in a code book and in the software program. A thematic map was also crafted and was written up in the results section 6.3 below.[191]

Open ended questions, from semi-structured interviews, were posed to the implementers to elicit their perceptions of the PC services that they are expected to offer. The transcribed data was checked by the researcher against the original audio recording for accuracy. The analysis of the virtual FGDs further informed the questionnaire for the virtual in-depth interviews with the operational managers.

The analysis of the data for this sub-study, acknowledges the centrality of the HCW as a key actor within the adoption system, and to human resource planning as an integral component of the health system characteristics, identified in the conceptual framework on integration.[8] Although the FGDs were stratified by higher and low morphine usage, the data from all the FGDs and in-depth interviews (IDIs) were put together and analysed and findings from both FGDs and IDIs are referred to as discussions in the results below.

6.4.5. Trustworthiness and rigor of this sub-study

In this sub-study credibility, transferability, dependability, confirmability and a reflexive approach as identified by Cresswell (2018) were used to establish rigor and trustworthiness of the reported findings.[192] The researcher, being a senior manager in the WCGHW, worked closely with the study supervisors to identify any existing beliefs regarding possible enablers and obstacles, which were assessed at regular intervals. An intentional reflective process was agreed upon to ensure that the researcher’s assumptions and context were not embedded in the findings. The interview guides developed by the researcher were discussed with supervisors which ensured that questions in the semi-structured guides remained open-ended and remained aligned to the aim and objectives for this sub-study.

To ensure transferability, a detailed description of the sub-study sites, sub-study population and processes of data collection was made explicit. Based on the information rich participants selected for this sub-study, transferability may be possible in settings outside of the CMD, since the CMD is similar to other large city health services in South Africa.

Dependability of this sub-study can be assured by the provision of the detailed description of the methodology. The 12 transcripts were coded by the researcher and three of the 12 were randomly selected and analysed by study supervisors as well as a master's medical anthropology student to ensure confirmability. All discrepancies were discussed and resolved by consensus.

In reporting this sub-study, all criteria for reporting qualitative studies (COREQ) according to Tong et al., was utilised.[193]

6.4.6. Ethical considerations

Beneficence and justice as ethical principles were considered throughout all interactions with the staff to ensure non-maleficence and that participants were treated in a fair and impartial manner.

In protecting participants, the rights of study participants were upheld, and attention was given to protecting their confidentiality as well as ensuring their anonymity and autonomy.

A range of public sector informants participated in in-depth individual interviews and FGDs, and power differentials were considered. Since the researcher was a senior manager, issues of overt or subtle coercion were addressed by reiterating that participation was not compulsory in the information sheets and at the start of the FGDs and in-depth interviews, and by recruiting an experienced research assistant, to promote good practice and reduce discomfort. All transcripts as well as survey data were anonymised, and all identifiers removed. Informed written consent was obtained from all participants and their identity, as well as the record of discussions, was kept confidential, known only to the researcher and assistant researcher.

6.5. Results

The results presented reflect the findings of the five FGDs and 7 in-depth interviews together.

Themes

Three main themes were generated from nine sub-themes which were generated from 36 codes, through thematic analysis. The codes and sub-themes are presented in Table 6.9 and the sub-themes and main themes are illustrated in Figure 6.1, overleaf.

Table 6.9: Initial codes and sub-themes generated from the five Implementer focus groups and seven Operational Managers in-depth interviews.

1. Implementer commitment to Palliative Care	**5. Leadership & Governance**	**8. Identifying patients eligible for palliative care**
i. Personal Experience in Palliative care of participants ii. Level of comfort or discomfort with palliative care	i. Leadership & governance support from management ii. Operations managers driving palliative care	i. Folder identification of palliative care patients ii. Value of using palliative care stationery
2. Capacity and time to provide palliative care	**6. Changes within the health system characteristics**	iii. Inadequate referrals for palliative care
i. Additional staff for palliative care ii. Burn out - staff stretched to capacity iii. Caring for the carer iv. Emotional investment	i. Finance & funding ii. Create awareness that palliative care is part of the service iii. Geographic referral mechanism iv. Measures of progress	**9. Appropriate palliative care** i. COVID Palliative care ii. Culture and language consideration iii. Family involvement
3. Training in palliative care is essential	**7. Capitalize on partnerships & existing**	iv. Morphine is essential for pain
i. Family Medicine Rotation ii. Having difficult conversations iii. Level of comfort or discomfort with palliative care iv. Staff shortage impacts releasing staff for training & provision of palliative care	i. Access to equipment & related resources ii. Linkage with CBS for palliative care	Place to support end of life v. Value of support groups for patients
4. MDT approach for interprofessional support		
i. Close collaboration between clinician, pharmacist & other team members ii. Improved communication between iii. MDT approach to holistic patient care iv. Palliative care expert support		

The three main themes that were subsequently generated from the sub-themes is illustrated in Figure 6.1 below. The main themes are colour-coded and incorporate the sub-themes of the same colour.

Figure 6.1: Map of the sub-themes and main themes generated from the five Implementer focus groups and seven Operations Managers interviews.

6.5.1. Provider capability for palliative care

The implementers and operations managers from the five facilities in all FGDs articulated what they consider essential for them to provide PC services. They voiced their commitment to the provision of PC, and highlighted the capacity, time, and training that would be required to provide PC services. In addition, they noted the need to function as part of a multidisciplinary team that could provide interprofessional support at facility level.

Implementers commitment to palliative care

In the various implementer group discussions and interviews, many informants' personal experience underlay their commitment to PC. The experiences included having lost a loved one who did or did not have access to PC, having themself required PC at some point in their lives, or having had a mentor who practiced palliative medicine,

> "For me, why I chose palliative care, … it was sort of personal journey having lost my dad with prostate cancer in 2014… I put myself in the shoes of the family members that are uhm having a family member that needs palliative care, you do not understand the process and you do not know how to feel or what to expect... when I'm even talking to the patients, guiding the patient or the family members, I know what I'm talking about because I have felt those feelings also. So that was rewarding for me." HMUS 2_FGD

Informants in all engagements furthermore raised concerns about adequate support for the patient's family caregivers in dealing with end-of-life care and that the health system should better respond to this need.

Some informants acknowledged that they have not focused on the provision of PC, but felt that more can be done, and volunteered that they are willing to do more. Family physicians in FGDs and interviews shared that their rotation through PC had been invaluable in preparing them to offer this service. Another family physician indicated that although this was not part of her rotation, she requested a PC placement so that she could become more knowledgeable in this field.

Some informants raised that policy that is negotiated and consulted at a provincial and national level hampers the initial buy-in from implementers and more effort is required to get them to commit. The informants proposed that the WCGHW needed to find a mechanism to ensure that the voice of the implementer is adequately heard or included when developing policy or when making changes in service delivery.

> "The vision of the department is ever growing and ever expanding, but it hasn't always filtered down to the staff in the facilities … One of the obstacles that I found, that when the manager hands over the policy, and you haven't been part of the team that put it together, or the staff in the facility was not involved, there was no focus groups …to get their input, then the buy in is very difficult. And it takes a while before that mind shift happens. So, I think going forward just to make it easier to implement policies, and … for the staff to come in line with a departmental vision, … the implementer's side is very important." HMUS 1_IDI

Furthermore, implementers indicated that once communities and staff become more aware of PC service provision, demand may increase, and more PC clinics will need to be established at the PHC facilities, or the weekly frequency of the PC clinics may need to be increased.

The operational managers regarded that it was their responsibility to ensure implementation about any policy that comes their way, and this depended on their context and resources.

> "I'm accountable to see that that policy is then fully implemented at that time. And if it's not implemented, … I must give the answers: this or that was the reason. But now it's almost like it's a new policy. It must be part of your services, … to implement it is basically- it's up to you."
>
> LMUS 1_IDI

Capacity and time to provide palliative care

PC requires time, capacity in terms of staff and emotional capacity. Informants in all discussions maintained that current service pressures made it impossible to spend adequate time with patients and families. Implementers raised that they often needed to write prescriptions for morphine without seeing patients and that this presented a barrier to engaging the patients and families about their perceptions and usage of morphine. Furthermore, these patients are often added at the end of an exhausting and long day, resulting in them having to work overtime. Many implementers particularly from the LMUSs disclosed that they have burn-out, as with current staff capacity there was insufficient time to provide the required information to patients. Implementers in all FGDs insisted that additional PC trained staff were needed to cope with the increasing demand.

> "We need to spend quite a bit of time with the family and the patient ... So, these scripts that just come to your room from assistants, they just quickly write up the morphine ... that doesn't work, you have to sit with a patient find out what do they believe about morphine is and what is their feelings about morphine, did anybody at home die when using morphine, will they actually use the morphine. Morphine definitely has the stigma around it, … which makes people refuse to use it, so you have to sit and talk ... you need to train them when to use it, … how to use the breakthrough dosages, you have to train them about be[ing] nauseous, but take the nausea tablet beforehand … what they need to take for constipation …because, if get constipated, they stop the morphine. If they get nauseous, they stop the morphine. If they don't know how to increase the dosage … they feel it doesn't work, and then they stop or take too big amounts ... You need time to do it properly. And if you do it properly, there's a good chance that it actually will work." LMUS 1_FGD
>
> "You will burn out if you do it on your own. It is impossible to handle that and your patient burden itself without burning out in palliative care or in your regular work as well. You can't see the patient as a whole person [if you] see the patient for the physical problems. I don't see their social, their emotional, their spiritual needs, their home circumstances. Palliative care is not morphine only. Palliative care is helping the patient reaching the goals, living the best life they can, until death. It's not just a morphine script. Nobody can do [it] alone" LMUS 1_FGD

The implementers described that they have developed long term relationships with the members of the communities that they serve and the resultant emotional impact when these patients required PC or end-of-life care and asked difficult questions. The operations managers at some facilities articulated the importance of caring for the implementers. Many had an open-door position and held regular group engagements for staff to talk freely in a safe environment.

Informants in all discussions expressed commitment to providing PC services, but re-iterated that they required time to provide quality care to all patients. They proposed that a well consulted plan that included adequate human resources needed to be drawn up at the local level, and at some sites they required physical space to offer this service.

> "With myself being the only dietitian in the hospital, I often don't get that many palliative care referrals … I think a lot of doctors know that I already have a quite a high patient load. So other patients sort of get precedence over the palliative care patients. So definitely more staff would help a lot in prioritizing palliative care as well." HMUS 3_FGD

Training in palliative care is essential.

Training in PC is essential for all role-players that form the various touch points in the patient care-pathway. This would include health facility-based encounters as well as those external to facilities, such as CHWs. Informants in all discussions raised this as it was important to offer quality care and to equip the implementers to have difficult conversations with the patients and their family caregivers. One rehabilitation professional articulated discomfort with providing PC and stated that training would need to provide the assurance that offering PC would be adequate care.

> "I'm just gonna go back to what makes me feel uncomfortable about palliative care. I think as a [XXX], our main job or our main focus is always on a patient's function and improving their level of functioning. And I think with palliative care, that often takes a backseat and then it's … what make[s] the patient comfortable? Is that actually enough from a [name of Professional Classification] perspective? And I think that's what makes it a little bit … iffy... From our perspective, maybe is that we feel like we could be doing more" HMUS 3_FGD

Implementers and operations managers maintained that although training in PC was essential and offered as various short courses (some being in-person and/or on-line), it was challenging to release staff for the training due to staff shortages, service pressures and staff discomfort with the provision of PC. Furthermore, some added that when they applied to attend the PC training short course, their applications did not progress beyond the People Development unit of their SS office.

> "We need replacements from in the pharmacy when we go on training, because the number of patients don't decrease in the facility when you are away, they still the same number of patients to be serviced, by less people" HMUS 1_FGD

Fortunately, the programme for family physicians at one Cape Metro located university has included a rotation in PC, which meant that these family physician graduates were well positioned to lead the MDTs in PC and guide other staff members. Family physician informants who specialised in former years, indicated that they had selected PC as an elective because they understood the value of the training from other mentors in PC. Participants, particularly from HMUSs, expressed the need and support for PC training for all clinical and administrative personnel.

> "I think it would be beneficial if more people were trained in palliative care ... Because, you don't have to be like a super specialist or a specialist to provide palliative care. And if we're talking about integrating it into the system, then everybody from the clerk to the most senior doctor should be, have some sort of training in palliative care and know … how to approach and how to talk to patients and their family." HMUS 2_FGD

MDT approach for interprofessional support

Informants in all discussions described the importance of the MDT which would give support to team members, improving patient related communication and facilitate providing holistic care to the PC patient.

Implementers trained in PC, stated that they relied heavily on the support from other team members who were qualified to provide care in areas that they felt ill-equipped to provide. Specific mention was made of the health professionals that offer rehabilitation services, social workers, dieticians, and home-based carers (CHWs). Some informants added that it would be helpful if PC experts located within the geographic care pathway, could join their MDT meetings to provide guidance and insight. These could come from a local hospice or referring hospital or family physician based at another facility.

Informants from various implementer groups were firm that the communication between clinicians and pharmacy staff was essential to ensure that the patient had adequate access to essential medicines. Titration of morphine was discussed and the need for pharmacists to provide additional morphine as required, was raised. Implementers were concerned about gaps in the communication between referring hospitals within the care continuum which then required patients to tell their story yet again.

> "I'm very passionate about palliative care. And I like the fact that the patient and all the other disciplines are actually involved in the planning and in the management of the prognosis and the diagnosis. So … what actually sticks out best to me is the fact that, you will actually, as a team, be looking at one patient at a time in a holistical manner. That I think is very important. Because if we are actually working in silos, we might miss the point we might also miss on, you know, what the needs of the patient are." HMUS 1_FGD

6.5.2. Health systems response to support palliative care

An open-ended question was posed to the implementers during the group discussions and to the operations managers during the interviews, asking them what needs to change in relation to the health system to support the implementation of the NPFSPC. They highlighted how the health system should respond to support PC and indicated that existing resources and partnerships should not be overlooked and rather capitalised on.

Leadership and Governance

Implementers and operations managers raised the need for support from the sub-structure management team (SSMT) and the local health facility manager, to guide them in implementing PC. Some implementer informants indicated that the SSMT expected PC services to be rendered by just providing the circular. Yet what they needed from this level of management was onsite support to guide the process, locate the physical space for the service. They needed the time to set out all processes and to go on training. Some of the operations managers maintained that they had not received any specific support from SSMT, other than the provision of the PC circular. Yet it was expected of them to ensure that the service was provided.

> "We certainly have received that support definitely in this COVID time, right from our CEO, being very open to get data to set up [some] sort of protocols. And also, our medical manager was very keen on and very supportive of anything, we wanted to do palliative care wise, even practical things like getting more pillows for patients, if they were going to be proned by the physios. Everybody was open to looking at finding the finances and just being supportive rather than blocking any ideas… I got the full support of the CEO who said if it's needed, it must be done." HMUS 3_FGD

Implementer informants, particularly at HMUSs, described that they could make the provision of PC a reality before and during the COVID-19 pandemic when they received local support from their CEO or Facility Managers. Implementers from some facilities highlighted that their operations manager would coordinate the allocation of patients to ensure that time is made available for seeing PC patients at the designated time of the weekly clinic. Patients would then be booked accordingly.

> "Because we have such high numbers at our day hospital, we needed management to get on board to allow one MO [medical officer] to be designated to palliative care for one afternoon. So, we came to a … compromise or agreement where the [medical officer] would see 20 patients before 12 o'clock and then for the rest of that afternoon, her palliative care patients would come. It would be pre-booked, and then she would be able to draw the folders beforehand. So, I think that was quite instrumental in sort of getting the palliative care ticked off." HMUS 2_FGD

Perspectives of operations managers on the actual implementation of PC services, varied significantly. Some still viewed PC as the role of the hospice and, at the time of the interview, realised that they would need to start taking ownership of it. Others indicated that they required a firm instruction and would then include PC in the performance plans of staff. Yet, other operations managers agreed that this was core business and is aligned to UHC.

> "It's because we're so used to palliative care is being rendered via hospice, we still don't see it as part of our service package. What I can say is we weren't given clear deadlines or, you know, instruction to say, by the end of 2020, you must be you should have fully implemented the policy within your service package. You see, it was just here is the new policy, you need to streamline it into service delivery." LMUS 1_IDI

Changes within the health system

Informants from all discussions articulated what they believe the health system should do, to support PC implementation.

Some operations managers indicated that PC was not funded and that no additional funding was required since the multidisciplinary team members and other resources were available and should be appropriately utilised. On the other hand, other operations managers indicated that they did not participate in any budgeting processes, while some described that they utilised savings in their facility budgets at mid-year, to shift their budgets for PC and other pressing needs. Furthermore, implementers in all groups raised concerns with poor access to specific equipment and consumables that PC patients would need for adequate home care. These included wheelchairs, urinals, bedpans, syringe drivers and adult diapers.

> "[I] don't want to sound as if I'm bragging, but we almost always stay within budget. And we have a yearly capital expenditure meeting where all the departments come and engage. They tell us what they want. We see if we can get it, we prioritize. So everybody has access to anything they want, whether it's syringe drivers, or high flow oxygen, it doesn't matter. So we're flexible and then obviously, anything under R5000, if there's money, … we get it … So I think the budget is very flexible to enable clinical services and palliative care." HMUS 3_IDI

Demand generation is an important health system characteristic. A common comment highlighted by implementers and operations managers, was the value of creating awareness amongst communities and staff about what PC is and the availability of the service. This should be communicated as part of the comprehensive package of care that is offered. Informants added that responsibility for this communication would reside at all levels from local, to SS, chief director MHS and Provincial level. Creating awareness, would help to reduce stigma since PC was still regarded as end-of-life care, which was not something that many people were comfortable with. They further added that this information would encourage those in need of PC to come forward and express their needs.

> "The mindset of the personnel and the community needs to change that palliative care is not death care. It is an improvement of quality of life. But for them to believe that we need to actually deliver a service that can actually improve quality of life." LMUS 1_FGD

> “So I think that we need to change people's perceptions or understanding what palliative care is. So that we can start palliative care earlier for patients and hopefully be more effective in providing palliative care” HMUS 2_FGD

> “I've noticed that the term palliative care tends to alienate some people, staff and patients because you can be in palliative care for a long time and it's an approach to a better quality of life. It's not you're gonna die in the next three days. You might, but even that – it's not necessarily that that’s going to happen” LMUS 1_FGD

Informants from all groups articulated the importance of measuring progress for PC. Some argued that PC was not viewed as equally important when compared to other priority services such as HIV and TB treatment. TB and HIV are tracked at facility level using tally sheets and are part of the performance indicator data set included in the annual performance plan of the WCGHW, while PC is not. Informants also mentioned that there is a culture in the WCGHW of measuring performance through outputs, and simple measures for PC could easily be tracked at local level. These could include the proportion of clinical staff trained in PC at each facility; numbers of functional MDTs that conduct folder audits, death reviews and tracking patient outcomes; and numbers of PC patients referred for support to CHWs.

> “Maternal health and child health and HIV and TB health we've got very specific indicators, and we've got specific interventions and specific targets. And there's a lot of discussion and planning that goes into getting interventions in place to reach targets, I think the same should apply for palliative care because [otherwise] it is an area that is thought of as less critical … Effort and time that should go into it. So, it just doesn't get the same energy put into it.” LMUS 2_FGD

> “So we haven't done any data collection. We basically know how many patients we have given syringe drivers; how many we have done that and that. But it hasn't been a formal counting or auditing process to be honest … [What] we are lacking at this stage is basically to document the processes more formally.” HMUS 3_IDI

The implementer group informants also described the value of having a geographic referral mechanism in place to facilitate up and down referrals of PC patients. They added that for this to be of value, it would require adequate and accurate patient details to facilitate continued care. That their experience of the VULA (referral) APP aided in facilitating referrals as well as consultations.

Capitalise on partnerships and existing resources

Informants in all discussions described the value of partnerships that existed within their geographic areas. They made specific mention of NGO operated hospices or intermediate care facilities (ICF) and the CHWs, funded by the WCGHW, who provide support to patients and their families who require PC.

They maintained that the ability to refer patients for dignified care was vital and the process of referral was simple and embedded into the health system. Some operations managers remarked that they do nothing for PC patients other than to refer them the hospice or CHWs. On the other hand, implementer groups from the LMUSs saw the opportunity of capitalising on the expertise that lives within the hospice environment and discussed how they could engage this resource to provide support to PC services at the local facility level.

> "I need the people from hospice to come and help us. We need … help to teach the homebased care people how to work with morphine and with patients … So we need people to help us and then we can help the other people around us." LMUS 1_FGD
>
> "We need somebody who's knowledgeable in palliative care who has been doing it a lot, who doesn't only have the theoretical training, to check up on us to make sure that we are actually doing the right things because we can make a whole bunch of nonsense and not even know it. But somebody needs to help us and guide us and make sure we are moving in the right direction and that needs to be somebody who has been doing it for a long time. They don't need to be here all the time. They just need to keep an eye on us." LMUS 2_FGD

Concerns were raised by informants in various implementer FGDs regarding the support that families have in the home for the PC patient and specifically when the patient reaches the end-of-life stage. They added that the CHWs are not trained in PC, and this would limit their knowledge regarding morphine use and the support that they provide to the family at the end-of-life. Furthermore, they indicated that the health system needs to reconsider its role and boundaries as a health system in providing adequate end-of-life support for the patient and family.

> "The other thing that that really worries me is end-of-life care. If we have a palliative care in the facility, we are not equipped to give end-of-lifecare. End-of-life care – people need to go to the house to help there and you need to be able to support the family members and the patient himself in that really difficult time. And we cannot leave the facility to do that, so palliative care will need another entity who will take over at the end stage. And we can help from diagnosis to when they can't come to the clinic anymore. Then we really can't help them anymore. I know how the hospitals work around it, but I don't know how the other clinics works around that."
> LMUS 1_FGD

6.5.3. Provision of patient-centred palliative care

Informants from both the FGDs and IDIs described what they regarded as important in the provision of patient-centred PC. They voiced that it was important to identify new PC patients and ensure that existing PC patients are identifiable as they journey through the health system. This is necessary to prevent them from falling through the cracks and to ensure access to appropriate patient-centred care.

Identifying patients eligible for palliative care

Informants from implementer FGDs shared the various facility specific identification mechanisms that they had put in place to identify PC patients. Some facilities marked the patient card and folder of new or existing PC patients. To gain momentum in locating eligible PC patients within communities, some implementers indicated that they depended on CHWs to help identify and refer these patients into the primary healthcare facility.

> "So we already kept … all our known hospice patients' files separate from our other files. They are marked and they are kept separate... As long as it doesn't get lost into the general system, there's already a system in place that we can use for that." LMUS 2_FGD

Informants further described the current inadequate referrals from the tertiary level hospitals to PHC facilities for PC patients. Gaps in information provided and challenges in locating the referring clinician at that level of care made adequate assessment and management of these referred patients very difficult for the PHC clinician.

> "One of the things we are still struggling with is that we don't have really clear communication from like the higher facilities like [x]and [y]. They just send the patient to us, so it's like a discharge letter… No clear plan or no input from anywhere else like from their social worker, from their psychologist, from their dietician or stuff." HMUS 2_FGD

Some also raised the benefit of having the VULA referral app for consulting and referring PC patients across the service platform. Furthermore, they suggested that standard care plans and stationery would go a long way in ensuring continuity of care for PC patients.

> "A good suggestion that I could make is maybe have a set care-plan document, that all the different … team members can contribute to. So that we have … the same document for all palliative care. So we make sure that all the steps are managed adequately."
>
> HMUS 3_FGD

Appropriate palliative care

Informants in all discussions maintained that PC provision should be relevant to the context that the health system faces and sensitive to the patient and family's need for care that considers their circumstances.

Matters such as the appropriate provision of PC, that considered the risk and context of the COVID-19 pandemic, were raised. During the pandemic many PC patients could not access care and clinicians resorted to providing virtual care for PC in-patients, and virtual connects with family members were arranged.

> "And I think COVID as such was a challenge to us, uhm not being able initially to bring in patients' families. And we had to improvise with the WhatsApp calls and the video calls to families…, How important that was to the extended family; to be familiar with what is going on … behind the unknown scenes [for] my loved one" HMUS 3_FGD

The language and culture of the patient and family was raised, and informants discussed the importance of including the family in care decision-making. Support groups were raised by the implementers as being important, with the rider that it would be ideal to allow patients to own the space and set up their own support groups.

Informants in all discussions raised that adequate pain management was essential to ensure quality of life. PC could never be appropriate or adequate without this. On the other hand, they also raised concerns about the possible misutilisation of morphine by some family members or carers, the risk to children living in the home, managing morphine side effects and the anticipated resistance from younger clinicians to prescribe morphine until pain was excruciating and there was no other option.

> "The family is refusing to give it to them, and withholding the morphine from them, thinking that by giving them the morphine, they will hasten their [the patient's] death. It's not so much the patient themselves, but more the family members that need buy-in to the actual dosing of morphine. Morphine makes a lot of patients sick, more sick than they are, because there's nausea. So, you hold back on the morphine, before you do it. That is the last resort. Yeah, and the constipation." HMUS 2_FGD

One informant described many patients' living circumstances in the facility's catchment area. The physical infrastructure space was not conducive to support end-of-life care, since families with children share small spaces. It was suggested that the WCGHW consider providing adequate dignified spaces that allows the family to remain with the patient during this period.

> "[name of] hospital needs to have a palliative care ward where people for end-of-life can actually go to. So we can help up to a point because the poor people in the community cannot afford people to come to them and help them and they cannot bring the patients to the clinic all the time and so we need a place where people can die in peace with their family around them that's not the emergency room at the hospital. Because you can teach people and tell them what is going to … happen when this patient is going to die at home. But then nobody's ever equipped enough to deal with that when it actually happens and that's when the ambulance gets called … and that's when they end up dying at the eight-hour facility. So, we need buy-in from our referral hospitals to help us with that, or with the hospice itself. We can't stand on our own." LMUS 1_FGD

6.6. Discussion

This sub-study explored the factors influencing the implementation of the NPFSPC amongst implementers at selected higher (HMUS) and low (LMUS) morphine usage sites. It elicited the experiences of PC implementers at least one year after some of them had received training, explored their level of confidence in breaking bad news and building hope, their approach to PC integration at the identified sites and identified the need for support from management.

The three main themes generated were i) provider capability for providing PC services, ii) the health systems' response to support PC implementation and iii) integration and the provision of PC that is patient centred. These themes align to key elements for assessing integration in

Atun et al.'s health system characteristic and adoptions system. The sub-study emphasises the consideration of the critical role of the implementers and health care user needs as part of the adoption system, which is considered but not emphasised by Atun et al. and others.[106],[104],[108] This sub-study highlights that special attention must be given to capacity building within the planning and service delivery functions as part of the health system characteristics.

The experiences of the implementers were explored and there were some notable differences between the implementers experience of support from the SSMT and facility managers as well as stakeholder engagement at the HMUSs and LMUSs. At the HMUSs and LMUSs there were differences in leadership and governance arrangements, knowledge about PC and functional MDTs between as well as knowledge about PC. At the LMUSs there was limited knowledge on PC policy with greater dependence on partners, while the HMUSs implementers and operations managers had more insight into PC, were very responsive to the research assistant's communication and offered additional operations managers for the in-depth interviews.

6.6.1. Provider capability for palliative care

Provider commitment to providing palliative care

The sub-study found that public sector health care providers agreed that it was critical to provide PC as part of the package of care. This finding is consistent with a study conducted by Morgan (2014)[14] in the CMD.

HCW commitment to providing PC was shaped by either their own PC experience or that of a loved one or the influence of a PC mentor or training programme. Although this finding was not directly confirmed in the literature as a reason for commitment to PC, the systematic review conducted by Tehranineshat et al. (2019) showed that HCWs personal experience of suffering makes for compassionate care, which is core to providing PC.[81] Furthermore, a study conducted by McIlfatrick et al. (2014) in Ireland and the UK on public awareness and perceptions on PC amongst members of the public, it was found that the public's interest in PC was shaped by their personal experiences or that of a loved one in need of PC.[212]

The operational managers in this sub-study regarded that leadership for implementation of any new policy or intervention was their responsibility. However, they emphasised that the lack of i) consultation and clarity, ii) support from the SSMT, iii) available resources and iv) acceptance of PC by staff, does place limitations on what they can feasibly deliver. This confirms what other researchers have found and regard as important, in that implementer and leadership commitment to PC is essential for implementation and integration.[181],[23] Giannitrapani et al. (2021) and Stjernwärd (2007) indicated that leadership that is supportive, along with interdisciplinary coordination and the identification of local champions, were all essential to improve clinical commitment at the lowest level.[181],[23] One unanticipated and interesting finding in this sub-study was about the culture in the WC of measuring performance through outputs. Some informants regarded PC as less important than other priority programmes such as HIV and TB, since they are not expected to collect and report on any indicators for PC as part of their routine data collection. This influenced the effort that was placed on PC compared to any other priority programme. According to the WHO (2021) actionable indicators guideline for assessing the development of PC, "*the inclusion of PC indicators in national health information management systems contributes to awareness raising and action on PC from health care managers and workers*".[2]

The informants in this sub-study from HMUSs proposed indicators such as i) monitoring PC training, ii) functional MDTs and iii) PC patient referrals for home care, being simple measures to track progress at health facility level. Goal three in the NPFSPC recommends the establishment and maintenance of a system to monitor and evaluate the PC programme. However, proposed indicators have not yet been approved for inclusion into the national indicator data set (NIDS).[213] The NIDS in turn determines the provincial indicator data set.

Street level bureaucrats and policy making

An important finding in this sub-study was that policy consultation and negotiation that includes the opinion and voice of the implementers – the SLBs – during the initial policy development stage was essential. This could ensure buy-in from these influential front-line public HCWs. Lack of consultation in the developmental stages of the NPFSPC meant that a new intervention is less likely to be easily implemented and may require more support at the frontline, as Loyens et al. (2010) also found. They noted that the discretionary powers of the SLBs are open to abuse and therefore supervision was required to ensure adherence to standard operating procedures, guidelines or policies.[185] Gilson et al. (2015) agreed, elaborating that these SLBs are critical in ensuring that policy is implemented with due consideration for context,[214] which strengthened the case for their inclusion in the developmental stages of new policy or new intervention.

This sub-study confirmed the complexity in the relationship between SLBs and policy makers. SLBs regarded that policy makers lacked insight into their context and were disconnected from their reality at the frontline. These findings are supported by a study conducted by Davidovitz (2021) in Israel and a book by Lipsky (2010), that reflect on this disconnect. On the one hand, SLBs need for guidance at the frontline from the decision-makers and policy formulators, and on the other hand, during a time of crisis, the expectations from the SLBs are not adequately met by decision-makers.[215,205]

The finding that current policy development is conducted at the national, provincial[216] and district level, is consistent with the literature and enshrined in legislation. The SLBs are either invited to comment at the final stage of development, or at the end of the policymaking process during road shows that introduce them to the new policy, but in most instances new policy is communicated by email. This sub-study makes a strong case for bottom-up policymaking that considers street level discretion and the reality at the frontline. Furthermore, the SLBs expressed the need from policy makers for support and guidance in 'doing' policy and raised the need for appropriate platforms to facilitate the expression of need. Davidovitz et al. (2021) confirm this gap and support this shift in policy making.[215]

This sub-study showed that the operational managers' opinions regarding their roles in the PC policy implementation process varied significantly. Notably the operations managers at the HMUSs regarded PC policy implementation as their core business and saw the alignment to components of Universal Health Care. While the operations managers at the LMUSs regarded PC as essential, some indicated that it was the responsibility of the hospices, and others indicated that they required an instruction to include PC as part of the service package and in the performance plans for the staff. Davidovitz et al. (2021) reported that certain professional categories that are exposed to risk as part of their normal functioning are less likely to require an instruction, than professional categories that are not exposed as part of their profession.[215] This was evident during the COVID-19 pandemic.

Additional capacity and time to provide palliative care

The literature confirms that PC service provision requires adequate quotas of PC trained staff to cope with the increasing patient load,[154] as well as the necessary time that it takes to ensure quality PC.[7]

However, in this sub-study, since PC is not routinely offered as part of undergraduate training for health professionals, the time away from the work environment to attend the PC training programme was expressed as challenging by all implementing groups. Reasons included staff shortages at the health facility with increased service pressures, staff absenteeism and the backlog in training for routine PC training due to the COVID-19 pandemic. Furthermore, the sub-study shows that there was poor planning for PC training which included an inadequate response to applications for training from those responsible for training coordination.

Both the WHA resolution and the NPFSPC emphasises that training in PC is essential for all HCWs and providers.[30],[5] According to the WHO and Rhee et al., this training must also include all community health workers who render care outside of the health facility.[113],[154]

In this sub-study, implementers expressed varying degrees of comfort and discomfort with offering PC. Some indicated that PC was not adequate care because their undergraduate training taught them to provide care that cured and strengthened patients physically and they did not view PC in this light. This strengthens the need for inclusion of PC in undergraduate training to help shape their perspectives. This was reiterated by Centeno et al. (2016) in a study on including a PC course in the medical officer undergraduate programme in Spain. The

Spanish medical officers indicated that the course had opened up a new field of knowledge, helped them to become and act like doctors, encouraged deep reflection and personal development, which allowed them to have a holistic view of patients and also consider the families.[217] To move forward with PC training and build capacity within the health system, it is essential to include PC in undergraduate training for health care professionals in addition to post graduate training courses.

MDT's and interprofessional support

The implementers in this sub-study indicated that they depended on other team members so that they could offer holistic care that addressed the needs of patients and families. These MDT members should include some who are PC trained, and others not yet trained, in the same health facility and in many instances, also within the geographic service area. Den Herder-van der Eerden (2018), an authority on PC in Europe, confirmed that a MDT approach facilitates interprofessional support[207] and extensive literature supports the value of MDTs for PC.[176,11,35,3] Furthermore, the three year district health plan (2021-2024) for the Metro Health Services within the CMD advocates for a broader MDT approach and focus[4] which further encourages an MDT approach to care and interprofessional support.

Informants acknowledged that MDT development was essential but would need to be developed in stages. The LMUS sub-study site informants highlighted the value and need for MDTs but had not yet formed them while MDTs at the various HMUS were at different stages of development. According to Fernando et al. (2019) these stages of development commence with forming and then evolve through the stages of storming, norming and ultimately performing, becoming well-oiled team in the best interest of the patient and family caregivers.[176]

6.6.2. Health systems response to support palliative care

Leadership and palliative care integration

The sub-study showed that providing a policy circular via email was not adequate when communicating new policy and that leadership and onsite support to guide implementation was essential. Furthermore, a greater need for leadership was highlighted by COVID-19. Astute and flexible leaders needed to manage the negative impact of the COVID-19 pandemic on the provision of routine services, the increased demand for care to patients infected by SARS-CoV-2, give attention to infection control measures and the national state of disaster restrictions, which is consistent with other studies in UK, SA and Israel.[58, 94, 215] Davidovitz et al. (2021) conducted a study during the COVID-19 pandemic on the impact of rapid government policy formulation to promulgate regulation during a crisis, on clinicians and nurses – the SLBs. SLBs were faced with changes in policy and infection prevention control directives several times per week and with little time to change practice. These policies or regulations were vague at times or conflicting with other policy[215] and confirms the need for onsite visible leadership. On the other hand, this sub-study found that the pandemic brought an urgent need for the provision of PC, with leadership support. This presented opportunities to rapidly develop PC capacity and procure PC commodities. This too was found in various studies.[58, 94, 215]

In this sub-study, the implementers at the HMUS experienced enabling supportive leadership from their facility managers or CEOs, which allowed them the space to make rapid decisions that were required to make the provision of PC a reality before and during the COVID-19 pandemic. Furthermore, they indicated that the support they received included the coordination of the allocation of patients to ensure adequate time to attend to the PC patients at the designated times (weekly clinic). This worked well and they did not express need for support from the next management level.

The implementers at the LMUS expressed that there was a lack of support from managers at the SSMT and this included an expressed need for more support regarding policy implementation. As indicated in the Lancet editorial, this includes leadership to strategically support the implementing teams.[93]

Leadership and governance arrangements are essential to ensure that support is provided for implementation of new policies or interventions from facility and SS managers. Consideration should be given to the time needed to prepare; attend training; the time it takes to provide adequate care to patients and their families; as well as the physical space to render the service.

This sub-study showed that while some operations managers have an open-door position and were easily accessible to the implementing teams, implementers needed a well consulted implementation plan that guided them through the implementation process. The HMUSs implementers had access to unambiguous internal processes that provided direction on PC service delivery, and these processes were integrally supported by their operations managers. LMUSs did not have such processes clarified and the clinical service provision and care for patients were offered by one individual. Hamdan et al. confirmed that a well consulted implementation plan is necessary, with standard operating procedures that guide the process of implementing PC as a new intervention.[218]

Value of greater community awareness of palliative care

McIlfatrick et al. (2014) reported that low levels of public awareness regarding PC remained one of the significant challenges hampering the development of a public health approach to PC. This was needed to build public policy on supporting death, dying, grief and loss.[212]

This sub-study confirms the vast literature that greater community awareness of PC reduces stigma, the misconception that PC is end-of-life care only and that this may increase patient demand for and access to PC.[3],[122],[123],[212] Informants regarded that this required co-ownership and work at all levels within the health system. Notably, increasing demand for PC could lead to a bigger need for the provision of support to families of patients during the care journey and at the end of life, and would also need to be met with greater heath system readiness to accommodate these needs. The public sector hospitals would need to consider providing access to end-of-life care beds for patients and accommodating family caregivers, to ensure dignified deaths. This was not highlighted in the literature, but in a post bereavement survey conducted by Donnelly et al. (2018) a case was made for end-of-life care beds at hospices.[203] Furthermore, NGOs funded by the WCGHW would need to provide support for the patients at home where possible.

Stakeholders supporting palliative care integration

Findings in this sub-study highlighted that capitalising on partnerships[219] and utilisation of CHWs in the provision of palliative home-based care[47,52] can greatly benefit the broader PC support to the patient and family and ultimately reduce unnecessary hospital and EC admissions, as well as PHC facility visits. A systematic review conducted by Dimartino et al. (2014), found that good cancer and PC did not result in a reduction in EC visits.[220] However studies conducted by Delgado-Guay et al. in the US and Canada (2015), and Dumnui et al. (2022) in Bangkok, support that PC support and good communication can reduce EC admissions by 25%.[221, 222]

In line with the international literature, informants in this sub-study agreed that MDTs were important to provide and co-ordinate holistic care for palliative care patients. DeMiglio and Williams, in a study in Ontario Canada (2011), confirmed that an interprofessional team was needed to meet the complex needs of the PC patient and family.[47] This requires partnerships but the extent to which partnerships had been established and the value given to these differed significantly between HMUSs and LMUSs. The HMUSs had established partnerships with their local hospice and home-based care NGOs. Consequently, CHWs formed part of their MDTs so that concerns and the need for support was raised and addressed in this consultative platform. The LMUSs indicated the need to access hospice partners to assist them at the health facility and raised concerns regarding the CHWs' training in PC and knowledge about the use of morphine.

6.6.3. Provision of patient-centred palliative care

Each facility had a different mechanism for identifying patients with PC needs in the health system. Although these differed, the mechanisms were understood by all HCWs at each sub-study site. This shows that efforts were made to ensure continuity of care of the PC patient within health facilities.

However, members of these MDTs faced care continuum and communication gaps between health facilities. There was inadequate patient information contained in the referral letters from some acute hospitals to health care providers at the PHC facilities, and electronic down referrals had inadequate patient information, which hampered continuity of care. There was a strong call for the health system to standardise referral mechanisms, care pathways, care plans and stationery. Barriers were further exacerbated by the inability to locate a clinician at the referring hospital and the non-availability of electronic patient records across the health service platform.[118] Informants advocated that structuring MDTs at facility or geographic area levels could facilitate communication and engagement to address challenges.

The COVID-19 pandemic called for appropriate care while being aligned to the regulations that governed the disaster response. PC needed to be provided to support patients and families. Consequently, virtual platforms connected patients and families admitted to hospital; virtual care was delivered by PHC facility clinicians to patients at home; there were a home-based PC service; and home delivery of chronic medication was arranged.[96, 133, 135, 143, 167] It remained important to consider and consult patients and families in all care decisions to ensure that the manner of provision of care was acceptable and appropriate to meet patients' needs. Notably, the CHWs do require more capacity building to provide home-based PC.[167]

This sub-study showed that the housing conditions of a significant proportion of public sector dependent patients, are not conducive to accommodating patients' end-of-life needs. Consequently, due consideration should be given to the provision of and access to end-of-life care beds at acute hospitals for patients and their family caregivers who need it, to ensure an environment that is conducive for a dignified death.[203] An exploratory review of international PC policy in five countries (Switzerland, England, Singapore, Australia and Ireland) conducted by Robinson et al. (2016) found that hospitals do not make provision for end-of-life care, while patients and families report preference for and benefit in hospital admission in these settings.[223] A study by Donnelly in (2012) indicated that dying in an acute hospital is a common occurrence in developed countries[203] and the literature furthermore makes a case for end-of-life care beds at hospices. However, there is a continued preference in African countries for home care with support from the community or home based care.[35,223] Since it is unknown if home deaths are preferred in this context, further research is required. Nonetheless, some capacity for accommodating deaths in hospital is required.

6.6.4. Strengths and limitations of the sub-study

A strength in this sub-study was the willingness of so many participants at the HMUSs to participate in this sub-study with very little prompting as they were enthusiastic to share their lessons and experiences. However, there were several limitations to this sub-study. This sub-study took place early in the PC policy implementation journey in the CMD, and findings show various starting block bottlenecks.

Some sites experienced service pressures on the day of the group discussions, which impacted negatively on the number of attendees at the FGDs. Other informants could not be released to participate in a relaxed manner. At the LMUSs, some participants agreed to participate and then did not show up for the agreed sessions and this resulted in one group having only one participant and the second LMUS only having three participants.

Fewer LMUSs than HMUSs were included in the sub-study, as there were mostly HMUSs in the two sub-study sub-districts. This could skew the findings more towards the views and experiences of the HMUS implementers and operational managers.

Since the interviews were conducted online, this limited the ability to gauge the non-verbal communication of the informants and interpersonal dynamics, since some of them turned their cameras off due to bandwidth.

6.7. Conclusion

Health services on the frontline are delivered by nurses and clinicians who have deep insight into their own reality and work context. These SLBs know the communities they serve and can identify key obstacles to integration of new interventions, troubleshoot and offer solutions.

It is critical to recognise the SLB as a key contributor to policy and every effort should be made to ensure that platforms for engagement are made available so that their voice can be incorporated into policymaking from its inception. This inclusion of the SLB in the policymaking process will facilitate consideration for context, resource needs and allocation, monitoring and evaluation and reporting system requirements, and ultimately policy buy-in. Without SLBs buy-in to PC or any policy, implementation may not take place.

PC is essentially holistic care that is not in the domain of any single health professional but requires multi-disciplinary teams operating together within and between levels of care. Policy that endorses MDT as standard practice, guides its functionality, and considers shared health professionals, is required. To ensure continuity of care, a standard functional referral mechanism must be in place, not only for PC but for all patients within the entire health system to ensure that referrals up and down the care pathway are appropriate and adequate. In addition, COPC is a vehicle that ensures a multi-stakeholder approach to addressing health priorities within a defined geographic area and includes community members. This approach is ideal for rallying stakeholder support to the provision of PC and create greater community awareness about PC.

Service pressures and staff capacity, present barriers to their ability to spend the necessary time needed for PC patients who often present with complex needs. Adequate numbers of

PC trained health professionals at each health facility are required to accommodate patients with PC needs. This means that PC training must be included in undergraduate training for all health professionals in SA and this training for all qualified health professionals must be encouraged and supported by management. Furthermore, PC training for CHW is non-negotiable.

It is an essential enabler that leadership, strategy, and support at the frontline is provided by the immediate managers. This motivates SLBs, guides potential changes in service design, patient access, and patient flow, and without such support, implementation suffers. Although the implementers and operational managers agreed that PC was critical, its implementation remains dependent on their commitment to providing it and their buy-in.

Following this exploration of the implementation experience, chapter 7 will focus on the expectations and needs of PC patients and their family caregivers.

Chapter 7 : Expectations and Needs of Palliative Care Patients and Family or Carer

Chapter 6 noted that a range of health professionals operating at various levels within health systems are required to render integrated comprehensive palliative care (PC) which brings synergy and coherence across the health service platform.

7.1. Introduction

Patients and their family caregivers have needs and expectations of the health system and this chapter explores these expectations and needs in relation to PC services offered in the Cape Metro District (CMD).

Patients form part of the adoption system as users.[8] As beneficiaries of the health services, they can provide information about the nature and quality of services received. In addition to this they provide valuable input that describes whether the PC service received was rendered as part of the health service package.

The focus of PC services has shifted from managing cancer and terminal diseases to chronic conditions, particularly for those with a life limiting prognosis. For service response planning, Gómez-Batiste et al. make a case for the application of a population-based approach to determining PC needs. This approach is based on mortality from chronic conditions and the prevalence of chronically ill patients with PC needs in a defined geographic area. This can inform the health care system's response to that need.[224]

It is important to identify patients in need of PC in all care settings,[224] including the primary health care (PHC) setting. Notably this setting is a primary access point to health care through screening for and management of chronic conditions that may be life-limiting.[4] Commonly, when patients with advanced disease access PHC facilities for the first time, it is through the emergency centres at these facilities. Furthermore, as Gómez-Batiste et al.[224] argue, PC is as an essential component of the management of chronic care within a community-oriented primary care (COPC) approach.

There are various methods and screening tools to assess patients' eligibility for PC. The Supportive and Palliative Care Indicator Tool (SPICT) supports clinical judgement by multidisciplinary teams to identify patients at risk of deterioration and death, while also assisting in identifying unmet needs.[225],[163] A validated SPICT was the preferred tool to assess adult patients in SA with advanced life-limiting illness.[210],[225] In 2021, Krause et al. , through a Delphi study, finalised a South African SPICT (SPICT-SA), which includes disease specific indicators, general indicators of deteriorating health, supportive needs and care planning.[200]

7.2. Literature Review

7.2.1. Patient and family caregiver expectations and needs from palliative care services

The complex needs of PC patients require an integrated and well-coordinated health response and solution. Vočanec et al. (2022), in a study that aimed at identifying factors influencing integration of PC in Croatia, found that this approach goes against the increasing super-specialised professional training and consequent fragmented care systems which can result in poor access to care.[156] Synchronised health policy, funding and organisational culture lead to improved efficiency, quality of care, quality of life and patient satisfaction. Furthermore, as Vočanec et al. (2022) reported, patient-centred care that intentionally ensures continuity of care and holistic interdisciplinary approach to care, is needed to address these current shortcomings due to specialisation, mindsets and silos which are embedded in health systems.[226]

Once disease modifying treatment is deemed unlikely to be beneficial, end-of-life care should be explored in a gentle compassionate manner, while considering the patient and family caregiver needs and culture. Rangaraj et al.(2022) in a study exploring Early PC helps the patient and family manage symptoms and better prepares them for end of life.[227] The systematic review conducted by Davis et al. (2015) found that while multiple studies demonstrate the benefit of early home and outpatient PC, it highlights that further studies are required to better guide the optimal time to intervene with an appropriate model of PC.[20]

Furthermore, as Krakauer (2021) maintains, good end-of-life care should include aggressive pain and symptom management. It must consider symptoms that may present to reduce anticipated suffering, identify the location of care along the patient journey and include psychological, social or spiritual needs.[111] A study conducted by Donnelly et al. (2018), found that bereaved family members report that quality of end-of-life care diminished when care teams did not take the time to talk to the patients in a sensitive, compassionate and supportive manner.[203]

Place of death remains a concern of patients and the families and a large cross-national study conducted by Cohen et al. (2015)[22] in 14 non-African countries, found that various factors influence preferences. These include proximity and access to hospital services, cancer diagnoses compared to natural non-cancer diagnosis, socio-economic factors and degrees of urbanisation.[22] Patients who lived closer to hospitals and long-term stay health care facilities, were more amenable to hospitalisation, than patients who would be further removed from their family and loved ones if they were admitted. In addition, higher proportions of patients who were married or had cancer died at home than those who were divorced or had natural non-cancer conditions.[22] A study conducted by Rangaraj et al. (2022) found that culture has a significant influence on the choice of place of death.[227] Those seeking health care support from traditional healers, complimentary medicine practitioners and considerations of cultural customs associated with death and dying, are more likely to prefer dying at home.[227]

7.2.2. Spiritual care in health services

When addressing the care needs of people who have pain and suffering as a result of severe illness, PC offers holistic care that includes medical, psychological, social and spiritual care.[2] The patient with PC needs requires pain control, alleviation of symptoms, assistance with everyday function, psychosocial support, and spiritual care – albeit to varying degrees.[2,10]

A systematic review conducted by Gayatri et. al. in fifteen developing countries found that patients regard social and spiritual support as the most important factors that influenced their quality-of-life score.[228] Furthermore, Ferrell et al. (2020) raised the increased need for rapid access to spiritual care and support during the COVID-19 pandemic and that all health professionals are responsible for the provision of spiritual care as a component of holistic care.[140] Providing appropriate spiritual care can be complex. Mayers et al. (2022) who reflected on the experiences of volunteers providing telephonic support to patients during the COVID-19 pandemic lockdown period in the CMD, found that many patients and their family caregivers were isolated and vulnerable, and needed spiritual care and support. They noted the religious and cultural diversity that influences the provision of spiritual care, and commented that the inability to practice certain religious and spiritual rituals due to the national state of disaster regulations caused much strain amongst family members patients who died.[42] The WHO (1990 and 2021) re-iterated that the family members, caregivers and loved ones need bereavement support after the patient has died. [2,10]

7.2.3. COVID-19 impact on provision of palliative care

The COVID-19 pandemic presented many unanticipated challenges to the health care system. In SA, as part of the national disaster regulations,[59] health care services regarded as non-urgent or non-emergency were de-escalated at PHC facilities in the CMD.[57] According to a circular issued by the MHS (2020), the de-escalation was implemented to foster social distancing and to allow time to prepare the health system for the expected increase in the volume of patients with COVID-19 symptoms,[57] however the needs of the PC patients and their family caregivers did not change.[168]

The effects of the COVID-19 pandemic on the PC patients and family caregivers are well described by Gerlach et al. (2022) in a qualitative study conducted with 31 PC patients/family caregivers in two cities in Germany, over a six-month period. The study showed that it placed additional strain on family caregivers due to the lack of support from the health system and resulted in a decline in the quality of end-of-life care in 40% of PC patients.[168] Family caregivers were conflicted when deciding on the balance between the risk of exposure to COVID-19 and the social contact that the patients and families needed. Furthermore, patients and their family caregivers experienced pandemic related challenges such as not being allowed to visit patients admitted to hospital due to hospital visitation policy restrictions.[168]

7.3. Aims and Objectives

The overarching study aimed to describe, explore, and explain the factors that influence integration of PC within the district health service platform in the CMD. As patients were the intended beneficiaries of such care, their experience of the care offered is a key element. Consequently, this sub-study aimed to determine the perceptions, expectations and experiences of patients and their family caregivers or 'buddies' who have been in PC at selected sites within the CMD.

The objectives of this sub-study are to:

i) Assess whether the care needs of the patients and their family caregivers or 'buddies' who were enrolled into PC, have been met.

ii) Determine their experience of the service.

iii) Identify areas for improvement that are suggested and proposed by them.

iv) Determine their symptom control using the African Palliative Care Association Integrated Palliative Outcome Scale (APCA IPOS).

7.4. Methodology

7.4.1. Sub-study design

For this sub-study, a qualitative, exploratory, descriptive study design and research method[209] that explores the perceptions and lived experienced of PC services provided to patients and their family caregivers or 'buddies' – was used.

Consideration was given to the facilities where patients would be recruited. It was hypothesised that patients attending facilities that offered PC services would have good experiences of the services offered, compared to those attending facilities that did not offer PC. As there was no data on patient attendance, a proxy indicator was used: morphine prescribing. It was thought that facilities with higher morphine usage would perform better at providing a PC service that addresses the health needs of the patients more comprehensively, and conversely that facilities with low morphine usage would have some unsatisfied patients. Consequently, to ascertain a range of patients' experiences, three higher and two low morphine usage health facilities were identified in the Mitchells Plain and Eastern sub-districts – the same as were used for the manager and implementer sub-studies.

Sub-study Population

The sub-study population were patients who attended the identified facilities, who were assessed and identified eligible for PC, and participated in an established support group or received individual telephonic or home-based support from a heath care worker. Only adult[xiv] patients who were assessed as eligible for PC and in support for at least six engagements and for a minimum of three months, were eligible. Furthermore, patients who were unable to cognitively and physically engage and thus were unable to give informed consent were excluded.

Sampling and Recruitment

Purposive sampling was used and the same facilities that were used for the sub-study in Chapter 5 were included for this sub-study. The recruitment and enrolment into the sub-study commenced with the researcher contacting the facility managers of these sites by email, requesting the names of a health care provider that the researcher could liaise with to identify eligible patients and family caregivers for this sub-study. Telephonic contact was then made with these identified health care providers and the inclusion and exclusion criteria to guide patient selection was discussed. The health care providers selected the patients based on the criteria and provided the researcher with the contact details of patients who could be invited to participate in these in-depth telephonic interviews. The researcher made telephonic contact with patients and family caregivers and informed them about the sub-study according to the information sheet (Appendix 16). The patients and their family or support buddy had an opportunity to ask any questions for clarity and were reassured that choosing to not participate would not affect their care plans in any way. The patients who agreed to participate, were then scheduled for a telephonic appointment at a time and date that would suit both patient and caregivers.

Of the nine patients included in this sub-study, four patients requested to proceed with the interview immediately, and appointments were scheduled for the remaining five patients. One patient died before contact was made by the researcher. A further patient died two days prior to the scheduled appointment resulting in the cancellation of the interview. None of the patients and family caregivers who were contacted declined to participate. The researcher obtained audio-recorded informed consent from all patients and family caregivers or support buddies.

[xiv] Adult patient is 18 years and older

7.4.2. Data collection

Due to the COVID-19 pandemic and the national state of disaster regulations that were in place at the time, face-to-face interviews were not permitted, and in-depth telephonic interviews were therefore conducted.

Data collection tool

The data collection tool (Appendix 15) consisted of open-ended questions that served as probes, which followed the patient's line of discussion, trying to unearth central issues. The questions explored experiences, expectations, access to care and support groups, the value in support groups and any unmet needs that would require a health systems response. This was then followed by the validated APCA IPOS tool (Annexure 8).[229] The APCA IPOS had 10 questions addressing the physical and psychological symptoms, spiritual, practical, and emotional concerns and psychosocial needs of the patient and family. Questions 1-7 were directed at patients and questions 8-10 at the family or carer.

The in-depth interviews were audio-recorded, and notes were captured on the interview guide. The recordings and the notes were transcribed verbatim by a professional transcriber and checked by the researcher against the audio-recordings for accuracy. Each transcript was saved using the archival number as the computer file name and indicated the site name (Mitchells Plain (MP) and Eastern (E)), method of data collection (In-depth interview (IDI)), participant category (higher morphine usage sites (HMUS) or low morphine usage site (LMUS)), and sequential number (1-n).[127] All written notes were placed in a marked envelope, using the same allocated archival number, and locked in a cupboard that was dedicated for this sub-study. All audio-recordings will be deleted after five years from all devices and computers once the analysis was completed, to maintain confidentiality.

Distress protocol

A distress protocol (Annexure 3) adopted from the HPCA[34] was in place for the patient in order to identify if the telephonic interview is too stressful.[230] All participants were fully informed of the nature of the issues that would be included in the telephonic interviews. Upon request from the researcher, each health facility manager provided a counselling staff member and a clinician, who consented to be on standby to provide telephonic support if the patient required support for distress. During the interviews, the researcher listened carefully for any signs of apprehension, emotional or physical (e.g., shortness of breath) distress. None of the patients presented with any form of emotional or physical distress or needed to pause or abandon the telephonic interview. All information was held confidential and none of the patients presented with a safety risk that would have required further action or intervention.

7.4.3. Thematic Analysis

Data from the in-depth interviews were inductively analysed in search of key themes and concepts[211] in order to gain insight into the patients experience of PC service provision at the primary level of care.

Thematic narrative analysis was conducted according to Braun and Clark's approach.[191] First, the researcher became familiar with the narrative by repeated reading and immersion in the data in search of meaning and patterns.[191] An initial list of ideas was then coded into meaningful groups by using the NVIVO software program. The entire data set was reviewed in order to ensure equal attention to each data item.[191] Extracted data included data that was coded many times, coded once and even un-coded, which were then further explored to identify sub-themes and then main themes. Each sub and main themes were defined, named, and captured in a code book and in the software program. A thematic map was also crafted and was written up in the results section 7.3 below.[191]

The analysis of the data for this sub-study, ties into the health care user, patients and family as key actors within the adoption system; and to service delivery as an integral component of the health system characteristics of the conceptual framework on integration.[8] Furthermore, there was opportunity to identify areas for improvement as suggested by the patients and their families. Quotations that illustrate the sub- and main themes were extracted from the interview transcripts and used in the results section according to the archival number described.

7.4.4. Data Analysis

Demographic data and data collected from the APCA IPOS was captured in Excel. The data specifically derived from the APCA IPOS was used to determine pain and symptom control for each patient. Patient reported outcome measures were conducted once only to determine the scoring for pain and other symptoms. Pain and each symptom were scored 0-5 with 0 being no pain or no symptom present, and 5 presenting very severe pain or symptom.

The scoring is reversed when it comes to the four IPOS elements that assesses the patients emotional and spiritual strength, included the ability to share feelings with family, feeling that life is worthwhile living, feeling at peace and adequate help and advice from family to plan the future. The score of 0 means that they are not able to share with family, do not feel that life is worthwhile, are not at peace, and have no access to help and advice. Scoring 5 means that they do have adequate access to all these elements. This data set was interpreted from the Excel data sheet and not further statistically analysed, since it was once off data.

7.4.5. Trustworthiness and rigor of this sub-study

In this sub-study credibility, transferability, dependability, confirmability and a reflexive approach as identified by Cresswell (2018) were used to establish rigor and trustworthiness of the reported findings.[192] Credibility was ensured through an intentional reflective process, to ensure that the researcher's assumptions and work context were bracketed[231] and not embedded in this study. Regular engagement with supervisors were held to present findings and discuss interpretations.

To ensure credibility, a detailed description of sub-study sites, population and processes of data collection, is provided. Informants ranged by culture, home language, gender, socio-economic status, and residential area. Consequently, transferability may well be possible in settings outside of the CMD since these informants encompass the diversity of the broader WC and SA.

Dependability of this sub-study can be assured by the rigorous data analysis methodology. All nine transcripts were coded by the researcher and three of the nine were coded by three other experienced researchers to ensure confirmability. Notably there were discrepancies that were discussed and resolved by consensus. In reporting this sub-study, all the relevant criteria for reporting qualitative studies (COREQ) according to Tong et al., were utilised.[193]

7.4.6. Ethical considerations

Beneficence and justice as ethical principles were considered throughout all interactions with the patients to ensure non-maleficence and that participants were treated in a fair and impartial manner.

In protecting participants, the rights of sub-study participants were upheld, and attention was given to protecting their confidentiality as well as ensuring their anonymity and autonomy.

PC patients are considered a vulnerable population. Engaging them in research is often neglected and not giving them the opportunity to be heard, is an injustice, as they deserve equal opportunity to take part in research and to benefit from research. A distress protocol[34] (Annexure 3) was in place to mitigate emotional or physical distress that became evident to the researcher. Voluntary informed consent was obtained, and patients were asked to explain to the researcher what the sub-study was about, to demonstrate understanding. They were assured that participation or reasons for non-participation would not be disclosed to their health care provider and would not affect their care plans in any way. Patients and their family caregivers were invited to ask questions. Patients disclosed symptoms that were poorly managed and to mitigate the risk of expectation that the interview would result in a change in their care plans, they were encouraged to raise these with their health care providers and advised that the interviews formed part of a study that would contribute towards improved understanding of the health care service delivery platform and practices.

7.5 Results

Patient profiles

Nine patients were interviewed telephonically, and all were accompanied by a caregiver or family member. Three of the patients were from the two low morphine usage sites (LMUS) and six patients were from the three higher morphine usage sites (HMUS), two from each site. One patient, from a LMUS, passed on before the interview could take place.

Table 7.1 provides the demographic profile of the patients who were included in this sub-study. Five female and four males were included and their ages range between 45 and 72 years and the period in PC ranged from three to 72 months. They represented the three official languages spoken in the WC and three of them were from the Muslim faith and six were Christian. Some patients had no source of income while most were dependent on state grants or pensions. Their housing represented two of the three broad housing classifications[xv] used within the Western Cape.[232]

Table 7.1: Demographic profiles of the patients

Facility Code	Gender	Age	Diagnosis	Months in care	Home Language	Source of Income	Classification of Housing	Faith	Primary Caregiver
HMUS 1	Female	45	Uterine Cancer	30	Xhosa	State Disability Grant	Human Settlement	Christian	Daughter
HMUS 1	Female	52	Renal Failure	12	Xhosa and Eng	Unemployed & No Disability Grant	Human Settlement	Christian	Male Partner
HMUS 2	Male	68	Brain Cancer	72	Afrikaans	State Pension	Privately Owned	Muslim	Daughter
HMUS 2	Female	67	Lung Cancer	24	Eng & Afrik	State Pension	Privately Owned	Muslim	Daughter
HMUS 3	Male	53	Rectal and Colon Cancer	13	Xhosa and Eng	Self-employed	Privately Owned	Christian	None
HMUS 3	Male	72	Prostate Cancer	12	English	Private Pension	Privately Owned	Christian	Wife
LMUS 1	Male	69	Paralysis	3	Eng & Afrik	State Pension	Privately Owned	Muslim	Daughter
LMUS 2	Female	70	Pancreatic Cancer	8	Afrikaans	State Pension	Human Settlement	Christian	Husband
LMUS 2	Female	55	Breast Cancer	15	Afrikaans	Unemployed & No Disability Grant	Human Settlement	Christian	Male Partner

APCA IPOS

The nine patients and their family caregivers were assessed using the APCA IPOS tool which provided a snapshot of their PC needs and symptom control. This is summarized in Table 7.2 (overleaf) and the rows shaded peach contains the HMUS patients and the area shaded light green contains the score for the patients in the LMUSs. The red highlighted cells are the scores that reflect symptoms that were not well managed or controlled and areas of concern raised by family members during the interviews. For questions 1 (pain), 2 (symptoms), 3 (worry about

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[xv] Housing classifications: The three classifications are i) Human Settlement Housing refer to properties that are owned by the state or municipality and includes informal, low cost and RDP; ii) Privately Owned Housing which also refers to some human settlement properties where the status has changed when the Title deeds have been issued for RDP and low-cost houses; and iii) Commercial Housing which refers to apartment complexes and similar structures.

illness) and 10 (family worry), the score of 0-2 indicates that the symptoms are managed well to fair. For the same questions the score of 3 – 5 indicates that the symptoms are moderate to severe. For questions 4 (ability to share feelings), 5 (life feeling worthwhile), 6 (feeling at peace), 7 (help and advice), 8 (family info) and 9 (family confidence), the scoring is reversed.

Table 7.2: Summary of the findings of the APCA IPOS tool applied to the nine patients and family caregivers.

Out of 5 with 5 being the worse and 0 the least												Over the Last 3 Days					Questions to Carer		
ASK THE PATIENT																	ASK THE FAMILY or CARER		
Q1	Q2											Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Pain	Shortness of Breath	Weakness or Lack of Energy	Nausea	Vomiting	Poor Apetite	Constipation	Sore or dry mouth	Drowsiness	Poor Mobility	Additional Symptoms indicated by the Patient and Family or Buddy		Worried about illness	Able to share feelings with Family	Felt that Life was Worthwhile	Felt at Peace	Enough help & Advise for Family to Plan future	How much Info have you & family been given	How confident does family feel caring for patient?	Is family worried about patient in last 3 days?
3	0	0	0	0	0	0	0	0	0		0	0	5	5	5	5	5	5	5
5	0	5	5	3	2	2	0	2	2		0	3	5	0	5	1	5	5	5
5	0	0	0	0	0	5	0	0	5		0	5	5	0	5	5	5	5	5
3	4	4	3	0	3	0	0	5	5	Night sweats	5	5	5	0	0	2	2	5	5
2,5	0	0	0	0	0	4	0	0	4	Insomnia	4	0	5	5	5	5	5	5	3
0	0	0	0	0	0	0	0	2	1		0	0	5	5	5	5	5	5	5
5	0	4	0	0	5	2	3	2	2	Dizzyness	2	0	5	0	5	5	1	5	3
3	0	0	3	0	2	4	0	0	0		0	0	5	5	5	5	5	3	3
0	0	0	0	3	3	0	0	0	0	Insomnia	5	0	5	4	5	0	0	3	4

The assessment of the physical elements showed that 70% of symptoms included in the tool were either well controlled or not experienced by the patient at all. Three of the nine patients experienced poor pain control, and the management of their other symptoms was not adequate. When comparing the scores for pain and physical symptom control across the HMUSs and LMUSs there was no difference, with a third from both HMUS and LMUS having inadequate symptom control. Four of the nine patients reported additional symptoms – insomnia, night sweats and dizziness – that were not listed in the Africa IPOS, and these were included and scored according to the same scale of 0-5.

The four IPOS elements that assesses the patients emotional and spiritual strength, included the ability to share feelings with family, feeling that life is worthwhile living, feeling at peace and adequate help and advice from family to plan the future (Questions 3-7). The average score for all patients was high at 16 out of 20, which is an excellent score, and this was the same for both HMUSs and LMUSs. Only three of the nine patients scored low in one of these elements and one patient scored low in two elements.

Of the nine family members or carers interviewed, six indicated that they had adequate information on the patient's condition and seven indicated that they were confident in their ability to care for the patient. This was found among all six HMUS informants but was absent in the LMUS informants. All nine caregivers indicated that they were concerned about the patient in the preceding three days.

Themes

The three main themes are made up of six sub-themes and 14 codes which were generated through thematic analysis of the individual interviews with patients and their family caregivers. Table 7.3 presented the initial codes and the six sub-themes.

Table 7.3: initial codes and sub-themes generated from the nine interviews with patients and family caregivers.

Patient & Family Needs	Expectations of the Health System	Impact of COVID-19 pandemic on palliative care service provision
1. Physical Needs	**4. Expectations of health facilities**	**6. Impact of COVID-19 pandemic on palliative care services**
i. Experience of clinical care	i. Waiting Times	i. Impact of COVID-19 pandemic on care services
ii. Pain control	ii. Access to palliative care resource	
2. Emotional & Psychological Needs	iii. Patient referral	ii. Connecting with other patients
i. Family & buddy informed on patients	**5. Access to other members of the MDT**	
ii. Supportive family members	i. Access to other members of the MDT	
iii. Patient & family knowledge of palliative	ii. Support	
3. Spiritual Needs	iii. Financial aid	
i. Spiritual care		

7.5.1. Patient and family needs

The patients, their family members or carers discussed their physical, emotional, psychological, and spiritual needs and how these needs were met.

Physical needs

While some patients and carers shared that their pain was well controlled, others disclosed poor control and some experienced break through pain. One family caregiver volunteered that they often ran out of pain medication due to the health facility prescribing and providing doses that the hospice team subsequently adjusted because of poor pain control. Pain control not only affected the patients, as family caregivers felt distressed when the patient had pain.

> "Yes, when is when he's on pains I was very, very, very frustrated because when she gets pains and me also, I get pain." HMUS 1_C

Experience of clinical care was discussed by all patients and family caregivers. Some patients indicated that they felt cared for, because their symptoms were well controlled, and the health care workers (HCW) were kind. One patient compared both in- and out-patient care to being in a hotel as their needs were met. On the other hand, other patients perceived their clinical care as not being aggressive enough, while one felt confused about their diagnosis. Some voiced frustration of repeated visits to the local community health centre before a decision was taken to refer them for further investigations and diagnosis. These informants expressed their frustration and deep disappointment about this delay and believed that they could have had better health outcomes if the referrals were made sooner.

> *Translation from Afrikaans* - "So I went to the day hospital, and they kept telling me it's an infection in my breast, and again it's an infection, it's an infection, it's an infection, but it was just

> getting worse. But I went again for months until they sent me to [name] hospital and that hospital then sent me to [name] hospital and then they told me it's cancer…now I have it in both breasts"
>
> LMUS 2_Pt

In almost all cases, both patients and their carers agreed about the quality of care provided. However, there was one patient who was happy with the care received, but the family caregiver interjected and stated that the patient was not providing a true reflection of the experience. He went on to state that the quality of the service at their community day centre was poor and that they had no idea what to expect at their next visit and were only offered return visits to the facility for dressing changes and collection of dressing packs. Every attempt that they had made to secure an appointment with the clinician at the PHC facility had not materialised. On numerous occasions they had been advised that a community health worker (CHW) would be sent to their home to assist with dressings and check in with them, but this too had not happened.

> "So I don't know why is it like that, that they know if you are on stage four cancer, as in is it because if you are on stage four cancer, that the doctors automatically neglect you, because they want to focus more attention on stage one stage two stage three cancer. "
>
> HMUS 3_Pt

One patient who, while being enthusiastic about his care, elaborated that he was still not clear as to whether he had cancer, as the information provided by different clinicians was contradictory.

> "I want to know what's wrong with me. And I want to know, I don't know where to go or what must I do. But I want to know what's wrong with me because I get uh thinner and thinner. And the doctor said, it's not… some doctors said it's cancer some doctors said it's not cancer, because they must first take a test to see if it's cancer" HMUS 2_Pt

Emotional and psychological needs

Various patient informants expressed their need for emotional support. They shared that the support and concern for their well-being they received from their families and caregivers, helped them cope with their condition. Some shared how they welcomed telephonic check-ins from family and friends who lived in other provinces and that this helped them make it from one day to the next.

All patient informants indicated that they needed family members and loved ones to accompany them on hospital and PHC facility visits and that they felt supported when their family members and caregivers engaged the attending clinician.

> "And my son-in-law mostly talk to the doctors because, I don't understand so lekker [well]… He's the one that talk to the doctors most of the time." HMUS 2_Pt

Some family informants indicated that when they did not have a clear understanding of the patient's condition, they felt unable offer adequate emotional and physical support. They were asked about their understanding of the term PC and whether anyone had every explained this term to them. Responses varied between some being very clear and others not ever having heard the term at all during their care journey.

> "Mind you, I did my own bit of research when I heard that big word first."
>
> LMUS 1_C
>
> *Translation from Afrikaans* – "No I don't understand … not yet spoken to me about that".
>
> HMUS 2_Pt

Spiritual Needs

The patients and carers, particularly from the HMUSs, shared that they accessed spiritual support from their religious leaders, church groups and family members. Some mentioned that the hospice nurse and the hospice PC CHW would provide spiritual support. One informant, however, avoided responding to this question.

Most patients remarked that spiritual support was not offered by the health care team and was never discussed at any visit. Only one patient remarked that the doctor had asked him if he had access to his religious leader or church group, which prompted him to seek support.

One patient discussed his spiritual state at length and voiced that having hope did not mean that he was in denial. He knew about his condition, the journey that he had been on, what PC meant and his intentional embrace of PC. His hope was fuelled by his ability to stand and walk after many months in a wheelchair.

> "No, every Sunday we go to the church. Spiritually, [okay] yes." HMUS 1_Pt
>
> "There was also someone from the church. They will always come to just help you guys, pray with you guys, they were always there" HMUS 3_Pt
>
> "… I'm not in denial about my condition, not in denial at all. I just have hope. And my trust is that of healing (stutters) that's my, that's my lifestyle." HMUS 2_Pt

7.5.2. Expectations of the health system

Each patient was asked about their health journey and whether their initial expectations of the health services as it related to PC, had been met. They were also asked to give what they felt should change within the health system to improve their experience. They shared experiences of waiting times, to being referred within the health system, their access to support, resources and to the broader health care team.

Expectations of health facilities

Some patient informants indicated that they waited for long periods before they were attended to. One described her frequent long visits, attending the local PHC facility three days per week for wound care, arriving early before the facility opens and leaving just before midday. On the other hand, some had satisfactory waiting times, as they accessed a clinician at a set time on a specific day. Some patients highlighted that they are seen promptly when presenting at the hospital emergency units after hours.

> *Translation from Afrikaans* – "And when she goes, she sits and waits and watches and is helped very late. Yet she is a regular patient, and she is an old patient." LMUS 2_C
>
> "So, I had [a catheter] and then it pulled out. So you know the bladder was very full. So when that was about three, four o'clock in the morning … My wife took me to the emergency section department. I had the most fantastic reception there and they were just there to help immediately." HMUS 3_Pt

Some patients who were referred from a tertiary hospital to a primary care facility said that they were told that there is nothing further that can be done for them at that level of care, yet they were not given referral letters. They were frustrated about arriving at the local PHC facility, being asked for referral letters, which they did not have, and then expected to tell the clinician their medical history, which some found difficult. On the other hand, there were a few patients who described seamless referrals with detailed referral letters, together with the referral facility contact details.

Some patient informants indicated that public sector facilities linked them to hospice care swiftly, while others said that they had not yet been contacted by anyone despite having completed and submitted the referral forms for hospice support.

Most struggled to access PC commodities[xvi] when in care at local PHC facilities. The provision of these items was either delayed or unavailable and resulted in a financial burden for those whose only source of income were social grants. However, when in care at a tertiary, regional or district hospital level, patients had adequate access to consumables.

> "Finally, now a few months ago we at last received a wheelchair. We had to borrow every time [from] a ladies' opposite by our house. To borrow her wheelchair. It's a real struggle just to get my father to the day hospital just for his appointments" HMUS 2_C
>
> "I even asked doctor to find out anywhere that we can get sponsors, where we can get diapers and linen savers, because my daddy has to sleep on plastic so that he doesn't wet the mattress.

[xvi] Palliative care commodities refer to wheelchairs, adult diapers, commodes, urinals, linen savers, dressing packs, syringe drivers, etc

> And I buy kimbies [diapers], two to three packs a week... My father gets pension, I get child grant." HMUS 2_C

Access to other members of the multi-disciplinary team (MDT)

There were several patients and family carers who had difficulties in accessing support from CHWs, physiotherapists, speech therapists, dieticians and social workers based at or linked to the local PHC facility. Some family caregivers raised concerns about their ability to adequately care for patients without the necessary support, advice, and nutritional supplements, that they should access from other members of the MDT.

> "My main concern was that [name] day hospital did not have a dietician to see to [name]'s needs. And then it was also the 3rd of June when he had his appointment, and then there was nobody there at [name] day hospital. And my worry was that he's been … using the Ensure. So, I didn't know how I was going to get a script for Ensure, you know." LMUS 1_C

> "We're still waiting for them. He had to go for physio and ... speech therapy there. But today still. Today still. They never even came back to us. We tried to do it again afterwards, and still they didn't come again back to us." HMUS 2_C

Many informants indicated that their only support other than the clinician at the health facility, was the hospice team which included the hospice social workers who provided emotional and psychological support.

> "Yeah, in terms of support, it's not really bad on my side, because … I speak to [name] from [the] hospice … she did visit me at home. Now she moved from hospice but she [is] doing something else under hospice care. Then she directed me again to other people there who I'm also going to speak to, on Monday." HMUS 3_Pt

Many informants had access to disability grants. However, one remarked that the doctor was not willing to approve the grant application. Some carers voiced frustration that they were unable to access the social worker at the local clinic to assist them to apply for a caregiver's grant. One family caregiver shared that she had lost her income to become a caregiver and was unable to gain access to a caregiver grant.

> "It's the doctor that is doing the grant but doesn't want to approve." HMUS 1_C

> "I've been home since this... from the beginning, a month after he came home. So, I had to give my job because I have to help my mommy." HMUS 3_C

7.5.3. Impact of the COVID-19 pandemic on palliative care services

Patients described that their access to care was disrupted by the pandemic. For some, all their appointments were cancelled, and they were advised to call the local health facility should they require any assistance. When health facilities were contacted, some were offered appointments three months later. On the other hand, for some, family members or carers were contacted and invited to see clinician. They discussed the patients' condition and were provided advice and medication. Some informants were concerned about seeing different clinicians each time they visited local facilities. Furthermore, some informants were negatively affected by their inability to connect with their regular clinicians.

At the time of the study, none of the patients and carers were accessing a support group. Some also indicated that they had no connection with other patients because of the COVID-19 pandemic. One patient's caregivers accessed the PC clinician at the health facility instead of the patient, due to the risk of contracting COVID-19. Some patients, visited at home by hospice nurses and teams, were informed that this would stop as the level four lockdown precluded such visits according to the declared national state of disaster regulations.

> "She didn't go herself. The [palliative care] doctor phoned us in, her family. Then it's just me and her sister and my brother that went. And then we had to go tell them about her condition... There was still COVID, and so then they didn't want mommy to come in herself for palliative care."
>
> HMUS 2_C

> "So, I've had two or three visits from them [hospice nurse and team] thus far. Yes. But I was also told now this afternoon because she called me to go and get some medication for him, but because of lockdown level four things are tight [access to care]. And I did try to explain to [patient's name] that we won't probably be seeing them [hospice nurse and team] because of level four. You understand, he didn't look too happy about that." LMUS 1_C

7.6. Discussion

Patients and their family caregivers are the users of the health system and form part of the adoption system in the conceptual framework for analysing integration of an intervention into the health system.[8]

In view of the interventions to institute PC services in primary care facilities, this sub-study elicited patients' and their care givers' experience of PC, through purposively selecting nine patient informants from five health facilities. The interview, using open ended questions, explored their experience of care and a validated tool elicited their symptom control and health status. Interview questions focused on their perceptions of PC, their care needs during their PC journey, suggestions to improve their health service experience and their symptom control.

The themes and sub-themes generated (Figure 7.1 overleaf) were the physical, emotional, psychological, and spiritual needs of patients and their families; their expectations of the health services, access to care and resources; and the impact of the COVID-19 pandemic on their care. There were some notable differences in the experiences of patients who received care from LMUS and those who were in care at the HMUSs. Findings are discussed in the light of the literature.

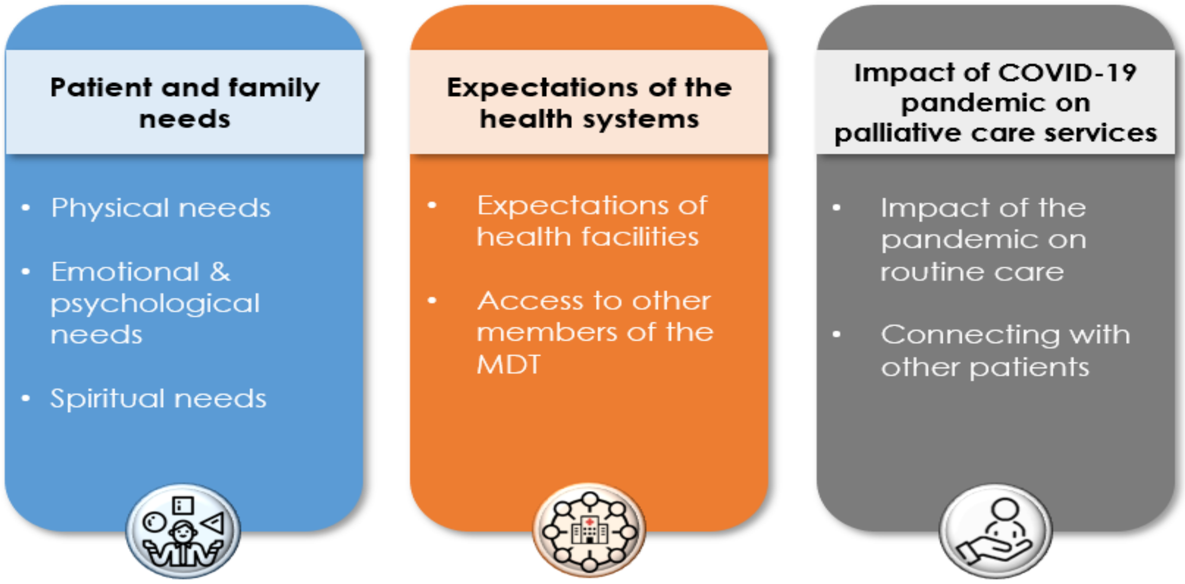

Figure 7.1: Map of the sub-themes and main themes generated from the nine interviews with patients and caregivers

7.6.1. Ensuring pain control

As mentioned in Chapter 3, according to Hosking, morphine is used as a gold standard measure for PC in Low- and Middle-income countries.[114] A global study conducted by Knaul et al. (2015) found gross inequity in access to pain control, with 94% of the global morphine being accessible to high income countries (HICs) that comprise 15% of the population.[233] The Lancet editorial[75] on access to opioids, reported that in 2017, approximately 80% of the global population did not have adequate access to analgesia for pain relief. Despite this, African countries where poverty is rife, such as Rwanda and Uganda, had prioritised PC programmes, access to opioids and oral morphine production programmes.[233]

A study conducted by Gwyther (2019), on the availability of PC in SA, reported that there was no restriction on the prescribing of morphine in SA, and regulations allowed for a medical practitioner to prescribe schedule six (most restricted level) medication for 30 days.[234] The standard treatment guidelines and essential medicines list (2020) for SA confirms that morphine should be available at primary healthcare and hospital level.[235]

This sub-study found that pain control experienced by informants varied across all the sites with no difference between informants from HMUS and LMUS facilities. Poor pain control and breakthrough pain was mostly due patients running out of morphine as they titrated morphine to manage breakthrough pain. Although morphine stock availability in SA has been limited since 2022 due to the national contracted supplier's inability to meet the increasing demands, the provincial medicines management directorate in the WCGHW confirmed that the WC had no stock outs.[236]

7.6.2. Burden of caregiving

In the Lancet commission report (2017), Knaul et al. reported that family caregivers are viewed by patients as their sentinel support.[119] The editorial by Radbruch and Kern (2014) indicated that women traditionally assume the role of caregiver while men may find this role difficult.[237] This sub-study also found that women assumed carer roles. However, men who were caregivers were willing and committed to providing care and support their female partner.

Knaul et al. (2017) further reported that family caregivers make significant financial sacrifices when supporting patients in need of PC and this often places the entire family at financial risk.[119] The burden is exacerbated when they have to procure items that the health system does not provide and often resign from fixed income employment to care for patients as was also found in other studies. Both Knaul et al. (2017) and Radbruch and Kern (2014) confirm that caregivers often forfeit work to care for patients and face difficulties in accessing carer social support grants from government.[119, 237]

Caring for a dying relative is demanding.[238] The emotional hardship and the impact on the mental wellbeing of family caregivers should not be under-estimated. Sultana et al. (2021) argued that psychosocial health is a global PC concern that also affects the patient with PC needs, their health care provider, and the family caregivers. A case is made for the use of digital health technology based on evidence of various digital health interventions– to provide support for the patient and family caregivers and more so over the COVID-19 pandemic that limited face to face encounters.[239] Digital interventions can extend beyond this support to include training and online access to resources and information. However, this could be a limitation in low resource contexts where patients and family carers cannot afford the necessary data.[239]

The physical care that the family caregivers provide is often during the night, which impacts on the quality of their sleep, stretching their physical capabilities to provide personal care to the patient.[239] Furthermore, they experience the distress that comes with watching the patient deteriorate – particularly when patients' pain and symptoms are poorly controlled.[239],[119]

In this sub-study, patient informants often regarded their family caregivers as being an adequate source of psychological, emotional, and physical support. The sub-study also showed that the patient and family caregivers need clarity regarding the diagnoses and care journeys. However, there was a difference in the direct support to and contact with the family caregivers from the clinicians and clinical teams at the HMUS and LMUS. The family caregivers of patients who received care at the HMUSs were clear about patients' diagnosis and probable prognoses and were confident in their ability to care for them. However, family caregivers of patients who were in care at the LMUS posed many questions and they were concerned about their gap in knowledge of the patients' diagnoses, prognosis and PC. The importance of supporting family caregivers cannot be underestimated.

Optimal support to family caregivers is required, but as Hudson et al. (2004) warned, health system support should be aligned to the needs and context of the caregivers. Various notable barriers should be considered, such as the caregivers' readiness and willingness to engage as well as the health systems ability to respond to their needs.[238] Various training programmes exist for caregivers and family caregivers, including a five-day programme offered by the Hospice Palliative Care Association in the WC and SA. The effectiveness of such a programme, the US Caregivers at Life's End (CGLE)[xvii] training programme, was evaluated and showed that such a modular programme was beneficial to the caregiver when dealing with end of life. A systematic review, looking at mental health risk reduction for family caregivers, that included 16 randomized control trials conducted by Alam et al. (2020), proposed a CARES framework to guide family caregivers. This CARES framework stipulates that caregivers be considered as part of the unit of care, and *"Assessing the caregiver's situation and needs, Referring to appropriate services and resources, Educating about practical aspects of caregiving, and Supporting caregivers through bereavement"* are all required.[240]

7.6.3. Spiritual support needs

Spiritual care is a key component of holistic care – whole-person PC provided to patients and their families.[170],[172],[140] As mentioned by Gayatri et al. (2020), religious practices or the practice of spirituality does contribute to improved quality of life for PC patients. The responsibility for the provision of spiritual care is not the same in all countries and in all settings.[228] Ferrell et al. (2020) regarded spiritual care and support as the responsibility of all disciplines.[140]

In this sub-study patient and family caregivers reported that health care providers did not provide spiritual care, and that they did not express spiritual support needs to their clinical teams. One patient indicated that the clinician referred them for spiritual care. Although this was a limited group, the patients and families accessed their spiritual support from various religious leaders and included their family caregiver as their source of spiritual care.

Ferrell et al. (2020) in a study reflecting on the increased global need for spiritual care during the pandemic could not be met by the few available hospital chaplains,[140] which raises the possibility of an unmet need for spiritual care. Although PC clinicians are more prepared to provide spiritual support, and other clinicians are not, all clinicians are responsible for identifying patients in need of referral for spiritual care.[140]

[xvii] CGLE training programme contains nine modules based on: 'The Hospice based on Experience Model of care' developed by Egan and Labyak

7.6.4. Health system experience

Various important matters were raised regarding the experience of the health system by patients and their family caregivers. These included referrals between levels of care that failed to communicate adequate patient care information, delays in referrals to the next level of care for definitive diagnoses, delays in referral from the PHC facility to the hospice and HCBC teams for ongoing support, and delays or no referrals to other members of the MDT at the same PHC facility to access nutritional advice, support and social grants.

These health system experiences placed significant stress on patients and family caregivers. It is likely that patients expect seamless care across the health platform, as was found in Morey et al.'s study (2021) amongst PC patients and their caregivers. They explored PC patients' understanding of continuity of care who transitioned from in-patient to homebased care, and confirmed that transitions across care settings, especially for older patients with life-limiting conditions, is burdensome for patients, their families, and the healthcare system. Furthermore, they found that patients with complex disease management issues were more vulnerable to challenges when transitioning between levels of care and recommended that strong continuity of care will mitigate some of the challenges during and following transitions.[116]

Daniels et al., 2017 defined that waiting time refers to the time that the patient waits for a service after arriving at the PHC facility.[241] Waiting times in this sub-study, exacerbated existing physical and emotional discomfort. This is a longstanding issue in CMD services. Since 2003, long waiting times were reported to have led to user frustration which was further exacerbated by poor communication on expected waiting times.[241]. Furthermore, long waiting times may exacerbate patients' physical condition and result in frustration. This was found in a Cape Town study on patient experiences' of PHC facility waiting times, where elevated blood pressures and reduced blood glucose were reported among patients with hypertension and diabetes, who additionally felt unwelcomed, and unhappy.[242] As was recommended, encouraging adherence to the appointment system, improving patient flows through health facilities and better supervision of staff who waste time by having discussions during working time could alleviate long waiting times.[242]

Informants in this sub-study reported that it was easier to access PC commodities at the central and acute hospitals, than at the PHC facilities. They experienced added financial burden since their transition to receiving care at PHC facilities, as families then had to procure adult diapers, dressing packs, and nutritional supplements. Although differences in access between hospitals and PHC facilities was not reported in the literature elsewhere, general access to pharmaceuticals and PC commodities were raised as a challenge in Sub-Sahara African countries, including SA and according to studies conducted by Namisango et al. (2016) and Janse Van Rensburg et al. (2013).[243, 244]

7.6.5. Impact of COVID-19 pandemic on palliative care service provision

The declared national state of disaster and the invoked regulations to manage the COVID-19 pandemic, restricted people's movement, and curtailed access to non-urgent health care, such as visits for in-facility PC services. In a context where the impact of the COVID-19 pandemic was unclear, health care providers and volunteers were deployed to services that were expected to be overwhelmed.[245] Consequently, service provision, particularly continuity of care was negatively impacted at health facilities. In addition to this, access to other members of the MDT were restricted due to poor referrals within the health system. Furthermore, the support that was received in the home in the form of home and community-based services was halted as CHWs were deployed to home delivery of chronic medication.[143]

Interestingly during the pandemic, differences between LMUS and HMUS facilities were found particularly around engaging the family caregiver. There was intentional engagement of the family caregivers by clinicians at HMUS facilities and this was not the case at LMUS sites. The intention was to ensure that the family caregivers were supported and to protect the patients from undue exposure.

Some of the patients and family caregivers reported feelings of isolation and disconnect from health care providers. To reduce visits to the health facilities and to mitigate the absence of home visits, some informants proposed that family caregivers could be trained in dressing techniques.

7.6.6. Strengths and limitations of the sub-study

This was a small exploratory sub-study which intended to raise the PC experiences and needs of patients attending a full range of PHC facilities and from demographic backgrounds that reflected MHS's service users. The small sample size may not reflect the larger population of patients accessing PC. This may limit its generalisability to the CMD and elsewhere.

Dependence on the clinical teams to identify eligible patients meant that a few patients were approached before informants interviewed were approached. Reliance on clinicians to refer patients for interviews may have introduced a desirability bias. Additionally, there was no guarantee or evidence that the patients had been assessed according to the SPICT for PC eligibility. Although patients were reassured that the interviews were confidential and that this would not impact their care, this anxiety may have been a factor and could have resulted in them moderating their responses.

Interviewing patients virtually via telephone, limited the ability to observe the patient and family caregivers' non-verbal communication, an important part of the communication and interview process. In-person interviews would have been better, but due to the COVID-19 pandemic restrictions, this was not possible. While the COVID-19 pandemic and the national state of disaster regulation restricted access to care that was not regarded as urgent or emergent, this allowed informants to highlight challenges related to the access restrictions.

Since this was a small sub-study, further consideration of this neglected vulnerable population is needed to adjust and address service delivery.

7.7. Conclusion

A health system that values and includes patient-centredness in strategic documents, commits to hearing the voice of the patients served. This sub-study provided insight into how the PC patients view the health system and where improvements can be made to address the needs raised.

Improved pain control and flexible access to pain medication is required. Attention to morphine utilisation is important. This could become a useful indicator to measure PC service provision and could be investigated further for inclusion as a proxy indicator for PC service provision in primary care settings.

Alleviating the burden of care on the family caregiver and supporting them requires an MDT approach to understand and address patients' and family caregivers' needs. Checking on, providing, or referring for spiritual care and addressing the health system discomforts, such as waiting times, are all critical to meet the needs and expectations of the patients and their family caregivers.

Patients have needs that extend beyond what the WCGHW clinical teams routinely provide and not all members of the care team are PC trained and see holistic care that includes spiritual care as part of their role and function. However, it is important to note that the WCGHW has as a goal to provide an environment and culture of care that affirms the patient at the centre of the care continuum and related decision-making.

Chapter 8 will focus on the SS managers' experience, changes in practice and lessons learned over the 24 months since the PC policy was implemented.

Chapter 8 : Sub-Structure Management Teams: 2 years after policy implementation

Chapter 5 focused on three sets of actors' perceptions of palliative care (PC) at baseline, within the adoption system who, by nature of their role, relationships and management support to the service delivery teams, influenced the extent of integration of the PC policy.[153] This chapter explores the experiences of the sub-structure management teams (SSMTs), 24-months following policy implementation of the PC policy. These SSMTs participated in the focus group discussions (FGD) reported in Chapter 5.

8.1. Introduction

The focus of this sub-study was to elicit changes in managers' approaches and lessons they had learnt regarding enablers for and obstacles to the implementation and integration of PC in the public health system. Furthermore, this chapter details the impact of the COVID-19 pandemic on the health system and PC, what had enabled and sustained a new intervention 24-months following implementation and what should change moving forward.

These SSMT informants form part of the executive teams of two of the four sub-structures (SS) in the Metro Health Services (MHS) in the Cape Metro District (CMD), each led by a director (senior manager). They were responsible for providing leadership, and governance arrangements that enables decision-making about the community-based services platform (home and community-based care and intermediate care facilities), the primary health care (PHC) facilities and the district hospitals in the geographical area.[79, 246]

8.2. Literature review

8.2.1. COVID-19 pandemic and compassion

Core to PC is the display of compassion, which is an essential element in quality patient care, and as reported by Sinclair et al. (2017) from a grounded theory study, compassion is empathy in action.[247] Galea (2022) reported in a Lancet article, that the pandemic had "*triggered enormous displays of pro-social behaviour*" and "*admirable empathy*" from community members to those in isolation and from the public to healthcare workers.[248] Many felt a sense of empathy based on the knowledge that they could be next, but compassion calls for action beyond just empathy because compassion is not motivated by the knowledge of our own risk for harm. Galea believes that "*a world rooted in compassion would embrace health as a public good*" and argues that if the health had been viewed through the lens of compassion, our response to the COVID-19 pandemic would have been different. Here is a call to reflect and reinvest in compassion as a foundational approach to health.[248]

Hofmeyer et al. (2020) in an article on health system leaders' response to the pandemic in the UK, asserted that compassion is the foundation of good health care and is based on empathy, respect, the ability to listen and communicate, and insight into patients' needs. Offering compassion, benefits both the person receiving it and the person offering it and they put forward that it improves patients' satisfaction and boosts the morale of the clinical teams who operate from a position of compassion. They further indicate that the anxieties and fears that frontline workers and clinical teams faced during the grief-stricken and turbulent pandemic, and with the potential risk of post-traumatic stress disorder, must be met with appropriate support and compassion.[249]

8.2.2. Policymaking for palliative care

Good national policy is developed through a process that begins with engagements with key leaders regarding the problem, cost effective interventions that integrate into the work of services and improve quality of life. Stjernswärd et al.'s (2007) reflection on integrating PC into national policies, outlined that good national policies are the cornerstone for facilitating the implementation of equitable access to PC services, affordable medicines, and therapies for all citizens. Additionally, advocacy to policy makers and the public, sensitization of all stakeholders through various workshops and the development of policy guidelines are required. They elaborated that effective policy should include provision for drug availability, education of healthcare professionals, access to PC experts as well as implementation guidelines that include funding for services and staff, and guidance on supporting family caregivers and the acquisition of technology.[21]

According to Vočanec et al. (2022), who reported on the integration processes within the Croatian PC model in 2014 – 2020, a bottom-up approach to integration is easier to achieve than when the PC policy is imposed top-down through a regional or national model. They further indicated that the policy processes instituted three key steps: a new organisational structure that addressed the fragmentation in PC provision and financing; improved PC through professionalisation; and the intentional identification and removal of barriers which included the strengthening of stakeholders and their roles in the provision of integrated PC facilitated.[156]

8.2.3. Educating communities and public on health policy

Gaitonde et al. (2020) in a study conducted in India, made the case for collective sense-making to ensure that contested policy or interventions are integrated into complex health systems through developing robust processes of community engagement. This initiative – a community action for health project, ensures that new interventions or policy are often contested in the broader community, since underlying perspectives, belief structures and divergent views of actors in the health system and broader context, affect how a policy or intervention is assessed and ultimately implemented. Appraisal of these processes is important to determine the system-fit of new interventions. Platforms are required where divergent views can be thrashed out before leaders in hierarchical structures formally implement new initiatives.[250]

8.2.4. Application of the framework for analysing integration of targeted health interventions into the health system for this Sub-study[8]

As in Chapter 5, the conceptual framework was unpacked in relation to the adoption system and its actors. Figure 8.1 below shows the relevant objective for this sub-study with specific focus on the repeat FGDs with the SSMT.

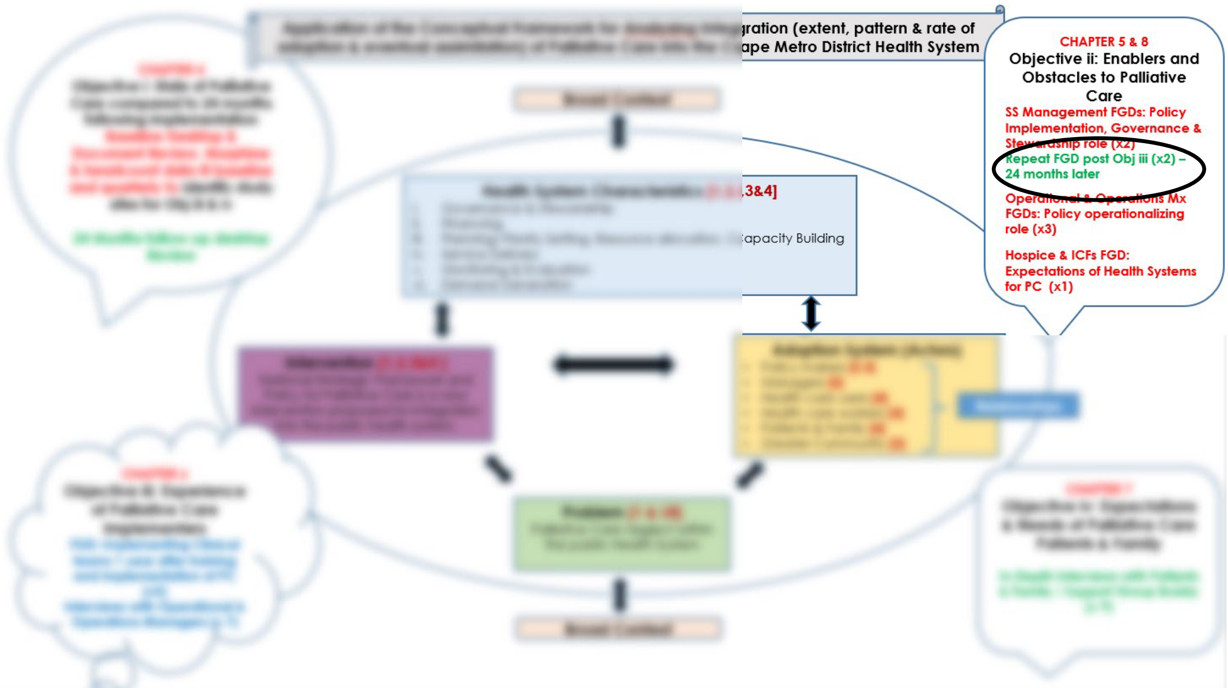

Figure 8.1: The application of the framework by Atun et al.,[8] for this sub-study objection – Repeat FGDs with sub-structure management teams as a component of the Adoption System

Health interventions as innovations are often introduced into complex adaptive health systems that are not fully predictable.[78] These may change and adapt in response to endogenous and exogenous actions, disturbances and triggers.[8] As with dynamic complex systems, the effects of decisions or system responses are not always immediately visible or accurately predictable, since these are affected by the cultural norms, values and beliefs of actors within the system, which could lead to unintended consequences.[8]

According to Mayhew (2017) and Walt et al. (1994) and as indicated in Chapter 5, the adoption system is influenced by interactions and relationships between staff in positions of power and should be considered when engaging actors.[102,87] Notable that leadership is central to aligning agendas of various government sectors towards a holistic approach of securing health for a healthy population.

8.3. Aims and objectives

The aim of the overall study was to describe, explore and explain the factors that influence the integration of PC within the district health service platform in the CMD. This sub-study elicited lessons learned during PC project implementation and the effect of the COVID-19 pandemic, 24-months following implementation.

This sub-study's objectives were to identify enablers and obstacles to the introduction of the PC approach and set of services, among senior management teams for the two study sites and to learn lessons to embed it further.

8.4. Methodology

8.4.1. Sub-study design

An exploratory qualitative study was designed to gain insight into the perspectives on PC from managers, 24 months after the implementation of the PC policy.

Sub-study population

The SSMTs for Khayelitsha Eastern SS (KESS) is in Metro-East and Klipfontein Mitchells Plain (KMPSS), in Metro-West, are also known as the executive members for each SSMT. Purposive sampling was used to select information rich informants for the FGDs (one FGD per SS) and particularly the 16 SSMT members who participated in the SSMT FGDs at baseline and as reported in Chapter 5.[189] All participants were provided with an information sheet for this sub-study and signed consent that included confidentiality, which was also re-iterated at the start of each FGD.

8.4.2. Participant recruitment

At the baseline FGDs, SSMTs were informed about the repeat FGDs, taking place 24-months later, to which they would be invited. Consequently, the directors for KMPSS and KESS were emailed to determine their willingness to participate. It was uncertain that these teams would be able to honour the original agreement due to the added health service pressures from the COVID-19 pandemic.

Both directors confirmed their initial commitment to participate in the follow-up FGD. They provided names of all relevant SSMT members who the researcher could approach as well as two preferred dates for the engagement, with a lead time of approximately two weeks. The identified executive team members were then individually contacted by email, requesting their participation in the FGD, provided with the information sheet and consent form(Appendix 7b), advised to pose questions for clarity, and to indicate their preferred date. Once the preferred date was agreed upon by all participating informants, the researcher sent a calendar invite for the MS Teams virtual meeting. Notable that eight (50%) of the 16 participants from the SSMT baseline FGDs participated in the FGDs for this sub-study and one FGD was held for each SSMT.

8.4.3. Data collection

Data collection tools

A discussion guide (Appendix 2b) for the FGDs was developed by the researcher, with guidance from the PhD supervisors. A set of open-ended questions, probing any changes in approach to PC, lessons learnt from the integration of this policy into the health system, the impact of the COVID-19 pandemic on PC and proposals to move forward for PC services, were asked.

Data collection procedure

Participants were invited to pose any questions for clarity and those who agreed to participate in the virtual FGDs, were asked to print, sign, and return consent forms via email. All completed emailed consent forms were received from each participant before the virtual FGDs took place. The contact details of all participants who requested a copy of the research report, was captured on a database for that purpose only. The FGDs were moderated by the researcher who led the discussion.

Data management and confidentiality

Both FGDs were audio recorded using a digital audio voice recorder, and the standard recording function on MS Teams. At the start of the FGDs, the implementers were reminded that the proceedings were confidential, that they should not talk about what was discussed with others as this could violate other participants right to privacy, and that they could opt out at any stage during this research. The recordings were downloaded from MS Teams and deleted from the online application. All notes were transcribed verbatim by a professional transcriber and were checked by the researcher before analysis. Each transcript was saved using the archival number as the computer file name and was indicative of the site name (Khayelitsha Eastern (KE) and Klipfontein Mitchells Plain (KMP)), method of data collection (focus group discussion (FGD)), participant category (sub-structure management team (SSMT), and sequential number (1-n). Printed transcripts were placed in a marked envelope, using the same allocated archival number, and placed in a lockable cupboard that was dedicated for this study. All audio recordings will be deleted from all devices and computers, three years after the study is concluded.

8.4.4. Thematic analysis

The transcribed data was checked by the researcher against the original audio recording for accuracy. The researcher approached the analysis using thematic analysis as described by

Braun and Clark[191] was used to explore the narrative from the FDGs and during this process remained mindful and reflective of biases. Data from the focus groups were analysed in search of meanings and patterns,[191] and key themes and concepts[211] regarding their changes in approach, lessons learnt, the impact of COVID-19 on PC and proposals that may influence the extent, pattern and rate of integration of PC into the health system.

The researcher became familiar with the narrative by repeated reading of the transcripts and immersion in the data in search of meanings and patterns. An initial list of ideas was coded into meaningful groups by using the NVIVO software program. The entire data set was worked through to ensure that equal attention is given to each data item.[191] Extracted data which had been coded many times or coded once and even un-coded data, was further explored to generate themes. A thematic map was developed from the identified codes to the generated sub-themes and ultimately the main themes, each of which were defined and named[191] and described in section 8.3 below.

From these two FGDs, 22 initial codes were generated and categorised into six sub-themes, which were grouped and categorised to generate four major themes. These themes are described in the results section along with relevant quotes extracted from the transcriptions. In recognising research bias, the code book, access to the data set as well as the transcripts were shared with both PhD supervisors.

8.4.5. Trustworthiness and rigor of this sub-study

As indicated in Chapter 5, the same process was followed in this sub-study regarding credibility, transferability, dependability, confirmability and a reflexive approach to this inquiry were used to establish rigor and trustworthiness of the reported findings.[231],[184] Notable only two transcripts were coded by the researcher, and shared and discussed with the supervisors to ensure confirmability.

8.4.6. Ethical considerations

Beneficence and justice as ethical principles were considered throughout the interactions with the staff to ensure non-maleficence and that participants were treated in a fair and impartial manner.

In protecting participants, the rights of sub-study participants were upheld, and attention was given to protecting their confidentiality as well as ensuring their anonymity and autonomy.

Participants in the FGDs were public sector staff and power differentials were considered. Since the researcher was a senior manager, issues of overt or subtle coercion were addressed by reiterating that participation was not compulsory in the information sheets and at the start of the FGDs to promote good practice and reduce discomfort. All transcripts were anonymised, and all identifiers removed. Informed written consent was obtained from all participants and their identity, as well as the record of discussions, was kept confidential, known only the researcher and assistant researcher.

8.5. Results

Table 8.1 below summarises the sub-study population and provides the code that was allocated for each FGD, which is used when illustrating quotes from these FGDs, for the thematic results section below.

Table 8.1: Sub-study Population for the follow-up FGDs with the sub-structure management teams

Group	**Study Site**	**Number of groups**	**Selection criteria**	**Number of participants**
SSMT 1 FDG	KESS: Metro East	1	SSMT members from each of the two study sites, who are responsible for providing leadership, governance, and policy decision making were invited to participate prior and 24 months into policy implementation.	9
SSMT 2 FDG	KMPSS: Metro West	1		10

A total of 19 informants participated and Table 8.2 below provides their gender, median age, and years of experience.

Table 8.2: Profile of the Sub-Structure Management Teams (n=19)

Focus Group	**Gender**	**Median Age**	**Years of Experience in Current Capacity**				
			<1 year	1-5 years	6-10 years	11-20 years	20 + years
2 FGDs for Sub-Structure Management Teams (n=19) Repeat **FGD 1: 24 months later**	Female	50,3	2	2	8	1	1
	Male	50,2	1		3	1	1

Themes

From the two FGDs with the SSMTs (one per SS), four main themes were generated from six sub-themes which were generated from 22 codes. The initial codes and sub-themes are illustrated in Table 8.3, overleaf.

Table 8.3: Initial codes and sub-themes generated from the two focus groups

1. Policy at the Coalface	**2. Creating Awareness & disseminating information**	**3. Impact of SARS-CoV-2 on Palliative Care services**
Clear Position Statement on Palliative Care	Political influence on provision of care	Palliative care before SARS-CoV-2
Including palliative care in daily business	Importance of creating awareness on palliative care	SARS-CoV-2 impact on Palliative Care services
Palliative care and all staff categories	Educating communities on palliative care	Pandemic and compassion
Value of communication with the patients family		
4. Leadership & Governance	**5. Policy Development Lessons**	**6. Planning for & supporting Policy Implementation**
Teamwork, support & caring for each other	End user involvement in policy development	Plan policy implementation support
Strengthen referral mechanisms and pathways	Policy communication	Pilot policy for sustainability
Involvement of other government departments	Inappropriate Policy	Policy user resistance to change
Integration is key	Policy consultation processes	Champions for palliative care

The four main themes were subsequently generated from the sub-themes illustrated in Figure 8.2 below.

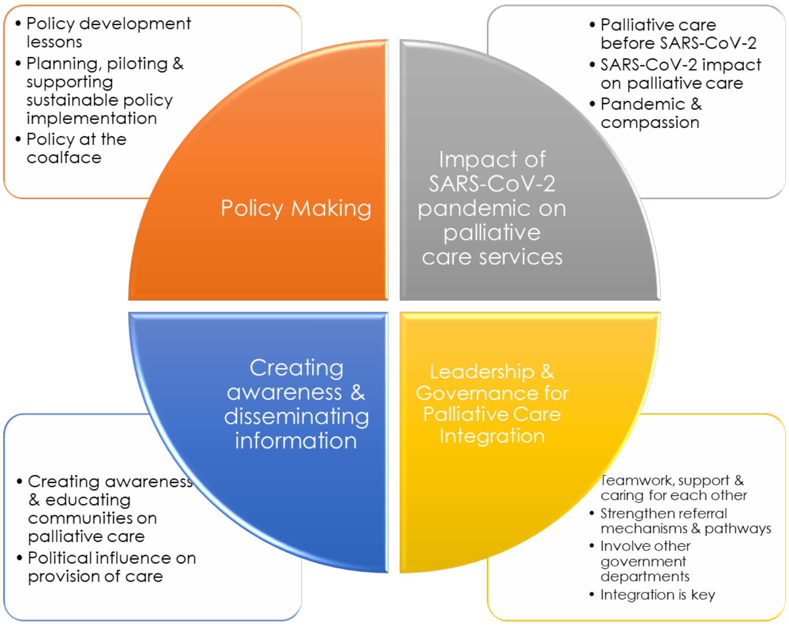

Figure 8.2: Map of the sub-themes and main themes generated from the two focus groups

8.5.1. Policy making

Policymaking formed a significant part of the discussion in both groups. The informants reflected on what should be considered during policy development processes with specific reference to consultation, the need for adequate and inclusive planning for policy implementation, and the needs that the frontline have, to sustain policy implementation.

Policy development lessons

The Informants maintained that policy would be more implementable, relevant, appropriate and with less contradiction to other policies, if the end users were included in the policy development processes from the start. They added that it would also be of value to understand from the end user, whether the policy is required in the first place or whether existing practices could be enhanced or altered to achieve the same result for the patient and the health system.

Informants made a case for improved policy communication from the SS office to the facility teams, which allows for discussion and questions. They added that if policy were simplified and the practical implementation unpacked, it would further aid buy in and implementation.

> "A policy cannot be too narrow…but if it's opened-up for interpretation, then you have many different interpretations. If we take the AOS [assurance of supply] there's a delegation, that says, at the discretion of the supply chain manager. So if all supply chain managers … [the problem is that you] have 10 different interpretations on one particular thing." SSMT 2

Informants from corporate governance indicated that they were repeatedly consulted on various policies by policy writers at the level of the province or chief director MHS. This negatively impacted on their usual employment obligations and conversely their day-to-day work limited the time to do due diligence to the policy consultation process.

> "You know, when I worked at head office, I always used to say that people don't respond from the facilities. But now I'm at the institution [health facility], and the people are saying the same thing about me now, because they're sending you an email and [name] is not even reading his emails until tonight, when he gets home. Because 10 different people is asking one person for something different. So that is the environment on the ground that is not always taken into consideration" SSMT 2

Informants in both FGDs highlighted that policy writers positioned at the provincial or chief director MHS level, were disconnected from the reality at the frontline, resulting in policy that is not always implementable. They made an example of the change in the visitor's policy during the COVID-19 pandemic, that allowed one visitor per patient. However, when implemented the number of individuals in one ward at the same time exceeded the numbers put forward in the national state of disaster regulations.

> "Because remember you are writing the policy, in the ivory towers of 4 Dorp Street [provincial head office], … then it must be implemented here. And the environment is just not the same."
>
> SSMT 2

Planning, piloting, and supporting policy implementation

Planning for policy implementation from the SSMT level was raised as important and acknowledged as not being prioritised. Informants indicated that interpreting policy takes time within contexts and should clarify roles of all stakeholders from the SSMT to the health facility level. Due consideration should be given to staff expertise and experience, as well as context and resources that vary from one facility and community to the next.

> "When the policy comes out, head office and CD office will just send it to us electronically. Then we have to read it … and get our minds around [it] to understand … what it's stating. But what should happen, or … what will help is if there's more engagement and interaction from head office team and CD [chief director] office to actually explain it so that we all are on the same page, because often you're left to your own devices to read, interpret it and then carry it over."
> SSMT 2

Informants from one FGD discussed the value of piloting policy and taking a slower approach, to identify and address pitfalls before further roll-out. This would also allow the SSMT the time to plan the ongoing support required until the policy is fully implemented and integrated. Informants from other FGD discussed that implementation at every facility at the same time would be ideal. They further articulated their plan which included conducting road shows to communicate policy, providing onsite engagements to simplify and clarify policy, ensuring policy dissemination through adequate communication, addressing bottlenecks and adapting resource allocation as they move forward, and creating spaces to share practice.

Informants presented two views regarding identifying facility level champions for PC. In one FGD, some indicated that they often nominated champions at facility level without due consultation and then expected them to drive the agenda. Informants in the other FGD described that a champion who was passionate about the policy, would add great value in driving and supporting policy on the frontline.

> "I am a firm believer in piloting things, I think [name of organisation] has taught me a lot of good things… If we pilot something, we assess the resources required to implement it in a structured way, and not rolling out that everything is a one-size-fits-all roll out plan, and it comes from somebody who's a champion, who is also pressurised … to perform and implement these things. And we just take a little bit of a … slower approach, and pilot it and find out what the pitfalls are, because most of our interventions, which we've implemented in that way, has been sustained up to this day." SSMT 1

> "The champions were people who are passionate about palliative care. So it was not just anybody who was asked to be a champion… People who volunteered and said, "I will be the champion". So it people were passionate about what they were doing. And that usually rubs off to other people." SSMT 2

Policy at the frontline

Informants shared their experience of ensuring a clear position statement on PC at facility level. They described how regular discussions on PC with all staff, had streamlined their governance processes. To ensure buy-in and responsiveness, informants voiced the value of having every contributor to the health system at the SSMT and health facility level, well informed of all policies. Supply chain management processes were described by a few informants as being drawn-out because of the many questions posed to the clinical teams to understand why certain items needed to be procured. Informants shared how this had changed since the supply chain management teams were included in the PC policy sessions, resulting in enhanced responsiveness to need.

> "… why should the policy be implemented, and the value thereof. We do not advocate that adequately to everybody and sometimes to the end user, which creates some stumbling blocks and dynamics when coming to implementation. And sometimes policies … that have been implemented … but it doesn't reach everybody … [like] put them on the notice board, [so that] even if a porter that is transporting a patient from EC [can see it] … We forget that not everybody has got … email system. We don't ensure that. We [should] take it up to the level of groundsmen that is working in the garden … And the other thing is rigidity when coming to change of mindset. Sometimes we are used to doing things in a specific way. And when … new things come into place, we become rigid, we do not shift our mind and adapt to new changes."
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> SSMT 1

Informants added that the inclusion of PC in the daily statistical data counts and reports, as well as staff meeting agendas would help to facilitate integration at facility level.

8.5.2. Creating awareness and disseminating information

The importance of creating awareness about PC, by educating communities and the challenges of political interference in the provision of care were raised by informants in both FGDs.

Creating awareness and educating communities

Informants indicated that communities, family members of patients, and some of the staff still believe that PC is only end-of-life care. They described that PC was viewed as the health system had given up on the patient and that there was nothing more that could be done for them. They indicated that it was important to share information to create the awareness of what PC is. Myths needed to be debunked through media, social media, meeting platforms, in-service training, optimal utilisation of the SS based communications officers, and stakeholders who were trusted in the communities.

The informants shared that they had tapped into support from faith-based organisations, community structures and various volunteers who gave their time, to form part of the SS team that provided spiritual care and helped with accurate messaging regarding the pandemic and PC.

> "So who is taking out the time or making the effort to educate and transform the patient or the family side or the community side on palliative care. We've been very much focused on palliative care in facilities, institutions, in health care. But I'm not sure if there is a project underway of palliative care in communities. Because that is essential. Because if we don't get the balance, right, all the communities are going to see is 'oh, you've decided my loved one must die, or there's nothing more we can do'. And that puts a different stress burden on the system, as well as on the emotional wellbeing of the healthcare workers." SSMT 2

Political influence on the provision of care

The interference of politicians and influential families was raised as concerning by various informants who shared examples of how members of parliament requested facility visits with the hidden agenda of wanting to influence clinical decision-making for family members or acquaintances. Some informants added that they required protection from these political leaders who placed clinical teams under pressure, due to pressure from community members. This was exacerbated during the pandemic.

> "I think the politicians need[s] to be on board with and have good clear understanding of where we're heading. Because I think the pressure that was placed on the healthcare system, and health care workers, … our pressure isn't often directly from communities, it's community, to politicians, to the healthcare (system) to healthcare workers…I don't think that the powers that be in our health department actually understand the onslaught that we get on a daily basis. There [are] people that's connected to political figures, or people who feel they have a sense of importance… And I do believe that the communications department must try to get on top of this… Communications need to improve … with the community, [because] our people in parliament is also part of the community" SSMT 1

8.5.3. Impact of the COVID-19 pandemic on palliative care services

The COVID-19 pandemic was referred to as a period that shifted PC service provision within the health services. Informants described where the PC services were before the pandemic and the impact of the COVID-19 pandemic on PC services and compassion.

Palliative care before COVID-19

Informants reported that they were at the starting block of implementing the PC policy with training underway, when the COVID-19 pandemic started. They shared that they were considering its inclusion in relevant care packages and that some facilities had started to plan PC service provision. Informants added that while some facilities had included PC in an MDT approach, other facilities had one clinician offering PC without an MDT. With the onset of the pandemic, the need for rapid integrated PC had dramatically increased.

COVID-19 impact on palliative care

Some informants disclosed how vulnerable they felt when the extent of the PC service gap became evident. They expressed how hopeless and overwhelmed they felt by the sheer numbers of patients that the pandemic brought into the health care system. Those who form part of hospital management, shared how they had to support the internal medicine teams in making hard decisions about which patients qualify for intensive care and ventilation, and had to rally support from other colleagues to help with the sudden increased burden of updating patients' family. Some informants indicated that the 'no visitors' policy that was issued during the COVID-19 pandemic had severely compromised the much-needed support to patients from their family members.

> "Nobody was ready for COVID and the type of clients that we treated at the time, as we all know, the patient's conditions deteriorated so suddenly. And most of the patients were classified under the palliative care radar. So from a nursing perspective, you know, you couldn't really deviate your thinking from palliative care versus any other care because the patients, the families had expectations, we couldn't really engage with them, people couldn't visit."
>
> SSMT 2

They added that the rapid response and guidance from the provincial and chief director MHS in providing guiding circulars, clinical guidelines, training videos and virtual meetings to facilitate rapid sharing of essential information, helped them to offer PC services.

> "There was a palliative care PACK[xviii] guideline very quickly and that also helped to integrate palliative care in what we do. Very often in palliative care when you look at different guidelines and what needs the support it was very vague but, it was very clear" SSMT 1

Furthermore, they valued the nationally amended supply chain management delegation that allowed for the rapid procurement of equipment for PC and all patients. Much of the red tape was removed and the daily petty cash limit was increased. This streamlined procurement time and allowed for purchasing of equipment and consumables at a much lower price.

> "So with COVID, ... people in supply chain was willing, we didn't have to sit for months and motivate why you needed something, because it was understood ... for us to get the phone to get the airtime to [allow video calls between patients and family] ... so that definitely facilitated [and] enabled that." SSMT 1

Pandemic and compassion

Informants shared how their own personal experiences and losing family members, friends and colleagues made it clear that everyone was in the same position. This pandemic could affect anyone, and informants reflected on the immense pain and sadness they experienced as some colleagues had died from COVID-19. Some shared how their teams felt valued when

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[xviii] PACK – Practical Approach to Care Kit

they went to the shops after work and were fast tracked in queuing systems; how various organisations brought small tokens of appreciation for frontline staff; how the 'Jerusalema Challenge'[xix] helped to keep many teams going. This had shaped their experience of compassion from others and influenced their expression of compassion towards colleagues, patients, and family members.

> "I think most health care workers, by nature are compassionate human beings. And I think when you are faced with a pandemic, that kicks in, because … you're not only experiencing that with a patient, you're experiencing that with your own family, with your own friends... I think it's that compassion of a healthcare worker that kicks in, could potentially be the reason that you respond." SSMT 1

Some informants raised the challenges that implementers experienced with the provision of care during the COVID-19 pandemic – how patients' conditions could change suddenly and the subsequent sad communication with families. They also reflected on the value of regular communication with patients' families. Even if the news was not good, families were well informed, and this resulted in fewer frantic calls that clinicians had to field.

> "COVID actually robbed all of us of the care that … people were supposed to receive … It was not easy to convey the messages… The family members would phone the hospitals where their people are admitted, and they will be told "No, she's doing well" or "He's doing well". Because remember, they couldn't go and see them. So the only voice they could relate to was that of the staff in that ward. And tomorrow, … the condition has changed completely. So that was …confuse[ng] to people. How does it happen that I speak to the doctor or the nurse today, and they tell me, my mother is doing well? And then … in the evening, … the condition has changed completely, or you are actually receiving news that the person is no longer with us. Sorry, to inform you that. So in that case, their families were actually robbed of the part of the role that [they] would be playing during the time." SSMT 2

8.5.4. Leadership and governance for palliative care integration

The informants in both groups shared their views about lessons they had learned and what they believed should change, or be enhanced, to ensure health service integration of PC. Essential elements were leading by caring for team members, ensuring a seamless referral system, and collaborating with other government departments within a governance framework that holds integration at the centre.

Teamwork, support and caring for each other

Informants from both FGDs described how they had grown in caring for and supporting each other, and their teams. Within a bureaucratic system, the pandemic had brought them closer

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[xix] Jerusalema challenge was a dance challenge that various frontline and backline teams in the health and other essential services participated in to motivate each other globally.

to not only their direct subordinates, but all team players irrespective of rank. They indicated that the only way to survive the devastation that the pandemic had brought, was through pulling together as one big team. They regarded the pandemic as the catalyst.

> "I think it was the great teamwork … We may not have been fully ready for the impact of COVID. But what happened is we rapidly got together and put the things in place for us to be able to care for the sick people in our community. And I think standing together and working as a team, with various role players, because it was all the role players came together and willingly worked their fingers to the bone to put the systems in place and to reach out and do as we needed to."
> SSMT 2

Strengthen referral mechanisms and pathways

These manager informants further voiced that it was important to strengthen referral pathways, and that existing referral mechanisms needed to be streamlined to ensure continued and appropriate care for all patients at the right level of care. They added that home and community-based care and intermediate care facilities should be integrally linked to the PHC facilities in the patient care pathway. The PHC facilities in turn should be linked to and supported by the district hospital. Informants indicated as the health system was under tremendous pressure, strengthening the referral system within the health system, would add significant value.

> "Then you need to already [consider] your exit strategy, think of where this patient should actually end up to recover fully… That should be part of your planning, prior to the discharge of that patient, or prior to the referral of the patient. That doesn't mean because … hospital[s are] open after hours, that is the appropriate space for the person to be. Can the person wait for the next day to go to the PHC or what should be happening?" SSMT 1

Involve other stakeholders and government departments

The informants highlighted the need to engage and collaborate with stakeholders and other government departments to address the social determinant of health that affect patients' access to PC services. There were concerns about inadequate housing and sanitation, food insecurity, poor access to clean running water in the home and delays in accessing social grants. Informants indicated that the public sector health services were not able to solve these challenges and that other government departments were needed in this space. In one FGD, an interesting point raised by informants responsible for hospital management, was the importance of educating the labour unions about PC, so that they could support the staff who were members of their respective unions and who deal with sick patients.

> "it's also housing and sanitation, it's all those things that affect the household and fix the person. So, it's those sorts of [government] departments that I can think of and of DSD [department of social development] … These definitely are the departments that can come to the fore in supporting the family and the patient." SSMT 1

> "You know, we had it [palliative care] as part of our IMLC [labour meeting] two days ago, … so it's still being kept in front of us, it's still part of our monthly programme on IMLC, to bring the staff on board … it's also the labour caucus that is being kept on board." SSMT 2

Integration is key

Informants in both FGDs described the importance of service integration within a health facility and across the health platform within a defined geographic area. They articulated that the patients should be seen holistically and consequently, due to resource constraints, all clinical policies that advocate for a vertical approach should not be accommodated. Informants from one SS added that they had appointed a professional nurse in the hospital to assess patients for PC eligibility, to draw up care plans with the MDT, and who then referred patients for further care in the PHC and HCBC services.

> "it's always been a thing of integration in our substructure, we've always been pushing for integration. And it comes obviously from my side, they call me the queen of integration on the primary healthcare platform … not just the hospital and the PHC platform and the CBS platform … [we] see it as one platform" SSMT 2

> "Because the aim of palliative care is to provide holistic care, and to involve the family ... And there was also ... stigma that palliative care was associated with death, when people hear palliative care, "Oh, he's gonna die". So once we started to make that clear to the staff, the interest actually increased… Now today we [are] sitting with about six, seven people that's trained on palliative care who went for the short courses. ... we really need palliative care more than ever before ... also the hospital board was involved. That is why we have a pastor now that's there for spiritual care in times in case of families doesn't have somebody."
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> SSMT 2

8.6. Discussion

The two SSMT groups discussed what had changed because of the PC policy implementation and reflected on the impact of the COVID-19 pandemic on the provision of care. The managers proposed important considerations for better policy making, raised the value of citizens being well informed regarding PC, reflected on the impact of the COVID-19 pandemic for compassionate care and discussed the value of leading the health system with care and compassion. These reflections align to the health system characteristics of planning, service delivery and leadership and governance, as well as the adoption system of Atun et al.

8.6.1. Better policy making

This sub-study found that these managers – the end users of policy – knew their own work context and environment well. This included successes, challenges and problems that require resolution. Including end users of policy through a robust consultative process starting with determining the need for policy, to policy initiation and, throughout policy development phases, was essential. It allows for adequate engagement to determine policy need, facilitates policy communication, and ultimately, buy-in for integration. This was argued by Briassoulis (2004), in a paper on policy integration for complex policy problems. He asserted that actors play a crucial role from the time of identifying the problem that requires an intervention (policy), the consultation and development of the policy, and the implementation and related measures for implementation.[88]

According to Atun et al. (2010), the perceptions of actors within the adoption system to the new policy are influenced by whether they see benefit or risk in the intervention.[8] A systematic review conducted of the evidence on integration of targeted interventions in health systems, by Atun et al. (2009), made the case that donors and implementers both develop a context-specific evidence base that could inform and guide policymaking and its related policy practices, and that they move away from the historical way of doing policy.[106]

The informants in this sub-study agreed that in their role as the SSMT, they were responsible for policy, planning and providing support to the street level bureaucrats (SLB) for policy implementation. Although the two groups of informants had differing views on the need to pilot policy and the value of champions for PC, they agreed that policy planning and support from the SSMT could reduce policy-user resistance to change. Notably this would require close collaboration between the SSMT, representing the SLBs, and the policy writers. This process may be complex and fraught, as raised in the study by Davidovitz, Cohen and Gofen, (2021) on government's response to crisis. These authors remind the reader that the relationship between policy makers and SLBs is complicated as the two often represent the opposite camps.[215]

Furthermore, in this sub-study it was found that the need for a clear departmental position statement on PC was important. It was essential to include all staff categories in discussions on PC at all levels of care. This would reduce the need for SLBs and clinicians to spend time clarifying policy related resource needs and motivations for procurement of resources, staff training, and finances.

8.6.2. The value of educating the public about palliative care

Informants in this sub-study saw that creating awareness and disseminating information about PC, was important among staff and the public. This was also found in the two sub-studies reported in Chapters 5 and 6. In addition, there is vast literature that greater community awareness of PC reduces stigma and myths regarding PC and consequently, this may increase patient demand for and access to PC.[3,122,123,212]

Chapter 5 found that poor education of the public and inadequate community awareness about PC, were barriers and this was confirmed by Graham-Wisener et al., (2022) and Ahmed et al., (2022). In this sub-study and as reported in Chapter 6, it is important to ensure that all categories of staff are informed about PC as gaps in knowledge of health care providers were found in various studies to be a barrier to PC integration.[3,122,123] McIlfatrick et al. (2014) reported that low levels of public awareness regarding PC were a challenge that hampered the development of a public health approach to PC. This was needed to build public policy on supporting death, dying, grief and loss.[212]

This sub-study found that although political interference during the pandemic resulted in frustration and informants indicated the need for senior/top managers in the WCGHW to provide protection from them, they also acknowledged the role that local politicians play in communities and the value of educating them regarding PC to debunk myths and share accurate information about PC. May and Winter (2009) also found that politicians influenced policy outputs and outcomes at the local level.[83]

8.6.3. COVID-19 and compassion

This sub-study highlighted that the COVID-19 pandemic was a catalyst that highlighted and brought back compassion and compassionate care into the health system. Compassionate care was acknowledged by the SSMT as having been a weakness in the public sector health service and this was also found in Chapter 5.

Various studies confirm that compassion is the basis of holistic quality care and that good care is perceived as not just good clinical care, but benchmarked by how clinical care was offered and then perceived.[80, 248] Front-line health care workers (HCW), the SLBs, displayed compassionate care, and the reasons for this may be the compassion that they received during the pandemic from society as a whole, together with the risk that the pandemic posed to themselves, their own family members, and all members of society. However, as studies have shown and cautioned, compassion that is rooted in their personal risk is not sustainable and this will require a departmental reflection into how the WCGHW can advance towards a compassionate health system that is not only motivated by risk or kindness from other entities.[248]

An interesting finding was the discussion on the importance of including patients' families in all communication related to the patient care journey, which would reduce complaints and enquiries and allow families the space to engage and express their need for support in caring for the patient. Although this approach is supported by various studies.[238, 240] It must be noted that this has not been standard of practice at various facilities within the CMD and WCGHW. Policies such as patient escort access to health facilities remain in place, limiting the patients' families and caregivers from entering certain health facilities and emergency centres.

8.6.4. Leading the health system with care and compassion

This sub-study highlighted that leadership that is supportive, engages with compassion, provides change management support, is visible and responsive to the frontline, was required to drive the PC agenda. Mayhew reminds us that the frequency of supervisory visits and team support is crucial to integration and diminishes frontline teams' experience of occupational stress.[102]

This sub-study found that leadership that considers the role of other government and non-government sectors and seizes the opportunity for collaboration is required to address social determinants of health, such as food security, housing, access to clean water and sanitation. Rifkin (2018) reminds that the Alma Ata declaration proposed viewing health in a holistic manner to ensure equity, community participation and address the social determinants of health[xx].[45] It is important to acknowledge that the health system has not made the necessary connections with all available partnerships and stakeholders at the local PHC facility level.

The need for a well-defined care pathway and referral mechanism for all patient movement within CMD was highlighted as essential. Esquivel et al.'s (2012) study found that electronic health records facilitated referral communication and feedback loops.[118] Although the WCGHW has commenced the role-out of the electronic continuity of care records (eCCR) which includes PC,[117] a province-wide, documented, standardised, implemented referral process is needed.

8.6.5. Strengths and limitations of the sub-study

This sub-study took place after the fourth wave of the COVID-19 pandemic, so the impact of the pandemic overwhelmed the discussion and rightfully so. Consequently, there was much discussion about the need for PC services, the involvement of families, about integration and compassion.

While there were only two FGDs with 19 participants, these were a broad spectrum of experienced manager informants, and none declined participation.

A strength in this sub-study was the willingness of a broad spectrum of experienced senior and middle managers to participate and inform this sub-study with no declines to participate.

The limitation that comes with conducting FGDs virtually limits the ability to gauge non-verbal communication. Due to data issues the informants had to switch cameras off after the introductions at the start of the FGDs. At the same time this can be viewed as a strength, as it was more anonymous with a senior leader as a researcher.

8.7. Conclusion and recommendations

Two years after the PC policy was implemented, SSMT members shared their reflections on valuable lessons and have made key recommendations. COVID-19 has highlighted the need for PC as part of the comprehensive package of care. Having experienced the Covid-19

[xx] Social determinants include access to proper nutrition, education, adequate supply of safe water, basic sanitation, maternal & child health care, preventative medicine such as family planning & immunisations.

pandemic, planning for future pandemics needs to include the ongoing care for PC patients and the increased demand and complexity of such services. This extends to including the family while the patient is alive and into bereavement support. A spiritual carer database should be established at each SS, so that MDTs from all health facilities can access support for patients and family, as needed.

Leadership that drives the integration agenda, listens, is visible at the frontline, provides support, connects with other government departments, NGOs, labour unions and stakeholders to collaborate on their role in addressing social determinants of health, is needed.

Compassionate care and a compassionate health care system needs concerted effort and should not be something that occurs when HCWs have personal risk as with the COVID-19 pandemic. The WCGHW culture journey should have a specific focus on developing a compassionate health system.

Policymaking at provincial and chief director MHS level must change, and implementers must be included from the start, consulted about the need for policy and engaged throughout the process to reduce resistance to change, confusion and contradiction with any other policy. Policy that is not consulted does not adequately consider context. Clinical policy should present implementers with a framework that they can use to adapt and fit to their context.

Creating awareness about PC among both staff and communities, helps to de-bunk myths, and reduce stigma. The staff responsible for communications in health systems, in this case the communications directorate of the WCGHW, need to be engaged to assist. Champions at sub-structure and health facility level, who are selected based on their passion for PC, can provide insights and give support to the staff and community awareness initiatives. In turn, SS programme coordinators should partner with these champions to provide support and unblock barriers.

In-service PC training must be scaled-up and weekly meetings must PC and all clinical, administrative, and corporate governance staff categories, should be in attendance. The WCGHW must use existing fora of engagement with higher education institutions regarding the inclusion of PC in undergraduate programmes of health professionals.

Chapter 9 will focus on engaging Atun et al.'s framework on integration, drawing the key elements and compare findings from the various sub-studies into a conclusion and make recommendations.

Chapter 9 : Discussion, conclusion, and recommendations

This study set out to explore the extent to which the new National Palliative Care Framework and Strategy on Palliative Care (NPFSPC) has been integrated into the public sector health services in the Cape Metro District (CMD) of the Western Cape (WC) province; and the factors that influenced integration of palliative care (PC) services. Although the focus of this study was on the public sector health services, it should be noted that the integration of PC in service delivery refers to the availability of PC services at all levels of care of the health system, which includes all health care sectors such as the public, private and NGO sectors, according to Rhee et al.[154]

In this final chapter, the findings of the four sub-studies are presented and analysed using the assessment framework for the integration of PC, as a new intervention and policy, in the public health system of the CMD, and the objective is to determine if the NPFSPC was sufficient to enable integration into the health system. These four sub-studies were designed according to the conceptual framework for analysing integration of targeted heath interventions into health systems, according to Atun et al. (2010).[8]

9.1. Overview

The four sub-studies spanned two years of data collection. This includes one sub-study that focused on: i) a description of the PC services at baseline and an assessment of integration 24 months following implementation of the PC policy in the CMD focusing on the elements of integration in the health system characteristics, according to Atun et al. (2010). It was followed by three sub-studies: ii) an assessment of the perceptions and investigation into the enablers and obstacles to the introduction of the PC approach and set of services, among managers and external stakeholders and a follow-up with sub-structure management teams (SSMT) 24 months following implementation; iii) an investigation into the factors influencing the implementation of the PC policy amongst frontline health workers; and iv) an exploration into the perceptions and expectations of PC services amongst patients and their families enrolled into care and whether their care needs have been met, considering the conceptual framework of Atun et al. (2010).[8]

9.2. Application of the framework to the study findings

Findings from the study overall suggest a significant increase in the provision of PC services in the CMD over the 24-month period of data-collection. The sub-studies highlight various factors that influenced PC integration. The findings from each sub-study were examined and linked to findings from other sub-studies. Commonalities, differences, and gaps were identified. This triangulation process is presented in a concept map in Annexure 10.

The Atun et al. (2010) framework for analysing integration of targeted interventions into health system enabled a comprehensive assessment of integration using the elements for integration provided for the health system characteristics of the framework. Although Atun et al. argues that the combination of "*the perceptions and positions of these actors (will) determine the receptivity of the adoption system to these interventions,*"[8] the adoption system elements for integration were not as clearly articulated in Atun et al.'s literature, as well as literature that applied this framework. Literature from Mayhew et al. (2017) on how interactions influence integration[102] was used to complement Atun's framework.

9.2.1. Problem

The first important step in applying the conceptual framework by Atun et al. is to understand the problem.[8] The premise of the study was that PC was poorly understood and neglected within the public sector health services of the CMD. Findings from all interviews concurred that this was indeed a problem. Various implementers and many patients and their families were not familiar with the term or services related to PC. Some of the operational managers were familiar with the term PC, while others had noticed emails about the policy but had not taken the time to read them.

9.2.2. Intervention

The second step towards integration is the development of the intervention to address the problem, to understand the complexity of the intervention,[8] followed by communication about the new intervention. In this study the intervention was the implementation of the NPFSPC which suggested integration of PC services into existing health care service platform.[5]

As identified in FGDs with the SSMT, OMT and implementing teams, this study provides insights into the inadequacies in the policymaking process, and calls for robust policymaking that is consultative, and bottom-up. The study accords with the findings of various authors,[183, 185, 205, 206] and suggests that the voice of the street level bureaucrat's (SLBs) – frontline health workers – must be included to ensure that policy is appropriate and that there is buy-in and health care provider commitment. Furthermore, according Shigayevu et al. (2010) intentional interactions with key stakeholders forms the basis for sustainability for targeted policy that addresses health problems.[251]

This study has raised the importance of better policymaking through planning for, communicating, and supporting policy implementation at the coalface by the managers from SSMTs. Furthermore, close collaboration between SSMTs which represent SLBs, and policy writers was highlighted. In a study conducted in Israel, on the government's response to crises and its implications for SLBs, Davidovitz et al. (2021) report that the government's response does not consider contextual realities. They report that the relationship between policy decision-makers and SLBs is complicated as the two often represent the opposite ends of government, with policymakers aiming for control, expecting implementation, and limiting implementer discretion. The COVID-19 crises further intensifies this already complex relationship.[215]

9.2.3. Adoption System

The third step in Atun et al.'s framework regards the key actors and institutions that can influence the integration of the new intervention.[8] Qualitative research among the key actors in policy implementation is important particularly as people form the basis of health service delivery, and based on their values and beliefs, influence policy implementation. Consequently, the perspectives of the various actors involved formed three of the four sub-studies and are presented in Chapters 4-8. These included managers at implementation and after 24 months; frontline providers, and patients and their caregivers during the 24 months.

An unexpected, interesting finding was how the managers and implementers have internalised core principles and vision of Health Care 2030 (HC2030); patient-centred quality care through a person-centred approach to care across the life-course and towards integrated provision of care that ensures continuity of care for the patient; building strategic partnerships; developing managers who lead and strive to ensuring equity.

Policy makers

This study found through the FGDs with implementers and SSMTs that the complexity in relationships and the "*gulf*"[183] between SLBs and policy makers, as they represent opposite ends of government. As noted by various health policy authors (Walker, (2004), Gilson (2015), Davidovitz, (2021)),[215,183,214] these are real and not just perceived. SLBs maintained that policymakers lacked insight into their context and were disconnected from their reality at the coalface.[205] The SLBs needed guidance to operationalise policy from decision-makers and policy formulators, yet during a time of crisis – COVID-19 pandemic -, the expectations from the SLBs were not adequately considered by policy decision-makers due to the rapid generation of policy to close urgent service gaps. Policy that contradicted other policy was often approved for implementation, which required line managers (OMT) to step in to guide and navigate policy implementation. This raises the roles of frontline managers within the adoption system.

Managers

The managers from the SSMT and OMT FGDs viewed themselves as leaders and change-agents responsible for ensuring change management and applying systems thinking for implementation, along the lines articulated by Gilson et al. (2014).[216] The study found and accords with what others have found – that managers play a vital sense-making role to ensure coherence of resource allocation and utilisation within the broader context, while considering the health system building blocks, towards alignment of processes for referrals and patient flow between all levels of the care continuum.[216] The SSMT regard it as their function to capitalise on partnerships and stakeholders to support PC, and the benefit of these were highlighted during the pandemic. Furthermore, the FGDs with OMT and implementers demonstrated that leadership, strategy, and support at the coalface was provided by the immediate managers or supervisors.

The value of appropriately, carefully selected champions at each level of care to drive the PC policy integration agenda, was raised as an important mechanism that has previously worked. If properly implemented, these champions must be supported and mentored.

Health care users

Through the in-depth interviews that explored the health care user experience, waiting times exacerbated patients' existing physical conditions and emotional discomfort. Long waiting times for consultations were also found by Daniels et al., suggesting that has been a longstanding issue in the Metro Health Services (MHS). In their study, long waiting times led to patient frustration which was further exacerbated by poor communication from the health care workers (HCW) on expected waiting times.[241]

The findings from all FGDs suggest that a compassionate health system is built on the display of compassion to users of services and is integral to holistic patient-centred care. This depended on three components: leadership driving the compassionate care agenda; personnel's ability to navigate difficult conversations with patients who confront life-limiting health conditions, while ensuring that carers themselves feel cared for. The literature on compassionate care towards a compassionate health system, supports strong leadership that models compassion and efficient support to subordinates.[81, 199]

Health care workers

From the various FGDs, HCW commitment to providing PC was shaped by either their own PC experience or that of a loved one or the influence of a PC mentor or training programme. This accords with the systematic review, conducted by Tehranineshat et al. (2019), that showed that HCWs personal experience of suffering makes for compassionate care, which is core to PC.[81]

Findings from the FGDs with implementers, SSMTs and OMTs demonstrate that public sector health care providers agree that PC was a critical part of the package of care and should not be a standalone service. This finding is consistent with the findings in a study conducted by Morgan (2014)[14] in the CMD, that both patients and HCWs welcomed the integration of PC interventions as part of the comprehensive package of care. This differs from the historical introduction of new services such as HIV counselling and testing, and antiretroviral treatment.

These HIV services were commenced as standalone silo services and not included in a comprehensive package of care.[105] However, in low morphine usage sites the service was centred around one clinician and that needs to be guarded against.

Specialisation mindsets and silos are embedded in health systems and Vočanec et al. (2022) reported that silos can only be overcome through patient-centred care that intentionally ensures continuity of care and holistic interdisciplinary approach to care.[226]

An important request from frontline HCWs, is the welcoming of visible support at the coalface from the SSMT, particularly to support and guide new interventions or policy. This request aligns with HC2030 leadership and governance principle that advocates for support from "*managers at all levels to be visible at the coalface to support the frontline staff, listen to their issues, needs and ideas ad address challenges with creative solutions*".[51]

Patients and family

Pain control varied across all the sites with no difference between informants from higher and low morphine usage sites. Many experienced break-through pain mostly due to running out of morphine as they titrated their dose to better manage pain. Inadequate access to morphine is a global phenomenon. Pettus and Radbruch (2023) discuss disparities in access to morphine, which is a global crisis. There is poor access to those who need it, which contrasts to the epidemic of misuse of opioids, characterised as access vs excess.[252]

Holistic patient care was raised by many informants and seen as 'back to basics', caring for the patients' body, soul, and spirit. Furthermore, they maintained that caregivers within the health system should understand and respond to patients' and families' needs, preferences, and desires. They saw that this is best provided by an interprofessional team, as DeMiglio and Williams found in a study in Ontario, Canada (2011). The Canadian study found that these teams were needed to meet the complex needs of the PC patient and family.[47]

One of the more unexpected findings to emerge from this study was the expressed need for more inclusion of families of patients in the provision of PC and the proposal to have at least one private family room at public sector hospitals to accommodate families who need to be close by when patients reached the end of life. Such space would also facilitate and accommodate discussions between the clinical team and the family. This was raised in the SSMT, OMT and HIMT FGDs and was an expressed need during the in-depth interviews with patients and families. An Irish study in two hospitals, by Donnelly et al. (2018), agree that the value of access to a private room to support bereaved families, who expressed their gratitude for this privacy to support the dying patient.[203]

The in-depth interviews with patients found that they regarded their family caregivers as an adequate source of psychological, emotional, physical, and spiritual support. However, family caregivers suffered emotional stress when they saw patients endure pain and suffering due to various symptoms that were inadequately managed. Both patients and family caregivers needed clarity regarding the diagnoses and care journeys. There was a difference in the direct support to and contact with the family caregivers between higher (HMUSs) and lower (LMUSs) morphine uptake sites. Family members of patients attending HMUSs were clearer about diagnosis and prognosis, as clinicians at these facilities had communicated these to caregivers. This facilitated building their confidence to care for loved ones. In contrast, family caregivers of patients attending LMUSs had many unanswered questions regarding patients' diagnoses, prognosis, and care. The importance of including and supporting family caregivers cannot be underestimated and yet this is not usually considered in the public sector health care setting. Hudson et al. (2004) found that health system support should be tailored to the needs and context of caregivers, their readiness and willingness to engage, as well as the health systems ability to respond to their needs.[238]

Greater community

The findings of this study suggest that educating communities about, advocacy and creating awareness in communities about PC is important. These initiatives should be directed at creating acceptance for PC services, as holistic care for people with life limiting illnesses, not only for cancer. Additionally, information that debunks myths and reduces stigma about PC would promote creating acceptance for PC services. This accords with McIlfatrick et al. (2014), who reported that low levels of public awareness regarding PC were a challenge that hampered the development of a public health approach to PC. This was needed to build public policy to support death, dying, grief and loss.[212]

9.2.4. Health System Characteristics

The fourth step in policy planning towards integration, as described by Atun et al., is to understand the impact of and give due consideration for the new intervention on the health system and its characteristics.

Governance and leadership

An important finding from this study was that initially the various managers in the CMD were uninformed about PC, as indicated in the manager's survey, and based on FGD findings conducted at baseline. It seems that a combination of factors led to managers becoming more knowledgeable about PC. These are i) the identification and participation of champions for PC, ii) the various roadshows and information sharing sessions conducted by these champions, iii) the impact of the COVID-19 pandemic that highlighted the need for PC, and iv) the significantly increased numbers of managers accessing PC training. This resulted in managers displaying compassion towards their teams, which highlights the findings of

Mitchinson et al.[94] in a rapid appraisal of HCW experience in providing PC during the COVID-19 pandemic in the UK. Managers were offering support and caring for carers, intentionally engaging stakeholders to support PC awareness, and developing implementation plans for PC for their geographic areas.

Further findings showed that SLBs working at the coalface want SS managers to shift from just emailing new policy for implementation, to being visible – actively supporting PC integration, and the implementation of any new intervention or policy. SSMT and OMT informants agreed that leaders must be change-agents who actively manage change and drive the integration agenda. This requires them to consider the context, evidence, available resources, as was reported in a study by Davidovitz et al. (2021).[215] They need to provide clarity to their teams about how new interventions and policies fits with the service design, particularly with new elements such as community oriented primary care (COPC), and make decisions about allocating resources – human, financial, infrastructure - to align to the needs.

Leaders who promote teamwork, offer ongoing support to team members, and present themselves as authentic caring leaders, are essential. They also need to identify opportunities and capitalise on the contributions of and support from stakeholders, other government departments, NGOs and labour unions that staff are members of, which accords with an article by Rifkin on the Alma Ata after 40-years.[45] Crucially, leaders need to identify and support appropriate champions at the various levels within the health system.

Financing

The NPFSPC advocates for the use and equitable redistribution of existing financial resources for the integration of this policy. However, this study found that informants in all FGDs expressed a need for additional human resource capacity as well as funding for HCW training. Adequate PC was seen to take time and consumables, other than drugs, are required.

While SSMT and OMT informants reported that changes in procurement practices, permitted during the COVID-19 pandemic, facilitated the procurement of essential PC commodities, furniture, and equipment. They were able to utilize the additional COVID-19 emergency funds through a less stringent procurement system and had increased bargaining power when procuring certain furniture or equipment.

Furthermore, informants in all FGDs highlighted that departmental funding allocations should be reviewed as most patients are seen on the primary care platform and not in hospitals. The District Health Services policy framework and strategy (2014) acknowledges that the health system will remain unresponsive to the needs of communities until such time that the required financial and management delegations are devolved to the right decision-making level.[194]

Planning: priority setting, resource allocation, capacity building

There were differing views on the need to pilot policy. One view was to pilot at one site, learn lessons and gradually roll out to other facilities, while others believed that one mass roll-out is ideal. Regarding the value of champions for PC, some supported the role of champions and others criticised their value because of inappropriate selection of champions. There was, however, an agreement that policy planning and support from the SSMT for front-line HCWs would reduce resistance to change due to new policy. Briassoulis (2004) agreed that planning for policy that considers context at multiple levels of implementation are critical levers for policy integration.

Findings from the FGDs suggest that PC training and capacity building is a gap. As proposed by the WHA resolution,[30] this is needed for all HCWs. However, existing HCWs reported challenges when trying to access in-service courses. Various FGDs discussed that capacity building for PC could be offered through informal in-service training, formal courses, and should be included in the curricula of undergraduate health professionals. Catch-up training in the MHS for all existing health professionals is required, such as the contracted 40-hour introduction to PC course. Furthermore, motivations for the inclusion of PC training in undergraduate health professional training, including social workers is required. Additionally, there should be consideration for training in and access to PC specialists in SA. The WHO (2016), Rhee et al. (2018) and van Heerden et al. (2022) confirm the findings that community health workers (CHW) require capacity building in PC to provide home-based PC. [113],[154],[167]

Findings in this study highlighted that partnerships[219] and utilisation of CHWs in the provision of palliative home-based care[47],[52] could greatly benefit broader PC support to patients and families, which would reduce unnecessary hospital and emergency centre admissions, as well as primary health care (PHC) facility visits. Their roles and capacity building needs must be identified and made explicit in policymaking and planning.

Service delivery

These findings provide insight into the need for a compassionate health system that offers compassionate care to health care users and carers. This approach is essential for offering PC and quality patient centered care. Breaking bad news and building hope requires skillful, kind, and compassionate communication, which influences the patients' experience of the heath system.

Capacitating and strengthening multi-disciplinary teams to support clinical decision-making and offer inter-professional support is important. This patient sub-study found that access to some MDT members for PC patients was limited during the COVID-19 pandemic. A strong case was made for the inclusion of the CHWs in the MDTs.

Many informants in all FGDs suggested the appointment of a hospital-based PC nurse. They could serve as the point person to ensure that patients are assessed according to the SPICT-SA[200] tool to determine eligibility for PC, develop care plans in consultation with hospital MDTs, then link patients to the PHC platform to continue their care. This accords with the WHO (2016) guide to programme managers, that suggests that an in-patient PC consultation service be established, which is accessible to all departments within the hospital. This can build capacity among other staff about pain management and PC, and facilitate district-wide referral pathways.[113]

Clarifying of roles of the various role-players within the sub-district is also essential so that connectedness is established and communication regarding client care is enabled. It is essential to connect hospitals, clinics and NGOs to ensure integration and continuity of care for patients.[113]

Both the desktop review and findings from the FGDs show that although provision was made for spiritual support during the COVID-19 pandemic, in-hospital patients were referred for support, but patient informants and their families generally did not regard spiritual care as part of the responsibility of the attending clinician. Ferrell et al. (2020), in their US study, also raised the increased need for spiritual care during the pandemic that could not be met by the few available hospital chaplains.[140] This raises the possibility of an unmet need for spiritual care. Although PC clinicians are more prepared to provide spiritual support than others, all clinicians are responsible for identifying patients in need of referral for spiritual care.[140]

Community oriented primary care (COPC) was identified as an important vehicle to ensure a multi-stakeholder approach to addressing health priorities within a defined geographic area and includes community members. This approach is ideal for rallying stakeholder support to the provision of PC and creating greater community awareness about PC.

To ensure continuity of care for PC patients, this study found that a seamless and interconnected care pathway with the necessary electronic communication network that facilitates referrals and feedback, was essential to hold the patient at the centre of health care system. The desktop review highlighted this, and it was raised at the SSMT FGD. This would facilitate all health disciplines and role-players to purposefully engage and communicate in the best interest of quality patient-centred care. A well-defined care pathway and referral mechanism for all patient movement within the CMD is required that includes electronic health records and facilitates referral communication and feedback loops.[118]

Monitoring and evaluation

PC indicators are required to adequately monitor progress towards integration. In this study, available indicators such as morphine data and ICD-10 coding were used to provide an indication of PC services. However, this data was not yet mature enough, due to poor utilisation and recording.

One unanticipated and interesting finding was the culture in the WC of measuring performance through recording outputs. Some informants regarded PC as less important than other priority programmes such as HIV and TB, since they are not expected to collect and report on any indicators for PC as part of their routine data collection. This influenced the effort that was placed on PC services compared to any other priority programme. According to the WHO (2021) actionable indicators guideline for assessing the development of PC, "*the inclusion of PC indicators in national health information management systems contributes to awareness raising and action on PC from health care managers and workers*".[2]

Demand generation

Demand generation is an important health system characteristic. Managerial and implementing informants raised that there was value in creating awareness among communities and staff about what PC is and the availability of the service. There is vast literature that greater community awareness of PC reduces stigma and myths regarding PC and consequently, this may increase patient demand for and access to PC.[3,122,123,212]

9.2.5. Context: COVID-19 pandemic – the critical event

Since the broader context and the health system are intricately linked, change in either one will affect the other.[107] According to Atun et al. (2010), contextual factors range from changes in drugs or technology, prevention mechanisms or critical events. [8] The year 2020 marked the start of the COVID-19 pandemic in SA, one year into data collection for this study. The WCGHW department had just embarked on implementing the NPFSPC. As deaths rates climbed due to COVID-19, the local epidemic highlighted the need for access to the rapid provision of PC, which became urgent.[245] According to Rodin et al. this was the case globally.[55] This demand for more PC beds resulted in an increase of 30 intermediate care facility beds in the CMD in the 24 months following the PC policy implementation.

The need for PC beds is reflected in the excess natural deaths report published by the SA Medical Research Council (SAMRC). They found that 85-95% of excess deaths in SA over the period 1 March 2020 to 8 Feb 2021, were due to COVID-19.[60]

The desktop review and FGDs with implementers demonstrate that the pandemic exposed gaps in PC service delivery and design within the CMD, while limiting patient and family caregiver access to various health services. COVID-19 highlighted the PC training deficit amongst health care providers, the gap in the provision of spiritual care, and the need for rapid integrated PC, issues also reported elsewhere by Etkind et al. (2020).[245]

While highlighting these gaps, the pandemic was the catalyst that challenged the health care system to respond by ensuring rapid access to quality PC to patients and their families and brought compassionate care back into the health system. Many patients died alone with no contact with loved ones[140] since no visitors were permitted due to the COVID-19 pandemic restrictions.[59] The health system in the CMD responded with the rapid procurement of devices that facilitated communication with loved ones, even during the active dying period.

Interestingly, in the CMD, the study showed that the COVID-19 pandemic resulted in building much needed PC capacity such as fast-tracking PC training, provision of additional in-patient PC beds, establishing a spiritual care support databases facilitating access to spiritual support, and procuring equipment needed for the provision of PC. Ferrell et al. (2020) highlighted the need for spiritual care generalists and specialists to respond to spiritual suffering as a result of unexpected death, loneliness and isolation that came with this pandemic.[140]

This study demonstrates that pandemic preparedness should include PC. Globally, according to Bausewein et al. (2022), the COVID-19 pandemic has highlighted the need for pandemic preparedness to include the provision of PC for severely ill and dying patients and their relatives, at all levels if care including the home environment.[139]

9.2.6. Assessing integration of palliative care in the CMD

Chapter 4 reported on the integration of PC services within the public sector health system of the CMD between 2019 and 2021, using Atun et al.'s[8] framework for analysing the integration of interventions into health systems. While highlighting gaps – access to training, ICD10 code reporting; inadequate quota of social workers and spiritual counsellors; and opportunities, such as top management support and buy-in to PC; and available contract for PC training – it demonstrates a significant shift towards integrating PC into the health system in the CMD. It moved from no integration in many of the health system characteristics analysed, to partial integration.

PC task team had shifted from being a MHS structure to being positioned within the provincial structures of the WCGHW. Progress was made to include PC in important policy and strategic documents. However, implementation plans are required to guide the line and programme managers regarding the next steps.

This sub-study reported on managers' baseline knowledge about PC before attending the PC information session, highlighting various gaps. Their vital role as leaders in the MHS made it imperative that investment is made in their knowledge and understanding of PC; the need for integration; policy; and the support that the operational teams require. The WHO guides for programme managers (2016),[113] planners, implementers and managers (2021)[7] affirm this need and role. Dahlin et al. (2019), in a study focusing on interdisciplinary palliative leadership, concurs and reports that PC leadership is essential to promote the focus on patient-centred quality care and navigate the change in service delivery.[141]

In a SA study, Gwyther et al.,[147] found that social workers are uniquely positioned and qualified to work as a crucial component of the interdisciplinary team in the provision of PC. Their roles often extend beyond the functioning of the team within the health care setting, into the larger community setting.[147] Consequently, although there was a significant increase in the recruitment, appointment and PC training of social work categories over the 24 months of NPFSPC implementation, it is concerning that in TB hospital settings that the numbers of social workers had reduced.

This study shows the establishment of a spiritual counsellor, albeit volunteer, database in the CMD took place during the pandemic. Volunteers were onboarded, trained, added to the database which was coordinated at SS level. Maintaining the spiritual counsellor volunteer support was important and required sustained efforts.

Training staff in PC is essential and this study has shown significant progress in access to this training amongst various health professional categories. However, the glaring gap in the desktop review was the training for CHWs providing HCBC in PC, which needs to be prioritised, since they are critical role-players in providing cost-effective PC in the home and supporting family caregivers. Not only is this more appropriate but it is more cost-efficient as demonstrated by Daviaud et al. (2018). They found that in SA the cost of home-based PC offered by CHWs, was 10% of the cost of in-patient PC over a two-week period.[112] This supports what DesRosiers et al. (2013) found, in that offering support to patients and their families in the form of outpatient hospital-based services reduces admissions and increases the rate of home deaths, offering a feasible and cost-effective model.[109]

The morphine data that was analysed as part of the desktop review confirms the evidence that SA has a much lower morphine average consumption (1,75 mg/person) than the global average consumption (6,1 mg/person)[149] and re-iterates the concern that LMIC have inadequate use of morphine.[149] According to Pettus and Radbruch (2023), the United Nations 2023 agenda to meet the sustainable development Goal 3 – *"ensure healthy lives and promote wellbeing for all at all ages"* – advocates for governments to convene dialogues address knowledge gaps amongst affected patients, families, health care providers which should promote equitable and sustainable access to opioids for pain control. [252] They attribute this dual crisis to inadequate clinical education for health care providers on the correct use of opioids, cultural attitudes of HCWs and patients towards opioid use, patients and families' fear that morphine could hasten death, and restrictive policies.[252] Notably in the CMD, there are HCW training gaps in PC and opioid use, concerns about substance abuse and side effects, and restrictive dispensing resulting in patients running out of morphine before they are due for their monthly supply.

Consequently the extent to which integration occurs within the health system characteristics, is influenced by the actors within the adoption system, who are affected by context. The COVID-19 pandemic was the predominant context during the data collection period for this thesis, and it highlighted the need for- and gap in PC services. Management actors prioritised PC and therefore made decisions regarding the use of finances, human resources, changes in service delivery, which were influenced by this reality. This in turn influenced the extent of integration noted over the 24-month period. Furthermore, these decisions may be a reflection of the internalisation of the values of the WCG - which advocates for an ethos of care, competence, accountability, integrity, respect and responsiveness – resulting in an increase in the provision of in-patient PC beds, home delivery of medication, and the provision of guidelines to care for the increasing PC need and burden.

9.3. The impact of the study in the WCGHW

The researcher became a member of the operational executive committee (OPEXCO[xxi]) of the WCGHW in 2021 and tabled a budget bid submission at the end of 2021 to address immediate PC health systems' needs. This was based on the findings from this study, the literature, and subsequent discussions at the PC task team (PCTT). The provincial treasury approved the budget submission and the funding became available in April 2022 for the appointment of a 15-hospital based PC nurses at 15 district hospitals that were identified in collaboration with the OPEXCO; funding for the training of these nurses through the short course in PC nursing offered at a local university; funding for PC training of 600 CHWs in 2022 to 2023; and the establishment of nine PC equipment loan stores across the WC.

The process of adopting PC was participatory with key role-players and experts involved in the policymaking process and the inclusion of managers and leaders during the COVID-19 pandemic and in this research. This resulted in some senior and middle managers becoming advocates and champions for PC within the health system. Consequently, the district offices and SSMTs across the WC province, have each developed geographic based PC implementation plans in 2022.

9.4. Matrix Tool for assessing policy integration.

A product of the four sub-studies was the researcher's development of a matrix tool (Annexure 4), for assessing the integration of the NPFSPC. Although it will require further validation, it can be modified and applied to assess the integration new policy. The matrix tool was developed with due consideration for the PC elements for integration according to Atun et al. (2010).[8]

[xxi] OPEXCO is the most senior group of services and clinical support services managers in the WCGHW

additional adoption system elements for PC integration informed by Mayhew (2012),[102] and the findings from the four sub-studies.

This tool was presented to national and provincial PC experts and champions, and PhD supervisors. Annexure 4 further provides a table that reflects the methodological flow for the development of the matrix tool for assessing integration of new interventions in the health system; the scoring system that quantifies each element that accords with the literature on the subject;[8, 104, 106-108] This draft will require further refinement and validation. Limitations include the gap in consultation with other provincial experts in PC service provision, research, policy development, and health systems, which should be addressed in further iterations. Table 3.1 in Chapter 3 contains the health system characteristics and elements for integration and Table 9.1 below provides the adoption system elements for integration.

Table 9.1: Adoption system elements of integration included in the Matrix for Integration

Adoption System (Actors)	Elements of Integration
Policy makers and Policy Implementation Support	• Transparent and inclusive policy decision-making processes
	• Initial project management process
	• Defined strategy and guidance
	• Implementation support tools
Managers (Decentralised Programme-, Project- and Service Managers)	• Leaders as advocates
	• Guidance and support plan to operational teams
Health Care Users	• Knowledge of and acceptance of service
	• Communication
Health Care workers	• Employee Health and Wellness
	• Relationships and platforms of engagement
Greater Community	• Partners and Stakeholders engagements
	• NGO and Health Facility collaboration

9.5. Recommendations for health systems globally

This study has raised important factors that influenced PC integration, and highlights considerations and proposals emanating from this study.

The matrix tool (Annexure 4) that was developed as part of this study, for assessing the integration of the NPFSPC could be considered for further validation, adoption, and application to assess integration of PC and indeed other new policy in the SA setting and elsewhere globally.

9.5.1. Adoption system

Importantly, pandemic preparation and resurgence strategies at a global and local level should include PC planning. In addition, embedding compassionate care in health systems globally is important,[82] and may facilitate retention in care for chronic diseases, HIV and TB as well as PC.

Commitment to compassionate care should include top management and political endorsement and consideration for the inclusion of compassionate care training with gradual inclusion in staff performance management plans.

In the WCGHW a compassionate culture could be institutionalized and framed in the already articulated values of WCG - iC^2AIR^2 - innovation, care, competence, accountability, integrity, respect, and responsiveness. A consulted plan should be developed that includes commitment from all service settings, that can be measured, and contains sanctions for non-compliance. Since non-compliance may be hard to measure, further research is required to elicit good measures for compassionate care. A provincial indicator data set is required that is aligned to the national indicators data set for all approved PC indicators.

9.5.2. Health System Characteristics

Governance and Leadership

To drive the UHC agenda, all components of UHC should be included as part of the public sector health departments' annual performance plans and reporting. Specifically, WCGHW should be intentional in driving all components of UHC within the COPC model to ensure that PC is non-negotiable.

Finance

The disparities in the service scope, location, and funding envelope for ICFs should be reviewed to ensure equity in packages of care and geographic access to ICFs within each sub-district. Adequate financing for additional PC trained staff in the hospital setting to ensure assessments for PC eligibility, linkage to care in the PHC platform, training of staff in appropriate PC courses and programmes, and social workers to provide adequate psychosocial support as well as social services.

Planning

Standard operating procedures (SOPs) for the development of robust policymaking processes that consider the local context, should be produced to guide the implementation of new policies and PC. This should ensure the inclusion of the voice of the end users, patients, and corporate support members. It must be officially communicated, with implementation principles that can be generalised into the broader context and considers the health system realities.

SOPs should include the establishment and convening of working groups to make an initial consulted proposal that includes all stakeholders. They should consider the levels of compulsory consultation for new policy and review of policy. The voice of SLBs must be included from the onset – from identifying the problem to policy development.

These SOPs should include training and capacity building of HCWs; advocacy for staff and community engagement; finance, supply chain and resource planning; roles of government, NGO and other stakeholders that support policy; project plans with timelines; monitoring and evaluation plans; guidelines for pilot for roll-out; and give due consideration for service design reform principles within the health system. A policy implementation framework should be included that defines and clarifies roles and functions of role-players, including leaders that drive, visibly support, refine, clarify, and guide policy implementation.

Service delivery

Robust departmental referral and linkage to care system are well-defined is essential. These should include the community-based service platform, with appropriate information and communication technology, and adequate feedback loops on patient progress.

SOPs for service delivery must guide the establishment, participation, and frequency of multidisciplinary teams (MDTs). This guide, while providing standardisation, should allow a degree of flexibility for varying contexts. In addition, untapped resources including differentiated models of care should be considered. These include telehealth for offering virtual care, psycho-social and spiritual support.

Human Resources

For WCGHW, the need for social worker categories to support PC within TB hospitals and across the health platform, must remain on the SSMT agenda and receive attention in human resources planning. Additionally, departmental spiritual care framework should be developed that includes a database for the entire health system and facilitates networking.

9.6. Further research

More research is required into the financial implications of introducing a new policy into resource constrained environments. It is important to determine whether the expectation to integrate complex services – that require careful attention and training, with skilled staff and additional resources – into existing services, such as PC, is valid and realistic.

Further work is needed in developing a step-by-step guide for policy making, that includes the policy consultation steps and defines the key role-players that includes the SLB and the patient, and the further validation and piloting of the matrix tool that is useful for assessment of the extent of integration of the palliative care policy, and measurement of gaps.

Furthermore, in addition to the work measuring compassion raised, research that determines sensitive indicators that measure progress towards integration, explores the experiences of in-service training for PC, and the skills mix requirements for all appropriate HCWs, is required, particularly, in resource constrained health care settings facing high disease burdens as found in SA.

9.7. Limitations

Limitations to each of the sub-studies are included in the relevant chapters. Ascertainment of whether PC added further cost to the service delivery package, this was not directly addressed, since the overall study did not include a financial analysis on the proportion of departmental funding for PC over time. Expenditure was incurred to accommodate the additional 50 ICF beds, funding was channelled to training in palliative care, a bid was secured for 15 hospital based professional nurses for PC, the establishment of nine loan stores and costs for training and for NGO funding has increased. It is unclear whether this was at the expense of another priority service or competing demand.

The qualitative methodology used was appropriate for the assessment of the implementation of a new policy. However, the informants may include those self-selecting participation, and therefore not represent the full spectrum of perspectives of health care workers in these settings. The quantitative data reported, such as proportions of staff trained, indicates uptake in training probably due to the COVID-19 pandemic, and may not be part of the implementation of the NPFSPC. It is not known if training translated into an increase in the delivery of PC.

A strong limitation for this study is the under-reporting of ICD 10 codes in the health system – the selected metric to estimate the extent of PC services, rendering it an insensitive metric for PC provision. This limited the identification of PC patients for this study and the quantitative analysis on to determine the number of PC patients over time. Using morphine usage as a metric for PC need, presents a limitation, since the proportion use in SA remains way below the global average.

9.8. Conclusion

PC is a neglected yet complex core component of health care in the public sector, needed in the over-burdened district health system that is characterised by high patient loads and the quadruple burden of disease. PC embodies holistic, people-centred, compassionate care, focussing on vulnerable patients, and their families, with life threatening illness, to enhance their quality of life. Globally and in South Africa (SA), it has been delivered by NGOs such as hospices.

In response to the WHA call for countries to take up the ethical responsibility of integrating PC into the health system, and with the increasing realisation that it is important, SA in 2017, developed the NPFSPC which prescribed the integration of PC services into the public health care system. This NPFSPC directive was taken up in the WCGHW, resulting in the establishment of the PCTT and PC was initiated without additional resources prior to the COVID-19 pandemic.

In this context and based on the researcher's experience in line management and programme management of stand-alone new services, it was decided to research the integration of PC. Due to the complex nature of PC services, Atun et al.'s conceptual framework to assess integration of new interventions was selected as it was designed to consider the complex nature of PC services and the complexities within the health system itself. The focus for this study was on the adoption system and actors, while also conducting a baseline and 24-month follow-up desktop review and document analysis that focused on the health system characteristics of this conceptual framework.

During the data collection period of this study the COVID-19 pandemic commenced and while it exposed the gaps in PC provision, it became the catalyst for PC as it exacerbated the need for provision of PC and highlighted the need and opportunities for PC as an essential service.

This study met its overall aim of describing, exploring, and explaining the factors that influence integration of PC within the MHS in the CMD and the objectives of assessing integration in the CMD, at baseline and 24-months following implementation of the NPFSPC.

In summary within the WC, the following key factors were enablers for PC policy integration into the health care system. First and most importantly, national policy had set the tone and direction for PC implementation in the public sector health services in SA. Each province is expected to comply. The implementation of the NPFSPC increased the availability of PC services in the CMD and resulted in a partial integration of PC into primary care services. There was clear commitment to improve the pattern and rate of adoption of PC, towards eventual assimilation into the health system functions. The document analysis found that governance arrangements included PC in provincial priority setting and operational service planning, indicating the growing importance given to this service.

At a health service authority level, an enabling strategy such as the WC's provincial strategy, HC 2030 The Road to Wellness[51] – the long-term vision that guides the WCGHW mandate and shifts the departmental approach towards a person-centred health system approach, focused on wellness and the need for universal health coverage (UHC) - facilitates a PC approach, and therefore its delivery.

It is important to note that specifically in the WC provincial level, a supportive top management structure bought into the PC policy content and proposal for integration in the health system. This is evident through welcoming in role-players such as NGOs active in PC, and making resources available, such as the appointment of professional nurses, and procurement of equipment to establish loan stores. Furthermore, management prioritised resource allocation towards HCW training in PC and CHWs that are employed by NGOs.

PC should be part of the health systems response to care, towards UHC. PC is dependent on a compassionate health system and on the other hand moves the health system towards compassionate care. The COVID-19 pandemic, as a critical event in the broader context, has exposed the PC gap globally and within the CMD. It highlighted that crucially, PC must be included in all pandemic preparedness plans.[1]

Capacity building for PC amongst the health care workforces, that does not exclude any category of HCW, is critical when providing appropriate care for those in need. Training contracts need to be in place. While the need for PC services is recognised, inadequately trained staff limits its implementation.

Participation in policymaking is critical, particularly for SLBs and role-players within corporate governance, so that policy is aligned to health system functioning. An agreed policymaking SOP is needed. This study has shown that implementing teams want and need leadership to be visible in providing frontline support to guide new policy or intervention.

The expectation that integrating a new policy or intervention within an existing resource envelope is not possible in LMICs, since heath systems are already resource constrained. Additional resources are required as seed funding to initiate a new intervention that is complex within a health service, that requires it.

This study has identified key components required for integration, that can facilitate the incorporation of PC and new health services into health systems, particularly those in resource constrained settings. Furthermore, this study highlights the critical impact of the power and influence of the actors in the adoption system, on the elements used to assess integration. PC should no longer be a neglected component of health care. Additionally, as PC embodies holistic care, focused on managing the health care needs of patients and their families with life limiting illness, a culture of compassionate care will evolve to characterise the interactions between frontline HCWs and patients. This would embrace and catalyse a robust COPC model that facilitates quality care for all and not only for PC patients.

References

1. Western Cape Government. Circular H67 of 2020_Provincial Palliative Care Postion Statment & Plan for COVID-19 Response. In: Health, editor. Cape Town: Western Cape Government Health; 2020. p. 137.
2. Assessing the development of palliative care worldwide: a set of actionable indicators [Internet]. World Health Organisaton. 2021 [cited 2022].
3. World Health Organization. Strengthening of palliative care as a component of integrated treatment throughout the life course. J Pain Palliative Care Pharmacotherapy 2013(2).
4. Metro Health Services. District Health Plan 2021/22 to 2023/24: Cape Metro Health Service District. In: Health, editor. Cape Metro District: Metro Health Services & City Health; 2021.
5. National Department of Health R, ,. National Policy Framework & Strategy on Palliative Care. In: Health NDo, editor. Pretoria: National Department of Health; 2017.
6. Western Cape Government Health. Western Cape Burden of Disease_Rapid Review Update 2019. In: Health, editor. Cape Town: Western Cape Government Health; 2020.
7. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implements and managers [Internet]. World Health Organisation. 2018 [cited 2021]. Available from: https://apps. who. int/iris/handle/10665/274559.
8. Atun R, De Jongh T, Secci F, Ohiri K, Adeyi O. Integration of targeted health interventions into health systems: A conceptual framework for analysis. Health Policy and Planning. 2010;25(2):104-11.
9. Cloete KR. Personal Communication with Dr Keith Cloete. In: Arendse JO, editor. 2017.
10. World Health Organization. Cancer pain relief and palliative care.; 1990.
11. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. Journal of pain and symptom management. 2002;24(2):91-6.
12. Gwyther E. South Africa: The Status of Palliative Care. Journal of Pain and Symptom Management. 2002;24(2):236-8.
13. Drenth C, Sithole Z, Cur B, Pudule E, Wust S, GunnClark N, et al. Palliative Care in South Africa. Journal of Pain and Symptom Management. 2018;55(2):S170-S7.
14. Morgan JM. A prospective cohort study and evaluation of an end-of-life programme intervention in a primary health care setting [MMED]. Cape Town: University of Cape Town; 2014.
15. Palliative Care Fact Sheet [Internet]. World Health Organisation. 2018.
16. Lynch T, Connor S, Clark D. Mapping Levels of Palliative Care Development: A Global Update. Journal of Pain and Symptom Management. 2013;45(6):1094-106.
17. Webster R, Lacey J, Quine S. Palliative care: a public health priority in developing countries. Journal of Public Health Policy. 2007.
18. Brennan F. Palliative Care as an International Human Right. Journal of Pain and Symptom Management. 2007;33(5):494-9.
19. Gwyther L, Brennan F, Harding R. Advancing Palliative Care as a Human Right. Journal of Pain and Symptom Management. 2009;38(5):767-74.
20. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. Ann Palliative Medicine. 2015;4(3):99-121.
21. Stjernswärd J, Foley KM, Ferris FD. Integrating Palliative Care into National Policies. Journal of Pain and Symptom Management. 2007;33(5):514-20.
22. Cohen J, Pivodic L, Miccinesi G, Onwuteaka-Philipsen B, Naylor WA, Wilson DM, et al. International study of the place of death of people with cancer: a population-level comparison of 14 countries across 4 continents using death certificate data. British Journal of Cancer. 2015;113(9):1397-404.
23. Stjernswärd J, Foley KM, Ferris FD. The Public Health Strategy for Palliative Care. Journal of Pain and Symptom Management. 2007;33(5):486-93.
24. Jeba J, Kumar R, Muckaden M, Barnard A, Leng M, Munday D, et al. Joint position statement Indian association of palliative care and academy of family physicians of India – The way forward for

developing community-based palliative care program throughout India: Policy, education, and service delivery considerations. Journal of Family Medicine & Primary Care. 2018;7(2):291-302.

25. Luyirika EB, Namisango E, Garanganga E, Monjane L, Ginindza N, Madonsela G, et al. Best practices in developing a national palliative care policy in resource limited settings: lessons from five African countries. Journal Cancer Medical Science. 2016;10.

26. Ntizimira CR, Nkurikiyimfura JL, Mukeshimana O, Ngizwenayo S, Mukasahaha D, Clancy C. Palliative care in Africa: a global challenge. Ecancermedicalscience. 2014;8.

27. Lohman D, Abidjanova N, Amiryan D, Gherman L, Kiknadze N, Mayilyan Z, et al. Progress update: Development of palliative care from 2017 to 2020 in five countries in Eurasia. Journal of Pain and Symptom Management. 2022.

28. Dye C, Reeder JC, Terry RF. Research for universal health coverage. American Association for the Advancement of Science; 2013.

29. Gómez-Batiste X, Porta-Sales J, Pascual A, Nabal M, Espinosa J, Paz S, et al. Catalonia WHO Palliative Care Demonstration Project at 15 Years. Journal of Pain and Symptom Management. 2005;33(5):584-90.

30. World Health Organization. Sixty Seventh World Health Assembly Geneva: World Health Organisation; 2014 [37-41].

31. Clark D, Wright M, Hunt J, Lynch T. Hospice and Palliative Care Development in Africa: A Multi-Method Review of Services and Experiences. Journal of Pain and Symptom Management. 2007.

32. Selman LE, Higginson IJ, Agupio G, Dinat N, Downing J, Gwyther L, et al. Quality of life among patients receiving palliative care in South Africa and Uganda: a multi-centred study. Health and Quality of Life Outcomes. 2011;9(1):21.

33. Global atlas of palliative care [Internet]. WHPCA London. 2020.

34. Gwyther L. Personal Communication with Dr Liz Gwyther. In: Arendse JO, editor. 2018.

35. Ens CD, Gwyther L, Chochinov HM, Moses S, Jackson C, Harding RJIJoPN. Access to hospice care: multi-professional specialist perspectives in South Africa. International journal of palliative nursing. 2008;14(4):169-74.

36. PRICE M. Health care as an instrument of Apartheid policy in South Africa. Health Policy and Planning. 1986;1(2):158-70.

37. Hassim A, Heywood M, Berger J. Health and democracy: a guide to human rights, health law and policy in post-apartheid South Africa2014. Chapter 4: Statutory and Administrative framework of the public health system p.

38. Constitution of the Republic of South Africa, Act 108 of 1996, 378 (1996).

39. National Department of Health R, ,. National Health Act 61 of 2003. In: Health, editor. Pretoria: South African Government; 2004.

40. National Planning Commision. National Development Plan 1988-1990. In: RSA TP, editor. Pretoria: National Government, RSA; 2011. p. 2, 273-4.

41. Sulla V, Zikhali P, Cuevas PF. Inequality in Southern Africa: An Assessment of the Southern African Customs Union. 2022;1.

42. Mayers PM, Olckers L, Prinsloo EL, Raine J, Zweigenthal V. Reflections of volunteer counselors working remotely during the COVID-19 pandemic—Implications for policy and practice. Journal of Nursing Scholarship. 2022;n/a(n/a).

43. 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. Journal of Pain Symptom Management. 2011;41(6):1015-24.

44. Abramson JH, Kark SL. Community oriented primary care: meaning and scope. Community oriented primary care: New directions for health services delivery. 1983:21-59.

45. Rifkin SB. Alma Ata after 40 years: Primary Health Care and Health for All—from consensus to complexity. BMJ Global Health. 2018;3(Suppl 3):e001188.

46. De Maeseneer J. Scaling up family medicine and primary health care in Africa: statement of the primafamed network, Victoria Falls, Zimbabwe. African Journal of Primary Health Care & Family Medicine. 2013;5(1):3 pages.
47. DeMiglio L, Williams A. Shared care: The barriers encountered by community-based palliative care teams in Ontario, Canada. Journal Health Social Care in the Community. 2012;20(4):420-9.
48. Republic of South Africa. National Health Insurance Act, Towards Universal Health Coverage. In: Health, editor. Pretoria: Government Printer; 2017. p. 1-80.
49. Pillay Y, McCoy D, Asia B. The district health system in South Africa: progress made and next steps. In: Health NDo, editor. Pretoria: National Government; RSA; 2001.
50. Western Cape Government. Comprehensive Service Plan for the Implementation of Healthcare 2010. In: Wellness H, editor. Western Cape: Western Cape Government Health; 2007. p. 197.
51. Western Cape Government. Healthcare 2030 The Road to Wellness. In: Health, editor. Western Cape: Western Cape Government Health 2014. p. 170.
52. Bam N, Marcus T, Hugo J, Kinkel H-F. Conceptualizing Community Oriented Primary Care (COPC)-the Tshwane, South Africa, health post model: opinion paper. African Journal of Primary Health Care and Family Medicine. 2013;5(1):1-3.
53. Cloete KR. Service Transformation Strategy. In: Wellness WCGHa, editor. 2017.
54. Engelbrecht MC, Heunis JC, Kigozi NG. Post-Traumatic Stress and Coping Strategies of South African Nurses during the Second Wave of the COVID-19 Pandemic. 2021;18(15):7919.
55. Rodin G, Zimmermann C, Rodin D, al-Awamer A, Sullivan R, Chamberlain C. COVID-19, palliative care and public health. European Journal of Cancer. 2020;136:95-8.
56. Western Cape Government. Circular H79-2020: Clinical Guidelines: COVID-19 Providing Palliative Care. In: Health, editor. Western Cape: Western Cape Government Health; 2020. p. 41.
57. Metro Health Services. Internal Memorandum MHS 06 of 2020: De-escalation of Services at Primary Health Care (PHC) facilties in the Cape Metro during National Lockdown - Guidelines for PHC Facility Managers. In: Health, editor. Cape Metro District: Metro Health Services; 2020.
58. Peters F. COVID-19 Palliative Care Ward. unpublished: Klipfontein Mitchell's Plain Sub-Structure: Metro Health Services; 2022 15 March 2022.
59. Disaster Management Act (57/2002): Regulations mande in terms of Section 27(2) by the Minister of Cooperative Governance and Traditional Affairs No. 43148, Vol. 657 (2020).
60. Moultrie T, Dorrington R, Laubscher R, Groenewald P, Bradshaw D. Correlation of excess natural deaths with other measures of the COVID-19 pandemic in South Africa. SAMRC; UCT Centre for Actuarial Research; 2021.
61. Western Cape Government Health. Dependent Population & its Implications - Lessons from Western Cape. [Presentation to NDHSC]. In press 2016.
62. Western Cape Government. Finance Instruction FA21/2017 Standard Operation Procedure (SOP) for Transfer and Subsidies to Receiving Entities (NGO). In: Health, editor. Cape Town: Western Cape Government Health; 2017.
63. 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. 2014;104(2):138-41.
64. Metro Health Services. Palliative Care Policy Implementation Task Team. Terms of Reference. Cape Town Metro District: Metro Health Services; 2017. p. 3.
65. Western Cape Government. Proposed Model for the Implementation of the Palliative Care Policy in the Western Cape. In: Health, editor. Cape Town: Western Cape Government Health; 2018.
66. World Health Organization. Measuring the health systems impact of disease control programmes: A critical reflection on the WHO building blocks framework https://www.researchgate.net/figure/The-WHO-health-system-building-blocks-framework-Source-WHO-2007-1_fig1_261102054 [accessed 11 Sep, 2022]2007 [cited 2022 11 Sep].

67. Health policy and system research: a methodology reader: the abridged version [Internet]. World Health Organization; Alliance for Health Policy and Systems Research. 2013. Available from: http://www.who.int/about/licensing/copyright_form/en/index.html.

68. Whyle E, Olivier J. Social values and health systems in health policy and systems research: a mixed-method systematic review and evidence map. Health Policy and Planning. 2020;35(6):735-51.

69. Systems for health: everyone has a role. Flagship report of the Alliance for Health Policy and Systems Research [Internet]. World Health Organisation. 2022.

70. De Savigny D, Adam T. Systems thinking for health systems strengthening: World Health Organization; 2009.

71. Olivier J, Scott V, Gilson L, De Savigny D, Blachet K, Adam T. Applied systems thinking for health systems research: a methodological handbook: Maidenhead; 2017.

72. Peters DHJ. The application of systems thinking in health: why use systems thinking? Health Research Policy and Systems. 2014;12(1):1-6.

73. Abu-Odah H, Molassiotis A, Liu J. Lessons learned from countries that have introduced palliative care services into their national health system: a narrative review. Journal of Palliative Care. 2022;37(1):55-66.

74. Rhee JY, Garralda E, Torrado C, Blanco S, Ayala I, Namisango E, et al. Palliative care in Africa: a scoping review from 2005–16. The Lancet Oncology. 2017;18(9):e522-e31.

75. The Lancet O. Access to opioids: a balance of harms. The Lancet Oncology. 2017;18(10):1285-.

76. Seymour J, Cassel B. Palliative care in the USA and England: a critical analysis of meaning and implementation towards a public health approach. Journal of Mortality. 2017;22(4):275-90.

77. Luckett T, Phillips J, Agar M, Virdun C, Green A, Davidson PM. Elements of effective palliative care models: a rapid review. BMC Health Services Research. 2014;14(1):1-22.

78. McDaniel RR, Jr., Lanham HJ, Anderson RA. Implications of complex adaptive systems theory for the design of research on health care organizations. Health Care Manage Rev. 2009;34(2):191-9.

79. Gilson L, Elloker S, Olckers P, Lehmann U. Crises, routines and innovations: the complexities and possibilities of sub-district management: leadership and governance. South African health review. 2012:161-73.

80. Mohammed SA, Edae CK. Compassionate Health Care Service and Associated Factors among Mothers Attending Public Hospitals of East Hararge Zone. Journal EC Gynaecology. 2021;10:01-17.

81. Tehranineshat B, Rakhshan M, Torabizadeh C, Fararouei M. Compassionate Care in Healthcare Systems: A Systematic Review. Journal of National Medical Association. 2019;111(5):546-54.

82. Nigusie A, Endehabtu BF, Angaw DA, Teklu A, Mekonnen ZA, Feletto M, et al. Status of Compassionate, Respectful, and Caring Health Service Delivery: Scoping Review. JMIR human factors. 2022;9(1):e30804.

83. May PJ, Winter SC. Politicians, managers, and street-level bureaucrats: Influences on policy implementation. Journal of Public Administration Research Theory. 2009;19(3):453-76.

84. Ansari M, Rassouli M, Akbari ME, Abbaszadeh A, Akbarisari A. Palliative care policy analysis in Iran: A conceptual model. Indian Journal of Palliative Care. 2018;24(1):51.

85. Nilsen P. Making sense of implementation theories, models and frameworks. Implementation Science. 2015;10(1).

86. Walt G, Shiffman J, Schneider H, Murray SF, Brugha R, Gilson L. 'Doing'health policy analysis: methodological and conceptual reflections and challenges. Health policy and planning. 2008;23(5):308-17.

87. Walt G, Gilson L. Reforming the health sector in developing countries: the central role of policy analysis. Health policy and planning. 1994;9(4):353-70.

88. Briassoulis H. Policy integration for complex policy problems: What, why and how. J Greening of Policies: Interlinkages, Policy Integration, Berlin. 2004:3-4.

89. de Jongh TE, Gurol-Urganci I, Allen E, Jiayue Zhu N, Atun R. Barriers and enablers to integrating maternal and child health services to antenatal care in low and middle income countries. BJOG: An International Journal of Obstetrics & Gynaecology. 2016;123(4):549-57.

90. Stein J, Lewin S, Fairall L, Mayers P, English R, Bheekie A, et al. Building capacity for antiretroviral delivery in South Africa: A qualitative evaluation of the PALSA PLUS nurse training programme. BMC Health Services Research. 2008;8(1):240.

91. Nattrass N. Mortal combat: AIDS denialism and the struggle for antiretrovirals in South Africa: University of KwaZulu-Natal Press; 2007.

92. Radbruch L, Knaul FM, de Lima L, de Joncheere C, Bhadelia A. The key role of palliative care in response to the COVID-19 tsunami of suffering. The Lancet. 2020;395(10235):1467-9.

93. Lancet E. Palliative care and the COVID-19 pandemic. The Lancet. 2020;395(10231):1168.

94. Mitchinson L, Dowrick A, Buck C, Hoernke K, Martin S, Vanderslott S, et al. Missing the human connection: A rapid appraisal of healthcare workers' perceptions and experiences of providing palliative care during the COVID-19 pandemic. Journal of Palliative Medicine. 2021;35(5):852-61.

95. Fadul N, Elsayem AF, Bruera E. Integration of palliative care into COVID-19 pandemic planning. BMJ supportive & palliative care. 2021;11(1):40-4.

96. Allen Watts K, Malone E, Dionne-Odom JN, McCammon S, Currie E, Hicks J, et al. Can you hear me now?: Improving palliative care access through telehealth. 2021;44(1):226-37.

97. Borasio GD, Gamondi C, Obrist M, Jox RJSmw. COVID-19: decision making and palliative care. Journal of Swiss Medical Weekly 2020(13).

98. Bauer MS, Damschroder L, Hagedorn H, Smith J, Kilbourne AM. An introduction to implementation science for the non-specialist. BMC Psychology. 2015;3(1):32-.

99. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implementation Science. 2009;4(1):50-.

100. Keith RE, Crosson JC, O'Malley AS, Cromp D, Taylor EF. Using the Consolidated Framework for Implementation Research (CFIR) to produce actionable findings: a rapid-cycle evaluation approach to improving implementation. Implementation Science. 2017;12(1):15-.

101. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. The Milbank Quarterly. 2004;82(4):581-629.

102. Mayhew SH, Sweeney S, Warren CE, Collumbien M, Ndwiga C, Mutemwa R, et al. Numbers, systems, people: how interactions influence integration. Insights from case studies of HIV and reproductive health services delivery in Kenya. Health policy and planning. 2017;32(suppl_4):iv67-iv81.

103. Rogers EM. Diffusion of innovations. edition t, editor. New York: The Free Press; 2010.

104. Coker R, Balen J, Mounier-Jack S, Shigayeva A, Lazarus JV, Rudge JW, et al. A conceptual and analytical approach to comparative analysis of country case studies: HIV and TB control programmes and health systems integration. Health Policy Plan. 2010;25(suppl_1):i21-i31.

105. Loveday M, Zweigenthal V. TB and HIV integration: obstacles and possible solutions to implementation in South Africa. Tropical Medicine & International Health. 2011;16(4):431-8.

106. Atun R, de Jongh T, Secci F, Ohiri K, Adeyi O. A systematic review of the evidence on integration of targeted health interventions into health systems. Health policy and planning. 2009;25(1):1-14.

107. Atun R, Coker R. Health systems and communicable disease control: emerging evidence and lessons from central and eastern Europe2008. 193 p.

108. Atun R, de Jongh TE, Secci FV, Ohiri K, Adeyi O, Car J. Integration of priority population, health and nutrition interventions into health systems: systematic review. BMC Public Health. 2011;11(1):780.

109. 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. Journal of Pain and Symptom Management. 2014;47(4):786-92.

110. Gwyther L, Krause R, Cupido C, Stanford J, Grey H, Crede T, et al. The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. Samj South African Medical Journal. 2018;108(2):86-9.
111. Krakauer EL, Kane K, Kwete X, Afshan G, Bazzett-Matabele L, Ruthnie Bien-Aimé DD, et al. Essential Package of Palliative Care for Women With Cervical Cancer: Responding to the Suffering of a Highly Vulnerable Population. JCO global oncology. 2021;7(7):873-85.
112. Daviaud E, Besada D, Budlender D, Sanders D, Kerber K. Saving lives, saving costs. 2018.
113. World Health Organization. Planning and implementing palliative care services: a guide for programme managers. 2016.
114. Hosking M. Opioid Use in Palliative Care. CME. 2003;21(5):273-6.
115. O'Connor M, Palfreyman S, Le B, Lau R. Establishing a nurse practitioner model to enhance continuity between palliative care settings. International journal of palliative nursing. 2016;22(12):581-5.
116. Morey T, Scott M, Saunders S, Varenbut J, Howard M, Tanuseputro P, et al. Transitioning from hospital to palliative care at home: Patient and caregiver perceptions of continuity of care. Journal of Pain and Symptom Management. 2021;62(2):233-41.
117. Dyers R. eCCR User Adoption Report and Discharge Summary Progress in the Western Cape. In: Arendse JO, editor. Cape Town2022.
118. Esquivel A, Sittig DF, Murphy DR, Singh H. Improving the effectiveness of electronic health record-based referral processes. BMC Medical Informatics Decision Making. 2012;12(1):1-8.
119. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, 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;6736(17):1-64.
120. Horton R. Comment A milestone for palliative care and pain relief. The Lancet. 2017;6736(17):1-2.
121. Aldridge MD, Hasselaar J, Garralda E, van der Eerden M, Stevenson D, McKendrick K, et al. Education, implementation, and policy barriers to greater integration of palliative care: a literature review. Palliative medicine. 2016;30(3):224-39.
122. Graham-Wisener L, Nelson A, Byrne A, Islam I, Harrison C, Geddis J, et al. Understanding public attitudes to death talk and advance care planning in Northern Ireland using health behaviour change theory: a qualitative study. BMC public health. 2022;22(1):1.
123. Ahmed F, Kutluk T, Kirazli M, Yurduşen S, Cemaloğlu M, Boufkhed S, et al. Palliative Care in 2020 & Beyond Workshop: an expert symposium to develop palliative care advocacy in Turkey. Journal of cancer policy. 2022;34:100361.
124. Watt N, Sigfrid L, Legido-Quigley H, Hogarth S, Maimaris W, Otero-García L, et al. Health systems facilitators and barriers to the integration of HIV and chronic disease services: a systematic review. Health policy and planning. 2017;32(suppl_4):iv13-iv26.
125. Morgan J. Report on Palliative Care support during COVID-19. Metro Health Services; 2021 9 April 2021.
126. Gwyther E. Personal communication regarding palliative care expert access from the Ethics Committee. In: Arendse JO, editor. unpublished2021.
127. Bowen GA. Document Analysis as a Qualitative Research Method. Qualitative Research Journal. 2009;9(2):27-40.
128. Dalglish SL, Khalid H, McMahon SA. Document analysis in health policy research: the READ approach. Journal of Health Policy & Planning. 2020;35(10):1424-31.
129. Cloete KR. Organisational Redesign Journey MDP Stock-take. In: Wellness WCGHa, editor. Western Cape2022.
130. Western Cape Government. Annual Performance Plan 2018-2019. In: Health, editor. Western Cape: Western Cape Government Health; 2018. p. 197.
131. Western Cape Government. Annual Performance Plan 2021-2022. In: Health, editor. Cape Town: Western Cape Government Health; 2021. p. 160.

132. Metro Health Services. Internal Memoramdum: MHS 09 of 2020 HCBS Programme and Information Management Standard Operating Procedure. In: MHS CD, editor. Cape Town2020. p. 22.
133. Goliath C. Home Deliveries of Chronic Medication, Chronic Disease Service Coodinating Workgroup. 2020.
134. Western Cape Government. Policy Framework on Intermediate Care Circular No 154 of 2012. In: Health, editor. Cape Town: Western Cape Government Health; 2012. p. 14.
135. Metro Health Services. COVID-19 Risk Reduction Plan, Decongesting current services –Home drop-off of CDU parcels by CHWs. In: MHS CD, editor. Cape Town2020.
136. Ferreira M. NTSS Spiritual Counselling Support Report. Unpublished; 2020.
137. Peters F. Mitchells Plain COVID-19 Intermediate & Palliative Care Admission Criteria. In: Sub-Structure KMP, editor. WCGHW. Cape Town: Metro Health Services; 2020. p. 1.
138. Nations U. Handbook on Planning, Monitoring and Evaluation for Development Results New York: United Nations; 2009 [Available from: http://web.undp.org/evaluation/handbook/documents/english/pme-handbook.pdf.
139. Bausewein C, Hodiamont F, Berges N, Ullrich A, Gerlach C, Oechsle K, et al. National strategy for palliative care of severely ill and dying people and their relatives in pandemics (PallPan) in Germany-study protocol of a mixed-methods project. BMC Palliative Care. 2022;21(1):1-9.
140. Ferrell BR, Handzo G, Picchi T, Puchalski C, Rosa WE. The Urgency of Spiritual Care: COVID-19 and the Critical Need for Whole-Person Palliation. Journal of Pain and Symptom Management. 2020;60(3):e7-e11.
141. Dahlin C, Coyne P, Goldberg J, Vaughan LJJopc. Palliative care leadership. Journal of Palliative Care. 2019;34(1):21-8.
142. Byock I, Twohig, JS., Merriman, M., Collins, K. Promoting Excellence in End-of-Life Care: A Report on Innovative Models of Palliative Care. 2006;9(1):137-51.
143. Brey Z, Mash R, Goliath C, Roman D. Home delivery of medication during Coronavirus disease 2019, Cape Town, South Africa: Short report. Africa Journal Primary Health Care Family Medicine. 2020;12(1):e1-e4.
144. Pereira J, Giddings G, Sauls R, I. H, Antifeau E, Falkner J. Navigating Design Options for Large-Scale Interprofessional Continuing Palliative Care Education: Pallium Canada's Experience. Palliative Medicine Reports. 2021;2(1):226-36.
145. Zimmermann C, Seccareccia D, Clarke A, Warr D, Rodin G. Bringing palliative care to a Canadian cancer center: the palliative care program at Princess Margaret Hospital. Journa Supportive Care in cancer. 2006;14:982-7.
146. Mueller-Hirth NJD, Change. If you don't count, you don't count: Monitoring and evaluation in South African NGOs. 2012;43(3):649-70.
147. Gwyther LP, Altilio T, Blacker S, Christ G, Csikai EL, Hooyman N, et al. Social Work Competencies in Palliative and End-of-Life Care. Journal of Social Work in End-of-Life & Palliative Care. 2005;1(1):87-120.
148. Hofmeyr G, Phelanyane, F. An Analysis of oral Morphine use at Primary Health Care Facilities in the Cape Town Metro District. PAINSA Virtual Congress2021.
149. https://walthercenter.iu.edu. Global Essential Controlled Medicines Consumption Indiana University, School of Medicine & Supportive Oncology: Walther Global Palliative Care & Supportive Oncology; 2023 [
150. Nguyen LH, Dawson JE, Brooks M, Khan JS, Telusca NJAC. Disparities in Pain Management. Anaesthesiology_theclinicscom. 2023;41(2):471-88.
151. Fumaneeshoat OJJoHS, Research M. Prevalence of the Z515 (Palliative Care) Diagnosis from the ICD-10 System in Cancer Patients and the relationship between treatment and cost in Songklanagarind Hospital. Journal of Health Science Medical Research. 2018;36(4):269-76.
152. Arendse JO. The development of a tool to evaluate the quality of prevention of mother to child transmission programmes offered to the hiv exposed infants in a primary health care facility setting in Cape Town [Mini Thesis for Masters Degree]: University of the Western Cape; 2012.

153. Ager A, Strang A. Understanding Integration: A Conceptual Framework. Journal of Refugee Studies. 2008;21(2):166-91.

154. Rhee JY, Garralda E, Namisango E, Luyirika E, de Lima L, Powell RA, et al. Factors affecting palliative care development in Africa: In-Country experts' perceptions in seven countries. Journal of Pain and Symptom Management. 2018;55.5:1313-20.

155. van Gurp J, van Wijngaarden J, Payne S, Radbruch L, van Beek K, Csikós Á, et al. Integrating Palliative Care by Virtue of Diplomacy; A Cross-sectional Group Interview Study of the Roles and Attitudes of Palliative Care Professionals to Further Integrate Palliative Care in Europe %J International Journal of Health Policy and Management. International Journal of Health Policy and Management. 2020:-.

156. Vočanec D, Džakula A, Lončarek K, Sović S, Rechel BJHP. Integration processes within the Croatian palliative care model in 2014–2020. Elsevier. 2022;126(3):207-15.

157. Barasteh S, Parandeh A, Rassouli M, Zaboli R, Vahedian-Azimi A, Khaghanizadeh M. Integration of Palliative Care into the Primary Health Care of Iran: A Document Analysis. Middle East Journal of Cancer. 2021;12(2):292-300.

158. Mukambetov A, Sabyrbekova T, Asanalieva L, Sadykov I, Connor SR. Palliative Care Development in Kyrgyzstan. Journal of Pain and Symptom Management. 2018;55(2):S41-S5.

159. Kamonyo ES. The Palliative Care Journey in Kenya and Uganda. Journal of Pain and Symptom Management. 2018;55(2):S46-S54.

160. Luyirika E, Lohman D, Ali Z, Atieno M, Mahenge A, Mmbando P, et al. Progress update: palliative care development between 2017 and 2020 in five African countries. Journal of Pain and Symptom Management. 2022;63(5):729-36.

161. Lamba S, DeSandre PL, Todd KH, Bryant EN, Chan GK, Grudzen CR, et al. Integration of palliative care into emergency medicine: the Improving Palliative Care in Emergency Medicine (IPAL-EM) collaboration. Journal Emergency Medicine. 2014;46(2):264-70.

162. Basol N. The Integration of Palliative Care into the Emergency Department. Turkish Journal of Emergency Medicine. 2015;15(2):100-7.

163. Dogbey DM, Burger H, Edge J, Mihalik M, Savieri P. Identification of Palliative Care Needs in Cancer Patients in a Surgical Emergency Center. Journal of Pain and Symptom Management. 2022;63(2):260-70.

164. Head B, A., Schapmire T, Earnshaw L, Faul A, Hermann C, Jones C, et al. Evaluation of an Interdisciplinary Curriculum Teaching Team-Based Palliative Care Integration in Oncology. Journal of Cancer Education. 2016;31(2):358-65.

165. Castro JA, Hannon B, Zimmermann C. Integrating Palliative Care into Oncology Care Worldwide: The Right Care in the Right Place at the Right Time. Journal Current Treatment Options in Oncology. 2023:1-20.

166. Atreya S, Jeba J, Pease N, Thyle A, Murray S, Barnard A, et al. Primary palliative care competency framework for primary care and family physicians in India-Collaborative work by Indian Association of Palliative Care and Academy of Family Physicians of India. Journal of Family Medicine & Primary Care. 2019;8(8):2563-7.

167. van Heerden EM, Jenkins LS. The role of community health workers in palliative care in a rural subdistrict in South Africa. African Journal of Primary Health Care & Family Medicine. 2022;14(1).

168. Gerlach C, Ullrich A, Berges N, Bausewein C, Oechsle K, Hodiamont F, et al. The Impact of the SARS-CoV-2 Pandemic on the Needs of Non-Infected Patients and Their Families in Palliative Care—Interviews with Those Concerned. Journal of Clinical Medicine. 2022;11(13):3863.

169. Sriram V, Topp SM, Schaaf M, Mishra A, Flores W, Rajasulochana SR, et al. 10 best resources on power in health policy and systems in low-and middle-income countries. Journal of Health Policy & Planning. 2018;33(4):611-21.

170. Greer S, Joseph M. Palliative Care: A Holistic Discipline. Integrative Cancer Therapies. 2015;15(1):5-9.

171. Price B. Exploring person-centred care. Nursing Standard. 2006;20(50).

172. Abiodun OA. The need for a holistic approach to patient care. East Afr Med J. 1991;68(1):25-8.

173. World Health Organization. Framework for action on interprofessional education and collaborative practice. World Health Organization; 2010.

174. Kaasa S, Loge JH, Aapro M, Albreht T, Anderson R, Bruera E, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. The Lancet Oncology. 2018.

175. Kassa H, Murugan R, Zewdu F, Hailu M, Woldeyohannes D. Assessment of knowledge, attitude and practice and associated factors towards palliative care among nurses working in selected hospitals, Addis Ababa, Ethiopia. BMC Palliative Care. 2014;13(1):6.

176. Fernando GVMC, Hughes S. Team approaches in palliative care: a review of the literature. International journal of palliative nursing. 2019;25(9):444-51.

177. 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):940-4.

178. Gwyther L, Rawlinson F. Palliative medicine teaching program at the University of Cape Town: Integrating palliative care principles into practice. Journal of Pain and Symptom Management. 2007;33(5):558-62.

179. African Palliative Care Association. Essential Palliative Care Package for Universal Health Coverage. Uganda: Open Society Foundations; 2019.

180. Johnston FM, Beckman M. Navigating difficult conversations. Journal of Surgical Oncology. 2019;120(1):23-9.

181. Giannitrapani KF, Satija A, Ganesh A, Gamboa R, Fereydooni S, Hennings T, et al. Barriers and Facilitators of Using Quality Improvement To Foster Locally Initiated Innovation in Palliative Care Services in India. Journal of General Internal Medicine. 2021;36(2):366-73.

182. Birken SA, Lee S-YD, Weiner BJ, Chin MH, Schaefer CT, Review. Improving the effectiveness of health care innovation implementation: middle managers as change agents. Journal of Medical Care Research. 2013;70(1):29-45.

183. Walker L, Gilson L. 'We are bitter but we are satisfied': nurses as street-level bureaucrats in South Africa. Journal of Social Science Medicine. 2004;59(6):1251-61.

184. Marais DL, Quayle M, Petersen I. Making consultation meaningful: Insights from a case study of the South African mental health policy consultation process. PLoS ONE. 2020;15(1):e0228281.

185. Loyens K, Maesschalck J. Toward a theoretical framework for ethical decision making of street-level bureaucracy: Existing models reconsidered. Administration & Society. 2010;42(1):66-100.

186. Seal DW, Bogart LM, Ehrhardt AA. Small group dynamics: The utility of focus group discussions as a research method. J Group Dynamics: Theory, Research, Practice. 1998;2(4):253.

187. Powell RA, Single HM. Focus groups. International journal for quality in health care. 1996;8(5):499-504.

188. Gibbs A. Focus groups. Social Research Update. 1997;19(8):1-8.

189. Krueger RA, Casey MA. Designing and conducting focus group interviews: Citeseer; 2002 June 2001.

190. Qualitative Research Methods - A Data Collector's Field Guide [Internet]. Family Health International. 2005 [cited 30 June 2018].

191. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.

192. Cresswell J, Poth C. Qualitative inquiry and research Design: (Book) Sage Publishing. 2018.

193. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care;. 2007;19(6):349-57.

194. National Department of Health R, ,. The District Health System in South Africa: Progress made and next steps In: Health, editor. Pretoria: National Department of Health, RSA; 2001. p. 18.

195. Gamiet S. Health professionals' perceptions of rehabilitation care workers: University of the Western Cape; 2015.
196. Green A, de Azevedo V, Patten G, Davies M-A, Ibeto M, Cox V. Clinical mentorship of nurse initiated antiretroviral therapy in Khayelitsha, South Africa: a quality of care assessment. PLoS ONE. 2014;9(6):e98389.
197. Western Cape Government. 1st Annual Training Review, Western Cape Government Health. In: Health, editor. Western Cape: Western Cape Government Health; 2017. p. 33.
198. Daniel S, Venkateswaran C, Sunder P, Nair S, Chittazhathu RK, Manuel AJ, et al. Responding to palliative care training needs in the coronavirus disease 2019 era: the context and process of developing and disseminating training resources and guidance for low-and middle-income countries from Kerala, South India. Indian Journal of Palliative Care. 2020;26(Suppl 1):S8.
199. Serapelwane MG, Manyedi ME. Experiences of operational managers regarding their supervision at primary health care facilities in the North West province, South Africa. J African Journal for Physical Activity Health Sciences

2021;27(1):85-100.
200. Krause R, Barnard A, Burger H, de Vos A, Evans K, Farrant L, et al. A Delphi study to guide the development of a clinical indicator tool for palliative care in South Africa. 2021 Research Month, School of Public Health and Family Medicine; University of Cape Town2021.
201. Carlson MD, Bradley EH, Du Q, Morrison RS. Geographic access to hospice in the United States. J Palliat Med. 2010;13(11):1331-8.
202. Kowitt SD, Ellis KR, Carlisle V, Bhushan NL, Black KZ, Brodar K, et al. Peer support opportunities across the cancer care continuum: a systematic scoping review of recent peer-reviewed literature. Journal Supportive Care in Cancer. 2019;27(1):97-108.
203. Donnelly S, Prizeman G, Coimín DÓ, Korn B, Hynes G. Voices that matter: end-of-life care in two acute hospitals from the perspective of bereaved relatives. BMC Palliative Care. 2018;17(1):117.
204. Daire J, Gilson L. Does identity shape leadership and management practice? Experiences of PHC facility managers in Cape Town, South Africa. Journal of Health Policy & Planning. 2014;29(suppl_2):ii82-ii97.
205. Lipsky M. Street-level bureaucracy: Dilemmas of the individual in public service: Russell Sage Foundation; 2010.
206. Hupe P, Hill M. Street-Level Bureaucracy and Public Accountability. Public Administration. 2007;85(2):279-99.
207. den Herder-van der Eerden M, van Wijngaarden J, Payne S, Preston N, Linge-Dahl L, Radbruch L, et al. Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. Journal of Palliative Medicine. 2018:0269216318758194.
208. Western Cape Government. Service Packages for NPO Funding 2018/2019. In: Health, editor. Cape Town: Western Cape Government Health; 2018.
209. Saunders M, Lewis P, Thornhill A. Research methods for business students. England: Pearson Education; 2000.
210. www.spict.org. Using SPICT-4ALL 2017 UK: University of Edinburgh; 2017 [
211. Bowling A. Research methods in health: investigating health and health services: McGraw-Hill Education (UK); 2014.
212. 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. Journal of Palliative Medicine. 2014;28(3):273-80.
213. Madikiana L. Inclusion of Palliative Care Indicators in the NIDS, Email Communication. In: Arendse JO, editor. 2022.
214. Gilson L. Michael Lipsky,'Street-Level Bureaucracy: Dilemmas of the Individual in Public Service'. Oxford: Oxford University Press: Oxford Handbook of the Classics of Public Policy; 2015.

215. Davidovitz M, Cohen N, Gofen A. Governmental response to crises and its implications for street-level implementation: Policy ambiguity, risk, and discretion during the COVID-19 pandemic. Journal of Comparative Policy Analysis Research Practice. 2021;23(1):120-30.
216. Gilson L, Elloker S, Olckers P, Lehmann U. Advancing the application of systems thinking in health: South African examples of a leadership of sensemaking for primary health care. Health Research Policy and Systems. 2014;12(1):30.
217. Centeno C, Ballesteros M, Carrasco JM, Arantzamendi MJBs, care p. Does palliative care education matter to medical students? The experience of attending an undergraduate course in palliative care. 2016;6(1):128-34.
218. Hamdan Alshehri H, Wolf A, Öhlén J, Olausson S. Managerial and organisational prerequisites for the integration of palliative care in the intensive care setting: A qualitative study. Journal of nursing management. 2021;29(8):2715-23.
219. Grant L, Downing J, Luyirika E, Murphy M, Namukwaya L, Kiyange F, et al. Integrating palliative care into national health systems in Africa: a multi–country intervention study. Journal of Global Health. 2017;7(1).
220. DiMartino LD, Weiner BJ, Mayer DK, Jackson GL, Biddle AK. Do palliative care interventions reduce emergency department visits among patients with cancer at the end of life? A systematic review. Journal of Palliative Medicine. 2014;17(12):1384-99.
221. Delgado-Guay MO, Kim YJ, Shin SH, Chisholm G, Williams J, Allo J, et al. Avoidable and unavoidable visits to the emergency department among patients with advanced cancer receiving outpatient palliative care. Journal of Pain & Symptom Management. 2015;49(3):497-504.
222. Dumnui N, Nagaviroj K, Anothaisintawee T. A study of the factors associated with emergency department visits in advanced cancer patients receiving palliative care. BMC Palliative Care. 2022;21(1):1-11.
223. Robinson J, Gott M, Gardiner C, Ingleton C. The 'problematisation'of palliative care in hospital: an exploratory review of international palliative care policy in five countries. BMC Palliative Care. 2016;15:1-8.
224. Gómez-Batiste X, Martínez-Muñoz 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. Current opinion in supportive and palliative care. 2012;6(3):371-8.
225. Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ supportive & palliative care. 2014;4(3):285-90.
226. Vočanec D, Lončarek K, Sović S, Džakula AJJoCN. Nurse coordinator of care as a facilitator of integration processes in palliative care. Journal of clinical nursing. 2022.
227. Rangaraj A, Connor S, Harding R, Pinto C, Chitembo L, Ford N. Advanced HIV disease and health-related suffering—exploring the unmet need of palliative care. The Lancet HIV. 2022.
228. Gayatri D, Efremov L, Kantelhardt EJ, Mikolajczyk R. Quality of life of cancer patients at palliative care units in developing countries: systematic review of the published literature. Quality of Life Research. 2020.
229. 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 and Quality of Life Outcomes. 2010;8(1).
230. Draucker CB, Martsolf DS, Poole C. Developing distress protocols for research on sensitive topics. Archives of Psychiatric Nursing. 2009;23(5):343-50.
231. A practical guide for health researchers [Internet]. WHO Regional Eastern Mediteranean Series. 2004 [cited 2004]. Available from: https://apps.who.int/iris/handle/10665/119703.
232. Arendse S. Categorisation and Classification of Housing in the Cape Metro District. In: Arendse J, editor. 2023.

233. Knaul FM, Farmer PE, Bhadelia A, Berman P, Horton R. Closing the divide: the Harvard Global Equity Initiative–Lancet Commission on global access to pain control and palliative care. The Lancet. 2015;386(9995):722-4.
234. Gwyther E. How is palliative care part of the right to health? The South African evidence. Cape Town: University of Cape Town; 2019.
235. National Department of Health R, ,. Standard Treatment Guidelines and Essential Medicines List for South Africa: Primary Healthcare Level 2020 Edition. In: Health, editor. 7th ed. Pretoria: The National Department of Health, Pretoria, Republic of South Africa; 2020. p. 626.
236. Lowenherz K. Morphine Shortage. In: Arendse JO, editor. 2022.
237. Radbruch L, Kern MJJPM. Until the very end: is there equity in palliative care. 2014;17(3):262-3.
238. Hudson PL, Aranda S, Kristjanson LJ. Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. Journal of Palliative Medicine. 2004;7(1):19-25.
239. Sultana A, Tasnim S, Sharma R, Pawar P, Bhattcharya S, Hossain MM. Psychosocial Challenges in Palliative Care: Bridging the Gaps Using Digital Health. Indian journal of palliative care. 2021;27(3):442-7.
240. Alam S, Hannon B, Zimmermann C. Palliative care for family caregivers. Journal of Clinical Oncology. 2020;38(9):926-36.
241. Daniels J, Zweigenthal V, Reagon G. Assessing the impact of a waiting time survey on reducing waiting times in urban primary care clinics in Cape Town, South Africa. Journal of Public Health in Africa. 2017;8(1).
242. Tana VV. Experiences of chronic patients about long waiting time at a community health care centre in the Western Cape. Stellenbosch: Stellenbosch: Stellenbosch University; 2013.
243. Namisango E, Ntege C, Luyirika EBK, Kiyange F, Allsop MJ. Strengthening pharmaceutical systems for palliative care services in resource limited settings: piloting a mHealth application across a rural and urban setting in Uganda. BMC Palliative Care. 2016;15(1):20.
244. Jansen van Rensburg JJM, Maree JE, van Belkum C. Quality of life from the perspective of the palliative care patient in a resource-poor community in South Africa. Palliative & Supportive Care. 2013;11(1):21-8.
245. Etkind SN, Bone AE, Lovell N, Cripps RL, Harding R, Higginson IJ, et al. The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic. Journal of Pain and Symptom Management. 2020;60(1):e31-e40.
246. National Department of Health R, ,. District Health System Policy Framework and Strategy 2014 to 2019. In: Health, editor. Pretoria: National Department of Health, RSA; 2015. p. 32.
247. Sinclair S, Beamer K, Hack TF, McClement S, Raffin Bouchal S, Chochinov HM, et al. Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. Journal of Palliative Medicine. 2017;31(5):437-47.
248. Galea S. Compassion in a time of COVID-19. The Lancet. 2020;395(10241):1897-8.
249. Hofmeyer A, Taylor R, Kennedy K. Fostering compassion and reducing burnout: How can health system leaders respond in the Covid-19 pandemic and beyond? Journal of Nurse Education Today. 2020;94:104502.
250. Gaitonde R, San Sebastian M, Hurtig A-K. Dissonances and disconnects: the life and times of community-based accountability in the National Rural Health Mission in Tamil Nadu, India. BMC Health Services Research. 2020;20(1):1-12.
251. Shigayeva A, Atun R, McKee M, Coker R. Health systems, communicable diseases and integration. Health Policy and Planning. 2010;25(suppl_1):i4-i20.
252. Pettus K, Radbruch L. Parallel opioid crises: brakes on sustainable development? Palliative ans Social Practice. 2023;17:26323524231176574.
253. Western Cape Government. Finance Instruction G38-2003 Amendment of the Policy for the Funding of Provincial-Aided Hospitals and Amendment of the Memorandum of Agreement with the

Hospital COmmittees: Procedure Manual for use by Regional Offices. In: Health, editor. Cape Town: Western Cape Government Health and Wellness; 2003.
254. Western Cape Government. Home and Community Based Care Service Design Framework. In: Health, editor. Cape Town: Western Cape Government Health; 2016. p. 33.
255. Schneider H. A policy review & development of a framework for home and community based services. Western Cape: Univeristy of the Western Cape, Health SoP; 2013 10 June 2013.

Appendices: Consent forms and data collection tools

Chapter 4: Comparing the state of Palliative Care 24-months on from baseline

Appendix 1a_Desktop Review and Document Analysis Template

Health System Characteristic	**Documents and Desktop Information**	**Reason and / Purpose**
Governance and Stewardship	WCGHW Top Management Structure Organogram Survey: Managers knowledge in Palliative Care	Accountability function (Policy Structure, responsibility and roles), reporting and performance management for priority programme.
Finance	Finance Instructions for Transfer Payments	Governance of NGO funding
	NGO Service Package	Funding guidelines for NGOs including HCBC and ICFs
	Budgeting Framework for Financial Year	To determine funding norms for NGOs rendering HCBC and ICFs
Planning	Skills Based Work-plans Training Plan guidelines. Survey: Before and After training in Introduction to palliative care course	Training guidelines and planning with prioritisation. Needs assessment and resource allocation.
Service Delivery	WCGHW Packages of Care and Referral pathways	Describe the service delivery at each level of care and the referral processes
	Intermediate Care Policy Framework	Describe the package of care at ICF level with focus on palliative care provision
	Policy on HCBC	Describe the policy response to palliative care within HCBC
	UWC Review of Intermediate Care Facilities	To understand and contextualise the UWC recommendations for HCBC
Monitoring and Evaluation	WCGHW Indicator Data Set booklet	Describe state of palliative care indicators
	Palliative Care Cascade Identifiers and Headcount	Identify and describe palliative care indicators and cascades, i.e., all forms of cancers, TB care, conditions requiring palliative care
	Morphine Data	Indicator of Morphine Usage at each level of care

Appendix 1b_Data Extraction Tool Summary for Morphine

5 YEAR BEFORE PALLIATIVE CARE POLICY IMPLEMENTATION						POST PC Implementation	
Mist Morphine							
	2013-2014	2014-2015	2015-2016	2016-2017	2017-2018	2018-2019	2019-2020
Eastern	0	0	0	0	0	0	0
Khayelitsha	0	0	0	0	0	0	0
Klipfontein	0	0	0	0	0	0	0
Mitchells Plain	0	0	0	0	0	0	0
Northern	0	0	0	0	0	0	0
Southern	0	0	0	0	0	0	0
Tygerberg	0	0	0	0	0	0	0
Western	0	0	0	0	0	0	0
Total Mist Morphine Issued	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Total Number of Access Points	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Dues Out	**8**	**8**	**8**	**8**	**8**	**8**	**8**
Morphine Sulphate							
	2013-2014	2014-2015	2015-2016	2016-2017	2017-2018	2018-2019	2019-2020
Eastern	0	0	0	0	0	0	0
Khayelitsha	0	0	0	0	0	0	0
Klipfontein	0	0	0	0	0	0	0
Mitchells Plain	0	0	0	0	0	0	0
Northern	0	0	0	0	0	0	0
Southern	0	0	0	0	0	0	0
Tygerberg	0	0	0	0	0	0	0
Western	0	0	0	0	0	0	0
Total Morphine Sulphate Issued	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Total Number of Access Points	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Dues Out	**8**	**8**	**8**	**8**	**8**	**8**	**8**

Sub-District Facility level data sheet for Morphine

Mist Morphine							
	2013-2014	2014-2015	2015-2016	2016-2017	2017-2018	2018-2019	2019-2020
Facility 1							
Facility 2							
Facility 3							
Facility 4							
Facility 5							
Facility 6							
Facility 7							
Facility 8							
Facility 9							
Facility 10							
Total Mist Morphine Issued	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Total Number of Access Points	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Dues Out	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Morphine Sulphate							
	2013-2014	2014-2015	2015-2016	2016-2017	2017-2018	2018-2019	2019-2020
Facility 1							
Facility 2							
Facility 3							
Facility 4							
Facility 5							
Facility 6							
Facility 7							
Facility 8							
Facility 9							
Facility 10							
Total Morphine Sulphate Issued	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Total Number of Access Points	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Dues Out	**0**	**0**	**0**	**0**	**0**	**0**	**0**

Appendix 2a_FGD Guide: Mitchells Plain and Khayelitsha Eastern Sub-Structure Management teams

Welcome and introductions

Many thanks to you all for agreeing to be part of this focus group. As you know this focus group is with the substructure management team members who are involved with supporting and ensuring the implementation of the Palliative care services that was introduced and launched on the 29 October 2018. Palliative care driving teams were also established.

Our focus for discussion is on how, from the meso-level management perspective, one anticipates how the governance and integration of the new palliative care services will work in your substructure.

We also want you to know that all responses are important and that there are no right or wrong answers. All respondents should allow each person an opportunity to share their opinions and / or experiences. The information shared will be kept confidential and cannot be traced back to the respondents.

Firstly, we need to introduce ourselves (if people don't know each other).

As you know we will be tape recording the discussion. Is that OK with everyone? Anyone have a query about the purpose of the focus group or how it will run?

I am then going to start the tape recording. Ok? (switch on recorder)

Opening question:

Firstly, can you share with us your general roles and responsibilities within the Sub-Structure office, with us?

Introductory question:

What do you think about Palliative Care and the new palliative care policy roll-out in the Western Cape Province?

Transition question:

How do you see the new palliative care policy play itself out and how do you feel about palliative care?

Key Questions:

- What is your anticipated role to ensure the integration of palliative care into the health system?
- What do you feel needs to change regarding the health system characteristics in order for palliative care to be integrated?

  Probes:

  - Governance and Stewardship: performance management
  - Finance: pooling of funding or reallocation of funding or enough funding
  - Planning: needs assessment and priority setting; training in palliative care
  - Service Delivery: Human resources, Operational integration, supply chain management
  - Monitoring and Evaluation: data collection and analysis

  - Demand Generation: population level interventions
- Share with us the process you follow for the ordering and supply of Morphine? Are there any challenges you are aware of?
- Anything you wish to add that you see will enable or hinder integration of palliative care?
- Anything else anyone wants to add

Thanks so much for your time and participation.

Appendix 2b_FGD Guide: Mitchells Plain and Khayelitsha Eastern Sub-Structure Management teams

Welcome and introductions

Many thanks to you all for agreeing to be part of this focus group. As you know this focus group is with the substructure management team members who have been involved with supporting and driving the implementation of the Palliative care services that we introduced and implemented in our facilities on 29 October 2018.

Our focus for discussion is on how, from meso-level management perspective, the governance and integration of the new palliative care services have been working in your substructure and what lessons you have learned along the way that can inform policy makers.

We also want you to know that all responses are important and that there are no right or wrong answers. All respondents should allow each person an opportunity to share their opinions and / or experiences. The information shared will be kept confidential and cannot be traced back to the respondents.

As you know we will be tape recording the discussion. Is that OK with everyone? Anyone have a query about the purpose of the focus group or how it will run?

I am then going to start the tape recording. Ok? (switch on recorder)

Opening question:

We thought we start off by you sharing with us about your roles and responsibilities within the Sub-Structure office and how they have been affected by the palliative care policy.

Introductory question:

What have your learned about Palliative Care over the last 18 months?

Transition question:

Could you please share with us how do you now feel about palliative care? Do you see in yourself any change since the first session?

Key Questions:

- Has it been easy to get facilities to implement the services? What enabled this?
- So far what are the successes in getting the service going? **Probe**; what enabled the success?
- What have been your main obstacles to getting the service going? Probe: Please share some more about that.
- Has the service been integrated into the work of the staff?
- What have the main challenges been?
- We have been looking at the monitoring data and see that facility x has performed well in terms of … On the other hand, facility Y has performed less well in terms of … Why do you think that facility "X" has performed well, and facility "Y" has performed poorly regarding the integration of palliative care into their health system?
- What is your opinion on the influence of relationships as enablers or barriers to getting the palliative care service going?

- To what extent does adequate infrastructure play a role in ensuring integration?
- What do you believe enables integration of any new intervention into the health system?
- What do you believe will hinder or present as a barrier to integration of any new intervention into the health system?
- What has surprised you as being enablers or barriers for integration?
- What will you do differently to ensure integration of a new intervention or policy into the health system?
- What has been your biggest lesson learned?
- Reflection on some of the implementers and patient experiences – what can you derive as lessons learned?
- What will you never do again?
- What will you do again?
- Anything else anyone wants to add

Thanks so much for your time and participation.

Appendix 3_FGD Guide: Mitchells Plain and Eastern Sub-District Operational and Operations Managers

Welcome and introductions

Many thanks to you all for agreeing to be part of this focus group. As you know this focus group is with the sub-district' operations management team members who are involved with the implementation of the Palliative care services that was introduced and launched on the 29 October 2018. Palliative care driving teams were also established.

Our focus for discussion is on how, from an operational perspective, the new palliative care services can work in your sub-district and what you know is needed to ensure that it is operationalised. We are interested in your early lessons or warning signs that you may have encountered to date or are aware of.

We also want you to know that all responses are important and that there are no right or wrong answers. All respondents should allow each person an opportunity to share their opinions and / or experiences. The information shared will be kept confidential and cannot be traced back to the respondents.

As you know we will be tape recording the discussion. Is that OK with everyone? Anyone have a query about the purpose of the focus group or how it will run?

I am then going to start the tape recording. Ok? (switch on recorder)

Opening question:

We thought we would start off by asking you to share your accountability roles and responsibilities as an Operations Manager.

Introductory question:

What do you think about Palliative Care?

Transition question:

How do you feel about palliative care?

Key Questions:

- How do you see the new palliative care policy playing itself out within your area of responsibility?
- What do you think your role is in ensuring the integration of palliative care at operational level?
- What do you feel needs to be in place for palliative care services to be rendered?
- What do you feel needs to be in place for palliative care services to be integrated in the services at a facility and sub-structure level?

  Probes:

  - Governance and Stewardship: performance management of staff
  - Finance: opportunities for rethinking budgets and historical decision-making
  - Planning: needs assessment and priority setting; training in palliative care

  - Service Delivery: Human resources, Operational integration, supply chain management, Referral and care pathway
  - M and E: data collection and analysis
  - Demand Generation: population level interventions – what is appropriate?
- Do you think that the integration of palliative care into the existing health system in the longer term is possible and why?
- Anything else anyone wants to add

Thanks so much for your time and participation.

Appendix 4_FGD Guide: Funded and Unfunded HPCA Member Hospices and Funded Intermediate Care Facilities Managers

Welcome and introductions

Many thanks to you all for agreeing to be part of this focus group. As you know this focus group is with members of the hospice team and intermediate care facilities who have been involved and, in some instances, solely responsible for the provision of Palliative care services for many years. The national policy on palliative care was introduced and launched on the 29 October 2018 to the public sector and palliative care driving teams were also established.

Our focus for discussion is on the implementation of palliative care services at primary care level and how you envisage your relationship and engagement with these facilities.

We also want you to know that all responses are important and that there are no right or wrong answers. All respondents should allow each person an opportunity to share their opinions and / or experiences. The information shared will be kept confidential and cannot be traced back to the respondents.

As you know we will be tape recording the discussion. Is that OK with everyone? Anyone have a query about the purpose of the focus group or how it will run?

I am then going to start the tape recording. Ok? (switch on recorder)

Opening question:

We thought we would start off by asking you to share what your roles and responsibilities as a Manager of an Intermediate Care Facility or Hospice in the NGO sector

Introductory question:

What are your thoughts on the National Policy Framework and Strategy for Palliative Care?

Transition question:

Do you think that the current health system is able to integrate palliative care into routine services?

Key Questions:

- What do you feel needs to be in place in the health system to for palliative care services to be rendered?
- What do you think is needed in the health system to ensure palliative care services are integrated into the services?
- What role can NGOs or services like yours play to make a palliative care integration successful into the health system?

- What do you think the enablers will be to integrate palliative care into the routine services?

  Probe:

  - From the perspective of the hospice? The step down or intermediate care facilities?
  - From the perspective of the services? Clinicians? Facility managers? Community based services?

- Do you anticipate any obstacles regarding this?

  Probe:

  - From the perspective of the hospice? The step down or intermediate care facilities?
  - From the perspective of the services? Clinicians? Facility managers? Community based services?

- Do you have any recommendations or expectations regarding palliative care service provision going forward?
- Anything else anyone wants to add

Thanks so much for your time and participation.

Appendix 5a_Email Content to Sub-Structure Director

Subject: Request for identification of participants for two FGDs

Dear Sub-Structure Director

I am approaching you in the capacity of doctoral student registered at UCT and would like to thank you for providing approval (see attached) to the Provincial Health Research Committee for this research to take place in your sub-structure.

Attached please find the information sheet for this study. Two FGDs will be conducted during phase 1 and 3 of this study and the managers based at your sub-structure office who are responsible for governance and stewardship as well strategic policy decision making, will be invited to participate.

You are hereby invited to participate and also requested to assist in identifying the appropriate individuals who can be approached to participate. Each potential participant will then be invited via email to participate and will be provided with two dates from which to choose. Should you be willing to participate, your diary will be considered when providing date options to your management team.

I would appreciate it if you could provide me with the contact details of the person responsible for venue bookings, so that I can make the necessary arrangements for an appropriate venue.

A research assistant will be joining me and please do feel free to contact me should you have any questions or concerns.

Kind regards

Juanita O Arendse

Appendix 5b_Email Content to Sub-Structure Management Team

Subject: Invitation to participate in two FGDs

Dear Sub-Structure Manager

I am approaching you in the capacity of doctoral student registered at UCT and would like to invite you to participate in a FGD for this study that has received approval (see attached) from the Provincial Health Research Committee.

Attached please find the information sheet for this study which I would encourage you to read and to kindly consider. Two FGDs will be conducted during phase 1 and 3 of this study and you in your role as manager at sub-structure level are cordially invited to participate.

I would like to propose two dates for you to select from:

- Day / Month / Year
- Day / Month / Year

For your convenience, the venue will be at your sub-structure office and a research assistant will be joining me. Please do feel free to ask any questions or raise any concerns that you may have.

Looking forward to your response.

Kind regards

Juanita O Arendse

Appendix 6a_Email Content to Primary Health Care Manager

Subject: Request for identification of participants for a FGD

Dear Primary Health Care Manager

I am approaching you in the capacity of doctoral student registered at UCT and would like to thank you for providing approval (see attached) to the Provincial Health Research Committee for this research to take place in your sub-structure.

Attached please find the information sheet for this study. A FGD will be conducted during phase 1 of this study and the operational and operations managers at various clinical settings responsible for the operationalizing of policy and implementation support to the implementers, will be invited to participate.

You are hereby invited to participate and also requested to assist in identifying the appropriate individuals who can be approached to participate. Each potential participant will then be invited via email to participate and will be provided with two dates from which to choose. Should you be willing to participate, your diary will be considered when providing date options to your operational team.

I would appreciate it if you could provide me with the contact details of the person responsible for venue bookings, so that I can make the necessary arrangements for an appropriate venue.

A research assistant will be joining me and please do feel free to contact me should you have any questions or concerns.

Kind regards

Juanita O Arendse

Appendix 6b_Email Content to Operational and Operations Managers

Subject: Request for identification of participants for FGD

Dear Operational / Operations Manager

I am approaching you in the capacity of doctoral student registered at UCT and would like to invite you to participate in a FGD for this study that has received approval (see attached) from the Provincial Health Research Committee.

Attached please find the information sheet for this study which I would encourage you to read and to kindly consider. A FGD will be conducted during phase 1 of this study and you, in your role as operational / operations manager at your health facility, are cordially invited to participate.

I would like to propose two dates for you to select from:

- Day / Month / Year
- Day / Month / Year

For your convenience, the venue will be at your sub-structure office and a research assistant will be joining me. Please do feel free to ask any questions or raise any concerns that you may have.

Looking forward to your response.

Kind regards

Juanita O Arendse

Appendix 7a_Informed Consent Form for FGD: Sub-Structure Management

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Information Sheet for: The Integration of Palliative Care into the Western Cape Health System: Enablers and Obstacles at Meso Level (District Management)

Dear Participant,

Thank you for giving your time to hear what our study entails. I am a doctoral student at UCT and this information sheet tells you about a study that I would like to invite you to participate in.

What is the purpose of the study?

We are looking to determine the factors that influence the integration of palliative care into the health system and through analysis gain insight into the enablers and obstacles to integration that will allow policy makers to develop robust policy that will enable implementation will allow policy makers to develop robust policy that will enable implementation. Notable is that some of the information we gain out of this study will also be applicable to any new policy. As an individual involved in strategically supporting the implementation and integration of the new palliative care service, your insights and perspectives are invaluable and are highly appreciated.

The focus group

We would like to invite you to participate in the first of two FGDs looking at how, from the meso-level management perspective, you anticipate how the governance and integration of the new palliative care services will work in your substructure. In addition to this, we would like to engage in dialogue to gain insight regarding the current health system characteristics in order to understand what changes would be necessary to facilitate integration of palliative care (and any new policy) into the health system.

We would then like to engage you again 12 - 18 months later to determine what lessons you have learned along the way that can inform policy makers. Participants that will be invited are the Director, District Hospital CEOs, Deputy Director for Health Programmes, Primary Health Care Manager, Pharmacy Manager, Community Based Services Manager and Community Based Services Coordinators.

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 focus group at any time without giving us any reason. If you do agree to participate, 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 participate. There are no consequences for non-participation.

What will happen if I take part?

An experienced researcher will facilitate the FGD and an assistant will also be present to take notes. The sessions will take approximately 1½ hours (an hour and a half) at the very most and will be audio recorded. The second FGD will take place in approximately 12 – 18 months. Refreshments will be served afterwards. This information sheet is for you to keep.

Benefits of this study?

The anticipated benefits are to gain insight into the health system characteristics that are adequately geared to enable palliative care integration and to learn more about what needs to change in order to enable policy decision-making. Ultimately this study may positively influence the future of policy integration in general within the health system.

What are the risks of the study?

There remains the risk that you may feel that a question makes you feel uncomfortable. Whilst we ask you to agree to keeping the identity of the participants confidential and not talk about what was discussed with anyone who did not participate in the focus group, we cannot guarantee that participants will not discuss any details outside of this group.

Will my taking part in this study be kept confidential?

All information which we collect during the focus group session will be captured from the audio recordings and kept strictly confidential. You will not be identified in any way and your personal details will be kept separately from the information provided. We will use a number and not your name on any information that you provide during the FGD. No one outside of the study will have access to the information that you give us.

Since this is a group discussion, all participants will be requested to maintain confidentiality.

How will I know about the results of the study?

At the end of the study, a report will be available to all people who have participated in the study.

You may have some further questions to help you decide whether you want to take part. You can pose any further questions to the researcher or note taker. Please take your time to make a decision.

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 question about the study:

Juanita O. Arendse, email: arnjua003@myuct.ac.za, 0218158854

PhD Supervisors: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study:

UCT Human Research Ethics Committee

Ms Lamees Emjedi, Research Ethics Committee

E52 Room 24, Old Main Building, GSH, Observatory, Tel: 021 406 6338

Consent Form for: The Integration of Palliative Care into the Western Cape Health System: Enablers and Obstacles at Meso Level

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 and without any consequence.
3. I agree to participate on the above study.
4. I agree to an audiotape being used to record the FGD.
5. I undertake not to disclose the identity of participants in the focus group and will not divulge the content of the discussion to anyone else.
6. I would like to receive a copy of the research findings:

Yes	No

PARTICIPANT DEMOGRAPHIC INFORMATION

Age: ______________________ Gender: ______________________

Job Title: ______________________ Years in current post: ______________________

Total Years Work Experience in WCG: Health: ______________________

Current Physical Work Place: ______________________

______________________ ______________________

Participant Name: Signature of Participant

______________________ ______________________

Signature of Researcher: Date:

Appendix 7b_Informed Consent Form for FGD: Sub-Structure Management

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Information Sheet for: The Integration of Palliative Care into the Western Cape Health System: Enablers and Obstacles at Meso Level (District Management)

Dear Participant,

Thank you for giving your time to hear what our study entails. I am a doctoral student at UCT and this information sheet tells you about a study that I would like to invite you to participate in.

What is the purpose of the study?

We have been looking into the factors that influence the integration of palliative care into the health system and have been gaining insight into the enablers and obstacles to integration. Notable is that some of the information we have and will gain out of this study will also be applicable to any new policy that requires integration into the health system. Some of you have been part of the initial FGD held about 12 – 18 months ago and since this, various engagement with implementers of the policy and patients have also taken place. We want to further reflect on some of the outcome measures and facility level results on integration and engage you to understand what has transpired and may have changed in your strategic approach. Your insights and perspectives are invaluable and are highly appreciated.

The focus group

We would like to invite you to participate in the second of two FGDs looking at how, from the meso-level management perspective, your stewardship and governance function has played itself out in the integration of the new palliative care services in your substructure. In addition to this, we would like to reflect on some of the outcomes from other sub-studies conducted with implementers and patients as well as outcome measures in order to gain greater insight into possible obstacles and enablers within the health system characteristics. In addition, we would like to reflect on the lessons you have learned along the way that can inform policy makers. Participants that will be invited are the Director, District Hospital CEOs, Deputy Director for Health Programmes, Primary Health Care Manager, Pharmacy Manager, Community Based Services Manager and Community Based Services Coordinators.

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 focus group at any time without giving us any reason. If you do agree to participate, 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 participate. There are no consequences for non-participation.

What will happen if I take part?

An experienced researcher will facilitate the FGD and an assistant will also be present to take notes. The sessions will take approximately 1½ hours (an hour and a half) at the very most and will be audio recorded. Refreshments will be served afterwards. This information sheet is for you to keep.

Benefits of this study?

The anticipated benefits are to gain rich insight into the health system characteristics and whether these are adequately geared to enable palliative care integration and to learn more about what needs to change in order to enable policy decision-making. Ultimately this study may positively influence the future of policy integration in general within the health system.

What are the risks of the study?

There remains the risk that you may feel that a question makes you feel uncomfortable. Whilst we ask you to agree to keeping the identity of the participants confidential and not talk about what was discussed with anyone who did not participate in the focus group, we cannot guarantee that participants will not discuss any details outside of this group.

Will my taking part in this study be kept confidential?

All information which we collect during the focus group session will be captured from the audio recordings and kept strictly confidential. You will not be identified in any way and your personal details will be kept separately from the information provided. We will use a number and not your name on any information that you provide during the FGD. No one outside of the study will have access to the information that you give us.

Since this is a group discussion, all participants will be requested to maintain confidentiality.

How will I know about the results of the study?

At the end of the study, a report will be available to all people who have participated in the study.

You may have some further questions to help you decide whether you want to take part. You can pose any further questions to the researcher or note taker. Please take your time to decide.

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 question about the study:

Juanita O. Arendse, email: arnjua003@myuct.ac.za, 0218158854

PhD Supervisors: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study:

UCT Human Research Ethics Committee

Ms Lamees Emjedi, Research Ethics Committee

E52 Room 24, Old Main Building, GSH, Observatory, Tel: 021 406 6338

Consent Form for: The Integration of Palliative Care into the Western Cape Health System: Enablers and Obstacles at Meso Level

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 and without any consequence.
3. I agree to participate on the above study.
4. I agree to an audiotape being used to record the FGD.
5. I undertake not to disclose the identity of participants in the focus group and will not divulge the content of the discussion to anyone else.
6. I would like to receive a copy of the research findings: ☐ Yes ☐ No

PARTICIPANT DEMOGRAPHIC INFORMATION

Age: ______________________________ Gender: ____________________________

Job Title: _________________________________ Years in current post: _____________________

Total Years Work Experience in WCG: Health: ____

Current Physical Work Place: ____

_____________________________ _________________________

Participant Name: Signature of Participant

_____________________________ _________________________

Signature of Researcher: Date:

Appendix 8_Informed Consent Form for FGD – Operational and Operations Managers

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Information Sheet for: The Integration of Palliative Care into the Western Cape Health System: Enablers and Obstacles at Operational Level

Dear Participant,

Thank you for giving your time to hear what our study entails. I am a doctoral student at UCT and this information sheet tells you about a study that I would like to invite you to participate in.

What is the purpose of the study?

We are wanting to determine the factors that influence the integration of palliative care into the health system and through analysis we want to gain insight into the operational factors that enable integration or present as obstacles to integration. This will help us improve the way we continue to implement Palliative integration in the Province and enable policy makers to develop robust policy that will enable implementation. We would also like to engage in dialogue to understand what amendments would be necessary to facilitate integration of palliative care into the health system as a whole and then in particular at operational level. We regard your views on this matter as very important and your contribution would be of great value.

The focus group

We would like to invite you to participate in a FGDs looking at how, from an operational perspective, the new palliative care services can work in your sub-district and what you know is needed to ensure that it is operationalised. We are interested in your early lessons or warning signs that you may have encountered to date or are aware of. We would like to include operational and operations Managers for the Community Health Centres (Facility Managers), Community Day Centre Managers in charge, Assistant Managers Nursing, Operational Managers Nursing, Family Physicians and Social Workers at primary health care facilities and district hospitals.

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 focus group at any time without giving us any reason. If you do agree to partake, 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 participate. There are no consequences for non-participation.

What will happen if I take part?

An experienced researcher will facilitate the FGD and an assistant will also be present to take notes. The session will take approximately 1½ hours (an hour and a half) at the very most and will be tape recorded. Refreshments will be served afterwards. This information sheet is for you to keep.

Benefits of this study?

The anticipated benefits are to gain insight into the health system characteristics that are adequately geared to enable palliative care integration and to learn more about what needs to change in order to enable policy decision-making. Ultimately this study may positively influence the future of policy integration in general within the health system.

What are the risks of the study?

There remains the risk that you may feel that a question makes you feel uncomfortable. Whilst we ask you to agree to keeping the identity of the participants confidential and not talk about what was discussed with anyone who did not participate in the focus group, we cannot guarantee that participants will not discuss any details outside of this group.

Will my taking part in this study be kept confidential?

All information which we collect during the focus group session will be captured from the audio recordings and kept strictly confidential. You will not be identified in any way and your personal details will be kept separately from the information provided. We will use a number and not your name on any information that you provide during the FGD. No one outside of the study will have access to the information that you give us. Since this is a group discussion, all participants will be requested to maintain confidentiality.

How will I know about the results of the study?

At the end of the study a report will be available to all people who have participated in the study. You may have some further questions to help you decide whether you want to take part. You can pose any further questions to the researcher or note taker. Please take your time to decide.

Who is organising the research?

If you need to talk to anyone about this research, you can contact the following people.

<u>If you have any question about the study:</u>

Juanita O. Arendse, email: arnjua003@myuct.ac.za, 0218158854

PhD Supervisors: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study:

UCT Human Research Ethics Committee
Ms Lamees Emjedi, Research Ethics Committee
E52 Room 24, Old Main Building, GSH, Observatory
Tel: 021 406 6338

Consent Form for: The Integration of Palliative Care into the Western Cape Health System: Enablers and Obstacles at Operational Level

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 and without any consequence.
3. I agree to participate on the above study.
4. I agree to an audiotape being used to record the FGD
5. I undertake not to disclose the identity of participants in the focus group and will not divulge the content of the discussion to anyone else
6. I would like to receive a copy of the research findings:

Yes	No

PARTICIPANT DEMOGRAPHIC INFORMATION

Age: ______________________________ Gender: ________________________

Job Title: ____________________________ Years in current post: ________________

Total Years Work Experience in WCG: Health: ______________________________________

Current Physical Work Place: ____

________________________ ________________________

Participant Name: Signature of Participant

________________________ ________________________

Signature of Researcher: Date:

Appendix 9_Informed Consent Form for FGD – Hospice and ICF Management

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

Information Sheet for: The Integration of Palliative Care into the Western Cape Health System: Expectation from the Health System: Meso Level External Stakeholders

Dear Participant,

Thank you for giving your time to hear what our study entails. I am a doctoral student at UCT and this information sheet tells you about a study that you may wish to take part in.

What is the purpose of the study?

We are looking to determine the factors that influence the integration of palliative care into the health system and through analysis gain insight into the enablers and obstacles to integration that will allow policy makers to develop robust policy that will enable implementation and will help us improve the way we continue to implement Palliative integration in the Province. Since the hospices and intermediate care facilities have historically taken responsibility for and are experienced in palliative care, we consider your opinion to be invaluable to gaining the insights we require in order to move forward.

The focus group

We would like to invite you to participate in two FGDs looking at the implementation of palliative care services at primary care level and how you envisage your relationship and engagement with these facilities. We are also interested in understanding what you think is needed in the health system to ensure palliative care services are integrated into the services and also what you would consider to be enablers and obstacles to the integration of palliative care into the routine public sector services.

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 focus group at any time without giving us any reason. If you do agree to partake, 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 participate. There are no consequences for non-participation.

What will happen if I take part?

An experienced researcher will facilitate the FGD and an assistant will also be present to take notes. The session will take approximately 1½ hours (an hour and a half) at the very most and will be tape recorded. Refreshments will be served afterwards. This information sheet is for you to keep.

Benefits of this study?

The anticipated benefits are to gain insight into the health system characteristics that need to be adequately geared to enable palliative care integration and to learn more about what needs to change in order to enable policy decision-making.

What are the risks of the study?

There remains the risk that you may feel that a question makes you feel uncomfortable. Whilst we ask you to agree to keeping the identity of the participants confidential and not talk about what was discussed with anyone who did not participate in the focus group, we cannot guarantee that participants will not discuss any details outside of this group.

Will my taking part in this study be kept confidential?

All information which we collect during the focus group session will be captured from the audio recordings and kept strictly confidential. You will not be identified in any way and your personal details will be kept separately from the information provided. We will use a number and not your name on any information that you provide during the FGD. No one outside of the study will have access to the information that you give us.

Since this is a group discussion, all participants will be requested to maintain confidentiality.

How will I know about the results of the study?

At the end of the study a report will be available to all people who have participated in the study.

You may have some further questions to help you decide whether you want to take part. You can pose any further questions to the researcher or note taker. Please take your time to decide.

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 question about the study:

Juanita O. Arendse, email: arnjua003@myuct.ac.za, 0218158854

PhD Supervisors: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study:

UCT Human Research Ethics Committee

Ms Lamees Emjedi, Research Ethics Committee

E52 Room 24, Old Main Building, GSH, Observatory

Tel: 021 406 6338

Consent Form for: The Integration of Palliative Care into the Western Cape Health System: Enablers and Obstacles at Meso Level

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 and without any consequence.
3. I agree to participate on the above study.
4. I agree to an audiotape being used to record the FGD
5. I undertake not to disclose the identity of participants in the focus group and will not divulge the content of the discussion to anyone else.
6. I would like to receive a copy of the research findings:

Yes	No

PARTICIPANT DEMOGRAPHIC INFORMATION

Job Title: ______________________ Years in current post: ______________________

Work Experience in Palliative Care: ______________________

Name of Organisation: ______________________

HPCA Member:

Yes	No

______________________ ______________________

Participant Name: Signature of Participant

______________________ ______________________

Signature of Researcher: Date:

Chapter 6: Experience of Palliative Care Implementers

Appendix 10_Criteria for the Identification of the Implementers

The sub-structure management teams for Mitchells Plain and Eastern sub-districts will be engaged and requested to assist in identifying implementers who will be approached to participate in this sub-study, by the researcher.

Should the implementers agree to participate, their participation in a focus group will be required one year after NPFSPC implementation date and after they have been trained in Palliative care.

The target audience for selection will include the following staff categories:

- Professional Nurses
- Clinical Nurse Practitioners
- Medical Officers
- Family Physicians
- Social workers
- Support staff – admin and pharmacy

Each facility participants should comprise of at least 6 or more implementers of which at least 50% of staff trained in and implementing palliative care are represented in the FGD.

The selection criteria will be applied and only implementers that fulfil at least one of the following criteria will be approached for inclusion:

- Implementers who assess patients for palliative care eligibility according to the Supportive and Palliative Care Indicator Tool (SPICT)
- Implementers using referral documents and enrolling patients into support groups
- Implementers convening / conducting support groups for palliative care patients and their family / support buddy
- Implementers who draft palliative care care-plans
- Facility support staff involved in folder management,
- Personnel responsible for the dispensing of medication and
- Clinical staff responsible for the identification for referral to palliative care will also be included.

Appendix 11_FGD Guide: Implementers 1 year following training in- and implementation of palliative care

Welcome and introductions

Many thanks to you all for agreeing to be part of this focus group. As you know this focus group is with the implementers of palliative care services at facility level approximately one year after you have been trained in palliative care and have been implementing the palliative care policy. It is notable that while some of you are clinical staff who have been trained in and render palliative care services, others are facility support staff (administration and pharmacy) and clinical staff who are not implementing palliative care, but are identifying and referring potential clients.

Our focus for discussion is on your experience thus far in order to determine the factors that influence policy implementation. We are interested in understanding what has enabled you to implement and integrate palliative care services and what has been a barrier to do so. We want to know more about your lessons learned and support you may have required.

We also want you to know that all responses are important and that there are no right or wrong answers. All respondents should allow each person an opportunity to share their opinions and / or experiences. The information shared will be kept confidential and cannot be traced back to the respondents.

As you know we will be tape recording the discussion. Is that OK with everyone? Anyone have a query about the purpose of the focus group or how it will run?

I am then going to start the tape recording. Ok? (switch on recorder)

Opening question:

Can anyone start off by sharing their journey in palliative care over the last year

Introductory question:

Has the training in palliative care been beneficial for you to adequately manage patients who are eligible for palliative care?

Transition question:

What support did you require from your managers and have you received that?

Key Questions:

- Share with us about the things that make you uncomfortable regarding palliative care?
- Could you also share with us more about what made it easy for you to apply your new knowledge and skills in Palliative Care in this facility.
- How do you feel about Morphine prescribing?
- (Showing them the Health System Characteristics and clarifying these – ask) What needs to change to within the health system in order to improve the integration of palliative care?
- In your area of influence, what would you change that would facilitate the integration of palliative care into the health system?
- How does your relationship with the facility management affect your ability to implement this new intervention?

- How would you describe your relationships with external stakeholders (including CHWs) and how does this influence the integration and provision of palliative care service?
- How are you measuring whether things are changing? What indicators will add value?
- What else should change within the health system that you believe is crucial in making the integration of palliative care into the health system, a reality?

Appendix 12_In-Depth Interview Guide (Draft): Operational and Operations Managers Mitchells Plain and Eastern Sub-District

Welcome and Introductions

Thank you for being willing to participate in this in-depth interview. As you know, palliative care policy was launched in Oct 2018 and along with your teams this policy has been implemented into the existing public health services.

We want to understand how the new palliative care services have been working and what your role has been in ensuring this. In addition to this we would like to further explore some information that has presented itself during this study and gain your opinion on this.

We also want you to know that all responses are important and that there are no right or wrong answers. Everyone should allow others an opportunity to share their opinions and / or experiences. The information shared will be kept confidential and cannot be traced back to the respondents.

As you know we will be tape recording the discussion. Is that OK with you?

Do you have any questions?

I am then going to start the tape recording. Ok? (switch on recorder)

Opening question:

May you share with me about your accountability roles and responsibilities as an Operations Manager

Introductory question:

What do you know about Palliative Care and how has your role changed since the policy launch?

Transition question:

What has been your experience with palliative care roll-out since the launch?

Key Questions:

- How have you structured your support to the implementers within your area of influence?

- Have you received the support you expected from the sub-structure and sub-district level?

- What has your experience been regarding the integration of palliative care?

- What has changed regarding the health system characteristics for palliative care to be integrated?
  - Governance and Stewardship: performance management of staff
  - Finance: opportunities for rethinking budgets and historical decision-making
  - Planning: needs assessment and priority setting; training in palliative care
  - Service Delivery: Human resources, Operational integration, supply chain management
  - M & E: data collection and analysis
  - Demand Generation: population interventions – what is appropriate?

Note that this in-depth interview guide will be further refined after the FGDs held with Implementers has provided information that requires further exploration.

Appendix 13_Informed Consent Form for FGDs: The Implementers

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Information Sheet for Implementing Clinical Support Teams to determine the factors influencing the implementation of the palliative care policy

Dear Participant,

Thank you for giving your time to hear what our study entails. I am a doctoral student at UCT and this information sheet tells you about a study that you may wish to take part in.

What is the purpose of the study?

We are looking to explore the factors that influence the integration of palliative care at the coalface (facility level). During this study we want to gain a deeper understanding of the factors that influence the application of knowledge and skills in palliative care into practice, as well as whether perceptions and culture play a role in this. In addition, we want to gain insight into what your experience has been with implementing and integrating palliative care into your practices and to learn from this. Since you are key role-players, we highly value your opinion in this regard.

The focus group

We would like to invite you to participate in two FGDs looking at your experience thus far in order to determine the factors that influence policy implementation. We are interested in understanding what has enabled you to implement and integrate palliative care services and what has been a barrier to do so. We want to know more about your lessons learned and support you may have required. We will be including clinical staff categories who are trained and involved in providing palliative care services, as well as facility support staff (administration and pharmacy) and clinical staff who are not implementing palliative care, but are identifying and referring potential clients.

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 focus group at any time without giving us any reason. If you do agree to partake, 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 participate. There are no consequences for non-participation.

What will happen if I take part?

You will be invited to participate in a FGD which will be facilitated by an experienced researcher and an assistant who will also be present to take notes. This session will take approximately 1½ hours (an hour and a half) at the very most and will be tape recorded. Refreshments will be served afterwards. This information sheet is for you to keep.

Benefits of this study?

The anticipated benefits are to gain insight into the level of support and guidance required to implement the palliative care policy and possibly any policy that is expected to be implemented within the health system.

What are the risks of the study?

Your participation in the focus groups will remain anonymous but there remains the risk that you may feel that a question makes you feel uncomfortable. Whilst we ask you to agree to keeping the identity of the participants confidential and not talk about what was discussed with anyone who did not participate in the focus group, we cannot guarantee that participants will not discuss any details outside of this group.

Will my taking part in this study be kept confidential?

All information which we collect during the focus group session will be kept strictly confidential. You will not be identified in any way and your personal details will be kept separately from the information provided. We will use a number and not your name on any information that you provide during the surveys and FGD. No one outside of the study will have access to the information that you give us. Since this is a group discussion, all participants will be requested to maintain confidentiality.

How will I know about the results of the study?

At the end of the study a report will be available to all people who have participated in the study.

You can pose any further questions to the myself or note taker. Please read this and take your time to decide.

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 question about the study:

Juanita O. Arendse, email: arnjua003@myuct.ac.za, 0218158854

PhD Supervisors: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study:

UCT Human Research Ethics Committee

Ms Lamees Emjedi, Research Ethics Committee, E52 Room 24, Old Main Building, GSH, Observatory

Tel: 021 406 6338

Consent Form: To determine the factors influencing the implementation of the palliative care policy amongst implementers and support teams

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 and without any consequence.
3. I agree to participate on the above study.
4. I agree to an audiotape being used to record the FGD.
5. I undertake not to disclose the identity of participants in the focus group and will not divulge the content of the discussion to anyone else
6. I would like to receive a copy of the research findings:

Yes	No

PARTICIPANT DEMOGRAPHIC INFORMATION

Age: ______________________________ Gender: ________________________

Job Title: ____________________________ Years in current post: __________________

Total Years Work Experience in WCG: Health: _________________________________

Current Physical Work Place: ____

________________________ ________________________

Participant Name: Signature of Participant

________________________ ________________________

Signature of Researcher: Date:

Appendix 14_Informed Consent Form for In-Depth Interviews – Operational and Operations Managers

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Information Sheet for: The Integration of Palliative Care into the Western Cape Health System: Experience of Palliative Care Implementers

Dear Participant,

Thank you for giving your time to hear what our study entails. I am a doctoral student at UCT and 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 pose any further questions to the researcher or note taker.

Please take your time to decide.

What is the purpose of the study?

We have engaged palliative care implementers in the form of FGDs, approximately one year after having been trained in and providing palliative care services. Through this we have gain insight into some of the factors that enable integration or present as obstacles to integration. This information and what we gain from engaging you, will allow policy makers to develop robust policy that will enable implementation and will help us improve the way we continue to implement Palliative integration in the Province. In addition to this, we would like to engage in dialogue regarding some of the outcome measures as well as to further explore some information that has presented itself during this study and gain your opinion on this. Essentially, we need to understand your experiences and the possible changes that may have been necessary to facilitate integration of palliative care into the health system and in particular at operational level.

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 focus group at any time without giving us any reason. If you do agree to partake, 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 participate. There are no consequences for non-participation.

What will happen if I take part?

An experienced researcher will speak to you and ask you questions about your experience of the implementation and integration of palliative care services thus far. The session will take approximately an hour and will be tape recorded. Refreshments will be provided after the interview. This information sheet is for you to keep.

Benefits of this study?

The anticipated benefits are to gain insight into the health system characteristics that are adequately geared to enable palliative care integration and to learn more about what needs to change in order to enable policy decision-making. Ultimately this study may positively influence the future of policy integration in general within the health system and allow for a framework to be adapted to determine extents of integration achieved.

What are the risks of the study?

There remains the risk that you may feel that a question makes you feel uncomfortable. The answers and opinions that you provide will remain confidential.

Will my taking part in this study be kept confidential?

All information which we collect during the in-depth interviews will be kept strictly confidential. You will not be identified in any way and your personal details will be kept separately from the information provided. We will use a number and not your name on any information that you provide during the in-depth interview. No one outside of the study will have access to the information that you give us.

How will I know about the results of the study?

At the end of the study a report will be available to all people who have participated in the study.

You can pose any further questions to the myself or note taker. Please read this and take your time to decide.

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 question about the study:
Juanita O. Arendse, email: arnjua003@myuct.ac.za, 0218158854
PhD Supervisors: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study:

UCT Human Research Ethics Committee
Ms Lamees Emjedi, Research Ethics Committee
E52 Room 24, Old Main Building, GSH, Observatory
Tel: 021 406 6338

Consent Form for: The Integration of Palliative Care into the Western Cape Health System: Experience of Palliative Care Implementers

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 and without any consequence.
3. I agree to participate on the above study.
4. I agree to an audiotape being used to record the in-depth interview
5. I undertake not to disclose the identity of participants in the focus group and will not divulge the content of the discussion to anyone else
6. I would like to receive a copy of the research findings:

Yes	No

PARTICIPANT DEMOGRAPHIC INFORMATION

Age: ________________________ Gender: ________________________

Job Title: ________________________ Years in current post: ________________

Total Years Work Experience in WCG: Health: ________________________

Current Physical Work Place: ________________________________

________________________ ________________________

Participant Name: Signature of Participant

________________________ ________________________

Signature of Researcher: Date:

Appendix 15_In-Depth Interview Guide: Experienced Support Group Patients and their Families or Support Group Buddies

Welcome and Introductions

Thank you for being willing to participate in this in-depth interview. As you know, palliative care services are relatively new in the health service and we want to make sure that your needs are being met.

We want to understand how the new palliative care services are working and most importantly whether these services are fulfilling your needs and expectations.

We also want you to know that all responses are important and that there are no right or wrong answers. The information shared will be kept confidential and cannot be traced back to any of the respondents.

As you know we will be tape recording the discussion. Is that OK with you?

Do you have any questions?

I am then going to start the tape recording. Ok? (switch on recorder)

Opening Question

What do you understand when you hear the term Palliative Care?

Introductory Question

What does Palliative Care mean to you?

Transition Question

Walk me through your Palliative Care journey thus far.

Key Questions

- What have you received in this support group?

- Has this journey thus far met with your initial expectations?

- What should change in order to improve your experience?

- What has been your highlight or best experience thus far within the support group?

APCA African IPOS questionnaire will follow.

Appendix 16_Informed Consent Form for In-Depth Interviews – Patients and Families or Buddies in Support Groups

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Dear Participant,

Thank you for giving your time to hear what our study entails. I am a doctoral student at UCT and this information sheet tells you about a study that we would like to invite you to participate in.

What is the purpose of the study?

Palliative care services are relatively new in the health service and we want to make sure that people's needs are being met. We are also looking into the way the new palliative care services are working. Most important is whether these services are fulfilling the needs and expectations of beneficiaries of the services – which are patients and their families. Your perspectives and opinions about this would be so valued and we would be so grateful if you participate.

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, 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 your experience of the service so far, as well as what you expect going forward. The session will take about 30 minutes and will be tape recorded. We also want to find out what your symptoms are and if these have been controlled and want to ask you a set of questions that will be filled in on a form. Refreshments will be provided after the interview or, if required, during the interview. This information sheet is for you to keep.

Benefits of this study?

The expected benefits are to identify and understand your care needs. This may help us improve on providing health care services to people with health issues like your own in the future.

What are the risks of the study?

There is the risk that you may feel that a question makes you feel uncomfortable. If any question causes you to become upset, the researcher will stop the study and ask if you need any help or would like to take a break.

Will my taking part in this study be kept confidential?

All 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 provide to us for this study. We will also not inform your doctor or nurse that you have participated in the study. We will use a number and not your name on any information that you provide during the in-depth interview.

For patients in this study we will record your illness and this will be treated as confidential like all your other information that you give to us. No one outside of the study will have access to the information that you give us and no one will be able to identify you.

How will I know about the results of the study?

At the end of the study a report will be available to the clinic / out-patient department and to all people who have participated in the study.

You may have some further questions to help you decide whether you want to take part. You can pose any further questions to the researcher or note taker. Please take your time to decide.

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 question about the study:

Juanita O. Arendse, email: arnjua003@myuct.ac.za, 0218158854

PhD Supervisors: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study:

UCT Human Research Ethics Committee
Ms Lamees Emjedi, Research Ethics Committee
E52 Room 24, Old Main Building, GSH, Observatory, Tel: 021 406 6338

Consent Form for: Patients and Families or Buddies in Support Groups

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 and without any consequence.
3. I agree to participate on the above study.
4. I agree to an audiotape being used to record the in-depth interview.
5. I would like to receive a copy of the research findings:

Yes	No

PARTICIPANT DEMOGRAPHIC INFORMATION

Name :____

Signature : ______________________ Date : ____________________

______________________ ____________________

Signature of Researcher: Date:

Witness Name:____

(from clinical team or family member or buddy)

Signature : ______________________ Date : ____________________

Annexures

Annexure 1 : Palliative Care Mini Review Questionnaire

Name of “Mother” institution: ……………………………………………………………………………..

Tertiary Hospital	**Secondary Hospital**	**District Hospital**	**Stand Alone in CBS**

Name of Hospice / Palliative Care facility: ………………………………………………………………..

Responsible Manager: ………………………………………………………………………………………...

Sub-District: ………………………………………… District: ……………………………………………

Outputs:

Total Number of Adult Beds	**Adult female beds**	**Adult male beds**
Paediatric beds	**Isolation beds for IPC**	**Dedicated End-of-life beds**
ALOS	**Admissions per month**	**Discharges per month**
Deaths per month	**Deaths without PC consultation**	**Deaths with PC consultation**

Description of the Level of Palliative Care offered at this facility:

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Staff complement and their training:

Category of Staff	**# in employ / supporting facility**	**Training on Palliative Care (Training Institution and Duration)**
Medical Officers		
Registered Nurses		
Enrolled Nurses		
Enrolled Nursing Assistants		
Carers		
Social Workers		
Spiritual Counsellors		
Other: Specify		
Other: Specify		

Description of the link with the institution / facility, in which the hospice resides, i.e. regarding support with laundry, meals, specialists, etc:

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Description of the link with other health facilities in the Geographic Service Area within which the hospice resides:

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Describe the Specialist Support across appropriate disciplines that the Hospice / Palliative Care facility can access:

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Describe the referral process into this facility:

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Do you offer Home Based Palliative Care Services:

Yes / No

Describe the HBPC services that you offer:

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Alignment of HBPC services with the local Community Based Services within the District Health Services platform:

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When clients are referred for terminal care from a WCG (DoH) facility, has the client and family been informed and counselled accordingly or is there an expectation that the Hospice / Palliative Care facility should ensure that this happens?

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Do you find that you receive clients who should have been referred a while back?

Yes / No

Why do you feel there was a delay? What, in your opinion, are the possible reasons?

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Do you find that clients have a delay in accessing care at your facility?

Yes / No

Why do you feel there was a delay? What, in your opinion, are the possible reasons?

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What would you propose as a solution/s for this challenge?

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List your top 5 frustrations regarding clients that are referred into your facility from the WCG: DoH:

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5. ……………………………………………………………………………………
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Funding Sources:

DoH	Other donors	Fundraising	Monthly running cost	Annual running cost

General Comments:

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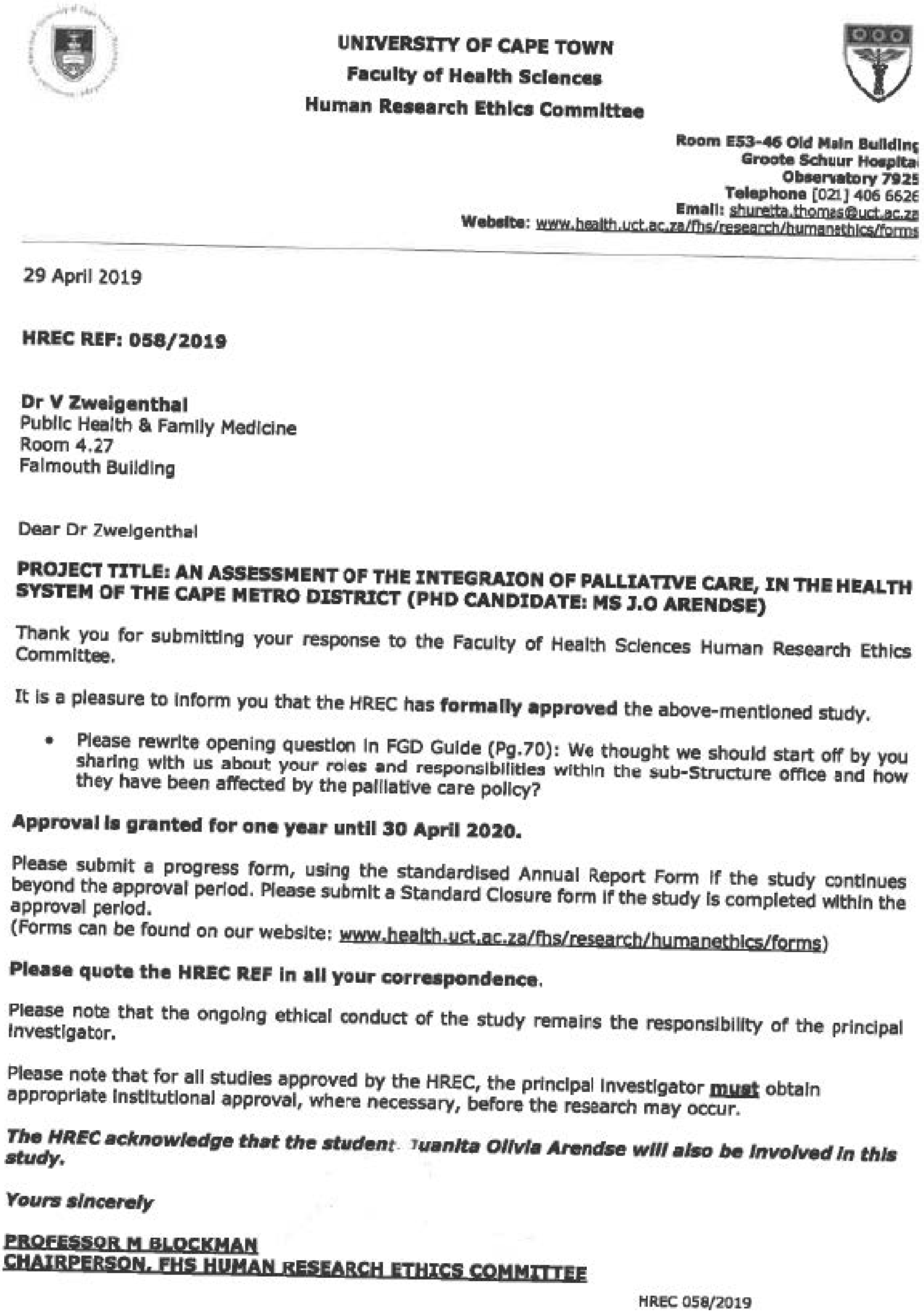
Annexure 2: Ethics Approval – 29 April 2019



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospita
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

29 April 2019

HREC REF: 058/2019

Dr V Zweigenthal
Public Health & Family Medicine
Room 4.27
Falmouth Building

Dear Dr Zweigenthal

PROJECT TITLE: AN ASSESSMENT OF THE INTEGRAION OF PALLIATIVE CARE, IN THE HEALTH SYSTEM OF THE CAPE METRO DISTRICT (PHD CANDIDATE: MS J.O ARENDSE)

Thank you for submitting your response to the Faculty of Health Sciences Human Research Ethics Committee.

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

- Please rewrite opening question in FGD Guide (Pg.70): We thought we should start off by you sharing with us about your roles and responsibilities within the sub-Structure office and how they have been affected by the palliative care policy?

Approval is granted for one year until 30 April 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

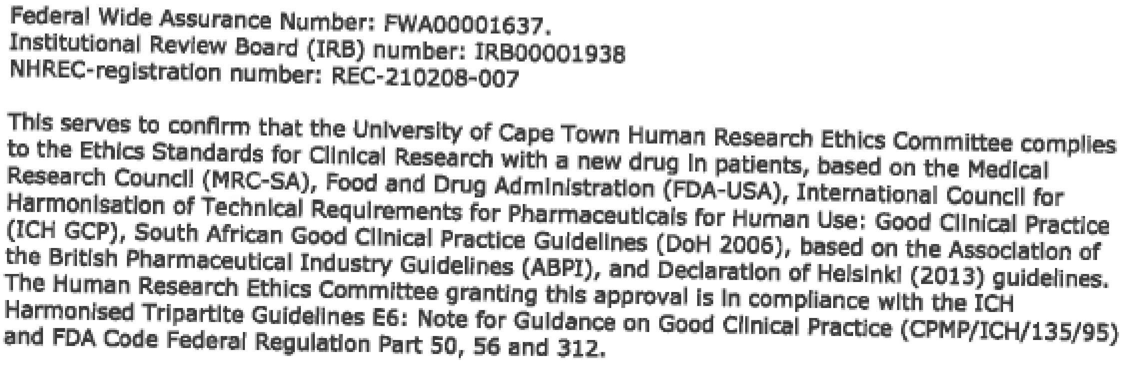
Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student Juanita Olivia Arendse will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

HREC 058/2019



Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Annexure 3: Distress Protocol

The distress protocol that will be used for this sub-study is as follows and is adopted from the Hospice Palliative Care Association and adapted.

Patients will not be recruited until a counsellor and clinician has provided consent to provide support if required.

- All participants will be fully informed as to the nature of the issues to be in the interview.
- Any respondent who appears to become emotionally or physically distressed will be offered the opportunity to stop the interview
- Respondents will be asked if they would like to either abandon or to restart when they are comfortable.
- The interviewer will offer referral to counselling staff if the patient is emotionally distressed, or to the clinician if physically distressed.
- All information will be confidential except in the situation of the patient's safety being at risk, in which case the information may be acted upon.

REQUEST YOUR SUPPORT IN ASSISTING WITH THE DISTRESS PROTOCOL

Dear Facility Manager,
I am a doctoral student at UCT and am writing to request your support in the provision of clinical care / counselling services at your facility.

Palliative Care services are relatively new in the public health sector, and the purpose of this study is to gain insight into whether the needs of the patient and their family or support buddy, are met. We also want to investigate how the new palliative care services are functioning and more importantly whether these services are fulfilling their needs and expectations.

In-depth interviews will be conducted with the patients and their family or support buddy. While conducting this, there is the risk that the patient may feel that a question makes them feel uncomfortable or upset. If this does happen the interview will stop, and the patient will be asked whether he/she needs any help or would like to take a break.

The distress protocol is explicit in that support to any patient experiencing emotional or physical distress, should be attended to by an appropriate competent individual that is easily accessible and this is the reason for requesting your support in identifying a clinician and a counsellor who can be approached to provide this kind of support and care should the need arise. Should they agree to assist, they will be requested to provide consent. Kindly note that patients will not be recruited until permission has been obtained from the appropriate clinician / counsellor.

Should you have any concerns or questions regarding this study, you can contact me on the following email address: arnjua003@myuct.ac.za or telephonically on 0218158854.

My supervisors are Dr Virginia Zweigenthal and Professor Liz Gwyther and their contact information is as follows: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study please feel free to contact the UCT Human Research Ethics Committee, Ms Lamees Emjedi at E52 Room 24, Old Main Building, GSH, Observatory, Tel: 021 406 6338.

Kind regards,

Juanita O. Arendse

REQUEST YOUR SUPPORT IN ASSISTING WITH THE DISTRESS PROTOCOL

Dear Dr / Social Worker / Other,

I am a doctoral student at UCT and am writing to request your support as a professional involved in the provision of clinical care / counselling services at your facility.

Palliative Care services are relatively new in the public health sector, and the purpose of this study is to gain insight into whether the needs of the patient and their family or support buddy, are met. We also want to investigate how the new palliative care services are functioning and more importantly whether these services are fulfilling their needs and expectations.

In-depth interviews will be conducted with the patients and their family or support buddy. While conducting this, there is the risk that the patient may feel that a question makes them feel uncomfortable or upset. If this does happen the researcher will stop the study and ask the patient if he/she needs any help or would like to take a break. Should the patient require assistance, you will be contacted immediately to kindly assist.

The distress protocol is explicit in that support to any patient experiencing emotional or physical distress, should be attended to by an appropriate competent individual that is easily accessible and this is the reason for requesting your support in the event that it is required.

Should you have any concerns or questions regarding this study, you can contact me on the following email address: arnjua003@myuct.ac.za or telephonically on 0218158854.

My supervisors are Dr Virginia Zweigenthal and Professor Liz Gwyther and their contact information is as follows: Dr Virginia Zweigenthal, Virginia.Zweigenthal@uct.ac.za

Professor Liz Gwyther, Liz.Gwyther@uct.ac.za

If you have any questions about your human rights or any ethical issues about the study please feel free to contact the UCT Human Research Ethics Committee, Ms Lamees Emjedi at E52 Room 24, Old Main Building, GSH, Observatory, Tel: 021 406 6338.

Should you agree to support the patients who may require support during this study, you will be expected to complete the following consent form.

Kind regards,

Juanita O. Arendse

CONSENT TO PROVIDE SUPPORT ALIGNED TO THE DISTRESS PROTOCOL

I confirm that I am able and agree to provide counselling / medical (circle) support in the event that this is required by the patient participating in this research sub-study.

I confirm that I have read and understand the information regarding this distress protocol that has been provided to me.

STAFF MEMBER DETAILS :

Name :______________________________Designation : ____

Signature : ______________________________ Date : __________________________

Witness Name:____
(Operational or Facility Manager)

Designation: ____

Signature : ______________________________ Date : __________________________

______________________________ __________________________

Signature of Researcher: Date:

Annexure 4: Matrix Proposal for Integration with Categorisation

Methodological Flow for the development of this iteration of the Matrix Tool:

Steps followed	**Process of developing the Matrix Tool**	**Stage of the study**
Literature Review	Engage Atun et al.[8] proposed elements to assess the extent of integration into the general health system	Planning (2018)
	Review of the Integration study conducted by Mayhew,[102] considering the hardware and software that make for integration.	
Draft 0 Matrix Tool	As part of proposal for this PhD, a draft matrix tool was developed based on Atun et al.[8] and Mayhew and included health system characteristics and adoption system elements	Proposal (2018)
PhD sub-studies	Sub-studies 1, 2, 3 and 4: - Data Collection - Data Analysis - Results	Research (2019 – 2021)
Draft 1 Matrix Tool	Draft 1 matrix tool further refined to include the results from the PhD studies	2021
Further Literature Review	Literature review conducted on the use of Atun et al.'s[8] conceptual framework and proposed iterations[104, 106, 108, 251104, 106, 108, 251104, 106, 108, 251104, 106, 108, 251104, 106, 108, 251104, 106, 108, 251]	2021
Consultation 1	Expert consultative group comprising key members from the PCTT were consulted to comment and review Draft 1.	2022
Draft 3 Matrix Tool	Inputs from the expert consultative group and further literature review included	2022
Email circulation for comment	Circulation to expert team for further comment and edits	2022
Draft 4 Matrix Tool	Draft 4 included next level of comments from experts	2022
Consultation 3	Consultative panel comprising national department of health senior managers and national palliative care coordinator	2022
Final matrix tool Annexure 4	Ready for further validation and piloting	2022

Cover Sheet:

Matrix Tool to Assess the extent and nature of Integration of the Palliative Care Policy

General Information Regarding the Tool

This tool is an iteration of the work done by Dr Rifat Atun etal and following four PHD studies and consultation with an Expert Consultation Panel in WC and the NDoH.

This tool is intended for application at all levels within the Health System, i.e. National, Provincial, District or Sub-Structure, District- Regional- & Tertiary Institutions, Primary HC facilities.

This tool is NOT a CLINICAL audit, but a tool for assessing extent of integration within the Health System

In preparation for the assessment

i.	**Determine the intervention or policy** that is being analysed / assessed for integration			
ii.	**Agree on the geographic area and institutions** that will be included in the analysis / assessment			
iii.	**Identify the team** who will form part of the assessment of integration of the Palliative Care policy within the health system			
iv.	**Ensure training** for all team members on the policy in question and the use of the tool			
v.	Score each element:		No Integration = 0	
			Partial Integration = 1	
			Full Integration = 2	
			Not Applicable	Use the comments column to indicate an element that is not applicable and indicate why
iv.	Scores will **automatically calculate**			
v.	Score Legend:	<22	No integration RANGE	
		22 to 43	Partial Integration RANGE	
		44 to 66	Full integration RANGE	
vi.	Proposed response to score outcome:			**No integration** = Management Team re-engage around the policy and determine support required
				Partial Integration = Develop plan of action and define support required
				Full integration = Determine review period with management teams

Instructions and Guide:

Instructions and Guide on scoring for each element:

Health System Characteristics

1.	Stewardship & Governance	Accountability functions	Determine the existing governance frameworks or arrangements at all levels.
			0 = policy has been officially communicated; information is exchanged and readily available; no integration into existing governance framework;
			1 = coordination has commenced and policy is being engaged; not yet formally included into all governance framework/s
			2 = policy included in all governance frameworks at applicable level/s of assessment
2.		Reporting	Determine the reporting requirements for the entire geographic area
			0 = palliative care not included in routine monthly, quarterly & annual reports
			1 = palliative care reported on as a project and / or as part of some routine reports
			2 = palliative care reported as part of all routine reports
3.		Performance Management	Determine the denominator of all relevant staff at all levels in the health system, who should have Palliative Care included in their Performance Plans.
			0 = palliative care only included in performance plans of clinical staff working in environments that are considered for Palliation or End of Life
			1 = palliative care included in the performance plans of 50% of all relevent managers and clinical & support staff
			2 = palliative integrated and defined as part of UHC in all relevant performance agreements
4.	Financing	Pooling of funds	Finance staff at appropriate level within the health system to complete this section
			0 = palliative care not considered in any budgets or only as part of ring-fenced funding with zero tolerance
			1 = budget made available for palliative care big ticket items as a ring-fenced allocation AND spend allowed within equitable share budgets as well
			2 = palliative care budget needs accommodated as part of the equitable share and conditional budgets
5.		Provider payment methods	Finance staff at appropriate level within the health system to complete this section
			0 = existing provider payment methods do not yet accommodate palliative policy needs
			1 = existing provider payment methods not yet applied in all programmes and sub-programmes
			2 = existing provider payment methods accommodate all service providers including those supporting palliative care. SCOA codes make provision for palliative care expenditure allocations. NPO funding finance instructions includes palliative care policy.

6.	Planning	Needs assessed	Operational MESO team or Institutional Mx team to engage and determine the extent of inclusion of the listed variables
			0 = needs assessment & related decision-making is focused solely on the intervention (palliative care) without consideration of general health care activities
			1 = needs assessment conducted centrally by programmes component or those who manage the policy space
			2 = needs assessment conducted by stakeholders who conduct same for general health care services
7.		Priority Setting	Determine the denominator of all operational plans within the geographic area or institution
			0 = palliative care not included in any discussions regarding priority setting
			1 = palliative care included in priority setting discussions and / or included in some operational plans
			2 = palliative care included in all operational plans
8.		Resource Allocation	Finance and management teams within the health system to complete this section
			0 = resource allocation focused on programme / policy needs and not considering general health care activities
			1 = resource allocation conducted centrally by policy makers and programme teams
			2 = resource allocation conducted by stakeholders who conduct same for general healthcare services
9.	Service Delivery	Structural	Operational MESO team or Institutional Mx team to engage and score
			0 = Palliative care services not included in the package of care at every healthcare facility
			1 = Palliative care offered by a trained team within the general healthcare services while clinical teams are in training
			2 = Palliative care offered as part of comprehensive package of care in all institutions & facilities
10.		Human Resources	Operational MESO team or Institutional Mx team to engage and score
			0 = Clinicians not offering palliative at the facility or institution
			1 = A clinical team within the bigger clinical team offer palliative care in the facility / institution
			2 = Clinical staff see all patients including the patient in need of palliative care and include these patients as part of the MDT discussions
11.		Shared Infrastructure	Operational MESO team, Facilities infrastructure Mx and Institutional Mx team to engage and score
			0 = policy not offered in the existing infrastrutcure
			1 = existing infrastructure utilised for new policy
			2 = policy needs included in new infrastructure planning; palliative care offered in existing infrastructure as for general health care services
12.		Operational Integration	Operational MESO team or Institutional Mx team to engage and score
			0 = palliative care patient not identifiable and channeled via the general care pathway
			1 = palliative care patient clearly identified and channeled to palliative care team
			2 = palliative care patient clearly identified and channeled through the general system based on acuity
13.		Referral and Counter-referral systems	Operational MESO team or Institutional Mx team to engage and score
			0 = no clear referral pathway and mechanism defined for the paliative care patients
			1 = palliative care patients are referred from palliative care team to palliative care team
			2 = all patients including palliative care patients are included in standard referral mechanisms (VULA; CAReS; Referral Letters; Telephonic referals; Email referrals) with due consideration for the ecosystem which includes the NPO sector
14.		Guidelines or care pathways	Operational MESO team or Institutional Mx team to engage and score
			0 = palliative care pathway and guideline are standalone and unique
			1 = palliative care patient pathway aligned and guidelines are standalone and contradict general guidelines
			2 = palliative care patients part of standard care pathway for general patients and palliative care guideline aligned to general patient guidelines
15.		Procurement	Supply Chain Management teams to complete
			0 = mini contracts and buy-outs in place for specific palliative care policy items
			1 = SCM SOPs and procurement systems accommodate palliative care, BUT end-users not aware of these
			2 = SCM SOPs and procurement systems accommodate all palliative care policy needs & contract notices have been communicated to end-users
16.		Supply Chain Management	Supply Chain Management teams to complete
			0 = policy related items, equipment, training etc, not accommodated in the SCM SOPs and standalone SOPs required and in place
			1 = Some institutions function on internal / standalone SOPs for palliative care items, equipment, training, etc; while others have aligned to departmental SCM SOPs
			2 = policy requirements included in all SCM SOPs
17.	Monitoring & Evaluation	Information technology infrastructure	Information Management teams to engage and complete
			0 = palliative care data collected and submitted via a programmatic process and not through the mainstream system
			1 = palliative care policy data flows through the mainstream system but patient level data is not accessible on the IT Infrastructure
			2 = Palliative care policy is monitored in the mainstream system, by the same responsible individuals and patient level data for palliative care patients can be accessed on the same relevant (e.g. SPV, Clinicom & PHCIS) IT infrastructure.
18.		Data collection and analysis	Information Management teams to engage and complete
			0 = palliative care data collection and analysis in discussion phase
			1 = palliative care episodes and cascades in progress of development
			2 = departmental dashboards for palliative care episodes and cascades available as with all other priority conditions
19.	Demand Generation	Ideal Clinic Signage	Operational MESO team or Institutional Mx team to engage and score
			0 = no signage communicating palliative care services visible and in place
			1 = ideal clinic signage not yet inclusive pf palliative care but notices are in place
			2 = palliative care communicated as part of health facility package of care on Ideal Clinic approved signage
20.		IEC materials & Activities	Operational MESO team or Institutional Mx team to engage and score
			0 = No IECs for palliative care available
			1 = IEC materials on palliative care are availlable, but not included in general health related activities coordination has commenced and policy is being engaged; not yet formally included into all governance framework/s
			2 = IEC materials on palliative care available and included in general health related activities
21.		Population interventions	Operational MESO team or Institutional Mx team to engage and score
			0 = no health media on palliative care
			1 = health media for palliative care silo'd and not included in packages of care communications
			2 = health media related to packages of care includes palliative care

Adoption System (Actors)			
22.	Policy makers & Policy Implementation Support	Transparent & inclusive policy decision-making process	NDoH; Provincial Service Priorities & / or Health Programmes; Central Hospitals; District Mx Teams
			0 = policy is developed and finalised as part of a central process with limited to no consultation beyond the centre
			1 = consultation process did not include representation from all relevant levels within the health system before the policy decision-making was concluded
			2 = representatives from all relevant levels in the health system are consulted before policy decision-making (new policy, policy reviews, policy translation) is finalised
23.		Initial project management process	Provincial Services Priorities &/or Health Programmes to engage and score
			0 = project plan developed; teams not trained
			1 = project plan developed; teams trained; not yet implemented
			2 = initial project plan in place to steer the policy towards assimilation and eventual integration; teams trained; implemented
24.		Defined Strategy & Guidance	Provincial Services Priorities &/or Health Programmes to engage and score
			0 = provincial strategy on policy not well defined
			1 = provincial strategy on policy is well defined with clear guidelines and not aligned to departmental strategy
			2 = provincial strategy on policy is well defined with clear guidelines and aligned to departmental strategy; formally communicated
25.		Implementation support tools	Provincial Services Priorities &/or Health Programmes to engage and score
			0 = implementation support tools not in use
			1 = tools are developed as stand along policy specific and not aligned or integrated where possible into existing departmental stationery; in use
			2 = tools are developed, aligned & integrated into existing tools where possible; in use
26.	Managers (Decentralised Programme-, Project- & Service Managers)	Leaders as advocates	Determine the number of leaders who are advocates for palliative care against denominator of agreed leaders.
			0 = < 30% of leaders are advocates for palliative care
			1 = 30 - 70 % of leaders are advicates for palliative care
			2 = 70 - 100 % of leaders are advocates for palliative care
27.		Guidance & support plan to operational teams	Operational MESO team or Institutional Mx team to engage and score
			0 = no visits to support palliative care in place
			1 = palliative care support conducted as standalone visits
			2 = palliative care included in managers regular support visits and engagements
28.	Health Care Users	Knowledge of & Acceptance of service	Engage IT support to interrogate the data. Calculate the proportion of patients with palliative care diagnoses who are in care.
			0 = < 30% of patients diagnosed with a palliative care diagnoses are in care at the appropriate level of care
			1 = 30 - 70 % of patients diagnosed with palliative care are in care and at the appropriate level of care
			2 = 70 - 100 % of patients diagnosed with a palliative care diagnoses are in care
29.		Communication	Operational MESO team or Institutional Mx team to engage and score
			0 = no communication mechanism in place for palliative care patients
			1 = communication to palliative patients is separatd from general patients
			2 = communication to all patients are adequate and includes the palliative care patients
30.	Health Care Workers	Employee Health and Wellness	People Management team to asssess this element
			0 = process not yet commenced with EHW service provider
			1 = palliative care related emotional support considered as part of EHW service provider contract; not yet integrated
			2 = contracted EHW service provider includes palliative care related emotional support to clinical teams
31.		Relationships and platforms of engagement	Operational MESO team or Institutional Mx team to engage and score
			0 = no platforms of engagement exist for palliative care
			1 = specific platforms and engagements for palliative care as a vertical programme
			2 = relationship and platforms of engagement built for general patient consultations, discussions, etc, includes the palliative care patient
32.	Greater Community	Partner & Stakeholder Engagements	Operational MESO team or Community Based Services teams to engage and score
			0 = no partners available to support community engagements
			1 = palliative care specific partners engage communities
			2 = partners and stakeholder engagements with the greater community includes palliative care
33.		NGO & Health Facility Collaboration	Operational MESO team or Community Based Services teams to engage and score
			0 = contracted NGO not included in MDT at facility level
			1 = Contracted NGOs are included in MDTs but not yet capacitated to support palliative care patients
			2 = Contracted NGOs are included on facility MDTs and capacitated to provide support to palliative care patients

Tool:

Matrix for Integration Tool with Categorisation						
	Integration Framework Domains			Extent and Nature of Integration		
Element Number	Health System Characteristic / Function	Elements of Integration	Measure	No Integration	Partial Integration	Full Integration
1.	Stewardship and Governance	Accountability functions	Management teams at all levels, coordinate palliative care policy within their existing accountability framework/s (in terms of answerability for performance, financial, & democratic / political functions).	0	1	2
2.		Reporting	Palliative care is included in routine monthly, quarterly & annual reports,as part of the package of care,	0	1	2
3.		Performance Management	Palliative Care, included in the Performance Plans of all relevant Managers and palliative provision of care included in the performance plans of ALL Clinical and Support staff in the client care pathway.	0	1	2
4.	Financing	Pooling of funds	Palliative Care is included in equitable budget and funding aligned to conditional grants supported within the corporate governance space.	0	1	2
5.		Provider payment methods	Provider payment methods are in place to accommodate all service providers including those supporting palliative care. All service providers loaded on relevant finance payment system (BAS, Logis); NPO Funding mechanism is in place for all NPOs	0	1	2
6.	Planning	Needs assessment	Needs assessment and costing exercise conducted for health services includes Palliative Care Policy needs and conducted by the same team/s who conduct these for general health services: i) required costing done to inform **budgets**, ii) **levels of competency** to deliver on policy needs are assessed, iii) **people development** needs assessed and plan in place (aligned to WPSP), iv) **post training support** plan in place, v) **equipment** needs assessed for palliative care policy vi) **infrastructure and physical space** needs assessed for palliative care policy vii) **drug supply needs** assessed for palliative care policy	0	1	2
7.		Priority Setting	Priority setting exercises at all levels within the healthcare system is inclusive of Palliative Care and reflected in all Operational plans.	0	1	2
8.		Resource Allocation	Health system resource allocation includes Palliative Care Policy requirements as determined by the needs assessment cycle of the department and considered alongside the general health service needs.	0	1	2
9.	Service Delivery	Structural	The palliative care services are offered as part of the package of care and responsibility of the general health care workers and at every level are care (Tertiary, Specialised, Regional, District, Primary Healthcare facility) and at the same cost as general health services. The patient flow considers the client in need of palliative care services as it would consider any other client who is assessed and channeled through the health facility or institution based on acuity.	0	1	2
10.		Human Resources	Clinical staff at health facilities include Palliative Care as part of the package of care offered to patients and part of MDT discussions.	0	1	2
11.		Shared Infrastructure	Palliative care services rendered in same physical infrastructure or on the same premises as the public sector hospital. Due consideration for policy (office space, family rooms, end of life care) needs are included in the processes for all new infrastructure project planning.	0	1	2
12.		Operational Integration of Policy	Palliative care policy integrated at operational level. Evidence of patients with palliative care needs being clearly **identified** to facilitate continuity of care within the care pathway. Inclusion of this policy in clinical annual audits (CGE).	0	1	2
13.		Referral & Counter-referral systems	Referral pathway for patients with palliative care needs is aligned to standard referral systems (via VULA or CARes) as for all general patients. The referral mechanisms (clinician to clinician) accommodates these patients to ensure care at the appropriate level of care, based on acuity.	0	1	2
14.		Guidelines or care pathways	Guidelines and care pathways for patients with palliative care needs are aligned to the general care pathways, with due consideration of related guidelines. Similarly other guidelines include palliative care.	0	1	2
15.		Procurement	SCM SOPs and procurement systems accomodate all Palliative Care Policy needs & contract notices, and are communicated to end-users.	0	1	2
16.		Supply Chain Management	Palliative care items, equipment, training etc included in the departmental standard operating procedures on warehousing, institution & facility stores and contract management.	0	1	2
17.	Monitoring & Evaluation	Information technology infrastructure	Palliative care policy is monitored in the same mainstream system, by the same responsible individuals. Patient level data for palliative care patients can be accessed on the same relevant (e.g. SPV, Clinicom & PHCIS) IT infrastructure.	0	1	2
18.		Data collection & analysis	Data collection and analysis forms part of the routine mainstream system with data collection elements clearly defined. (Morphine data, ICD 10 codes, Patients with palliative care needs). Dashboard with episodes / cascades accessible as with other conditions to facilitate planning	0	1	2
19.	Demand Generation	Ideal Clinic Signage	Health facility service package communication includes "Palliative Care"	0	1	2
20.		IEC materials & activities	Information, Education and communication activities and materials on palliative care available for use by all HCWs and included as part of general services activities.	0	1	2
21.		Population interventions	Health media & communication regarding the comprehensive health services and packages of care, is inclusive of Palliative Care	0	1	2
				0	**21**	**42**

Integration Framework Domains			Extent and Nature of Integration		
Adoption System (Actors)	Elements of Integration	Measure	No Integration	Partial Integration	Full Integration
Policy makers & Policy Implementation Support	Transparent & inclusive policy decision-making processes	Representatives from all relevant levels in the health system are consulted before policy decision-making (new policy, policy reviews, policy translation) is finalised. National: consult appropriate reps in all provinces Provincial: consult appropriate reps in all districts and central hospitals District: consult appropriate reps in all sub-districts, institutions and facilities	0	1	2
	Initial project management process	The agreed project plan for a new policy is managed until eventual assimilation & integration into the health system.	0	1	2
	Defined strategy and guidance	Strategy defined, aligned to the departmental strategy and communicated to all managers including operational managers	0	1	2
	Implementation support tools	Policy makers, project management team and programme managers ensure the development of required tools (stationery, tools, clear algorithms) that support implementation and ensure integration where possible.	0	1	2
Managers (Decentralised Programme-, Project- & Service Managers)	Leaders as advocates	Leaders as advocates for new policy driving towards sustainability as it evolves into general comprehensive package of care.	0	1	2
	Guidance & support plan to operational teams	Palliative care included in managers regular support visits and engagements.	0	1	2
Health Care Users	Knowledge of & acceptance of service	Data reflects that patients diagnosed with a palliative care condition are able to access care in general services.	0	1	2
	Communication	A values driven mechanism is in place to communicate changes in services and appointments to palliative care patients, as with all patients	0	1	2
Health Care workers	Employee Health & Wellness	Employee health and wellness contracted provider is informed of the needs aligned to the new policy	0	1	2
	Relationships & platforms of engagement	Relationships built across the health system includes the palliative care client as it would the general client	0	1	2
Greater Community	Partners & Stakeholders engagements	Partners and stakeholder engagements with the greater community includes palliative care	0	1	2
	NGO & Health Facility collaboration	NGO represented on the Multi-disciplinary teams at health facilities for all patients including palliative care clients	0	1	2
			0	**12**	**24**
			0	**33**	**66**

A scoring system was included for each element of integration to assess the extent (no integration = 0; partial = 1; full = 2) of integration. A score range of 44 to 66 indicates full integration across most of the elements of integration for the health system and the adoption system characteristics. These elements would be scored as ‘no Integration’ or ‘partial Integration’ or ‘full Integration’ as indicated in substantial literature.

Annexure 5: WCGHW Internal Documents Reviewed

WCGHW Internal documents were reviewed pertain to palliative care service provision contracted to NGO sector. **Documents that were reviewed**, include the following:

- The **2018 / 2019 NGO Service Package**,[208] is released annually by the WCGHW and defines the service packages for each health service that the WCGHW contracts NGOs to perform. The services and funding norms are reviewed and amended annually based on agreed priorities aligned to the short-, medium- and long-term strategies for the WCGHW, as well as the budget envelope. The seven service priorities funded include HCBC, Intermediate Care, nutrition projects, facility-based counselling, NGO driven wellness centres, community mental health and HIV high transmission area projects. This document forms part of the annual call for proposals made to the NGO sector by the WCGHW.
- **Finance Instruction G38 / 2003**[253] provides the policy position on funding provincial-aided hospitals and the memorandum of agreement that is signed between the District Managers and the Hospital Committees. This funding mechanism affects ICFs.
- **Finance Instruction FA 21 / 2017**[62] is the standard operating procedure for the transfer and subsidies to receiving entities (NGO). This finance instruction refers to all NGO funding transfer payments, irrespective of the type of health service that is aligned to the NGO service package.
- **Intermediate Care Facility (ICF) policy**,[134] indicates the service of package for these facilities that are inclusive of the provision of palliative care.
- **Home and Community Based Care (HCBC) Policy**[254] describes the package of care for this service rendered in the community and in the patients homes.
- **UWC Review document on HCBC Services**.[255] which was commissioned by the WCGHW to inform policy change

Annexure 6: Guidelines: Process and procedure for requesting, issuing, returning maintenance and control of palliative care equipment

<table>
<tr><th colspan="6">Guidelines: Process and procedure for requesting, issuing, returning maintenance and control of palliative care equipment within Northern Tygerberg Sub-structure</th></tr>
<tr><td colspan="2" rowspan="2">Type:</td><td>Regulation</td><td></td><td>Policy</td><td></td></tr>
<tr><td>Guideline</td><td>X</td><td>Procedure</td><td></td></tr>
<tr><td colspan="2">Relevant Legislation, Policies, Documents/Manuals/
Handbooks/ Systems</td><td colspan="4">WCGH - Proposed Model for the Implementation of the Palliative Care Policy in the Western Cape September 2018,
National Department of Health has developed a National Policy Framework and Strategy on Palliative Care (NPFSPC) 2017 – 2022</td></tr>
<tr><td colspan="2">SOP Reference and Version No:</td><td colspan="4">Internal control process and procedure of palliative care equipment for home use within the Northern Tygerberg Sub-Structure</td></tr>
<tr><td colspan="2">Certification and approval of Due process:</td><td colspan="4">_______________________ _____________
Mrs JO Arendse (Director) Date</td></tr>
<tr><td>Approval Date</td><td></td><td>Commencement Date:</td><td>August 2019</td><td>Review Date</td><td>August 2020</td></tr>
<tr><td colspan="2">1. Purpose and Objectives</td><td colspan="4">To formalize processes and procedures for requesting, issuing, returning and maintenance of palliative care equipment that will ultimately allow for:
1) Effective control over palliative care resources
2) Ensure equal access to palliative care equipment for eligible palliative care clients
3) Ensure the dignified quality client centred care
4) Ensure standardization of requisition processes and procedures</td></tr>
<tr><td colspan="2">2. Responsibility</td><td colspan="4">• Clinical Programme Coordinators
• Professional Nurses
• Non-Profit Organisations funded by the WCGH
• Supply Chain Management</td></tr>
<tr><td colspan="2">3. Process and procedure</td><td colspan="4">Requesting and Issuing</td></tr>
</table>

- Palliative care supportive equipment for home intermediate care use is only available for clients within the public health care service domain.
- All clients requiring home based palliative care must be referred by a clinician to the NPO responsible for the geographic area.
- Referral must be done on the standardised palliative care assessment and referral forms and must be forwarded to the Northern Tygerberg Sub-Structure Office (NTSSO) (cbsntss@westerncape.gov.za) for the attention of the Clinical Programme Coordinator: Community Based Services (CPC:CBS)
- The CPC: CBS will upon receipt of referral request the local NPO palliative care nurse to conduct an initial assessment of the home-based care client including supportive palliative care equipment for home use needs.
- The local NPO palliative care nurse will request the required equipment on the standardised form (annexure A). The completed form is forwarded to the NTSSO for the attention of the CPC: CBS
- The CPC: CBS will issue requested equipment for home based palliative care use.
- The local NPO together with the family should arrange for collection of palliative care equipment.
- Note palliative care equipment for home use is issued to the local NPO which must ensure the correct usage and application of the equipment.
- NPO nurses must advise and educate the client and their family on the purpose and usage of palliative care equipment for home use to ensure the safety of the palliative care client and families at all times. Where applicable clients and their families must not use

equipment on their own and must be informed of this by the NPO nurse.

- The NPO nurses as part of their duties must frequently assess the applicability, safety and the continued required use of equipment and implement the necessary interventions.
- The CPC: CBS as part of monitoring visits to the client must also assess the correct application and usage of palliative care equipment.
- Once equipment is no longer required it must be returned by the local NPO to the NTSSO and handed over to the CPC: CBS

Returning and maintenance

- Upon return of equipment the CPC: CBS must assess the condition of the equipment for future usage
- All equipment that requires maintenance and calibration must be send to the relevant workshop
- The CPC must liaise with the local intermediate care facility to clean equipment before storage
- Equipment must be stored safely as per manufacturers requirements
- Once equipment is in a usable state it must be booked back into the equipment store and on the inventory list
- The CPC: CBS must keep records of where equipment is e.g. for cleaning, maintenance etc.

Control

- The CPC: CBS will only issue equipment to clients in care of public health services.
- The CPC: CBS will only issue equipment based on client needs.
- The CPC: CBS will keep accurate inventory records of all equipment.

	- All equipment issued to NPOs for palliative care client home usage must be accounted for. - All equipment must be marked and identified by supply chain management before it can be issued to clients for home use. - An inventory list must be kept up to date and monthly inventory checks must be performed by the CPC.
4. Accountability and Authority	**4.1 Drafter of Guidelines** Deputy Director Comprehensive Health **4.2 Implementation** Clinical Programme Coordinator: CBS **4.2 Compliance** Assistant Manager: CBS **4.3 Approval Authority** Director NTSS
5. Appendices	**Palliative care equipment request form** **Inventory list**

Annexure 7: National Department of Health Indicator Data set for Palliative Care - DRAFT

Measurable	Indicator	Indicator Definition	Indicator measurement	Factor	Routine (Frequency)	Facility enabling requirements
Essential Medicines	**Pain management**	Equitable & sustainable access to morphone powder	**Numerator:** Total mg of morphine powder issued/facility **Denominator**: total number of clients prescribed (0-	% of ptns issued with morphine powder & medium amount of morphine issued/patient	Monthly	1. Raw materials avaliable for compounding morphine solution 2. National Standardised Concentrations of morphine solution defined 3. Standardised provincial policy for access e.g. renewal of prescriptions with patient assessment - written prescriptions are required for S6 4. Access to morphne tables; & other pain modalities where syringe drivers are not avaialble
	Pain management	Equitable & sustainable access to morphone tablets	**Numerator:** Total mg of morphine tablets issued/facility **Denominator**: total number	% of ptns issued with morphine tablets & medium amount of morphine issued/patient	Monthly	1. Raw materials avaliable for compounding morphine solution 2. National Standardised Concentrations of morphine solution defined 3. Standardised provincial policy for access e.g. renewal of prescriptions with patient assessment - written prescriptions are required for S6 4. Access to morphne tables; & other pain modalities where syringe drivers are not
	Access to drugs on the EML	Equitable and sutaianble access to Amitriptyline, Senekot, lactulose, Buscopan, Metoclopramide, Panado, haloperidol, diazepam, as aligned with the EML	**Numerator:** Total mg of EML drug issued/facility **Denominator**: total number of clients prescribed (0-17yrs)	% of ptns issued with EML drug	Monthly	1. Facility managers should approve orders as received from referral sites and supply chain (finance team) 2. Improve patient education pertaining to communicating with the facility when they are running out 3. Need to have commodities classified so that budget can be classified accordingly
	Consumable package	Consumable package includes the followig and is not limited to Gauze, bandages, catheters, gloves, colostomy bags, incontinence pads, aprons, APCA LIST, technologies and supplies (Oxygen, wheelchair, commods, radio theraphy, mobility devices)	**Numerator:** Total consumable packages **Denominator**: total number of clients prescribed (0-17yrs)	% of patients issued with consumable packages	Monthly	1. Facility managers should approve orders as received from referral sites and supply chain (finance team) 2. Improve patient education pertaining to communicating with the facility when they are running out 3. Need to have commodities classified so that budget can be classified accordingly 4. Improve communication with home based patients to decrease out of pocket patient expenditure
Facility Implementation	**Palliative care patient workload**	Palliative care patient workload	**Numerator:** Total number of palliative care patients seen **Denominator:** Total number of days per month according to facility month days	PHC ratio	Monthly	1. NDoH to motivate for palliative care head count data element included in the DHIS
	Palliative care family counseling	Provision of Palliative care family counseling	**Numerator:** Total number of palliative care families seen **Denominator:** Total number of days per month according to facility month days	PHC ratio	Monthly	1. NDoH to motivate for palliative care head count data element included in the DHIS
	Palliative care service provision	Palliative care service provision	**Numerator:** Total number of facilities offering palliative care services (PHC, CHC, District Hospital) **Denominator:** Total number of facilities in the province	PHC ratio	Twice a year	1. Provincial palliative care coordinators implementation audits twice each year
	Health workers (Staff) workload	Health workers (Staff) workload	**Numerator:** Total number of staff employed to render palliative care **Denominator:** Total number of staff employed within the facility	PHC ratio	Twice a year	1. Provincial palliative care coordinators implementation audits twice each year
	Health workers (Staff) workload	Health workers (Staff) workload	**Numerator:** Total number of dedicated palliative care team employed to render palliative care **Denominator:** Total number of days per month according to facility month days	PHC ratio	Twice a year	1. Provincial palliative care coordinators implementation audits twice each year
	Palliative care units	Palliative care units (DoH)	**Numerator:** Total number of DoH palliative care dedicated hospital beds/province **Denominator:** Total number of hospital beds/province	PHC ratio	Annually	1. Provincial coordinator should motivate for dedicated palliative care units 2. Provincial coordinator should quantify palliative care dedicated units within the province
Teaching and Training	**Basic In-service Trained**	Percentage of healthcare workers adequately trained in palliative care (Basic In-Service training)	**Numerator:** Total number of health workers trained within each facility on Basic In-Service training (Medical Officers, Registered Professional Nurses, Clinical Nurse Practitioners and social and Allied Workers) **Denominator:** Total number of staff in the facility	Trained percentage (Basic In-service)	Quarterly	1. Provincial pallitive care coordinator should motivate for paliative care trainings and budgeting 2. Facility manager should liaise with the Regional Training Centre about sending their staff for training
	Post Graduate Diploma Trained	Percentage of healthcare workers adequately trained in palliative care (Post Graduate Diploma)	**Numerator:** Total number of health workers trained within each facility on Post Graduate Diploma. (Medical Officers, Registered Professional Nurses, Clinical Nurse Practitioners and social and Allied Workers) **Denominator:** Total number of staff in the facility	Trained percentage (Post Graduate Diploma)	Quarterly	1. Provincial pallitive care coordinator should motivate for paliative care trainings and budgeting 2. Facility manager should liaise with the Regional Training Centre about sending their staff for training
	Master of Palliative Medicine Trained	Percentage of healthcare workers adequately trained in palliative care (Master of Palliative Meds)	**Numerator:** Total number of health workers trained within each facility on (Master of Palliative Meds). (Medical Officers, Registered Professional Nurses, Clinical Nurse Practitioners and social and Health and Rehab workers) **Denominator:** Total number	Trained percentage (Master of Palliative Meds)	Quarterly	1. Provincial pallitive care coordinator should motivate for paliative care trainings and budgeting 2. Facility manager should liaise with the Regional Training Centre about sending their staff for training
	NQF L2 & L3 Homebased care personal care work	Percentage of healthcare workers adequately trained in palliative care (Homebased care personal care work)	**Numerator:** Total number of health workers trained within each facility on (Homebased care personal care work) **Denominator:** Total number of staff in the facility	Trained percentage (Homebased care personal care work)	Quarterly	1. Provincial pallitive care coordinator should motivate for paliative care trainings and budgeting 2. Facility manager should liaise with the Regional Training Centre about sending their staff for training
	Number of Accredited Palliative Care Training institutes	Total number of accredited palliative care training institutes	**Numerator:** Total number of training institutes **Denominator:** Total number of available training sites	Ratio	Annual	1. Provincial pallitive care coordinator should motivate for paliative care trainings and budgeting 2. Facility manager should liaise with the Regional Training Centre about sending their staff for training
Finance	**NPO financial support**	Proportion of partners receiving financial support for provision of palliative care services	**Numerator:** Total number of palliative care partners receiving financial support from DoH (Hospices, Frail Care facilities, Old Age homes & other NPOs) **Denominator:** Total number of partners rendering palliative care	Annual Survey	Annually	1. Provincial coordinator should motivate for financial support to palliative care stakeholders 2. Provincial coordinator should quantify palliative care stakeholders within the province
Finance	**Palliative Care budget allocation**	Total amount allocated towards the support and provision of palliative care services per province	**Numerator:** Total amount of money allocated for palliative care **Denominator:** Total health budget for the province	Annual Survey	Annually	1. Provincial coordinator should motivate for financial support to palliative care stakeholders 2. Provincial coordinator should quantify palliative care stakeholders within the province
Governance		Availability of provincial Palliative Care SOP	**Numerator:** Yes **Denominator:** No	Yes/No	Annually	1. Provincial coordinator should motivate for financial support to palliative care stakeholders 2. Provincial coordinator should quantify palliative care stakeholders within the province
Community Engagement		Number of community engagements	**Numerator:** Total number of palliative care engagements **Denominator:** Total number of health engagements	Engagement Ratio	Annually	1. Provincial coordinator should motivate for financial support to palliative care stakeholders 2. Provincial coordinator should quantify palliative care stakeholders within the province

Annexure 8: APCA African Integrated Palliative Outcome Scale

APCA AFRICAN IPOS

ASK THE PATIENT	
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	**0 (no pain)** **- 5 (worst/overwhelming pain)**
Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past 3 days.	**0 (not at all)** **- 5 (overwhelmingly)**
Shortness of breath	
Weakness or lack of energy	
Nausea (feeling like you are going to be sick)	
Vomiting (being sick)	
Poor appetite	
Constipation	
Sore or dry mouth	
Drowsiness	
Poor mobility	
Please list any **other** symptoms not mentioned above, and rate how they have affected you over the past 3 days. 1. 2. 3.	**0 (not at all)** **- 5 (overwhelmingly)**

Q3. Have you been feeling worried about your illness in the past 3 days?	**0 (not at all)** **- 5 (overwhelming worry)**
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	**0 (not at all)** **- 5 (yes, I've talked freely)**
Q5. Over the past 3 days have you felt that life was worthwhile?	**0 (no, not at all)** **- 5 (Yes, all the time)**
Q6. Over the past 3 days, have you felt at peace?	**0 (no, not at all)** **- 5 (Yes, all the time)**
Q7. Have you had enough help and advice for your family to plan for the future?	**0 (not at all)** **- 5 (as much as wanted)**
ASK THE FAMILY CARER	
Q8. How much information have you and your family been given?	**0 (none)** **- 5 (as much as wanted)** **N/A**
Q9. How confident does the family feel caring for______________?	**0 (not at all)** **- 5 (very confident)** **N/A**
Q10. Has the family been feeling worried about the Client over the last 3 days?	**0 (not at all)** **- 5 (severe worry)** **N/A**

Annexure 9: Pre-workshop survey Health Managers

Pre-workshop Survey Health Managers Indaba

Sex: Male Female

Age:

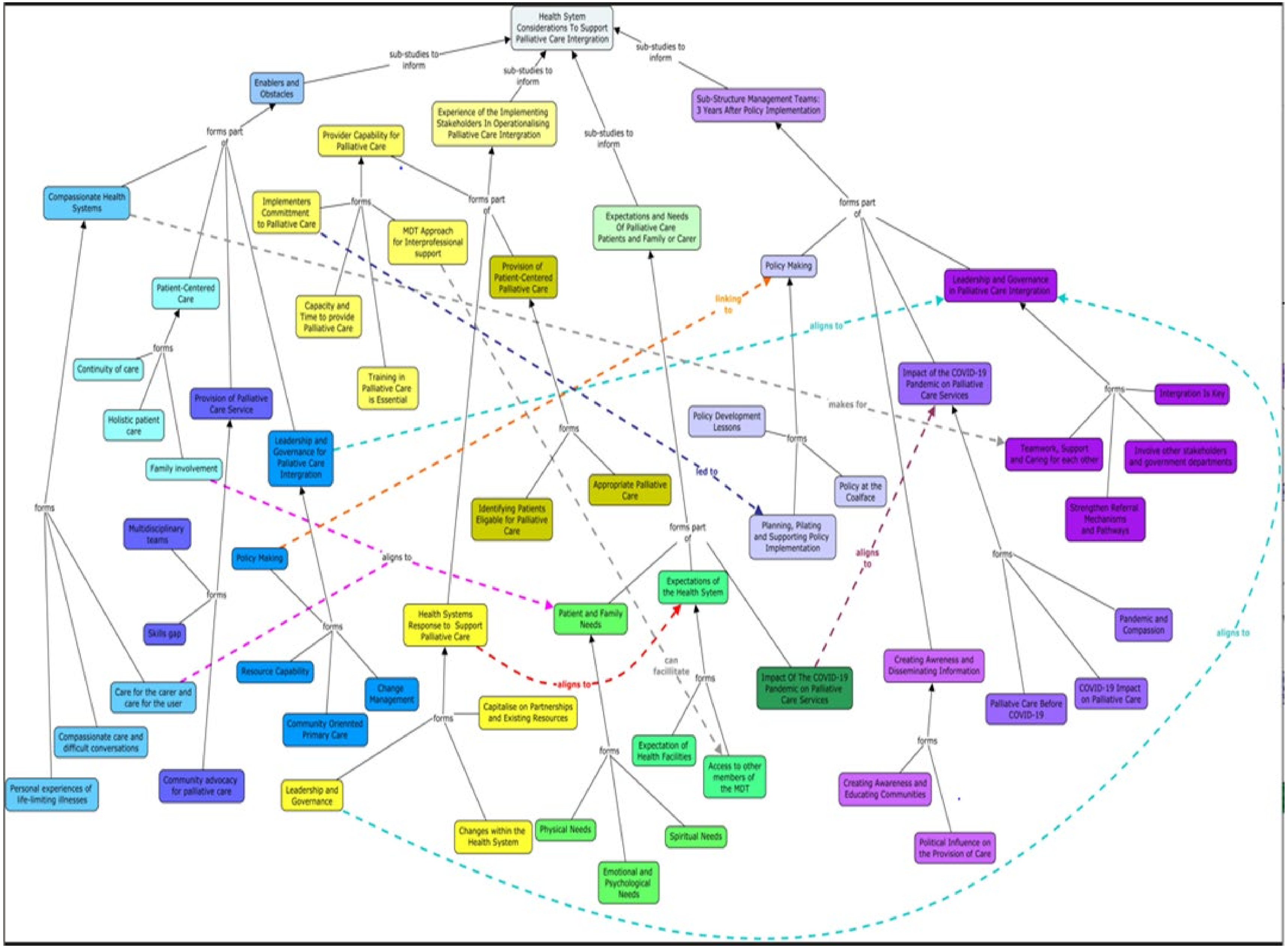
20 – 29 yrs	30 – 39 yrs	40 – 49 yrs	50 – 59 yrs	60 + yrs

Where do you work?

PHC Facility	Sub-Structure Office	Hospital

	Statement	True	False
1.	Pain is an inevitable part of dying		
2.	Palliative Care is care at the end of life		
3.	Palliative Care allows patients to die faster		
4.	People on Palliative Care who stop eating, eventually die of starvation		
5.	Palliative Care is for patients dying of cancer only		
6.	Palliative Care should be provided to all cancer patients		
7.	Palliative Care means that the Dr has given up		
8.	Palliative Care means that there is no longer any hope		
9.	Palliative Care involves a Multi-Disciplinary Team to provide holistic care		
10.	Morphine is sometimes administered to hasten death		
11.	Dying in a hospital is an indication of better care.		
12.	Taking pain medication in Palliative Care leads to addiction		
13.	Morphine is a safe and effective medication to relieve severe pain		
14.	Palliative care can be provided in the dying patient's own home		
15.	Only clients who are hospitalised can be identified as eligible for Palliative Care		
16.	Palliative care can prolong life with quality of life		
17.	Patients should have a choice where they are cared for if they are close to the end of life		
18.	Palliative care can be provided early in the course of a serious illness together with treatment targeting the illness		
19.	Palliative Care is the same as Euthanasia		
20.	Palliative care is not supported by my religion or cultural belief		
	If #20 is 'True', provide a reason or reasons:		

Annexure 10: Concept Map: Chapter 4 to 8



Annexure 11: Comparing theoretical frameworks for this study

Elements of integration according to Atun et al. (2010)	Bauer et al. (2015) Implementation Science	Keith et al. (2017) Consolidated Framework for Implementation Research (CFIR)	Greenhalgh et al. (2004) Diffusion of innovation in service organisations	Rogers et al. (1995 and 2010) Five stage model of diffusion	Mayhew et al. (2017) Integra initiative evaluation trial for HIV and reproductive health
Integration Lens: extent, pattern and rate of adoption and eventual assimilation of health interventions in each of the critical functions of a health system.	**Implementation Science**	**Implementation research**	**Innovation:** Assimilation of innovation to improve health outcomes	**Innovation: Diffusion**	**Integration:** structural integration is inadequate and makes a case for leadership and teamwork
Problem: Characteristics of the problem which the intervention or innovation needs to address. Urgency with which the problem must be addressed. Socio-economic burden caused by the problem.	Evidence based practice to identify quality gaps at provider, health facility or healthcare system level.	Intervention characteristics: complexity			
Intervention: These are inputs into service delivery, organisational changes, innovations, policy, institutional arrangement changes. Consider nature and extent of complexity – understand the interrelatedness and interdependency of the intervention. Trialability, benefits and potential adverse events, of intervention should be considered.	Implementation interventions compared to implementation strategy. Common examples: Education and training, audit results review, performance incentive		Systemic antecedents for innovation include: Structure and its maturity, absorptive capacity for new knowledge and receptive context for change. Consequence.	Small scale innovations that are increased in intensity over time. Decision to adopt or reject	Understand the nature of the intervention: new intervention for existing health service and the impact onto the hard and software of the health system.
Adoption system: Refers to key actors and institutions in the health system, with varied interests, values, and power differentials. Consider different perceptions and positions of the actors on the benefits and risks associated with the new intervention.		Characteristics of individuals: knowledge and beliefs about the intervention, by individuals with influence	Adopter needs, motivations, values, goals, skills, learning style and social networks must be considered.	Persuasion based on perceived characteristics of the innovation	Relationships and interactions between staff override the most perfectly structured intervention. Religious and values clarification.

These include the managers, policy makers, HCWs, health care users, patients and family and the greater community		Intervention characteristics: stakeholder perceptions			Managers have a strong influence over the acceptance of new interventions. Manager consultation before decision-making
Health system characteristics: Governance: includes alignment to existing regulatory frameworks, integrated reporting, performance management, leadership, stewardship Finance: common basket of funding, no ring-fenced funding, Planning: for training needs and capacity planning, resource planning and allocation, priority setting, Service delivery: changes and inclusion at the coalface, Monitoring and evaluation: use of shared indicators, integrated data collection, recording, analysis and reporting systems. Demand generation: could include tapping into financial incentives (health insurance, grants etc), health education and health promotion	Model of hypothesised pathway of change: Leadership engagement Available resources Relative priority based on the goals and feedback. Implementation outcomes Program outcomes Process, formative and summative evaluation	Inner setting: leadership engagement. Readiness for implementation. Implementation process: strategies and tactic, engaging the right people, reflecting, and evaluating	System readiness for change Implementation process includes: Decision-making devolved to frontline staff. Hands on approach by leaders and managers. Consider training and related matters. Communication and influence: Diffusion Dissemination	Implementation – put the innovation into use. Confirmation: evaluates the results of an innovation-decision already made	Frequency of supervisory support is important
Context: Consider critical events such a catastrophe, regime change New technology, new medication Available funding, donor funding with own objectives, changes in the fiscal environment	Consider that even in supportive contexts, there are barriers that must be identified and addressed.	Outer setting: external context or environment, external policy Inner setting: implementation climate		Knowledge of context and history to inform the innovation	Occupational stress should be considered