

An Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

Stephanie Rene Krause

KRSSTE007



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Supervisors:

Assoc. Prof. Liz Gwyther

Assoc. Prof. Jill Olivier

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2. Krause R, Gwyther L and Olivier J. *The influence of context on the implementation of integrated palliative care in an academic teaching hospital in South Africa*. *Palliative Care and Social Practice* 2024; 18: 26323524231219510.

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Date: 25 January 2024

Student Name: Stephanie Rene Krause

Student Number: KRSSTE007

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Abstract: An Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

Palliative Care is presently being integrated within an academic teaching hospital in South Africa. The World Health Organisation has stated that palliative care is an ethical responsibility of health systems. However, despite a National Policy Framework and Strategy for Palliative Care, there is a limited funding allocation for Palliative Care in South Africa. South Africa experiences distinctive disease-related and contextual challenges that influence the normalisation of palliative care practice. Consequently, specific palliative care implementation strategies have been devised in response to the constraints of limited resources to suit this context. This research aims to evaluate and describe the effectiveness of the current integration strategies for Palliative Care within the South African Academic Teaching Hospital context, specifically Groote Schuur Hospital. The author conducted a descriptive and explorative study to describe and evaluate how and why these strategies contributed to integrating palliative care within the academic teaching hospital. The author drew from Valentijn's Rainbow Model of Integrated Care to conceptualise the domains and extent of palliative care integration. Valentijn's theory emphasises the interlink between the normative and functional aspects of integration and, furthermore, the extent of integration, which can be at a clinical, professional, organisational or systems level. The interlinking of these aspects is imperative in palliative care integration. Palliative care is also a complex intervention; therefore, understanding the context in which this complex intervention is being integrated is core to understanding how and why these interventions work. The author provides an in-depth description of the context to explain why palliative care integration worked or not.

The author is an embedded researcher and was involved in developing and evaluating the strategies. The concerns of bias and trustworthiness of this research were ensured by using triangulation of data, member checking and including co-strategists from the implementation of these strategies in the evaluations.

In chapter 1, the author provides background information, the substantive relevance and an overview of the research. Chapter 2 is a narrative literature review that provides an overview of implementation research, integration research and PC research convergence to better understand PC integration and implementation. The following chapters use interdisciplinary mixed-method evaluations conducted in three parallel phases. In chapter 3 the author describes the hospital's specific context in relation to the integration of palliative care. Chapter 3 is a mixed-method study to explore contextual factors influencing the integration or lack thereof in an academic teaching hospital. This approach assisted in expanding on the contextual phenomena, corroborating findings and explaining the interconnectedness between the different levels. Chapter 4

describes a sub-study to evaluate a structural change (introducing a specialised palliative care team). It is a mixed methods sequential study that evaluates and describes how the service is integrated into GSH. Chapter 5. A mixed method parallel study describes the evaluation of an educational approach (training oncology trainees). Chapter 6, a qualitative study, describes the evaluation of the effect of integrating PC into oncology training on PC integration. Chapter 7 describes the evaluation of a change in hospital processes (quality improvement in the care of patients with pancreatic adenocarcinoma). Chapter 7 is a mixed method sequential design, and demonstrates how a quality improvement cycle contributed to palliative care integration. In Chapter 8, the strategies were analysed to assess their effectiveness in relation to integration and to identify the mechanisms that facilitate integration. The chapter draws conclusions from the research and makes recommendations on how to proceed with the integration of PC identifying areas for further research.

The research methodology included primary interviews (n=20), focus group discussions (n=3), secondary data analysis, training evaluations, analysis of hospital data, Palliative Care service data, and targeted document analyses to expand and corroborate findings. The qualitative data were analysed using thematic analyses (inductive and deductive) using NVIVO. Quantitative data provided descriptive statistical analyses.

This research has demonstrated that a specialised Palliative Care team successfully achieved clinical integration and normalised the practice of palliative care. Over a five-year period (2017-2022), a notable increase in referrals for Palliative Care services was observed. In 2017, the hospital received 737 palliative care referrals, which grew to 931 in 2020 and further escalated to 1202 in 2022, demonstrating a statistically significant upward trajectory. This increased reach extended initially from only medical wards but now includes include Outpatient services and Intensive Care Unit (ICU) care. The reason for the extent of the strategy is linked to the mechanism of observing palliative care being practised, which challenged the context-specific assumptions about Palliative Care.

Furthermore, professional and clinical integration were achieved when the specialised service strategically collaborated in an area with a high burden of patients, like the surgical care of pancreatic adenocarcinoma, using an interactive quality improvement strategy. This resulted in a significant increase in comprehensive care and palliative care referrals.

However, an educational strategy targeting junior trainees in oncology did not yield the expected clinical or professional integration outcomes. In oncology services documentation related to Palliative Care and perceptions among decision-makers remained largely unchanged.

Notably, while full organisational integration was not achieved, the presence of the specialised Palliative Care team had a substantial impact on the hospital's organisational culture, creating a ripple effect throughout the institution because it normalised palliative care within the academic teaching hospital. This research underscores the vital role of specialised Palliative Care teams in enhancing clinical integration and shaping the broader healthcare environment, prompting further exploration and strategic adjustments for future improvement.

This study confirms findings from other global studies that specialised Palliative Care teams play a central role in integration within a hospital setting and shaping the broader healthcare environment, prompting further exploration and strategic adjustments for future improvement. Even with limited resources, specialised teams contribute to the process of integrating Palliative Care due to their capacity to transform a hospital's culture in relation to palliative care. Although educational strategies are important, the focus of these strategies should be on influencing both junior and senior staff and developing a palliative care team within hospitals.

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Acronyms

CME	Continuing Medical Education
CCWR	Combined Care Ward Round
CMOCs	Context-Mechanism-Outcome pattern Configurations
IS	Implementation Science
GSH	Groote Schuur Hospital
HPSR	Health Policy and Systems Research
HCP	Health Care Professional
HCW	Health Care Worker
IS	Implementation Studies
LMIC	low- and middle-income countries
LTI	Life-threatening illness
NGO	Non-government organisation
RMIC	Rainbow Model of Integrated Care
PC	Palliative Care
PCR	Palliative Care Research
SA	South Africa
SOP	standard operating procedures
UHC	Universal Health Coverage
WC	Western Cape

Glossary

Integrated care	Networks of health care organisations and professionals who work together and provide coordinate services to meet their patients' and family needs. These networks are a way of linking fragmented services by increasing inter-organisation interactions and maximising system efficiency and seamlessness of patient transition. The integration of activities between network agencies may include shared staff, joint policy development, joint training programs or workshops, and shared information. It is also defined as the organization and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money. ¹
Integration	The act of making a whole out of parts; the co-ordination of different activities to ensure harmonious functioning in order to achieve the desired result.
Health systems integration	WHO health systems framework building blocks that have to 'work together' to achieve a specific goal.
Breadth of integration	The number of different functions and services provided along the continuum of care.
Vertical integration	Bringing together of services operating at different levels.
Horizontal integration	The linkage of services on the same level.
Integrated healthcare	Bringing together of inputs, delivery, management and organization of services as a means of improving access, quality, user satisfaction, patient outcomes and efficiency.
Dimension of integration	Linking integrated clinical health care with an integrated health system through identifying the main areas of integration namely clinical, professional, organizational, system, functional and normative integration
Normative integration	The development of mutual values, vision, trust and culture. ²
Functional integration	The extent to which back office-office and support functions are coordinated. ²
Clinical integration	The extent to which care services are coordinated. ²
Professional integration	The extent to which professionals coordinate services across various disciplines. ²
Organisational integration	The extent to which organisations coordinate care across different organisations. In a large Academic Teaching hospital an organisation can be viewed as a clinical unit in a hospital. ²
System integration	The alignment of rules and policies within a system.

Complex intervention	When there is flexibility, variances and feedback of the properties of the intervention itself, such as the number of components involved; the range of behaviours targeted; expertise and skills required by those delivering and receiving the intervention; the number of groups, settings, or levels targeted. ³
Sense-making	The turning of new circumstances into a situation that is comprehended explicitly in words and serves as a springboard into action. ⁴
Universal Health Coverage	a health care system in which all individuals and communities receive the health services they need without suffering financial hardship. This encompasses a full spectrum of essential, high-quality health services, including health promotion, prevention, treatment, rehabilitation, and palliative care, ensuring that everyone can access the services they require regardless of their economic or social status ⁵

Chapter 1: Introduction: rationale and structure of the thesis

This chapter serves as the introduction for this study, offering substantive relevance and rationale. In addition, it presents an overarching framework for the research methodology, provides a statement regarding the position of the researcher, and offers brief descriptions of each subsequent chapter.

Integrated care is more of an 'art form' founded on a colourful pallet of values and perceptions arising from several political, organisational, professional and clinical fields.

Valentijn⁶

Palliative Care (PC) has been practised since the 1980s in South Africa, although it has been on the periphery of the South African healthcare system. Non-governmental services and sporadic hospital services have mainly provided PC in the South African health system.⁷ However, due to the need for PC, the value that PC adds to a health system, and international advocacy for PC,⁸⁻¹⁰ PC is now being recognised by the World Health Organisation (WHO) and the South African Government as an important addition to health care services.¹¹⁻¹³ Moreover, it is recognised as an essential aspect of Universal Health Coverage (UHC).⁵ However, the implementation of sustainable, appropriate, effective and feasible PC in South Africa needs further exploration.¹² Currently, the integration of PC into the South African health system is under scrutiny and it has been argued that empirical research is needed to ensure its sustainability and effectiveness.¹²

The imperative for integration of PC into global health services was reinforced in 2014 when the World Health Assembly (WHA) unanimously approved resolution 67.19: "*Strengthening of palliative care as a component of integrated treatment within the continuum of care*" and described palliative care as "*an ethical responsibility of a health system*".¹⁴ This resolution recognised that PC:

*...is fundamental to improving quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received.*¹⁴

The resolution aimed to ensure that PC was strengthened as part of integrated care within the continuum of care in all member states. The palliative care approach focuses on whole-person care, quality of life and mortality acknowledgement.¹⁵

Although there is global support for PC integration, a 2017 Lancet Commission report on PC stated that there is an ‘abyss’ in the access to integrated PC globally and in pain control for patients diagnosed with serious illness.¹⁶ Furthermore, according to the Lancet Commission, 45% of global deaths were associated with serious health-related suffering, and 80% of these deaths were in developing countries.¹⁶ Non-communicable illnesses represented 90% of the burden for palliative care, with progressive non-malignant disease representing the highest proportion. In Africa, HIV and non-malignant diseases share a similar PC burden.¹⁷ The Commission stated that there cannot be UHC without access to PC. The abyss in the access of PC is further compounded by the lack of pain control in low- and middle-income countries (LMICs). Pain control is a measurable outcome of PC delivery that can be globally monitored. This ‘abyss’ in access to PC is confirmed by the low amount of morphine consumed in LMIC compared to developed countries.¹⁶ Of the 298.5 metric tons of morphine equivalent opioids distributed annually only 0.1 metric tonnes reach LMICs.^{16,18} The gap in access to PC became further evident when the COVID-19 pandemic highlighted the gaps in care because PC was not included in the initial pandemic planning.¹⁹

Global actors in health care, being cognizant of the need, are systematically incorporating PC into the health systems supported by PC NGOs.⁵ PC is being delivered in mainstream health care in developed countries with dedicated PC funding, and many developing countries are also implementing PC policies and services.¹⁷ Lynch et al. mapped the levels of palliative care services and demonstrated the development of PC globally and significant growth in PC from 2006. In this research group 1 was defined as countries where there were no known hospice palliative care activities and group 4 as advanced palliative care. In 2006, 115 of the world’s 234 countries (49%) had established one or more hospice-palliative care services, and in 2011, there was an increase in this number to 159 countries (68%).²⁰ However, of these countries, only 8,5% had advanced integration.²⁰ South Africa is defined as having preliminary integration. Advanced integration implies that palliative care has been integrated into the main health system of the country. In Europe, the USA, Canada, and Australasia, PC is incorporated as a medical specialty and integrated across the continuum of care.²¹ The urgency for PC integration is universally accepted, but the actual implementation of the integration of PC into health systems is slow, and the process has not been studied in depth, especially in the South African context.⁷ Although there is growth in PC services, the need for PC is still greater than the PC resources available.

1.1. The integration of PC in the South African health system

The implementation and integration of PC into the South African (SA) health system is proposed but has not yet been implemented across the health services in SA.¹² The 2014 WHA resolution prompted the decision of the South African Minister of Health, Dr. Aaron Motsoaledi, to create a national steering committee on palliative care to ensure the recommendations of the resolution are implemented in South Africa. The National

Policy Framework and Strategy for Palliative Care (NPFSPC) was approved by the National Health Committee in April 2017. In the forward introduction to the national policy, Minister Motsoaledi states:

...we cannot overlook the importance of integrating palliative care as an essential component in the continuum of health service delivery” and continues by stating: “I am confident that this Policy will translate into services which are responsive, appropriate and ensure universal access on an equitable basis.”¹²

The policy provides a framework on how PC should be delivered, and who and how patients should be referred, but the integration into the health system with limited resources must be further explored as there has been no budget for implementation of the policy. However, the policy has been extended until April 2025, and a National Palliative Care Co-ordinator was appointed part-time in 2019 using donor funding but in 2023 his contract was not extended. The Western Cape Province has developed a Model for Implementing the Palliative Care Policy in the Western Cape (WC), and Kwazulu-Natal is in the initial phases of the implementation process.²²

In the Western Cape (WC) province, PC integration into the health system is being supported by factors such as structured academic programmes in PC at the University of Cape Town, senior health care officials undertaking action research to integrate PC in primary care, multiple hospices around the WC and the official support of the WC Department of Health.²² In 2018, the WC launched the model for the implementation of the PC policy to enable PC integration and has an official task team driving the integration process.²² The WC responded to the COVID pandemic by launching an operational guide to care, opening dedicated PC wards and providing PC educational support to WC staff.²³ This has been further supported by the appointment of PC nurses and one medical officer in 2023 in the districts and hospitals in the WC. Although, these are positive steps the need still exceeds the resources that have been put in place.

The World Bank ranks SA as a ‘middle-income’ country, but a lack of resources impedes the delivery of healthcare services to more than 80% of South Africans using the public healthcare system.^{24,25} In a country with limited access to dialysis,²⁶ intensive care beds, essential cancer treatment,²⁷ and other innovative care, it is suggested by some that yet another new policy may further strain the health system.²⁸ This is further compounded by the fact that many HCP still do not understand the role of PC in the care of their patients and associate palliative care with end-of-life care only.^{29,30} To these HCPs, PC care may be seen as ‘giving up’ on a patient.

The South African healthcare system has been plagued by corruption and poor decision-making.^{31,32} New policies or interventions are, therefore, reluctantly accepted and may be viewed as having a hidden political agenda which places cost savings above patient care. This mistrust in the system has come to the forefront with the introduction of the new National Health Insurance (NHI) Bill passed in the South African parliament

in 2023.³³ Before the bill was passed, experts warned the lack of good governance, accountability, and corruption may actually worsen the South African healthcare system.³⁴ PC is written into the NHI bill under comprehensive care, but the scepticism about the whole new intervention may hamper the PC component.

The aim of the NPFSPC is to integrate PC at all levels of care. This includes the home, clinics district hospitals and tertiary hospitals, including private hospitals. PC is at these different levels are different stages of integration. This research focusses on PC in the ATH/ tertiary level.¹²

Academic Teaching Hospitals (ATHs) claim to be 'centres of excellence' not only for disease-specific care but also as an essential part of the comprehensive health system and its strengthening.^{35,36} ATHs achieve this through undertaking research and contributing to development of guidelines and policy, such as the Standard Treatment Guidelines and Essential Medicine List.^{36,37} In ATHs, HCPs are trained, and the foundation of their attitudes and values in HC are developed.³⁶ Many patients come to ATHs with complex illnesses to consult experts in these illnesses, which is, therefore, inevitably where many patients may be diagnosed with life-threatening illnesses. As stated before, PC is recognised internationally as an essential part of academic teaching institutions,¹⁴ and thus PC should be provided alongside disease-oriented care as part of comprehensive service delivery in academic institutions striving for excellence in care, research and teaching.³⁸

Groote Schuur Hospital (GSH) in the Western Cape in SA is an ATH with a specific environment and many role players from public health, research, education and service delivery in different departments playing an integral role in the hospital.³⁶ GSH is a large teaching hospital with 900 beds and over 3 500 personnel providing tertiary and quaternary care to patients and teaching to students from across Africa.³⁹ Many health interventions and research activities are launched from GSH of which the most famous innovation was the heart transplantation programme led by Dr Chris Barnard.³⁹ The investment in a PC service has grown over the years but is still minimal in relation to the investment in other service areas. PC, in an ATH such as GSH, aims to provide appropriate continuity of care along the trajectory of illness without abandoning patients whose condition is no longer responding to cure. GSH is also a teaching site, and most students taught in GSH will graduate and work in facilities with no access to quaternary services. It is important that students are competent to identify people needing palliative care and to provide this care.

PC in GSH differs from the traditional PC model of community PC. Traditionally, as mentioned above, PC has been delivered by non-government organisations such as hospices in South Africa. Hospice staff mostly visited patients and their families, known with life-threatening illnesses, in their homes or specialised care centres, supporting them through their illness, death and bereavement.⁷ In contrast, in GSH the researcher (RK) has experienced that patients receiving PC in GSH are seen for a short time, usually at a time when many treatment decisions and ethical decisions are being made. Recognising that these patients do have a life-threatening

illness and ensuring they receive appropriate care in the hospital and continuing care into the community at this critical moment is more important than developing a long-term rapport with patients and families as in-home PC. The role a PC team plays in an ATH in South Africa is in breaking bad news, ensuring prognostic awareness, providing pain and symptom control and ensuring continuity of care through developing a care plan appropriate for that patient.⁷ The role of the PC service has extended over the years from a clinical consultancy services to include assistance with managing a variety of patient-related complaints as part of hospital governance, staff education and counselling and assisting with complex decision-making. This extended role became apparent during the COVID 19 pandemic when the PC team played an important role in the care of patients and the extended care elements mentioned such as education, policy writing and debriefing staff.^{40,41}

This role of integrating a PC service in GSH, as experienced by the researcher, are similar to those described in international studies, NPFSPC and the WHA 67.19.^{12,14,42,43} This is further discussed in Chapter 3. Kamal et al. conducted a systematic review to describe quality measures for PC in oncology services in the United States of America.⁴³ The review described that to deliver quality PC in oncology services (mainly in hospitals), the structure and the process of care should adhere to the principles of PC which include early identification of distressing symptoms, continuity of care, team involvement, bio-psychosocial, spiritual care and culturally sensitive care for the patient and family. There should be good end-of-life care and impeccable ethical and legal care considering elements such as informed consent, patient and family involvement in decision-making, and advanced directives.⁴³ Furthermore, according to these international studies, these services must be supported with standard operating procedures (SOPs), guidelines, care pathways across the continuum of care for patients with life-threatening illnesses and adequate funding to support this process.⁴³ This integrated process is also not limited to a single discipline but a variety of disciplines across the spectrum of care.⁴³

1.2.Barriers to integration in an ATH in South Africa

As stated previously, South Africa has a PC policy which underpins and promotes the development of PC across many facilities in South Africa. The WC also has supporting factors that are currently enabling PC integration, as discussed. However, there are many barriers to the integration process of PC. There are barriers unique to PC but constraints that are not atypical from many health systems. In the USA, Aldrige et al., using the World Health Organization's *Public Health Strategy for Palliative Care* as a framework for analysing barriers to palliative care, identified the following barriers:

Education domain: lack of adequate education/training and perception of palliative care as end-of-life care;

Implementation domain: the inadequate size of the palliative medicine-trained workforce, the challenge of identifying patients appropriate for palliative care referral, and the need for a culture change across settings;

Policy domain: fragmented healthcare system, need for greater funding for research, lack of adequate reimbursement for palliative care, and regulatory barriers. ⁴⁴

Education domain

The lack of PC training in medical schools is not only a problem experienced by the USA population but also in ATHs in South Africa.⁴⁵ Currently, UCT is the only university in South Africa with a postgraduate PC programme which trains HCPs from all disciplines. Most of the professional nurse training is done through non-government organisations (NGOs) using short courses or introductory courses.⁴⁶ Before 2017, there was no formal PC training for an oncologist in South Africa, and there is currently no formal PC training in the internal medicine or surgery programmes.⁴⁷

The recent article published by Burger et al. on undergraduate medical PC competencies in South Africa confirmed that the extent of PC training in the curricula across South Africa varies widely and that standardised training programmes are not yet a reality.⁴⁸ Therefore, the lack of PC understanding and competencies are the reality, especially amongst more senior staff who have received no formal training in PC. The understanding of PC is especially important when difficult clinical decisions must be made in a highly skilled but also resource-constrained environment, and specialists may perceive interventional care as appropriate care.

Although the WHO definition of palliative care emphasises that PC is applicable early in the diagnosis of a life-threatening illness (LTI), access to PC is still limited by misperceptions that PC is for end-of-life care only. This means that many patients are, therefore, not referred for early PC.⁴⁹ This misconception leads to late referrals or even reluctance to refer by doctors and reluctance from patients and families to accept the referral.^{50,51} This is a fundamental barrier to PC integration into health services locally and internationally. These misperceptions were challenged in a study by Temel et al. in a randomised controlled study in patients with non-small cell lung cancer where PC was introduced early.¹⁰ Early PC not only improved the quality of life of patients but also marginally improved survival (11.6 months vs 8.9 months).¹⁰ These findings have been replicated in different settings for different diagnoses with evidence of improved patient outcomes (QOL and symptom burden).⁵² The extent of misperceptions in the South African system remains unknown and must be further explored.

Implementation domain

The process of identifying patients for PC in the South African setting is also an ongoing challenge.⁵³ The meaning of 'early PC interventions' or 'when is PC indicated?', as defined by the WHO definition of PC, is imprecise because it is dependent on the patient and clinician, on contextual and disease factors to identify patients requiring this care.²⁹ To fully integrate PC into ATHs, patients need to be referred from any discipline working with patients with an LTI. International guidance on the criteria for involving palliative care is mainly

described for cancer, diseases such as organ failure and elderly patients in a hospital setting.⁵⁴ Tools such as the Supportive and Palliative Care Indicators Tool (SPICT) and Gold Standards Framework Prognostic Indicator Guide are tools to guide HCP in the referral process to minimise over or under-referral.^{54,55} Patients were referred to PC in GSH using referral criteria for PC developed through a consensus among three clinicians and based on the Gold Standards Framework.⁵⁵ In 2019, the researcher and senior HCPs, of whom many worked in GSH, used a Delphi approach to develop consensus in South Africa on disease-specific and patient-specific indicators to identify patients who require PC.⁵³ This new indicator tool (SPICT-SA) includes infectious diseases, trauma and haematological diseases as well as cancer, organ failure and progressive neurological disorders. Infectious diseases, contributing to a major source of mortality and morbidity in South Africa, were an important inclusion, especially when the COVID-19 pandemic started.⁵⁶ This specific South African tool highlights the fact that the referral criteria need to be adapted to be responsive to local needs and resources.⁵³

Another barrier to PC is the complexity of the intervention. According to the UK Medical Research Council, a complex intervention is defined as “*complex because of properties of the intervention itself, such as the number of components involved; the range of behaviours targeted; expertise and skills required by those delivering and receiving the intervention; the number of groups, settings, or levels targeted; or the permitted level of flexibility of the intervention or its components.*”³ Referral to PC is a very emotive topic for patients, families and HCPs. The diagnosis of a life-threatening illness, is, naturally, a shock and an overwhelming experience for patients and their families. HCPs may also feel disheartened when cure is not possible for the patient.⁵⁷ They may even feel they failed the patient.

PC also requires a multidisciplinary team working seamlessly together to achieve the best possible outcomes for the patient.¹² This team needs to collaborate to provide bio-psycho-social and spiritual care. Spiritual care, an essential PC component, is difficult to include because it is not formally recognised as an element of health care.⁵⁸ LTI occurs in different settings and PC should, therefore, be available across many settings to be effective and accessible for all patients.¹² Patients move between disciplines and between tertiary hospitals, secondary hospitals, clinics and homes. A continuum of care requires networking across all these settings to be effective. Finally, PC is also a complex intervention because it is not only for patients but also for families. This widens the care circle and requires not only skills of caring for the patient in front of the HCP but also in preventative care, support for the family caring for the patient at home and support of the family bereavement.⁵⁸

Palliative care can also be integrated as a primary palliative care versus specialised palliative care. Primary PC practitioners should be able to provide basic pain and symptom control and manage basic end-of-life discussions. Specialised PC practitioners are involved in complex pain and symptom control, manage complex situations within families and between staff and families and are involved in cases of futility.²¹ These different skills should be taught at basic, intermediate and specialised level.⁵⁹

Policy domain

The current inadequate PC workforce is further compounded by the lack of reimbursement for PC. After years of advocacy, Palliative Medicine was only recently recognised in 2023 as a subspeciality in Family Medicine, Oncology, Emergency Medicine and Internal Medicine. It will take many years before trained PC providers are recognised for their PC skills. After personal communication with a senior doctor at Tygerberg Hospital, Tygerberg Hospital, an ATH in South Africa, with 1 300 beds, has only one doctor with post-graduate training in PC, and she is not reimbursed for her PC competencies. In GSH, there are only two doctors with post-graduate training in PC, of which only one is reimbursed for her PC skills. This lack of recognition of PC skills is also evident in the nurses who work in PC services. Nurses can, to date, not register their PC training with the South African Nursing Council. This impedes the opening of dedicated PC nursing posts. The experienced nurses in GSH are, therefore, not in dedicated PC posts, which implies that they can be moved to other clinical areas when other needs are prioritised.

Furthermore, PC was not integrated into the Essential Medicine Lists and Guideline before 2017.³⁷ This is an essential guideline which defines minimal, evidence-based care that needs to be provided and funded. Exploring these barriers in a local ATH will direct us to the right strategies to implement an integrated PC service.

1.3. The complexity of integrating PC

Understanding the barriers and enablers to integration of palliative care in GSH may illuminate the problem, but the goal of what we need to achieve in order to state that PC is integrated into a health system needs to be further described. PC integration into mainstream health care is an aspiration that is in the process of being actualised in many health care services in the world, and PC integration is currently in the process of being explored.^{42,60}

In 2016, Siouta et al. conducted a systematic review of the integration of PC into cancer and chronic disease in Europe.⁶¹ According to this review, 'integrative PC' involves the cohesion of administrative, organisational, clinical and service aspects to realise continuity of care between all actors involved in the care network of patients receiving palliative care. This review concluded that there is no particular accepted model of integrated PC in Europe. However, there are calls for generally acceptable models of integrated PC. It is theorised that generic PC-integrated models will be able to identify patients needing PC and to integrate PC into their care plans. A care plan is a flexible, individualised document that addresses a patient's care needs aligned with their values and principles using a multidisciplinary team along the continuum of care.⁶² This can only be achieved if palliative care is integrated into the whole system to ensure continuity of care. This

systematic review also identified a generic model of a multidisciplinary team that has a three-fold focus of treatment, consulting and training that underpins the PC services.⁶¹

To reach this level of service delivery with monitoring and evaluation in South Africa will require resources and a willingness from the whole health system to integrate PC.¹² In the South African setting with limited resources, misconceptions around PC, competing priorities and the fact that PC is a very new discipline, the above goals for integration can seem unachievable at this stage.

Topp et al., using a modified systematic review with aspects of a realist review, described health system preparedness for and capacity to implement integrated services of new programmes focussing on LMICs. The authors state that there needs to be organisational planning, assessment and preparedness and understanding of contextual factors to enable integration. They concluded that there are five 'contextual enablers' and four 'health system capabilities' necessary for integration.⁶³ The identified contextual enablers are the organisational framework of frontline services; healthcare worker preparedness; community and client preparedness; upstream logistics; and policy and governance issues. The intersecting 'health system capabilities' identified were: sufficiently functional frontline health services; sufficiently trained and motivated healthcare workers; availability of technical tools; and equipment suitable to facilitate integrated frontline services and appropriately devolved authority and decision-making processes.⁶³

PC integration will require whole health system integration. A whole health system can be described drawing from Van Olmen's dynamic framework of a health system.⁶⁴ Van Olmen's health system framework describes a health system as a dynamic interaction of the goals and outcomes; values and principles; service delivery; the population; the context; leadership & governance; and the organization of resources (finances; human resources; infrastructure and supplies; knowledge and information). Van Olmen et al. further argues that actors and their interrelationships are central to health systems and their interactions are non-linear, unpredictable and have multiple feedback loops. Health systems are also open systems and adapt according to opportunities and constraints. These interactions are, therefore, complex and change continuously.⁶⁴ PC at any level is not a simple linear intervention.

Whole system PC integration will require support from frontline health services, motivation and acceptance of the service, PC processes (for example, family meetings and follow up planning), constant evaluation and education.⁶⁵ PC integration in a South African setting into an ATH will require not only looking at the clinical structure, clinical processes, clinical outcomes, education and research, but also defining the context in which it is being integrated. HCP and community preparedness, motivation, education, leadership and governance, specific hospital needs and tools will influence the strategies and outcomes used to achieve an integrated PC service. PC must also be integrated as general PC where most HCP are trained in PC and a specialised team to provide more complicated PC.²¹ De Savigny and Adam argue that any change in the system will affect the

whole.⁶⁶ It will, therefore, be important to understand how PC integration affects other aspects of the systems directly and indirectly. Integrating a service dealing with a complex, inevitable reality such as death and dying may have multiple feedback loops. This is not only on the organisational level but also on societal and individual levels. This change will affect the whole system and must, therefore, be clearly understood within the context in which the change will take place to mitigate negative outcomes.

1.4. Rationale for the study

The lack of PC integration and the effect it had on the societal level was particularly evident when the COVID-19 pandemic created a global health and PC emergency. Globally, limited PC tools and guidelines, the lack of specialised PC providers, the lack of PC skills among frontline workers, societal fears and limited communication were some of the global PC gaps experienced. This left many patients suffering in isolation, ill-equipped frontline workers and the few PC providers exhausted.⁶⁷ Dr Tedros Adhanom Ghebreyesus, Director General of the World Health Organisation stated that:

*“The COVID-19 pandemic has highlighted the importance of palliative care in all healthcare systems. The need for relief from severe suffering, the difficult decision making, and complicated grief brought on by the pandemic are exactly the types of problems that palliative care was designed to help address.”*⁶⁷

Although the COVID-19 pandemic foregrounded the gaps in PC services, there are to date still multiple barriers that are experienced in GSH PC integration. These may not be dissimilar to global PC integration, or the integration of any new service. However, the context of South Africa and the context of South African ATHs have their role-players, cultures, specific disease profiles and societal needs that need to be carefully considered when integrating PC. PC integration is also occurring in a real-world setting, which, as illustrated by COVID-19, can change overnight. This research study aims to evaluate the impact of strategies used to integrate PC in GSH to firstly strengthen the current service, explore factors that can be applied in different settings and ultimately ensure better access to PC for patients and families.

The implementation and integration of PC into health services occurs in a real-world environment where circumstances such as the Covid-19 pandemic, contextual factors and people inside and outside the health system are contributing to the process. In order to make provisional recommendations on an effective strategy it is important to evaluate current PC integration implementation strategies and how they align or misalign with contextual factors, and domains of integration. Unpacking international trends, describing contextual factors and evaluating the impact of implementation strategies may assist in effective and focussed integration strategies in order to integrate PC in the hospital setting.

Therefore, this research evaluated integration strategies used in an ATH, to describe how the integration strategies and the context interplay to enable PC to become part of essential care, especially in hospital settings. The research was conducted in GSH, as an ATH in the Western Cape, where the implementation process is in the early phases.²² This research is also situated in a national process of integrating palliative care within the South African healthcare system of which ATHs form part.

In 2015, South Africa signed the Kampala Declaration on Palliative Care in which South Africa agreed to develop and implement a National Palliative Care policy.^{12,68} Furthermore, this research is also being conducted alongside a process of developing palliative care as a subspecialty for Family Medicine, Internal Medicine, Oncology and Emergency Medicine. This subspecialty will require ATH involvement to ensure hospital teaching platforms for registrars. This research thus falls within a broader scope of activities which aims to implement and integrate PC within all levels of care and to ensure we have the resources, tools, funds and, above all, leadership and governance for a reliable PC programme. In addition, it will seek to provide provisional recommendations on implementation strategies for the South African hospital context.

This research hypothesis is that PC integration into an ATH requires functional and normative integration. An effective strategy will impact the domains of integration and has to be perceived as appropriate for the context. For this reason, this research aimed to evaluate and describe how effective current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) are in reaching the goal of integration.

The research question:

Research Question:

How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration?

To answer the research question, the following sub-questions were asked:

Sub Question 1:

What contextual factors potentially influence the implementation of integrated PC in GSH?

In phase 1, the research investigated and described the contextual factors that influence the implementation of integrated Palliative Care in an Academic Teaching Hospital in South Africa. This research underscores the importance of understanding the context in which an intervention is integrated and the effectiveness of a specific strategy is better understood by understanding the contextual influence on the integration

strategy.^{3,69} Describing the contextual factors at play may further assist with the generalisability and transferability of the research and assist in understanding how and why integration strategies worked or did not work.

Sub Question 2:

Do current implementation strategies effectively assist in the integration of PC in GSH, and if so, how?

In **phase 2**, three integration strategies are described and evaluated: i) a Vertical- Nurse-Led-Doctor-Supported (VNLDS) service delivery strategy; ii) an education strategy for oncology junior trainee oncologists iii) and a quality improvement cycle for management of patients with pancreatic adenocarcinoma. Other strategies are being applied to facilitate integration in GSH, but this research study focuses only on the above strategies. These three strategies were chosen because of convenience and because these three strategies are three diverse strategies following recommended integration processes - education, structure (VNLDS service) and process (quality improvement cycle to change process). In this research study, all three strategies processes are explained, and outcomes are evaluated drawing from a theory-driven evaluation, which assisted in an in-depth understanding of the integration processes.

Phase 3

Across phase analyses

How do the contextual factors and strategies impact on PC integration in GSH?

In **phase 3**, an analytical approach was used to describe how the contextual factors and PC integration strategies impact PC integration in GSH. Knowing how the goals, context and strategies interplay provided provisional guidance on the mechanisms at play to facilitate assist or resist PC integration. Describing the mechanisms may in turn be used to assist PC integration in other hospitals. This research is current, but because of the ever-changing context and all findings are provisional It does provide valuable insight into what works, why and under which circumstances.

1.5. Methodology

This is an interdisciplinary mixed-method sequential study in 3 phases (although in phase 2, three sub-studies are conducted in parallel). A mixed methods study is used as both functional and normative integration aspects are explored. This research combines quantitative and qualitative data to expand and corroborate the findings.

The data collection and analyses are described in each sub study and below. Integration of data happened at different stages for each sub study, but the final integration of data occurred at the interpretation stage of this study. The limitations of this approach are discussed in detail in each sub study and in limitation section in chapter 8. The Valentijn Rainbow Model of Integrated Care is used as a framework to evaluate the integration of PC addressing the purpose of this research. The evaluation focussed on the meso (institutional) and micro (individual) levels.²

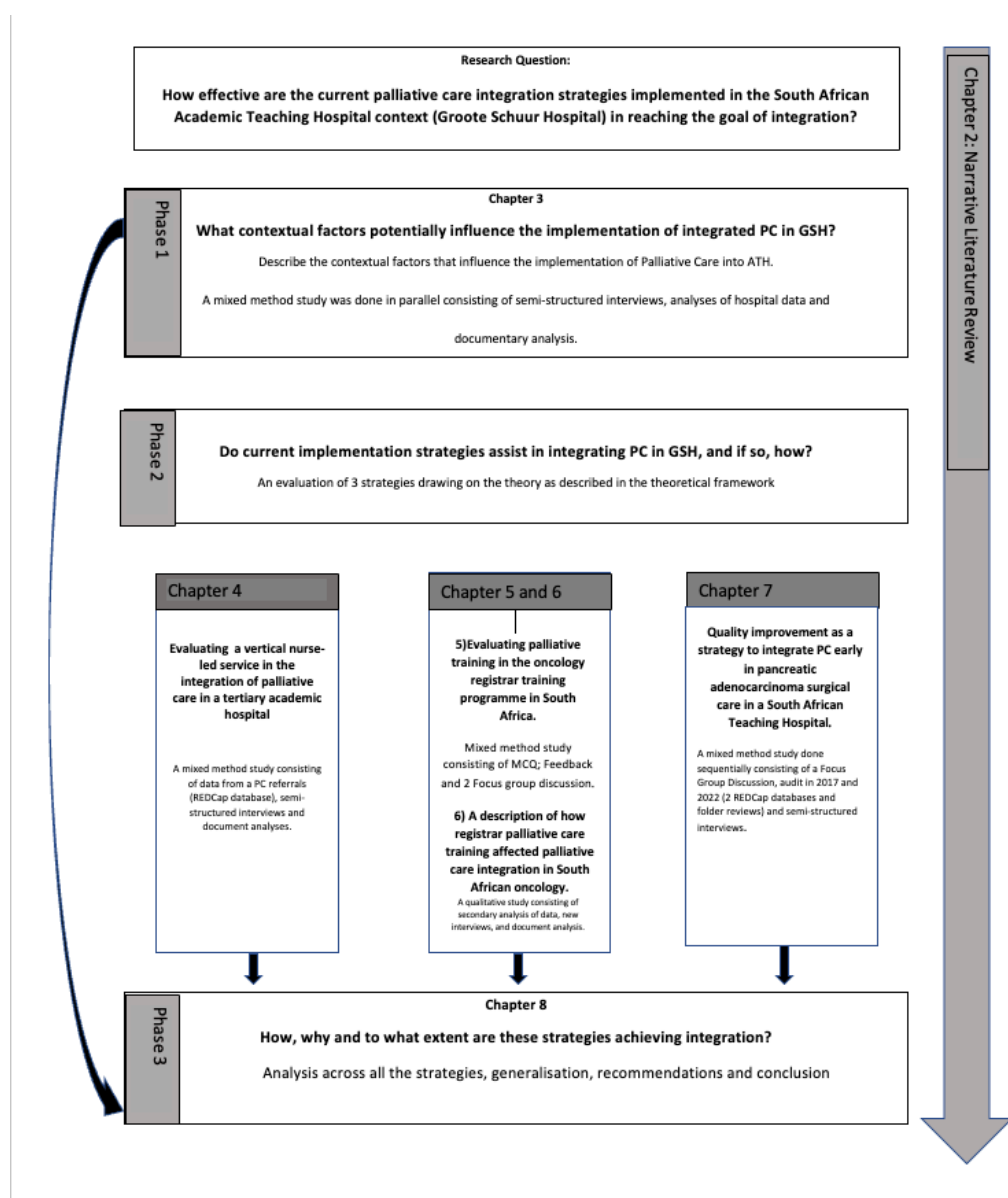


Figure 1: Overview of the methodology in this thesis: The reporting of the different phases and chapters are both indicated in this diagram.

This interdisciplinary research focusses on Palliative Care Research (PCR) and draws on Health Policy and Systems research (HPSR) and Integration thinking.^{2,70,71} Repko, an interdisciplinary research specialist, says that to gain a more in-depth understanding of a problem, especially complex real-world phenomena, a single disciplinary approach may not be sufficient to understand the problem. Complex real-world phenomena require the integration of disciplinary insights, and this study will, therefore, draw from HPSR and PCR to gain a better understanding of the phenomena of PC integration into ATH.⁷² Furthermore, the research is evaluating a complex intervention. Therefore, emphasis is placed on the context.³ The researcher's primary discipline is PC, and this research is embedded in PC principles.

PC research aims to develop an evidence-based approach to understand how to improve the quality of life of patients and their families with life-threatening illness following a bio-psychosocial and spiritual approach.⁵⁸ The ultimate aim of PC research is an evidence-based approach on how to relieve suffering using a team approach working with patients with life-threatening illnesses and may extend to policy, economics and service delivery.²⁹ An aspect of HPSR is Implementation Science (IS), which aims to describe the processes used in implementing initiatives and the contextual factors that affect these processes.⁷³ It can describe factors affecting implementation, processes of implementation and the outcomes. It is situated in a real-world setting and describes the gap between theory and practice and takes into account how changes occur over time.⁷⁴

1.6.Aim and objectives

Aim:

To describe and evaluate the implementation of integrated PC in the context of an ATH (GSH) in SA.

Objectives:

1. To describe the contextual factors that influence the integration of PC into ATH.
2. To evaluate barriers and enablers of strategies being applied to integrate PC.

Summary of key study features

- **Overarching design:** Mixed method

-- **Research purpose:** descriptive and evaluative

- **Research approach:** evaluation approach drawing on theory-driven evaluation.

Research methods: secondary data analysis, interviews, documentation analysis, and patients' records analysis.

Time: 3 years

- **Disciplinary framing:** Interdisciplinary research, combining HPSR and PCR

-**Research question:** How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration?

-**Phases:**

- **Phase 1:** Context mapping -To describe the contextual factors that influence the implementation of PC into ATH.
- **Phase 2:** To conduct evaluation of 3 strategies used to integrate PC (conducted in parallel)
- **Phase 3:** To analyse how the context and strategies influenced PC integration, discuss generalisation and provide recommendations.

3. To analyse how, why and to what extent these strategies are achieving integration.

1.7. Chapter outline

This study PHD study is presented in 8 chapters, building from Chapter 1 (this chapter), which provides an outline of the overall project. This is followed by two background chapters, a narrative literature review which considers the question of what is Integrated Palliative Care in a hospital setting, and what strategies can be used to achieve this (chapter 2). This is followed by paper which reflects on the importance of 'context' when studying PC integration (chapter 3). This chapter assists in understanding how certain strategies worked or did not. Four chapters follow, each considering a different implementation aspect, or integration of PC in a different service at GSH (chapters 4, 5, 6 and 7). Finally, chapter 8 presents findings relating to answering the main research question of the study, based on integration across all the mixed method approaches. It finishes with the conclusion of the research and recommendations that emanate from the research.

Chapter 1: Introduction: Rationale, positioning and overarching structure

This chapter serves as the foundation for this study, offering substantial relevance and rationale. In addition, it presents an overarching framework for the research methodology, provides an understanding of the researcher's position, and offers brief descriptions of each subsequent chapter.

Chapter 2: Exploring integrated palliative care and strategies to achieve it: a narrative literature review

This chapter provides an overview of implementation research, integration research and PC research convergence to understand PC integration and implementation better. This narrative review identifies what integrated PC is, justifies the reasons for it and learns from previous implementation strategies on how to achieve it. In addition, it also unpacks the complexity of integrating a new intervention into the health system and applies this knowledge to PC to develop a conceptual framework that was then applied in this research study.

Chapter 3: The influence of context on the implementation of integrated Palliative Care in an Academic Teaching Hospital in South Africa.

This is a mixed-method study to explore contextual factors influencing the integration or lack thereof in an academic teaching hospital. This approach assisted in expanding on the contextual phenomena, corroborating findings and explaining the interconnectedness between the different levels of the health system. Semi-structured interview guides and a data extraction sheet are used to collect qualitative and document data. These guides were piloted, and no changes were made to the interview guide. Data collection is conducted in parallel, and analysis of interviews with purposively selected managers (n=7) and the chair of the national

steering committee; routine hospital data, PC referral data and document analyses (n=10) are merged to describe the contextual factors. Deductive thematic analyses, using NVIVO, drawing the themes of the contextual factors are used to analyse the qualitative data and documents, and for the quantitative data, descriptive statistical analyses were used. The in-depth analysis steps are discussed in each sub study and below ([Data analyses](#)). Triangulation of data, member checking, and reflective discussions are used to ensure the validity of this study. Findings are integrated at the interpretation stage to describe the contextual factors influencing PC integration, to develop a timeline of implementation, and to assess the probable influence of context on the integration process.

Chapter 4: Evaluating the impact of a vertical nurse-led doctor-supported (VNLDS) service in the integration of palliative care in a tertiary academic hospital

The chapter evaluates the strategy of introducing a specialised vertical team as a resource. It evaluates the extent of integrations this team achieves, and how it integrated PC and unpacks why it was successful. It draws on Valentijn theory of integration. This mixed methods sequential study evaluates a VNLDS that evaluates and describes how the service is integrated into GSH. This study is done in 2 phases: In phase 1, the VNLDS staff (n=5) and PC patient referral data (n=3585; from January 2017 to June 2021) are merged at interpretation to describe the service. In phase 2, further interviews with purposively sampled ward staff (n=5) and document analyses (n=14) are used to corroborate the findings of phase 1. All the data is merged to interpret how this service integrates PC in the hospital.

Chapters 5 and 6: The Impact of training on integration

These two chapters evaluate an education resource as an integration strategy. These chapters describe how an oncology registrar (junior oncology trainee doctors) intermediate-level training programme contributed to PC integration. Education is a recommended tool to integrate PC in a health system but who and how we train affects the integration outcomes.¹⁴ Chapter 5 evaluates the feasibility and appropriateness of the resource and Chapter 6 evaluates how training oncology registrars in PC influences PC integration.

Chapter 5: Evaluating palliative training in the oncology registrar programme in South Africa

This chapter describes a mixed-method parallel study that evaluated this educational resource at a national level as a resource for integration. The evaluation is conducted using an educational lens to describe the training programme's appropriateness and feasibility within the South African context. Five universities participated (UCT, Stellenbosch University, Walter Sisulu University, University of KwaZulu Natal (Pietermaritzburg) and the University of the Free State) in this study. The data was collected through focus groups with the registrars of all 5 universities; 28 registrars participated); Focus groups with supervisors; pre- and post-module multiple choice questions results (n=10); Evaluation forms (n=10) and the online resource platform (Vula) statistics. Inductive thematic analysis of interviews and statistical descriptive analyses of

quantitative data are analysed and reported on separately. The data is merged at the interpretation stage to answer the aim of the study.

Chapter 6: A description of how registrar palliative care training affected palliative care integration in South African oncology

This chapter is a qualitative sub-study that describes how intermediate palliative training affected PC integration in Oncology at Groote Schuur Hospital in South Africa. The same theoretical framework discussed in Chapter 4 describes how the training programme influenced PC integration in oncology 5-years after its inception. It merges qualitative study combining secondary analyses of qualitative data from focus group discussions (n=2) from the study described in Chapter 5 study, with new interviews with supervisors not included in the Training Evaluation (n=3) and document analysis (n=3). This chapter evaluates how this educational resource assisted in integration, the extent of integration and what worked and what did not. The interviews are analysed deductively in relation to themes of functional and normative integration and the SOP's and guidelines were analysed using a data extraction sheet in relation to PC integration.

Chapter 7: Quality Improvement as a strategy to integrate palliative care early in pancreatic adenocarcinoma surgical care in a South African Teaching Hospital

This chapter describes how a palliative care quality improvement cycle is used as a strategy to integrate palliative care. This chapter uses both a top-down and bottom-up approach to integration. It aims to evaluate the effectiveness of a quality improvement approach in the integration of PC in surgical care for patients with pancreatic adenocarcinoma. It is a mixed-method sequential design which uses information from a focus group discussion to initiate the audit cycle. The FGD transcript was analysed using inductive thematic analyses to develop an audit tool. The audit is conducted retrospectively using two databases and file reviews in 2017(n=68) and 2022 (n=39) and was analysed using descriptive statical analyses. The intervention was the PC team working closer with the HPB surgeons, having weekly ward rounds with the junior surgeon in training, and having regular discussions with the senior teams. Finally, semi-structured interviews (n=6) were conducted to reflect on the process and to re-evaluate how care can be improved. These were analysed using inductive thematic analyses.

Chapter 8: Conclusion

This chapter describes how, why and to what extent integration occurred across all the strategies. In the chapter, the researcher maps how the context, strategies, and outcomes interplay to formulate possible interventional and contextual mechanisms at play. These mechanisms may assist in the transferability of the strategies. Furthermore, this chapter provides a map of the level of integration each strategy achieved. This chapter also answers the aims and objectives of the research questions. It provides implications of this research on clinical, professional, organisational and systems integration. It discusses the research gaps that

this research has identified and makes possible recommendations for further research. Finally, it describes the limitations of this research.

1.8. Summary of methodology

This is an interdisciplinary embedded study for PhD purposes - and it is important to be transparent about the study context. This mixed methods study drew on multiple sources of data, some primary data (such as interviews, folder reviews) collected for the purpose of the PHD, and some secondary analysis of pre-existing data (data bases and secondary review of transcripts). The candidate(RK), is also fully embedded in the research site, and led the implementation of the strategies which are being assessed here (discussed further below).

Site

Groote Schuur Hospital (GSH) is a 950-bed tertiary and quaternary teaching hospital. GSH was chosen as the site because it has integration strategies being implemented over the past 10 years. GSH is a leading academic hospital in South Africa with many contextual aspects such as discipline-specific care, complex illnesses and care of a wide variety of patients that are similar to other ATH in South Africa.

GSH is also in the Western Cape which has introduced a PC policy and is actively integrating PC along the continuum of care. Lastly, GSH has been chosen because it is convenient for the researcher and because the researcher has had a prolonged engagement with the stakeholders in GSH, which may assist in understanding the depth of the integration process.

Data collection tools

The development of the conceptual framework is described in Chapter 2 (diagram 2.3). This conceptual framework was used to develop the interview guides to explore the normative and functional aspects of integration, such as normative integration was explored using questions like: *Working with patients with life-threatening illnesses and dying patients can cause mixed reactions and emotions. Can we discuss these.* The documents were also reviewed to follow the themes from the conceptual framework. See Appendix E, such as the elements of patient-centred care. Construct validity was ensured by linking the questions to the interview guides with the theoretical framework.

Positioning the researcher

The researcher is an 'insider researcher', embedded in the research field and active in PC development in South Africa. This positionality brings both advantages and challenges to the research process. The challenges of bias, transparency and assumptions are explained below together with the mitigating factors. With regards to advantages, this positionality and exposure has provided the researcher with knowledge of the broader problem in South Africa and also with an understanding of the complexities of implementing PC in a local setting.⁷⁵ The researcher is involved in both research and programme development in PC. The researcher is involved in multiple studies in PC (table 1) as a primary investigator supervising Master's student's research in the field of PC and research on PC indicators.

The researcher also plays a role in service delivery and PC programme development. She is a contributor to developing the PC drug availability task team at a national level and was part of ensuring the PC chapter in the Primary and Hospital level essential drug list and guidelines. She also serves on the Western Cape PC Task Team. On this task team, she chairs the monitoring and evaluation subtask team in the Western Cape and serves on the education subtask team and the stationery development subtask team. This stationery is used to guide monitoring and evaluation and to ensure service delivery is comprehensive.

The researcher is qualified in Palliative Medicine, Family Medicine and Education. The researcher has attended ward rounds with oncologists once a week in a Combined Care Ward Round (CCWR) for the past 12 years, contributing to patient management. She was the primary investigator in evaluating a PC curriculum in oncology (Chapter 5). She also works weekly with the PC service in GSH and attends all their interdisciplinary ward rounds. She was a frontline worker implementing PC during the COVID-19 pandemic in GSH and the Hospital of Hope. She developed the REDCap PC database that has been used to monitor and evaluate the PC service since 2016. The researcher is thus immersed in the PC and openly favours integrating PC within a GSH. This experience and positionality brings major advantages to 'embedded research'.⁷⁶

However, it is also well known that embedded research can be exceptionally challenging as well. The researcher, therefore, had to take care to be constantly transparent about which research was conducted in which role whether for her employed position or her PhD study. The ethical considerations are discussed in more detail in the ethics section. All of these tasks give her insight into day-to-day contextual factors but may have introduced bias into decision-making from both a research point of view and from a service delivery and programme development perspective. However, without this in-depth knowledge and understanding of the integration, the authentic complexities of integration and implementation may not have been identified.⁷⁵

The researcher is also aware that she has certain assumptions about PC integration and that she is part of a certain discipline with certain epistemologies that are deeply embedded in her approach to the care of patients and the process of integration. The researcher believes strongly that PC does relieve suffering and that it does

improve the QOL of patients and families with life-threatening illnesses. She believes that PC is fundamental not only to improve the well-being of patients but also to improve how patient and HCP interact. These beliefs are underpinned by robust international research and international experience. Positive interactions impact the most HCPs own personal experience of working with patients who have a life-threatening illness. A truthful, compassionate, and constructive interaction with patients who are at the end of their lives and their families leads to fewer futile interventions and thus has a positive impact on the health system, especially with regard to economic savings. The researcher also believes that PC is not just a service to be provided in the community but should be available as part of the continuum of care, and, thus in ATHs. The researcher assumed, at the beginning of the research process, that PC was not fully integrated in the ATH because in ATHs, HCPs only see a snapshot of the suffering and do not understand the comprehensive care that is required to support the patients when they are discharged from ATHs. The researcher also believed that HCPs and ATHs do not currently have the necessary tools nor reporting mechanisms to gain a deeper understanding of the care that is being delivered and thus cannot understand the impact of not delivering PC. There is also, currently, no career motivation to deliver PC and thus, no professional accountability to ensure patients receive this care. The researcher used both a verbal recording before conducting the research and continuing journaling during the research to explore her own assumptions.

As stated, the researcher has been personally driving the integration strategies and believes that they may change some of the factors to improve access to PC. Her positive beliefs and bias in the strategies may blind her to what is not working, and participants might want 'to be nice' and not give the true picture. The researcher was also cognisant that she has been part of the process for a long time and has built multiple relationships with many of the stakeholders. This may have led to the blurring of roles, and the researcher was explicit about the role of her research in all discussions with stakeholders.

In order to ensure rigour in mapping the context and evaluating the strategies used to integrate PC, the context and history of the integration process were explained in detail. Multiple sources of evidence (documentation and participants) ensured confirmability. A key component of embedded research is trustworthiness.⁷⁷ Trustworthiness has been strengthened by asking permission from sources about using information obtained outside the formal research process.⁷⁶ Regular planning and feedback meetings were held with the PC management team to ensure a collaborative approach and data confirmation. This relationship might create unrealistic expectations from the PC team, and therefore, the researcher was explicit about her position.⁷⁶ However, this insider's perspective was also an opportunity to allow for feedback back into the system. A fundamental advantage of the embedded researcher is that the researcher can identify problems that might not be clear from the outside.⁷⁷ The researcher informed the PC managerial team about any newly identified problems. The researcher also kept a journal, which proved especially useful during phase 3. The research

assistant (see below) involved also kept notes, and the researcher had reflective meetings with her. All names are coded in this journal. The researcher also discussed all findings regularly with her supervisors and peers.

The REDCap data sources are on a dependable database that can be reviewed by other researchers. Contradictory explanations were discussed with supervisors and with members of the research group. The researcher utilised an advisory group outside the research process to discuss her data collection process and analyses in order to be an extra lens to limit bias. The researcher has an in-depth audio-recorded interview about her own assumptions, which has been used as a reflective process to gain deeper understanding of her own bias. Credibility was assured by discussing the convergence and/or divergence of the data between the three strategies, context description and the theory. A clear audit trail was used in order to describe the methods of data collection and analysis. A research assistant was used and trained and used to conduct the interviews. Reflexivity in data collection and analysis was ensured by firstly keeping notes during interviews having participants read transcripts before analysis. The analyses were checked with the supervisors and regular meetings were held to discuss the findings.

Training of research assistant

The interviews with stakeholders were conducted by the researcher (RK) with support of a research assistant. The research assistant was recruited with PC experience and interviewing techniques. The researcher and assistant are both trained on the research ethics, the protocol, the researcher's role in GSH, the conceptual framework and the interviewing technique. Interview techniques such as probing questions and how to respond empathetically to HCP revealing personal or other emotive experiences were revisited with the assistant. The research assistant was also trained on what to do when participants demonstrate distress during the interview process. However, distress was mentioned but during the interviews participants were contained. The research assistant kept field notes and reflected on them after each interview with the researcher in order to summarise the interview and to ensure the interview guide was appropriate.

Recruitment

The research was discussed with the chair of the PC committee. After ethics approval and site approval, all participants were contacted via their managers. All participants were emailed with the participant information sheet and the interview guide. Interviews were arranged at their convenience. There was no coercion into taking part in the research. The researcher was explicit that their willingness to participate in the research would not influence future PC relations or service delivery.

Informed consent

An information sheet and consent form ([Appendix B: Participant information: Phase 2a: Palliative care managers and Palliative care co-ordinator committee](#), [Appendix C: Participant consent form: Palliative care](#)

[managers and chair of the national Palliative Care steering committee](#), [Appendix G: Participant information: Supervisors of implementation mechanisms](#), [Appendix H: Participant consent form: Supervisors of implementation mechanisms](#), [Appendix J: Participant information: Palliative Care staff](#), [Appendix K: Participant consent form: PC staff and HCP](#)) was provided to the participants for each study explaining the research. The forms were drafted in easily readable form and provided contact details to complain about or to contact if concerns or further questions. Enough time was provided to read the forms and to decide whether or not to consent and to participate in the research. The research was conducted privately, and all individuals were anonymised. All interviews were conducted in English. The research was conducted with busy HCPs so the questions were few so as not to abuse the participants' time. All transcriptions of material were sent back to participants to read and edit it as member checking.⁷⁶ Research findings were also fed back to the participants via email.

Data storage and ownership considerations for the whole study

Data from this research and from previous studies that this research draws from adhere to the specific protocol's data storage rules and the University of Cape Town's Policy on Data Management.⁷⁸ All data is only accessible to specific research team members and will only be shared if the whole research team consents to data sharing. All sources were acknowledged, and by doing further in-depth research on already gathered data, the researcher obtained maximum benefit from the gathered resources. In order to understand the research process and validation of the research, the steps on how data was accessed are included in the articles.⁷⁸

All focus group discussions and interviews were transcribed by a transcriber who signed a confidentiality agreement. All data was anonymised and stored on a password-protected cloud. Data will be stored for a period of 5 years and then destroyed according to institutional recommendations.

RedCap is a web-based password-protected database. A data management policy governs these databases. The PC data is only available to the PC team leader, the researcher and the administrator. The team is working closely with the Clinical Research Unit at UCT to develop, implement and store the data. The data from the HBP data was extracted by their team, and the researcher did not see the entire database. The audit data is available to the audit team, as mentioned in Chapter 6. Once data were extracted, it was stored on a password-protected computer in a cloud which is password protected.

Data analyses

Qualitative analyses

All interviews and FCD discussions were analysed using thematic analyses. The interviews were transcribed and imported into NVIVO version 14.23. the researcher familiarised herself with the data of the study being analysed. The researcher also immerses herself the data sources like fieldnotes and interview notes taken by the research assistant. She reflected on the data with the research assistant and compared it with field notes of her own and that from the research assistant. The transcripts were analysed using both inductive (chapters 5 and 7) and deductive (chapters 3,4,6) thematic analyses to reflect the research question. The interviews were analysed using deductive coding looking for themes of integration, barriers, facilitators, processes used, norms, values, assumptions and motivational factors for integrating and establishing PC. Where inductive coding was the primary type of analysis, the process of familiarisation and immersion will be further supported by the supervisors to identify themes and subthemes. This was further informed by the literature on PC, education and integration. Negative cases or outliers were included and discussed. Themes and sub-themes that emerged from the analysis of the interviews were coded. Codes and analyses were discussed with the supervisor and research assistant. Codes were also discussed with advisors to check for bias of the researcher. These codes were applied to all the data sources and data was charted across all the data sources of a study. Selected quotes were used to illustrate the resulting themes of the analysis. Finally data was collated.^{79,80}

Document analyses

A data extraction sheet was used to analyse documents with regard to the name of the document, how, when and why the document is used, and for themes of functional and normative integration. Where palliative care is /not is in the document and how it is referred to. These factors where further supported by discussing them with participants.

Quantitative analyses.

Descriptive statistics was used across all the quantitative data from the REDCap databases and hospital referral data.⁸¹ It described the averages, percentages, mean and mediums, range and frequencies. In Chapter 7 the differences between the pre- and post-intervention were described using P-values to describe the statistical significance.

Merging of mixed method data

This research uses mixed methods to expand and corroborate findings. This approach assisted triangulation of data to ensure data validity, especially because interviews were the priority for multiple sources of data. Each component of the qualitative data, document analyses and quantitative data are discussed separately. Integration of the data happened at different stages of each study, but mainly at the interpretation stage to corroborate findings and to make inferences about the topic being analysed. All the interpretations and inferences were discussed with the supervisors and research assistant. Outliers and divergent findings were further explored and discussed with advisors and participants to further understand the phenomena and to ensure trustworthiness. This approach assisted in expanding understanding the integration of palliative care.

Ethical considerations across all phases of this research study

This protocol was submitted to the UCT HREC committee. Ethical approval was obtained for the overarching study from the University of Cape Town (UCT) Research Ethics Committee and updated annually (HREC 071/2020) ([Appendix O: Ethics approval for overall study and updated ethics](#)). Ethics approval was also obtained for all the databases in this study [(PC referral REDCap database (HREC R012/2016) and the Pancreatic Adeno Carcinoma REDCap database (HREC R016/2016)] ([Appendix Q: Ethics approval and update of REDCap database](#)).

Permission was obtained from GSH's Chief Operating Officer (COO) to conduct the research ([Appendix N : Approvals from Groote Schuur Hospital](#))

The HREC also provided ethics approval for four studies from which this research drew data: (*Evaluating care by the Groote Schuur Palliative Care Program* (HREC sub-study 012/2016); *A survey on the training needs of oncology registrars in Palliative Care* (HREC 259/2016); *Evaluating Palliative Care training in the oncology registrar program* (HREC 851/2016). Ethics and site permission approval were updated according to the given dates.

The research conforms to the Helsinki Declaration. It ensured individuals were respected, their right to self-determination was ensured, and that informed decision-making occurred. The research was also conducted using rigorous research principles, using individuals trained in research individuals and dissemination of findings will be available not only to policymakers but also to the participants.

Ethical and rigor challenges for insider research (see above)

To ensure ethical and rigorous research, the researcher was cognisant of all the ethical dilemmas that may arise because of insider research, as discussed ([Positioning the researcher](#)) In order to ensure an ethical approach was adhered to, the following steps were included in the research:

All assumptions have been explored, documented and are tested in all analyses. The researcher is transparent about the intent of the research and about the findings with all participants and with the managerial team at GSH. Regular planning and feedback meetings were held with the PC management team to ensure a collaborative approach and confirmation of data. Problems identified were fed back to the managerial team in a structured and regular manner. A key component of embedded research is trustworthiness⁷⁷. Trustworthiness was strengthened by asking permission from sources about using information obtained outside the formal research process.⁷⁶ The researcher and research assistant also ensured reflexivity in the research by keeping journals with short notes on discussions and interviews. All names were coded in this journal. The researcher discussed all findings regularly with her supervisor and research group.

Distress protocol

During the research, if a participant feel vulnerable or became distressed the research would have been stopped; a distress protocol ([Appendix Distress Protocol](#)) was available but not used as none of the participants identified or showed distress.

Specific ethical considerations for the different implementation strategies in this research

Registrar training program

Confidentiality and security of all data was upheld when doing secondary analyses of data. The new data analyses were fed back to the supervisors. We recognise that focus group discussion cannot ensure complete confidentiality, this was clearly explained to the students and supervisors.

PC service delivery in GSH

This research uses REDCap; a web-based password protected database available for UCT staff. Even though the proposed research does not directly involve patients, it does involve the patient's data and notes of a very vulnerable population at the very end of their life. Thus, meticulous attention is paid to the principles of ethics, namely autonomy (patient confidentiality), non-maleficence, beneficence and justice.

Patient confidentiality is assured by the following measures

- All data collection was done by the author/ research assistant at GSH or UCT
- All participants were anonymised
- The research assistant, transcriber and research group signed letters of confidentiality.
- Patient folder numbers are on a separate list which will be kept confidential.

- Study numbers were assigned by convenience record was kept identifying the folder number to the data collected separately and securely.
- Data capture was done on the password-protected laptop.

Quality improvement audit

Permission had already been obtained from Groote Schuur Hospital to enter patient records into the databases. The researcher works closely with the Hepato-pancreatic biliary (HPB) HOD to achieve this. From the beginning, the researcher has been explicit that this research will be part of her Ph.D. This study was also supported by the research assistant who works in the HPB team.

Focus group discussions cannot ensure total confidentiality. The researcher was explicit about this and asked participants to sign letters of confidentiality. No personal or emotive topics were discussed. All participants signed the consent to participate in the research and will be acknowledged in the research if they agree to this.

As stated, both the databases have ethics approval and patients have consented to be on the database. All data is anonymised.

Dissemination of findings

All findings have been presented to Groote Schuur management and verified with them. All findings were discussed with the stakeholders in their various departments. Findings were presented at a general GSH management meeting in 2023. Findings were not only limited to the outcomes of the study, but the theory and process were shared in order to assist in any further integration programs. The findings of the oncology curriculum is a published article in the African Journal of Health Professional Education in 2021 ([Chapters 5: Evaluating palliative care training in the oncology registrar program in South Africa](#)) Both the evaluation of the curriculum and the impact on the implementation were discussed with the Department of Radiation Oncology at UCT. The researcher will encourage the South African College of Medicine to share their experience of PC training integration with other colleges.

The findings and processes will be presented to the provincial PC steering committee to assist in policy planning. The national PC co-ordinator has subsequently not received an extension of his contract, but the findings will be discussed with the new incumbent.

Abstracts on the research will be submitted to national and international conferences where integration in PC is discussed. Five articles are planned to cover the research findings. Three articles have been published in international journals (Article: The, [Article: Evaluating a vertical nurse-led service in the integration of palliative care in a tertiary academic hospital](#)) and one articles are in the process of submission to a national journal ([Article: A description of how registrar palliative care training affected palliative care integration in South](#)

[African oncology](#)). These strategies for integration of palliative care were implemented within different disciplines, and the researcher aims to publish in discipline-specific journals to ensure a wider audience than PC professionals have access to the findings.

1.10. Conclusion

PC is being integrated into PC services in an ATH. Despite the presence of a policy, there are still barriers and enablers to this process. Currently, three of the integration strategies being used to integrate PC in the ATH are under evaluation to better describe and evaluate how effective they are in reaching the goal of integration. An exploration of the contextual factors that are influencing the integration or lack thereof in an ATH will assist in better understanding the interplay between the strategies and the context. The three strategies will be described and evaluated and finally how and why and to what extent these strategies are achieving integration will be analysed and described. Understanding what integrated PC is, according to the literature, and how this can be achieved will be the first step in better describing and evaluating the strategies.

Chapter 2: Exploring integrated palliative care and strategies to achieve it: a narrative literature review

This is a narrative literature review that provides an overview of implementation research, integration research and PC research, identifying how these converge. It identifies what integrated PC is, justifies the reasons for it and what can be learnt from previous implementation strategies on how to achieve integration of PC. In addition, it also unpacks the complexity of integrating a new intervention into the health system and applies this knowledge to PC to develop a conceptual framework that was then applied in this research study.

2.1. Introduction

Integrating palliative care (PC) into an established service structure with minimal additional resources, will require strategic actions to ensure an effective strategy with the biggest impact. However, PC, as discussed in Chapter 1, is a clinical approach and discipline that focuses on the care of patients and their families with life-threatening illnesses and does not focus on implementation. This review aims to apply an interdisciplinary lens, drawing on Palliative Care Research, Health Policy and Systems Research, and Implementation Science to better understand how to integrate and implement PC. The researcher's experience is that integrated PC is often confused with the idea everybody provides basic PC. However, drawing from evidence from various sources, the integration of any intervention can have various interpretations, and to achieve the integration of any intervention, it is best to be explicit about what you are aiming for.

This narrative literature review will aim to identify integrated PC, justify its reasons, and learn from previous implementation strategies on how to best achieve it. In addition, it considers the complexity of integrating a new intervention into the health system. The question for the literature review is: What is Integrated Palliative Care in a hospital setting, and how can it be achieved?

2.2. Review methodology

A narrative literature review was conducted drawing on the principles of a narrative literature review as described by Green et al.⁸² A narrative review was used to provide a broad overview of this large interdisciplinary topic to assist in developing a theoretical framework and to identify gaps in the literature. Furthermore, it provides comprehensive insights into contextual factors and strategies that enhance the effective implementation of interventions and programmes. *Further* analysis of PC integration is addressed in the empiric work presented in the rest of the thesis.

This included preparation by doing a wide range of reading, stating clearly where the sources of information were searched for and obtained, using selection criteria and identifying common themes.⁸² A database search was conducted in 2020 and updated in 2023, covering English-language peer-reviewed literature published between 2000-2020, from all geographies. The search was undertaken in the following databases: CINAHL, MEDLINE, Google Scholar, Google, APA PsycINFO, Africa-Wide (via EBSCOhost) and SCielo and Scopus. Several search term clusters were tested, and finally, the following main search terms and their variations were applied through all the databases.

Table 2.1: The main search terms and their variations

Main term	Variations
Palliative care	Palliat*, palliative medicine, end-of-life care
Implementation	Implem*, implementation science, implementation strategies, implementation methods, program implementations, system implementation.
Integration	Integrt*, integrative, integrating, integrating
Health system	Healthcare, health care service, hospital, academic teaching hospital.

Filters applied in the searches were articles from 2000-2020, articles in English, search terms had to be in the keywords, title or abstract. These filters were applied to ensure a focused approach and for convenience. Only peer reviewed articles were included, and further quality was assured by drawing from the tools from the Critical Appraisal Skills Programme (CASP).⁸³ Articles after 2020 were included, especially when reviewing the impact of COVID-19 on the topic. Further searches were conducted utilising snowballing, reference list searches, and topic expert advice.⁸⁴ Additionally, experts in the field of PC and Health Policy and Systems and Health Policy and Systems Research were consulted to assist in identifying key literature. This was further supported by conference attendance, webinars, journal clubs, textbooks, policies and institutional databases such as the World Health Organisation. This left the researcher with 56 articles from the search and 172 core disciplinary evidence from articles, policies, information sheets and textbooks. The broad nature of the review does not allow for the comprehensive review of all aspects of PC integration.

2.3. Integration as a concept

'Integrated care' is a complex concept to define.^{69,85-88} There is no single model to define integrated care nor a single theoretical framing to evaluate this phenomenon. One aspect that multiple authors agree on is that

integration must serve the goals and problems of the population it serves.^{86,89} Integrated care can be used to address different healthcare problems. The problem may be to improve patients' outcomes, patients' experiences or even to deliver more cost-effective care.⁷⁰ This trend of framing integration according to the problem in healthcare was described by Kodner and Spreeuwenberg, in a more patient-centred approach.⁸⁷ They stated that integrated care depends on what the patient needs.⁸⁷ Focusing on what the patient needs or 'the care that they need' as central to achieving integrated care may assist in defining it. These needs have been well described in the literature and the whole conceptual framework of bio-psychosocial and spiritual care, and the World Health Organisation's (WHO) definition of PC is based on what patients and families may need when managing a life-threatening condition.^{29,90,91} However, as discussed in Chapter 1, these needs are complex and require multiple role-players. Therefore, only focusing on patient needs or 'care that they need' may also create unrealistic goals.

Therefore, Gröne and Garcia-Barbero state that integration is: *"the act of making a whole out of parts; the coordination of different activities to ensure harmonious functioning."*⁹² But in PC where care is provided in different settings and along the disease trajectory, a more extended definition of integration should include continuum of care, as described by Bainbridge et al.:

*...networks of healthcare organisations and professionals who work together to coordinate services to meet their patients' needs. Conceptually, these networks are a way of linking fragmented services by increasing inter-organisation interactions and ultimately maximising system efficiency and seamlessness of patient transition. The integration of activities between network agencies can include shared staff, joint policy development, joint training programs or workshops, and shared information. It is also defined as the organization and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money.*⁶⁰

Working 'seamlessly' together is not always a feasible nor an achievable goal. For example, Lubuzo et al. focus on 'care coordination' rather than integrated care for cancer patients and foreground co-ordination as an important element which is lacking in the care of cancer patients in South Africa.⁹³ These researchers also highlight the complexities of defining coordinated care and the difficulty in providing coordinated care.

The problem of providing coordination might be related to multiple role-players having different needs, which are not always related to a patient-centred problem. Centring the definition around what the problem is may be more realistic and may assist in being more transparent, especially when working with multiple role players with different responsibilities. Furthermore, Kaasa et al. known for their work on integrating PC into oncology care, draw from Leutz on integration.³⁸ Leutz states that integration is: *"the search to connect the healthcare system with another human service system to improve outcome (clinical, satisfaction and efficiency)"*.^{38,70}

Therefore, on the one hand, we may have efficiency of the system and, on the other hand, satisfaction of the system.

These are important factors to consider when integrating a service such as PC, which focuses on the care of vulnerable patients, including patients with life-limiting illnesses, and whose care may be very expensive in a limited resource setting.⁹⁴ Notably, satisfaction, efficiency, quality and societal needs are well amalgamated when defining Universal Health Coverage. UHC means that *“all individuals and communities receive the health services they need without suffering financial hardship. It includes the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care across the life course.”*⁵ We can, therefore, conclude that integrated PC is when PC works seamlessly with preventative, curative, and rehabilitative services to achieve UHC. Reaching UHC is a common goal for health systems, especially in South Africa, where many services are not available for its citizens.²⁵

2.4.Challenges of the integration process

Although integrated care is advocated for, as discussed above, Leutz’s Five Laws for Integrating Medical and Social Services reminds us that many healthcare providers may see one healthcare individual’s vision of integration as fragmentation of their provision of care. He argues that it may move to a more general approach and force providers to expand their knowledge, perspectives (which may be fundamentally different) and interests.⁷⁰ The arguments for integration include more effective service provision, more efficient service provision, standardised protocols, better communication, patients getting the care that they need when they need it, cost-effectiveness and multiple more aspects specific to the problem.^{86,95,96} However, in a demanding, overstretched healthcare environment, collaborative care may seem, as stated by Leutz, as an extra burden on healthcare workers.⁹⁷ Shared resources and shared decision-making are not always acceptable nor feasible for all stakeholders. Therefore, Leutz states that you cannot fit a *‘round peg in a square hole.’*⁷⁰ In his sentinel article he further states that you cannot integrate all of the services for everybody.⁷⁰ This statement is a concern when we review the need for PC services across healthcare, together with the ethical imperative to integrate PC.^{14,16} Very importantly, he argues that integration costs money before it reduces costs. Finally, a very important law is *‘the one who integrates plays the tune.’* Therefore, how the final envisaged integrated service looks may be the opinion of the one who started the integration process.⁷⁰ Rhee et al. highlight a challenge in integrating PC in Africa is the complete misunderstanding and knowledge of PC. However, they state in Africa, it is important to align with government ministerial groups (top-down approach) to be able to integrate. It will, therefore, be important to have top management or influential stakeholders invested in the integration process.

There is a risk that the integrated service may exclude fundamental role-players, which is important to consider when evaluating integration in a limited resource, inequitable and disciplinary-specific context.⁷⁰ This is why when Krakauer et al. advocate for the integration of PC in the care of multidrug-resistant tuberculosis patients, the editorial includes authors who are very respected leaders in disease-specific disciplines, multi-country authors from both LMIC and High-Income settings and finally argues for integration not only from the patient point of view but also from a system point of view.⁹⁸ Although Leutz's laws were written 25 years ago, they are still very relevant in modern PC integration.

Exploring these complexities creates more achievable goals for integrated care, and in fact, Atun et al. state that integration is heterogeneous, and there are very few fully integrated services and also very few completely unintegrated services in healthcare service.⁹⁹ It is important to recognise that the integration is dependent on the context, the health system itself and also the complexity of the intervention.⁹⁹ Therefore, Atun et al. deconstructed the term integration into multiple facets which correspond to critical health system functions.⁶⁹ The Atun et al. framework hypothesises that the interplay between these facets influences the integration of interventions into the health system. The facets are the characteristics of the problem (the social narrative; the burden and the urgency of the problem around the problem); the intervention itself (*perceived attributes of innovations, such as 'relative advantage', 'compatibility', 'trialability', 'observability' and 'complexity'*); the adoption system (how key actors perceive and adopt the intervention); health system characteristics (how this intervention is integrated and aligned with the current health system) and the context (the interplay of the demographic, economic, political, legal, ecological, socio-cultural (including historical legacies), and technological factors in the environment.⁶⁹ However, this framework does not highlight the values, beliefs and assumptions about the intervention, which is important in PC integration because it is such an emotive, personal topic.

These factors were evident when reviewing why hemato-oncological patients receive far less PC than patients with solid tumours in a study by Manitta et al.¹⁰⁰ This literature review on *'Palliative Care and the Hemato-oncological Patients: Can we live together?'* concludes that integration is complex from both the PC services and haematology services points of view.¹⁰⁰ This is because, in general, haematologists still perceive PC as only end-of-life care, and technically, the diseases are very complex to treat and also to prognosticate for. Furthermore, considering the key actors, the haematologists build long-term relationships with their patients and find it difficult to refer or 'let go'. However, the observed benefits of PC in other cancers and the known advantages of PC have caused haematologists to reconsider the need for PC.¹⁰⁰ Consequently, where we are integrating, who we are working with, and consensus of what the problem is will assist us in determining how to integrate and at which level. In a study done in 2024 by Pereira et al., the Canadian model of integration is unpacked how PC teams interact with other teams.¹⁰¹ In this article, Pereira names the spectrum of models ranging from only consulting to shared care to taking care over care (C-R-T model) and concludes that all models

have strengths, limitations and roles.¹⁰¹ In the South African setting with limited resources a consulting model has been seen as the first step in integration.

2.5. Difference between health systems and healthcare integration

It is important to distinguish between health systems integration and integrated health care to conceptualise integration elements. In summary (unpacked below), health systems integration can be understood as the ‘working together’ of the whole health system, while health care integration focuses on integrated service delivery.

Health systems integration

Health systems integration uses the WHO’s building blocks framework to define the essential elements that have to work together to achieve a specific goal.^{70,102} This may include joint planning, training, decision-making, instrumentation, information systems, purchasing, screening and referral, care planning, benefit coverage, service delivery, monitoring, and feedback.⁷⁰ Browne et al. also focus on the importance of continuity of care across both the service platforms (primary to quaternary) and along the continuum of care (from prevention to palliative) as a component of an integrated health system.¹⁰³ The number of different functions and services provided along the continuum of care is defined as the ‘*breadth of integration*’.¹⁰⁴

The need for health systems integration, like all new interventions, is especially important when reviewing PC integration. Patients and families will use multiple healthcare services and facilities in the patient’s disease trajectory.¹² PC services depend on a multifaceted and multidisciplinary approach that ranges from community education, clinical care, availability of medication, spiritual care, HCW education, traditional healers and policy.^{105,106} Therefore, the breath of PC integration will include multiple factors to ensure service delivery.

In a systematic review, Suter et al. conclude that the ten key elements that have to ‘align’, ‘connect’ or ‘collaborate’ to ensure an integrated health system are comprehensive services; patient focus; geographic coverage and rostering; standardised care delivery through interprofessional teams; performance management; information technology; organisational culture and leadership; physician integration; governance structure; demand generation and financial management.^{69,95} Atun et al. also mention these elements in their conceptual framework for analysing an integrated health system. However, a common frame of reference, beliefs, and values are not mentioned. Furthermore, for PC integration, family care will have to be included to ensure PC is provided according to WHO’s definition of what PC is, and their understanding, beliefs, and values should also be considered.²⁹

Healthcare integration

Kodner and Spreeuwenberg state that integrated healthcare focuses on: *“bringing together of inputs, delivery, management and organisation of services as a means of improving access, quality, user satisfaction and efficiency.”*⁸⁷ Furthermore, in a position paper of the WHO European Office for Integrated Health Care Services, Grone et al. stated that the links of service delivery can also be vertical (bringing together services operating at different levels) or horizontal (the linkage of services on the same level).⁹² Practically, the integration may even be *‘oblique’*.⁶⁹ Therefore the bringing together of services can be done both vertically, horizontally or obliquely. Kaasa et al. recommend that integrating PC into cancer care requires both a horizontal and vertical integration approach or oblique integration.³⁸ The importance of vertical or PC specialised services is acknowledged by the World Health Assembly to manage integrated care for patients with more than routine problems.¹⁴ Furthermore, the sentinel article on the improved outcomes of patients with non-small cell lung cancer and follow-up articles by the same group are also based on specialised services.¹⁰ Shin et al. state that: *“Specialty palliative care can provide an extra layer of support for patients with lung cancer and their families by helping with more challenging symptom management, psychosocial support, complex decision-making, advance care planning, and transitions in care.”*^{10,107} In addition, specialised services are very important to manage complex symptoms when working alongside very specialised services. Drawing again from Leutz, who reminded us that *“you cannot fit a round peg in a square hole”* and, thus, PC service delivery may not be part of the skills set of very technical providers such as surgeons.⁷⁰ PC providers can find it stressful when moving outside their field. In a study done by Michael et al. exploring incorporating early integration of specialist palliative care, the study also found that when PC providers were asked to provide more acute care, they reported that integrated care was stressful and distracted them from their core discipline.⁹⁷

However, especially in the LMIC and HIC setting, with a high burden of disease and a limited number of trained PC providers, horizontal integration will also be a fundamental method of delivering care.¹⁰⁸ The WHA 67.19 resolution supports basic and intermediate levels of PC training as well as specialised training.¹⁴ All HCPs should be trained in a palliative care approach and be able to deliver basic PC. This generalist approach is especially important in an ATH where the sole reliance on the delivery of PC cannot rest only on a specialised PC team because of the high burden of cases and limited PC workforce.¹⁰⁸

Furthermore, In Africa, PC integration's strengths have been through a more horizontal approach using community health workers in the patient's home, taking advantage of the special role of nurses, diversity of services, and short training courses. The term 'Community Health Workers' (CHWs) has different meanings in different settings. In some settings, they are activists, community volunteers, or trained traditional healers. The CHWs were considered affordable extensions of the PC system, providing essential services such as visiting patients at home, in Africa.¹⁰⁹ This also aligns with the fact that most patients want to be at home, which requires multiple services to be able to provide basic PC, for example, all pharmacies must be able to stock

mist morphine. However, the same article also states that an aspiration in Africa is to develop more specialised PC services.¹⁰⁹ Thus, when viewing PC in Africa we are aiming for an oblique model of integration, both vertical and horizontal.

Although many clinicians, in general, work in collaboration without formal health system integration, it can be argued that this is not sustainable without formal health systems integration. This is because, as argued by Valentijn et al., the healthcare sector is too complex and interlinked to function in only one dimension.² Although there is a difference between health system integration and healthcare integration, evaluating delivering integrated care to a patient requires an approach that bridges health systems integration and healthcare integration. Therefore, to evaluate integrated care to a patient, it may be best to use an approach that bridges healthcare and health system integration.

2.6. The different dimensions of integrated care link health care with the health system

Different dimensions of integrated health care are extensively theorised. Atun et al., as mentioned, developed a conceptual framework to deconstruct integration into multiple facets to assist with program reviews. This framework assists in detailed mapping of the purpose, extent and nature of integration. Although this framework includes aspects of normative integration, it is not explicit nor specific on the normative aspects of integration, which are core to PC integration. In this section, the researcher will concentrate on the Rainbow Model of Integrated Care theory by Valentijn et al.⁸⁵ Valentijn et al. identified the main dimensions of integrated health care through a thematic analysis of a systematic literature review. They developed a theoretical framework to describe an integrative service model.⁸⁵ Although this framework was developed drawing from the primary care setting and did not include patients' or macro policymakers' opinions, it is still valuable to understand PC integration. Firstly, the authors linked integrated clinical health care with an integrated health system. Secondly, it unpacked the soft skills needed for integration systematically. This framework also takes account of the dynamic nature of a health system and the non-linear patterns of integration. This model is called the 'Rainbow Model of Integrated Care' (RMIC).

It identifies six integration dimensions, namely clinical, professional, organisational, system, functional and normative integration. According to this model, the integration of services can happen at different levels namely: micro, meso and macro levels. See Diagram 1.

Table 2.2: Integrated care dimensions of the Rainbow Model of Integrated Care ⁸⁵

Table 1. Integrated care dimensions of the Rainbow Model of Integrated Care

Level	Dimension	Description
Micro	Clinical integration	The coordination of person-focused care in a single process across time, place and discipline.
Meso	Professional integration	Inter-professional partnerships based on shared competences, roles, responsibilities and accountability to deliver a comprehensive continuum of care to a defined population.
Meso	Organisational integration	Inter-organisational relationships (e.g. contracting, strategic alliances, knowledge networks, mergers), including common governance mechanisms, to deliver comprehensive services to a defined population.
Macro	System integration	A horizontal and vertical integrated system, based on a coherent set of (informal and formal) rules and policies between care providers and external stakeholders for the benefit of people and populations.
Micro, Meso, Macro	Functional integration	Key support functions and activities (i.e. financial, management and information systems) structured around the primary process of service delivery to coordinate and support accountability and decision-making between organisations and professionals in order to add overall value to the system.
Micro, Meso, Macro	Normative integration	The development and maintenance of a common frame of reference (i.e. shared mission, vision, values and culture) between organisations, professional groups and individuals.

The authors further describe the dimensions of integrated health care in more detail by naming 59 features of integrated care. However, these dimensions, as discussed by Valentijn, are related to primary and not all of these dimensions apply to PC integration. It will be important to identify the dimensions that are aligned with PC integration. Valentijn's theoretical framework also discusses the fact that integrative care requires normative integration at all levels of care. Normative integration is seen as the final step to integration and describes the development of mutual values, vision, trust and culture. It encompasses the soft skills that glue the systems together. The dimensions are interconnected on each of the micro (clinical integration), meso (professional and organisational integration) and macro (system integration) levels. Functional and normative integration ensure connectivity between the levels.² This common frame of reference must not only be developed, but it must also be maintained. Furthermore, drawing from the work of Kodner, who earlier in 2002 emphasised under a professional integration, the need to have professional relationships to enable integration.⁸⁸ These relationships must be built and maintained. This highlights the fact that integration is a dynamic and ongoing process. These relationships flow into the normative aspects of integration. These relational aspects are not explicit in Valentijn's framework and may be important to evaluate in integration. As described by Meier, writing about PC leaders' experiences, PC is an emotive topic.¹¹⁰ Therefore, the normative aspects of PC integration need to be explored in depth because it relates to a core aspect of all human beings including the reality of death. Normative and functional integration are essential components that connect all the dimensions of integration.⁸⁵ Normative integration fostering common values may seem desperate and break trust if it is incongruent with resources and other functional integration elements.¹¹¹ In PC, these normative aspects are even more important as it relates to how we relate to death and dying in a healthcare system.⁵⁷

2.7. The importance of normative integration and organisational culture

Valentijn et al. further unpack normative integration as the common and shared frame of reference (values, mission, vision and culture) that needs to be developed and maintained in order to integrate.⁸⁵ Normative integration is recognisably closely linked to organisational culture and must be comprehended before a common frame of reference can be developed and strategies streamlined to normalise the intervention. Organisational culture is a complex phenomenon, something we all belong to, difficult to define, dynamic and with ambiguity. It is shared sets of understanding and meaning that guide behaviour and social interactions in a particular organisation.¹¹² *“This is the way things are done around here”* is a layman’s and easily understandable definition of organisational culture.¹¹³ A more formal definition of organisational culture is provided by Nakrem as a: *“...set of values, beliefs, norms, customs, rules, and codes that lead people to define themselves as a distinct group with a sense of commonality.”*¹¹⁴

Jung et al. state that values are formed in our homes early in our lives, while practices like customs, norms, and rules are acquired and socialised in the organisation.¹¹⁵ Values are the idealised, subjective aspect of organisational culture. These values can be described as core values of an organisation and may seem platitudinous or part of an advertisement campaign. Unwritten values are not always obvious at first glance but need to be deduced through careful interaction with members of an organisation.¹¹² Thus, values are not always shared among members of the same organisation. Still, members of the same organisational culture may have the same frame of reference or share the recognition of certain issues. When considering the early formation of values, we need to be cognisant of where Healthcare Professionals' (HCPs) values for providing care are developed, and it is clear how important early integration of PC competencies is in long-term integration.

Further in Martin’s book, *Organisational Culture, Mapping the Terrain*, to better explain organisational culture, Martin comments that organisational culture can materially and physically manifest in rituals, organisational stories, humour, dress code, office space and how staff are remunerated and can also provide important clues to what people are thinking, believing and doing.¹¹² Further, she states that stories may seem like the glue that keeps people together and serve as important tools to guide new members on how things are done correctly, for example in an ATH, the story of patients jumping out of the window after they receive bad news is an important tool to teach new doctors on how important safety netting is when you break bad news. According to Martin, humour is another important tool to bridge uncomfortable movements, to let off steam, especially when dealing with highly emotive topics that are too hard to verbalise.

Applying this to PC, we can argue that death is a highly emotive topic, and humour has allowed many HCPs to cope with this constant reality in the wards. Humour dealing with death and dying may seem careless and cruel

to an outsider, but on deeper interaction with the HCP it will become apparent that this is a coping strategy. Rituals are also important coping strategies used in hospitals, especially when dealing with the death of a patient. Dress codes in hospitals can also be truly discipline-specific; for example, young surgeons will walk around in scrubs while more senior surgeons will not. The true link between values and behaviour is understanding *assumptions* to understand how members feel, perceive and think about matters. Therefore, as Martin reminds us, core or unwritten values, humour, rituals, jargon, dress code and understanding assumptions make you fit in and must be understood to align or influence when integrating a new strategy.¹¹² Understanding how an organisation views and manages death and dying, vulnerable populations, and different viewpoints can also assist in understanding organisational culture.

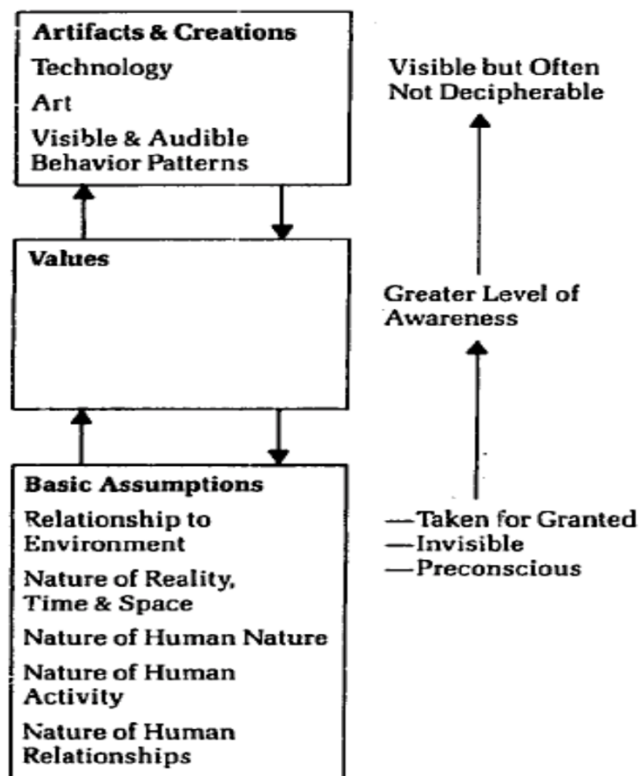
In a scoping review of organisational culture in the health sector, Mbau conceptualises organisational culture as a: *“system of values and practices: that are socially or relationally constructed and shared by actors within the health system; that influence their relationships, attitudes and behaviour towards changes in the health system; and, can be manipulated or influenced, at least in part, through managerial strategies to enable achievement of the desired organisational goals.”*¹¹⁶ Organisational culture is thus pliable and comes to the forefront, especially when change is introduced. It, therefore, requires deep understanding and sensitivity to the ‘way things are done’ if any change is to be introduced. Formal change may be easily introduced, for example, a new policy/ dress code, but the more unwritten values, rituals and humour must be tackled with sensitivity and understanding. Actors may perceive change differently, and the change may influence, align, or even disrupt organisational culture. Disruption of ‘how we always do things’ in an organisation is not always welcomed and can be met with the marginalisation of a new intervention.¹¹⁴ Actions such as disrupting a reality of forcing HCP to be present with suffering, not abandoning the patient when dying or recognising the patients are dying when they leave the clinic may come with disengagement with palliative care because it is actually not ‘part of the job’ and may ‘negatively influence bed occupancy’. Most HCP are deeply committed to the care of patients. Therefore Mbau emphasises that when values, behaviour and assumptions around care are disrupted, integrators must be able to put contingency plans in to manage the feedback loops.¹¹⁶ This concept, is especially important to consider when dealing with emotive topics in PC because delivering PC does evoke different emotions in HCP with both positive and negative effects.

The understanding of organisational culture is multidimensional and complex, and Jung et al. identified seventy instruments for exploring and assessing organisational culture.¹¹⁵ Jung et al. highlight the many self-report questionnaires that are used to explore organisational culture because of their ease to administration and cost-effectiveness.¹¹⁵ Tools must serve the aspects that are under review, and Martin gives caution to generalisability when describing culture and that many tools only provide a *‘thin description’* of organisational culture. A *‘thick description’* of a culture may include policies, informal practices, formal practices, rituals, stories, and the physical layout.¹¹² This takes time and requires a different approach to research, such as an

insider researcher perspective or ethnography. Nobody will share a joke with you until you have developed a relationship of trust and non-judgement. According to Geertz: *“the trick is to figure out what the devil they think they are up to.”*¹¹⁷ Thus if you want to *‘lift the veil’* or apply true hospital humour to *‘open the coffin’*, there needs to be an appreciation of contextual specific knowledge to gain in-depth knowledge of organisational culture, especially when reviewing highly emotive topics. Becoming part of the culture to be really able to provide a *‘thick description’* of the culture is explained best by reviewing the notes from Geertz: *Deep Play: notes from a Balinese Cockfight*. In these notes, he could only explore and understand the Balinese culture when he was accepted as an insider. He achieved this by putting himself in a risky situation with the community. Trust was developed, and thus, a situation, like a cockfight that may seem at a glance immoral, was much more a display of social structure with cultural roots.¹¹⁸

The Schein model is a theoretical framework for understanding organisational culture.¹¹⁹ According to this model, developing a deep understanding of organisational culture may include three levels of depth. According to Schein, at the first level, a description starts with artefacts such as stories, rituals, and dress codes. In the second level, values that are articulated with ease further develop understanding. In the third level, assumptions are difficult to determine because they are easily taken for granted.^{112,120} The best method, according to Schein, is to enter into a discussion to tap into the unconscious assumptions and to understand the assumptions behind aspects like the jokes, stories and dress codes.

Diagram 2.1: The Schein Model: a theoretical framework for understanding organisational culture ¹¹⁹



Understanding organisational culture can be further extended and verified through self-reported questionnaires. Unpacking policies, guidelines and physical arrangements to determine the alignment or misalignment between policies, organisational goals, professional goals and clinical care.¹²¹ This model highlights the interconnectedness between artefacts between artefacts, values and assumptions. This interconnectedness is very important in PC, where values play an important role in our assumptions about PC. Unfortunately, there are still many negative assumptions about PC which devalue the importance of PC. Furthermore, in healthcare, the artefacts may not be that plain to see unless there is a deep engagement with the system, such as dress code.

Mbau describes that the degree to which the members of an organisation share culture can be assessed from three perspectives: integration, differentiation and fragmentation.¹¹⁶ The perspective of integration tries to identify shared beliefs in an organisation that are consistent, shared, and clear. The differentiation perspective focuses on inconsistency and how different sub-cultures interact (and/or conflict) with each other. Assumptions in subcultures differ, and the differences in the subcultures are the focus of differentiation studies. The fragmentation perspective focuses on ambiguity in a culture of high complexity and different identities.¹²² South African ATHs are a milieu of different cultures in both the HCP population and the population they serve.

Martin further highlights inconsistency in organisational culture, which can be interpersonal, intra-organisational or inter-organisational. These inconsistencies or fragmentations in organisational culture can be seen as a normal part of the modern world, especially in PC services, serving and being served by people from all walks of life. In fragmentation studies, a common frame of reference or the recognition of issues are identified. These issues may be positively or negatively valued or may be seen as relevant or irrelevant by different members of the organisation. In hospitals, all HCPs are aware that patients die or have been diagnosed with life-threatening illnesses. However, how they behave towards this reality is ambiguous. Any attempt to understand the organisational culture should try to capture these complexities rather than excluding them.¹¹²

2.8. The role of context in integration

As important as culture is in integration, it is also important to explore the context where integration occurs. Context is important, firstly, to understand why and how certain outcomes are achieved.^{3,123} It is also often the context that is responsible for study-to-study variations and why things work in one setting and not in another.¹²³ Without understanding the context, new interventions may not be transferable to other settings.¹²³ In a scoping review conducted by Nilsen et al., 22 articles identified showed 17 different theoretical frameworks to describe context. These frameworks also included frameworks that were not linked to physical implementation nor knowledge of the actual implementations; therefore, there may be bias and practical relevance can be questionable. Therefore, considering the large variety of ways context can be described, a more universal and evidence-based understanding may be needed. Some of the principles mentioned are that context may be viewed as "*everything else that is not the intervention*"; it is always there and dynamic. Although there are common dimensions, contextual dimensions may vary so that context is unique to the topic.

Furthermore, common contextual dimensions are organisational support, financial resources, social relations and support, organisational culture, leadership, and patient-related determinants (especially in health care).¹²³ Context is also multi-layered, which is influenced at a micro, meso and macro level. One level also influences the other levels, and vice versa, or levels of context are intertwined.¹²³ Additionally, it is also important to consider the timing of a new intervention because getting things right at an opportunistic time is important.¹²⁴

Core dimensions needed in PC integration are derived when reviewing the article by Stjernsward et al. on the Public Health Strategy for PC.^{85,125} Thus, education, drug availability, patient population and policy are also important. In addition, when implementing integrated PC we must consider the important normative aspects of integration, such as current norms, values, beliefs, motivation, and culture. PC is also being integrated and interlinked with macro elements, and timing is fundamental in this integration process. Never has this been

more important than when the impact of the COVID pandemic highlighted the need for integration of PC globally.¹⁹ In research conducted by Wentlandt et al. in Canada, a country with a well-structured PC system, on the barriers and facilitators to palliative care integration in managing hospitalised patients with COVID-19, common contextual factors were identified. These were PC knowledge (education) and primary provider factors (time, attitude, and reimbursement), which can be more explicitly defined as norms, values, beliefs, motivation, and culture. Additional factors were leadership, previous relationships and culture. Therefore, the context was core to understanding how successful the integration was or was not.

2.9. Measuring integration

The degree and intensity of integration can be quantified as follows. Kodner highlights that the level of integration should be determined by consensus among stakeholders on what they want to achieve for a specific population group with specific needs.⁸⁸ The WHO document: **Assessing the development of palliative care worldwide: a set of actionable indicators look at whole country integration and not specifically at hospitals.** Ahgren and Axellsson conceptualised and validated a practical method to measure the degree and intensity of functional integration (Diagram 2.2).¹²⁶ Functional integration includes the integration of clinical services information systems and financial arrangements. Drawing on the work of experts in the integration field, such as Leutz⁷⁰, a measurement tool was conceptualised by Ahgren and Axellsson that can be used intra- and inter-organisationally to measure both vertical integration and horizontal integration. The degree of integration is further unpacked in Diagram 2.3. Ahgren and Axellsson, being cognisant that integration is not welcomed by all stakeholders, state that the intensity of integration depends on consensus among stakeholders, which then counteracts the normative aspects of the scale. The stakeholders should also determine the derivation of the intensity ranks and the terminology clearly stated in a guideline. This increases the value of the measurement tool to allow for self-assessment and self-correction.¹²⁶ Unfortunately, this only measures the actual level of integration and not the perceived level of integration. Furthermore, it does not consider the normative aspects of integration which are very important in PC integration.

Diagram 2.2: Scale and a description of the scale of functional clinical integration.¹²⁶

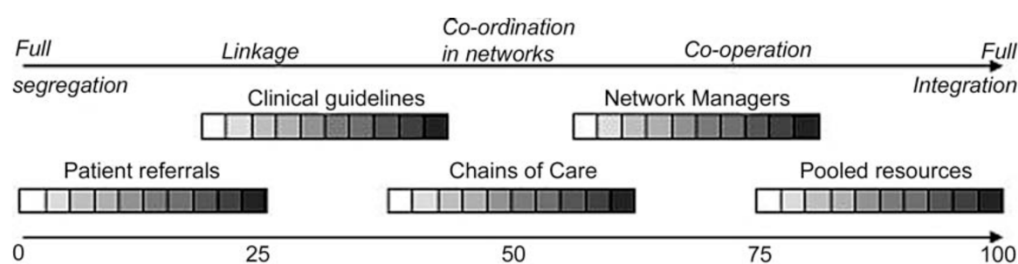


Table 2.3.: Description of intensity of integration: ¹²⁶

Full segregation	Absence of any form of working together
Linkage	<i>“an adequate referral of patients to the right unit at the right time and good communication between the professionals involved in order to promote continuity of care. The different units and professionals understand who is responsible for each type of service, and there is no cost shifting between them. Clinical guidelines describing what shall be done by whom and when, are examples of mechanisms used in this form of integration.”</i>
Co-ordination	<i>“The aim is to coordinate different health services, to share clinical information, and to manage the transition of patients between different units. Chains of care and other health care networks are included in this form of integration, but there is usually no network managers appointed. The existence of such managers would entail a higher degree of integration.”</i>
Co-operation	<i>“network managers are appointed to improve the contacts between the organizational units involved, but these units are still quite independent.”</i>
Full integration	<i>“resources of different organizational units are pooled in order to create a new organization’s aim is to develop comprehensive services attuned to the needs of specific patient groups. The comprehensive services are managed through the new organization, which includes close cooperation between different professional groups.”</i>

2.10. Implementation of integrated palliative care

Conceptually understanding what integrated PC is leads us to question how we can achieve integrated. Unfortunately, very few evidence-based interventions become practice and understanding how, why and how interventions worked or did not work can assist in developing better implementation strategies.¹²⁷ This is especially important to understand how interventions play out in the real world and in different settings.⁷³ The importance of context, as a domain to consider in integration, in starting a new strategy, is emphasised by the Consolidated Framework For Implementation Research (CFIR).¹²⁷ In the CFIR framework, five major domains are mentioned: intervention characteristics, outer setting, inner setting (context), characteristics of the individuals involved, and the process of implementation used.¹²⁷ The CFIR model is a well-recognised and acceptable model in implementation science.⁷¹

Unpacking this in relation to how we defined context, integration and PC in the previous sections, this research can draw from the CFIR model to work towards how to achieve integrated PC. As stated above, the first component of the CFIR model is the intervention itself. As previously explained, PC is a very complex intervention.³ The evaluation of the intervention itself aligns with RE-AIM conceptual framework as well that evaluates the fidelity of the intervention.¹²⁸ The inner and outer setting in this research will be described as

context, which has been unpacked, and the interconnectedness between ‘inner’ and ‘outer’ has been explained in detail. The fourth aspect is the individuals themselves, and as Damschroder et al. remind us, they carry power, and the individual and professional impact are core to understanding implementation.¹²⁷ These factors can also be compared to what Valentijn et al. describe as the normative aspect of integration.⁸⁵ The final domain is what you do (implementation process) to achieve the outcome. Valentijn et al. include outcomes in a Revised Rainbow Model of Integrated Care and state that cost and utilisation, population health and experiences of care are important outcomes to consider.⁶ Therefore, it will be important to review how these outcomes of Valentijn et al. are applicable to delivering PC services.⁶

The implementation process may be formally planned or an informal process. The processes may be dynamic, at multiple levels, interlinked, creating an intertwined lattice of linear and non-linear processes with direct and indirect feedback loops. Therefore, because implementation in a real world setting can be ‘messy’, Kirk et al. advise that a clear theoretical framework should be used in implementing a new strategy.¹²⁹ However, the researcher argues that it will be too complex to define absolute numbers of PC adoption in PC integration as recommended by the RE-AIM framework.¹²⁸ Peters et al. further argue that a good quality implementation project will reflect the following: 1) a description of what is being implemented; 2) what strategy is being used; 3) Is it been done in a real-world setting?; 4) Are the outcome variables clear?; 5) does the research consider the context or other influential factors?; 6) does it consider the change over time?; 7) Does it describe the target audience or how the research will be used?.⁷⁴ However, integration can be chaotic, and clearly defined aspects can be difficult to explain.⁶ Therefore, the process of what you are aiming to achieve is as important as the intervention itself. In the UK Medical Research Council’s report on developing and evaluating complex interventions, Skivington et al. highlight that the process is phasic, and in each phase, six core elements should be considered: how the intervention interacts with the context, what is the underpinning theory, how diverse stakeholders are included, how can the intervention be refined, what are the uncertainties and what are the comparative resource and outcome consequence of this intervention.³ This phasic approach is especially important when we consider how dynamic a healthcare system is. What is especially important about the Skivington et al. report is the importance of asking pragmatic questions of how and why aspects worked in evaluating complex interventions.

2.11. Strategies used to integrate new interventions

According to a Cochrane review done by Pantoja et al. on an overview of systematic reviews exploring implementation strategies for health systems in low-income countries, most implementation strategies focus on HCP and recipients and the strategies’ outcomes. There is limited evidence on strategies targeting organisations in low-income countries.¹³⁰ The findings showed that interactive techniques (audit/ feedback, academic detailing/outreach and reminders) were most effective for simultaneously changing physician care

and patient outcomes. These strategies allow for bidirectional growth and integration. This bidirectional growth aligns with how Kotter envisaged managing change, emphasising 'communicating for buy in' and 'getting the vision right'.¹³¹ Clinical practice guidelines and opinion leaders were found to be less effective.¹³⁰ We can thus conclude that whatever we do to integrate PC, stakeholder involvement and iterative strategies may be core to effectiveness. However, this process can be labour intensive and will require the skills to have very emotive conversations carefully. This Cochrane review further explored organisational strategies and patient outcomes. The findings showed that revising professional roles and computer systems for knowledge management improved professional performance. Multidisciplinary teams, integrated care services and computer systems for knowledge management or reminders generally improved patient outcomes. Integrated care services also led to cost savings as per this review, but by Leutz draws attention to the fact that these cost savings are only seen after an initial investment.⁷⁰

Expanding to a global perspective, Wensing et al. conducted a systematic review of implementation strategies at the organisational level (healthcare facilities) to improve patient outcomes.¹³² This review of 36 studies concluded that there was no one strategy with a consistent effect, but that organisational revision of professional roles and computer systems for knowledge management improved professional performance. This study supports Atun et al. that it is the interplay of facets that are required to determine the effectiveness of an intervention. Understanding the people, resources and processes are core to effective integration. Therefore, multiple strategies can be used to integrate a new intervention. What is important about all strategies is that they are named and defined, and can be described as to how the strategy was operationalised.¹³⁰ Operationalising implies it is clear a) who, b) performs what actions, c) drawing on what knowledge, d) relying on what skills, e) using what materials or tools, f) achieving what specific outcomes.¹³³ These aspects can sometimes be very difficult to unpack in a PC intervention, especially when normative aspects are so important in the integration. However, this level of detail may assist in providing transparent detail and, therefore, allow for the intervention to be replicable but it has to be interpreted within the context in which it was delivered.¹³⁴

Therefore, with limited resources, interventions need to be effective but also emphasise appropriateness for the context and culture of the organisation. An effective integration strategy is thus not only an intervention that works but is also acceptable, practical, helpful and viable.³ The stakeholders are core at what the intervention intends to do and what they want to achieve with such an intervention and thus whether it is effective or not.¹³⁵ The ability of an intervention to be transferred into a different setting requires understanding not only the positive outcomes but also the negative outcomes of the interventions and how the context interplayed with the intervention. For example, Bloom examined the role of continuing medical education (CME)'s different tools in changing physicians' practice and improving patient's health outcomes through a systematic review. CME aims to improve patient care, accepting new, more beneficial care and discontinuing lower-benefit diagnostic and therapeutic interventions. This review concluded that interactive

techniques are the most effective, clinical practice guidelines and opinions of leaders are less effective. Didactic presentations and distributing only printed information have little or no beneficial effect on changing physician practice.¹³⁶ This study was only looking at educational practices, and the integration of PC has to occur on many levels.

2.12. Strategies used for integrating PC

Relating this to knowledge of implementing integrated PC, all of the above become important, but another element to consider in PC is the timing of the intervention in relation to the disease trajectory.⁶¹ This can be compared to the specifics of the intervention.⁷⁴ The importance of this can be further related to knowing PC outcomes because research has shown the earlier PC is integrated, the better the outcomes.¹³⁷ Another element that Siouta et al. draw attention to in strategies to implement integrated PC is who the multidisciplinary team is. It must be clearly defined because the composition of the teams varies, which impacts outcomes. This is especially important in new PC interventions where teams have not been formalised. However, the level of PC training and experience must also be considered when evaluating a PC team. Furthermore, it is important to describe how and who is collaborated with to ensure transparency and replicability in PC strategies.⁶¹ But as Skivington et al. stated, why they collaborated is also important.³

Therefore, PC integration is a complex process that will have to occur on many levels with different approaches and actors to enable integration.³ The barriers, facilitators, context and intervention itself play an essential role in the type of approaches used to enable integration. Approaches to implementation have been well described in the literature.

Baggs conducted an ethnographic study exploring the complexities of end-of-life decisions in an Intensive Care Unit (ICU).¹³⁸ This study explored the complexities around roles, trust and communication between physicians and between physicians and patients in surgical ICUs. This study concluded that the whole system needed to change, especially the decision-making culture. The process tools, such as checklists, need to change to integrate PC into surgical ICUs. A follow-up editorial stated that:

*... other members of the care team should be educated about surgeons' perspectives on palliative care and the psychological, personal and practical factors that shape it, honouring the surgeon's profound commitment to achieving the best possible outcome.*¹³⁹

Although the study was conducted in only one unit, the study site was a complex ATH with predefined cultures and roles and responsibilities. The hierarchical and distinct roles and responsibilities of the different disciplines with little interdisciplinary collaboration are very similar to those of other hospitals. Baggs, further eloquently describes the need to understand the culture and reasoning behind the structure of the ICU. Integrating into these systems, therefore, requires approaches that speak to the culture of the system with processes and tools that support the integration.

The Baggs and Bloom studies highlighted how interactive approaches must be used to integrate on a micro level.^{136,138} However, as stated before, the PC has to be integrated at all levels, and the whole system needs to be able to integrate the PC and interactive sessions require resources.

2.13. Reasoning as an important component of implementation

Programmes cannot be kept constant or isolated, and the practicality of implementing integrated PC in a real setting must not be underestimated. Programmes, such as integrated PC, are also open because they are influenced by a changing context. This was evident when the COVID-19 pandemic created a palliative care urgency across the world.^{140,141} Programmes work (have successful outcomes) only in so far as they introduce appropriate ideas and opportunities (mechanisms) to groups in the appropriate social and cultural conditions. Programmes are constantly changing and therefore, it may be more important to understand the reasoning behind the actions. Understanding the reasoning may assist us in moving beyond context and strategies when implementing and may assist us in understanding the configuration of elements needed to integrate.¹⁴¹

This unpacking of the '*black box*' referred to by Suchman, provides implementors with an understanding of what actually happens in the real world.¹⁴² How strategies worked or did not work depends on how stakeholders interpreted and acted on the interventions.¹⁴³ For example, in a study conducted in England by Spacey et al. on advance care planning, resources were allocated to implement it, but implementing advance care planning was not achieved. The reason for this was that it was just emotionally too hard for the care workers to do.¹⁴⁴ This reasoning and interpretation may be highly emotive and personal, and therefore, the interpretation must be made within the environment where the intervention takes place. The actions that followed must also be seen within the environment. No findings are absolute and findings must be interpreted within the context of the research.¹⁴¹ Their reasoning about the intervention or how they make sense of the intervention is, therefore, core to gaining a deeper understanding of how and why interventions work.¹⁴⁵ Weick states that sense-making involves turning new circumstances into a situation that is comprehended explicitly in words and serves as a springboard into action.⁴ Consequently, it will be vital for integrating PC long-term to ensure stakeholders make sense of PC in their own practice so that provision of palliative care is assured.

Therefore, knowing the reasoning behind integrating PC and what action followed the reasoning may assist us in alleviating misconceptions about PC and integration of PC in order to plan future integration strategies using successful driving forces and actions.¹⁴⁶ It will, therefore, also be important to try to link the reasoning with the actions in the context of the impact of integration.

2.14.A conceptual framework for palliative care integration in relation to ATHs.

Framing PC integration in an ATH in relation to the theory of integration may assist us in developing strategies to integrate and understand gaps in the integration process. Hui et al. explored the integration of PC into oncology services in North America and Europe in hospitals with more than 100 beds.¹⁴⁷ This study concluded that although PC integration is widely accepted, it is a poorly defined concept. In a systematic review only looking at oncology care, Hui et al. refined processes for integrating PC according to specific care indicators, collaboration indicators, educational indicators, guidelines and policies; drug availability and leadership and governance aspects.¹⁴⁸ In another study, Hui et al. conducted a Delphi Survey to develop a consensus list of indicators on integrating speciality palliative care and only oncology programs for advanced cancer patients in hospitals with ≥ 100 beds. Specific outcomes for integrated PC service in oncology care were identified as: clinical structure, clinical processes; clinical outcomes, education and research. This Delphi study defined 13 major indicators and 30 minor indicators to measure PC integration into oncology care.¹⁴⁷ The major indicators focus on the presence of a multidisciplinary service and the structures, outcomes, processes and educational activities required to be a fully integrated service. The structures are the presence of an inpatient PC consultation service and an outpatient PC service. The processes are the presence of an IDT PC team, routine symptom screening in oncology clinics, routine documentation of advanced care plans in patients with advanced cancer and early referral to PC. Outcomes to be measured are the proportion of the patients with pain assessment in the last two visits before death, the proportion of patients with two or more ED visits in the last 30 days before death (negative indicator) and the place of death consistent with patient's preference. The educational activities are PC curriculum for oncology fellows provided by PC teams; CME in PC for oncologists; combined PC educational activities provided and oncology fellows having a PC rotation included in their rotations.¹⁴⁸

A conceptual framework for this research

In this research study, the following aspects of integration will be aligned with PC: functional integration and context factors (see diagrams 2.3), which include both the normative aspects of integration and the environment in which it is being integrated. Each component as described by global literature needed for PC integration is linked to an aspect of Valentin levels of integration. For example, guidelines form part of professional integration. Furthermore, the concept of complexity is emphasizing and, therefore, the context becomes an element as well.

Drawing on the literature of integration and PC, a deduction can be made that the following domains are required to achieve functional PC integration in an ATH. There are nine domains (blue) in which integration needs to occur, namely: The provision of patient and family-centred care;^{38,85,99} The provision of collaborative

care;^{85,99} Information systems;⁶⁹ Education;^{65,85,147} Leadership and governance;^{65,85,147} Guidelines and policies;^{147,149} Palliative care workforce;¹⁴⁷ Drug availability;^{43,147} Research.¹⁴⁷

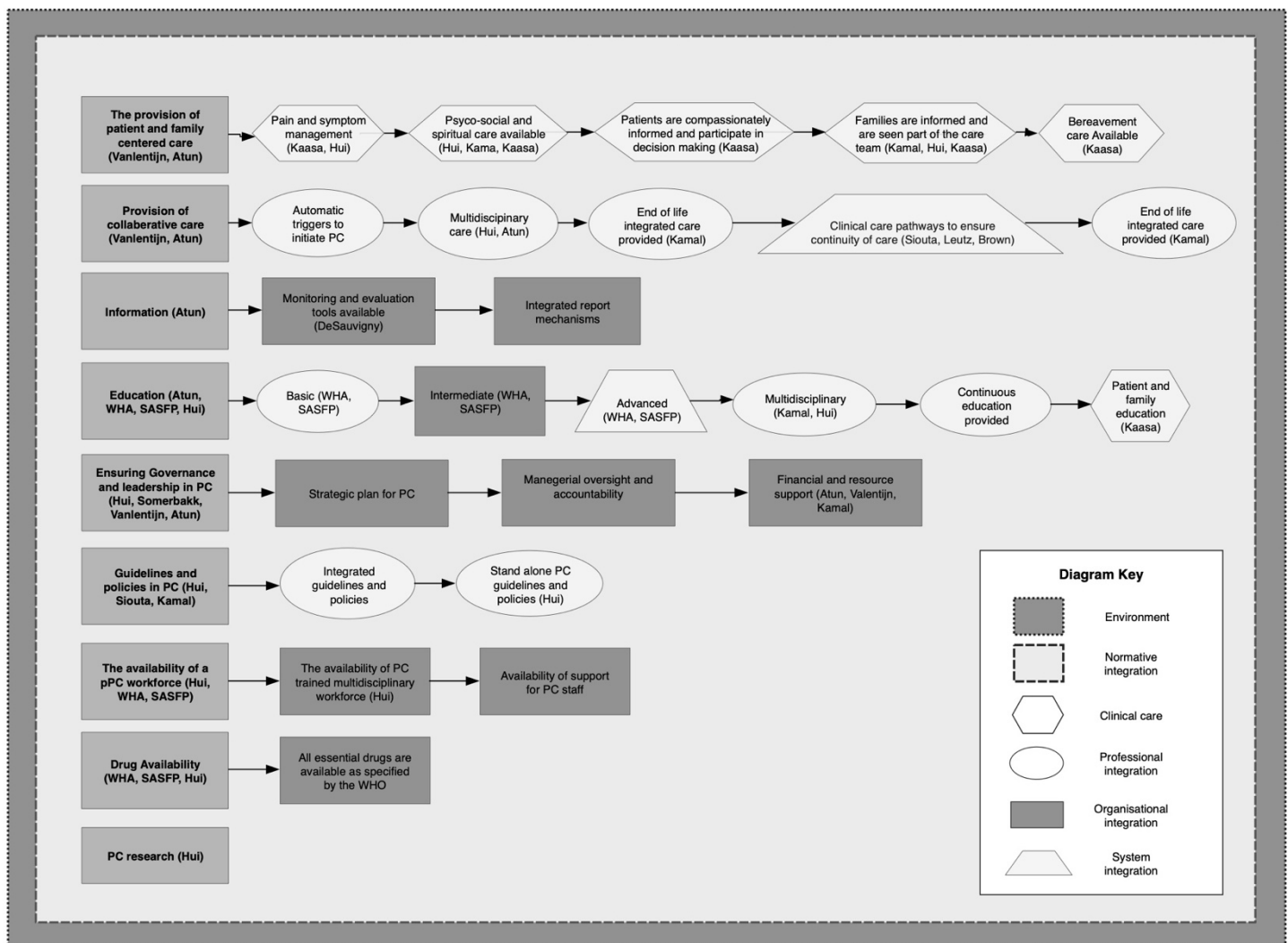
See Diagram 2.3 below.

Table 2.4.: Domains of PC integration drawing from multiple sources

The provision of patient and family centred care	<ul style="list-style-type: none"> • Pain and symptom management • Psycho-social and spiritual care • Informed and participatory decision making • Family are active members of the team • Bereavement care available
The provision of collaborative care	<ul style="list-style-type: none"> • Automatic triggers to initiate palliative care • Multidisciplinary care • Continuity of care • End of life care
Information systems	<ul style="list-style-type: none"> • Monitoring and evaluation tools • Integrated reporting mechanisms
Education	<ul style="list-style-type: none"> • Basic • Intermediate • Advanced • Multidisciplinary • Continues Medical Education • Patient and Family Education
Leadership and governance	<ul style="list-style-type: none"> • Strategic Plan for PC • Managerial oversight and accountability • Financial and resource support • Clinical leadership
Guidelines and policies	<ul style="list-style-type: none"> • Integrated policies • Stand-alone PC policies
Palliative care workforce	<ul style="list-style-type: none"> • The availability of a multi-disciplinary PC trained workforce. • Emotional and organisational support for the palliative care workforce
Drug availability	<ul style="list-style-type: none"> • Essential medication as specified by the WHO Essential PC Medicine List
Research	<ul style="list-style-type: none"> • PC specific research • Integrated PC research

Contextual factors include the environment the intervention of PC is being integrated into such as the PC need, patient factors, existing frontline services, existing resources and governance structures. This is discussed in the section above.

Diagram 2.3: Conceptual framework of PC integration in an ATH



This diagram illustrates the domains of PC integration and how this aligns with the principles of complex health system's intervention and the principles of Valentijn's theory on integration. The arrows indicate the development of the domains of integration.

2.15. Conclusion

Globally, there is a need and urgency to integrate PC into health services and systems.¹⁶ However, resources have not been forthcoming, and PC competes with other healthcare elements for funding. Therefore, those driving integration must be clear on what needs to be achieved and how to invest time and money in effective

strategies for integration. Although cognisant that integration may be chaotic at times, being aware of the aim of integrated PC is important to identify gaps and opportunities. This review has highlighted the importance of oblique PC that aligns with the principles of UHC. Additionally, the reasons for integrating PC vary between stakeholders with different goals and understanding of PC. PC is also a complex and emotive intervention. Therefore, the functional and normative aspects, organisation culture and context, are core to explore when reviewing PC integration. Valentijn et al.'s RMIC may be a useful theory to evaluate PC integration when adapted to PC because it highlights the importance of both the normative and functional aspects of integration. Evidence has demonstrated that iterative measures are effective as integration strategies. However, this requires resources which may not be currently available. Therefore, the process of how and why an intervention works in a specific context may assist in transferability.

Chapter 3: The influence of context on the implementation of integrated palliative care in an Academic Teaching Hospital in South Africa

Chapter 3 describes the contextual factors that influence integration of palliative care in an ATH. Chapter 2 highlighted the importance of context in integration and implementation. This chapter contributes to the thesis by highlighting the importance of context in integration, specifically focussing on the context in PC integration. Palliative care is a complex intervention, and it is recommended in the evaluation of complex interventions to provide a description of the context because it helps refine the how interventions contribute to change in a particular context. Secondly, the context description is important to explain why certain strategies were used and how and why they worked. Thirdly, a description of the context assists in advising transferability because it helps in understanding the mechanisms that bring about the change. Therefore, the results of this chapter are used to explain how and why the three integration strategies worked in chapters 4, 5, 6.

This chapter is written as an article that has been published in Palliative Care and Social Practice:

Krause R, Gwyther L and Olivier J. The influence of context on the implementation of integrated palliative care in an academic teaching hospital in South Africa. Palliative Care and Social Practice 2024; 18: 26323524231219510.

The researcher is the main author (60%) who developed the methodology, assisted in data acquisition, did the data analyses with the other authors and wrote the manuscript. The other two authors contributed to the conception, data analyses and manuscript editing.

The article format requires the researcher to explain concepts already described in the introduction and literature review, like the importance of PC, the South African context, Valentijn's Rainbow model.

This descriptive study uses a conceptual framework to analyse and describe the context drawing from literature on context of health services integration and Valentijn theory on integration. This framework is based on the importance of both functional and normative elements in context and the interplay between the micro, meso and macro levels. Furthermore, as discussed in the literature review, it introduces the dynamic nature of integration in and how things change over time.

This is a mixed-method approach that provides both quantitative data from routine hospital data, qualitative data from interviews and document analyses to expand and corroborate findings.

Article: The Influence of context on the implementation of integrated palliative care in an Academic Teaching Hospital in South Africa

Abstract

Background:

Palliative care (PC) has been integrated to a limited extent in the South African healthcare system. Contextual factors may be a pivotal influence in this integration.

Objectives

This study aims to explore contextual factors that are possibly influencing the integration or lack thereof in an academic teaching hospital.

Design

A mixed-method study was conducted in a large academic teaching hospital in South Africa.

Methods

The mixed methods were conducted in parallel and then merged. Findings were integrated to describe the contextual factors influencing PC integration, to develop a timeline of implementation, and assess the probable influence of context on the integration process. The mixed methods phases included a narrative review of published literature related to health systems, integration of health interventions, and PC in teaching hospital settings; followed by interviews, documentary and routine data analyses. Semi-structured interviews with purposively sampled participants provided the qualitative data. Primary national, provincial and organisational documents expanded the contextual phenomena and corroborated findings. Routine hospital admission and mortality data was statistically analysed to expand further and corroborate findings. All qualitative data was thematically analysed using deductive coding, drawing from the aspects of the contextual dimensions of integration.

Results

Enabling contextual factors for local PC integration were global and local advocacy, demonstrated need, PC being a human right, as well as the personal experiences of hospital staff. Impeding factors were numerous misconceptions, PC not valued as a health care priority, as well as limitations in functional elements necessary for PC integration: national and regional political support, leadership at all levels and sustainable financing.

Conclusion

The normative and functional contextual aspects interplay at macro, meso and micro levels positively and negatively. How stakeholders understand and value PC directly and indirectly impacts on PC integration. Strategic interventions such as mandatory education are required to ensure PC integration.

The health system is dynamic, and understanding the context in which the health system functions is core to the integration of PC. This may assist in developing integration strategies to address PC integration and the transferability of these strategies.

Keywords: Palliative Care, integration, context, normative, functional

3.1. Introduction

In 2014, South Africa was one of the co-sponsors of the World Health Assembly Resolution 67.19, “Strengthening of palliative care as a component of comprehensive care throughout the life course”.¹² In this resolution, member states committed to integrating palliative care (PC) into their health systems and to domestic funding of palliative care.¹⁴ However, despite this commitment, South Africa still lacks the ability to deliver PC to the whole country as a public service.¹⁵⁰

There is strong evidence that PC can be a cost-saving intervention.^{151,152} It is necessary to achieve Universal Health Coverage (UHC)⁵, and according to the World Health Organisation (WHO), PC is an ethical responsibility of all health systems.¹⁴ Support for PC integration was initiated with the approval of South African National Policy Framework and Strategy for Palliative Care (NPFSPC) in April 2017.¹² It specifically mentioned Academic Teaching Hospitals (ATHs) as academic centres of excellence for PC teaching, service delivery, advocacy and research.¹² However, this national policy has not yet been fully implemented across the public health service, including ATHs. Financial resources for integrating PC have thus far been limited, thereby contributing to the constraints on integration.¹⁵³ However, literature which describes integration of other complex interventions indicates that contextual factors other than limited resources may be inhibiting implementation. In addition, the fact that financial resources are limited may also be due to other contextual factors. Contextual factors in integrating any intervention are a crucial dimension of the complexity of the integration process. Furthermore, the integration of complex interventions may pivot around their suitability in a specific context.¹⁵⁴ This study will assess the contextual factors that potentially influence the integration of PC into an ATH in South Africa as an example of how contextual factors affect PC integration.

The process of integrating a new service or program into a healthcare system is complex and the intervention often fails to be translated into meaningful outcomes,^{61,99} as interventions cannot be fully isolated due to the influence of factors internal and external to a system. Atun et al. (2009) hypothesise that there is an interplay between complex facets that influence the integration of interventions into the health system.⁹⁹ These facets are the characteristics of the problem, the intervention itself, the adoption system, health system characteristics, and the context.⁹⁹ Furthermore, it is argued that context is pivotal to understanding the complexity of integration and consists of multifaceted aspects.¹⁵⁴

‘Context’ is not uniformly defined in the literature and requires insight into the intervention to unpack critical contextual factors that might influence the integration process. Certain standard dimensions are known to be important, such as organisational support, financial resources, social relations and support, leadership, organisational culture and climate, and organisational readiness to change.¹²³ In addition, the patient profile becomes important when evaluating the context of a healthcare system.¹²³ Furthermore, timing is critical for

understanding how contextual factors merge at a specific time to influence integration.¹²⁴ The human dimension relating to factors such as motivation, vision, organisational culture, education and assumptions add to the complexity of what constitutes context.¹²⁴

PC is recognised internationally as an essential part of ATHs as supported by the WHA 67.19, but the complexity of PC may play a role in challenges to its integration in that context.¹⁴ Kaasa et al.(2018) emphasise that PC should be provided alongside disease-oriented cancer care as part of comprehensive service delivery in ATHs striving for excellence in care, research and teaching.³⁸ The reality is that PC should be available for all patients with serious health-related illnesses.¹⁶ But as stated by Atun et al. (2009), the problem itself (the social narrative, the burden and the urgency of the situation around the problem) influences the integration process.⁶⁹ PC is a complex evidence-based intervention where bio-psycho-social and spiritual factors are interwoven with clinical factors to manage patients with life-threatening illnesses.²⁹ It involves care for patients with complex, incurable diseases, who often experience a heavy burden of complicated symptoms.¹⁶

Furthermore, the complexity increases because the symptoms are managed using scheduled drugs, such as opioids, which are subject to many misconceptions, such as risk of addiction.¹⁶ Patients and their families experience psycho-social change and loss when a patient is diagnosed with a severe illness. This is amplified when combined with poverty and limited access to disease-modifying treatments.⁹³ This leaves many patients facing death and their families economically and socially vulnerable and hopeless. Managing affective issues is a core part of PC not only among patients and families but for health care professionals as well. Feelings of failure and hopelessness are common findings among healthcare professionals working without PC resources when dealing with patients with life-threatening illnesses.¹⁵⁵ PC is practised in multidisciplinary teams that function closely to manage each situation's complexity.²⁹ It is also best practised across the continuum of care and thus requires care networks to ensure non-abandonment of patients and families.^{29,57} The integration of PC is, therefore, a complex intervention, and when that integration occurs in an ATH, even more so. Thus, successful integration of PC into ATHs, requires an understanding of the particular contextual factors facing implementors.

The interconnectedness of context

Multiple contextual dimensions are at play when integrating PC in an ATH. Moreover, these dimensions are interconnected and dynamic.⁶⁴ Valentijn et al. (2015) state that integration must occur across a health system's micro, meso and macro levels. They also separated these dimensions into the functional and normative elements that need to be developed and maintained to integrate an intervention.⁸⁵ Functional aspects include support functions and activities around the primary process of service delivery to coordinate and support accountability and decision-making between organisation and professionals. Normative elements describe the

common and shared frame of reference (values, mission, vision and culture).⁸⁵ Furthermore, functional and normative integration ensures continuity of integration across the levels of the health system.² For example, links of service delivery can be 'vertical' (bringing together services operating at different levels) or 'horizontal' (the linkage of services on the same level).⁹² Practically, the integration may even be 'oblique'⁶⁹ – which implies that elements of both vertical and horizontal integration may be needed to solve the problem or to attend to the patients' needs. It is proposed that PC can be a complex oblique intervention across all levels of the health system, from ATH and primary care to home care.¹⁴ PC is thus a complex, interlinked intervention that will only be successful if the integration happens across the whole health system.

Awareness of these interlinked contextual factors across the health system is core to the integration process and to evaluating what and why things happen. For example, it allows interventions to be transferred between different settings and explain different outcomes. Understanding context also assists in making general statements about interventions; this is especially important when we are integrating a new intervention, such as PC, across a country's health system. Finally, the importance of understanding context is especially relevant when managing limited resources because it assists in strategically managing interventions to have the most significant impact. Interventions should aim to be responsive and appropriate to the unique context.

Brief background to the context of PC integration in a South African academic teaching hospital

There are considerable socioeconomic and health disparities and a unique disease burden in South Africa. Thirty per cent of doctors in South Africa serve 84% of the public health care sector population.²⁵ HIV, tuberculosis, interpersonal violence, and high incidence of non-communicable diseases such as diabetes burden the South African Health sector.²⁵ Moreover, South African ATHs are renowned for addressing this unique disease profile with the latest technology and highly specialised skills, conducting cutting-edge research and training future healthcare professionals. ATHs are an essential part of a comprehensive healthcare system and contribute to strengthening the health system.^{35,37,39} Furthermore, ATHs are centres where research is undertaken, and staff are involved in guidelines and policy development, such as the Standard Treatment Guidelines and Essential Medicine List.^{36,37} Health Care Professionals (HCP)s are trained, and the foundation of their attitudes and values in health care are developed in this setting.³⁶ Many patients come to ATHs with complex illnesses to consult experts in these illnesses, where many patients are diagnosed with life-threatening diseases. Following this diagnosis, patients must be identified as requiring PC alongside disease-modifying treatment.

The PC context in an ATH in South Africa

The following dimensions can be considered part of the 'context' in an ATH in SA (see Diagram 1). Firstly, the macro factors where the global, national and regional political, social, leadership and financial factors constantly change and influence PC and the ATH,⁹⁹ that in turn are influenced by normative aspects such as motivation and relationships.⁸⁵ Secondly, at a meso level, functional aspects such as leadership, structure, education and training, the need, patient profile, availability of medication, documentation, outcome measurements and research interplay with normative aspects.^{85,147} These normative aspects are motivation factors, norms, assumptions and values in the hospital.⁸⁵ Finally, the individual or micro level, describes the values, assumptions, vision and motivation that play a role in PC integration. In addition, functional aspects such as level of training and HCP need also influence the context.^{38,147} All of the above factors are woven together to positively and sometimes negatively affect the implementation of integrated PC, creating a unique lattice in each setting. The uniqueness of this lattice should be considered when evaluating context.

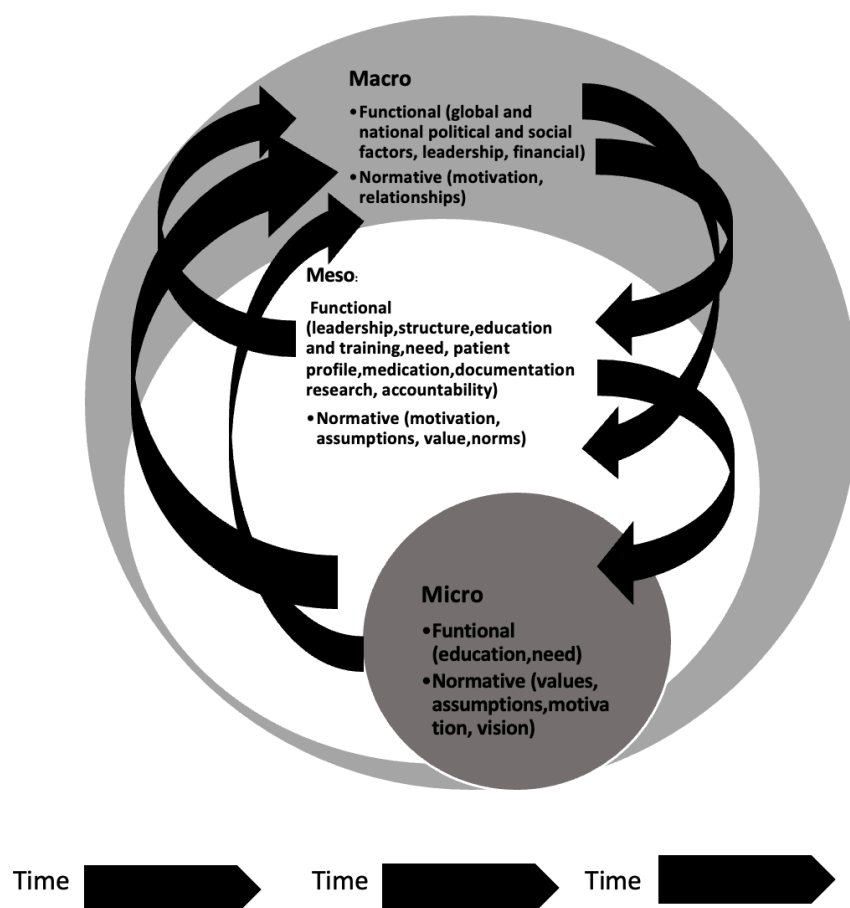


Diagram 3.1: The influence of contextual factors in an ATH (see discussion above)

Contextual factors are enablers or barriers, and their dynamic interplay is vital to achieving integration. The aims of this study are to explore potential contextual factors at play in an ATH to explain 'why' and 'how' PC integration is completed or not achieved, to identify appropriate integration strategies and increase transferability to different settings.

3.2. Methodology

A mixed methods study was conducted in Groote Schuur Hospital (GSH) in the Western Cape province of South Africa. GSH is a 975-bed ATH with over 3500 personnel. It serves patients in the Western Cape on a pay-as-you-earn basis, but most patients are from impoverished backgrounds and thus pay a nominal fee. Patients are referred to the hospital from primary care settings or from other hospitals in and outside the province and provide tertiary and quaternary care to . In addition, the hospital trains undergraduate and postgraduate HCPs across Africa. The hospital is linked organisationally and administratively to the University of Cape Town.³⁹

This mixed-method study integrated quantitative and qualitative data in four phases, beginning with a narrative literature review, followed by three phases conducted in parallel to expand on the contextual phenomena, corroborate and explain the interconnectedness between the different levels: semi-structured interviews (n=8) and analysis of organizational documents (both thematically analysed), and an analysis of quantitative hospital data displayed through descriptive statistics.

The narrative review of published literature in English over the last 20 years entailed searching databases such as CINAHL, MEDLINE, Africa-wide (via EBSCOhost) and Scopus and SCielo. Materials were gathered within a 2-year framework, and further literature was added, drawing from basic disciplinary research of Palliative Care Research, Health Policy and Systems Research and Integration and Implementation studies.

Qualitative data were collected through semi-structured interviews (n=7) at hospital- and national-levels. At hospital-level, the interviews were conducted with purposively sampled managerial staff from January 2020 until January 2022. The aims were to explore their understanding of PC, the value they accorded it and their experiences of implementation. The managerial staff interviewees were hospital PC executive team inclusive of doctors (n=5), a social worker manager (n=1), and a nursing manager (n=1). These managers represent heads of departments of all the major disciplines and professions involved in implementing PC (surgery, internal medicine, oncology, nursing, social work as well as health and rehabilitation). They are the 'gatekeepers' who manage and allocate resources to the PC team in the hospital as a collective decision-making body. The interview guide was developed, drawing on the literature and including aspects of normative and functional integration and contextual dimensions. To enhance rigor, face validity of the interview guide was ensured by presenting the interview guide to experts in the field of integration and the field of PC. Construct validity was

derived by aligning this tool with a theoretical integration approach and context. The interview guide was piloted on two managers and did not require adjustment.

At national-level an interview with the senior national manager in South Africa was conducted in (2021), and explored how the South African PC policy (NPFSPC) came about and how ATHs fit into this national integration. An interview guide was used, drawing from the theory of context. A description of the timeline, leadership, financial matters and history of the national development of PC and how it relates to ATH assisted in providing information about how external political and social factors contribute to the implementation of PC.

The hospital and national-level interviews were thematically analysed using NVIVO (see Supplementary materials). Hospital managers were de-identified and only identified as 'Man1' etc. The senior national manager is identified as 'NM'. The interviews were analysed using deductive coding for themes of contextual factors at the macro, meso and micro-level (see diagram 1). Inductive coding was used to identify emerging themes. The themes and sub-themes that arose from the analysis of the interviews were coded.¹⁵⁶ Thematic coding and analysis was checked between all researchers (n=3) and research assistants (n=2).

Quantitative data in the form of the number of hospital admissions, the number of deaths and the number of patients referred to a PC service were obtained from routine admission data from the hospital and Palliative Care Service collected on a RedCap database. This database records routine data on all patients receiving PC from a vertical nurse-led PC service. This research used descriptive data from the database to illustrate the PC integration process from January 2017 until June 2021. The quantitative data were statistically analysed to describe the patient population.

Additional information on the contextual factors that drive integration was drawn from secondary documents describing population, resources, guidelines and standard operating procedures that influence the integration of PC. This was further informed by analysing provincial and national policies on PC. Ten documents were purposively sampled, based on information derived from the interviews. Documentation identified and sourced were the National Policy and Strategic Framework for Palliative Care;¹² the National Cancer Strategic Framework for South Africa (2017-2022);¹⁵⁷ the National Strategic Plan for the Prevention and Control of Non-communicable disease (2020-2025);¹⁵⁸ the National Health Insurance Bill;¹⁵⁹ the National Hospital level (Adult) Standard Treatment Guideline and Essential Medicine list;¹⁶⁰ the National Tertiary and Quaternary Level Essential Medicine Recommendations;¹⁶¹ the Proposed Model for the Implementation of the Palliative Care Policy in the Western Cape;²² the Operational Guide to Implementing Palliative Care during COVID-19;²³ (Provincial)Providing Palliative Care during the COVID-19 pandemic;⁴¹ Standard Operating Procedures that include PC and stationery used in the palliative service used in the hospital.

The documents were analysed thematically, drawing from the themes of integration. The documents are referenced, and hospital documents are listed as HD in the results. Further document analyses enhanced findings by evaluating authorship, historical insights and factors excluded from the documents.

Finally, the results from the different approaches were merged and compared to identify consistencies or discrepancies across the datasets. These inferences are demonstrated (see Table 2) to explain the context and corroborate findings to gain a better understanding of the phenomena. A timeline describes how the context changes over time, and the impact of global and national PC integration.

The primary researcher is embedded in the national and local integration process of PC, including the process at GSH. In GSH she contributes to the leadership and evaluation of PC services. A fundamental advantage of being embedded is that the researcher may identify problems that might not be clear from the outside.⁷⁷ Although embedded research does provide further insight; bias may influence the trustworthiness of the findings. The methodological triangulation of data strengthened trustworthiness by asking permission from sources about using information obtained outside the formal research process and sharing results with participants before any publications.⁷⁶ Researcher assumptions were explored upfront using a recorded reflective interview between the researcher and supervisors before the research was conducted. Reflexivity was further ensured by keeping a journal with short notes on discussions by the researcher with the research assistant, who also maintained a journal recording thoughts after the interviews.

3.3.Results

The results in this section come from integrated analysis of all four research phases.

The palliative care context at a macro level in South Africa

This section describes 'functional' contextual factors which impact on PC integration, namely: global, national, regional political and social factors, leadership, as well as financial factors. As outlined above, they are influenced by normative aspects such as motivation and relationships at a macro level.

The PC National Co-ordinator (NCo) was appointed in 2020 and the post was funded by a donor funder. The incumbent confirmed that the motivations to integrate PC in South Africa were facilitated by global advocacy,¹⁴ national NGO advocacy using the advocacy trigger of PC as a human right,¹² as well as the quadruple burden of disease in South Africa which informed the development of PC policy. South Africa was one of the original sponsors of the WHA Resolution on PC, and the Minister of Health was committed to implementing the Resolution in South Africa.¹²

PC is integrated into the National Health Insurance Bill,¹⁶² the National Strategic Plan for the Prevention and Control of Non-communicable Disease (2020-2025),¹⁵⁸ and the National Cancer Strategic Framework for South

Africa (2017-2022).¹⁵⁷ These documents are aligned with the National PC Policy and advocate for PC in the tertiary setting.

“There is a need for an integrated, life course approach which includes prevention, education and awareness, screening and early detection, diagnosis and treatment as well as rehabilitation and palliative care. Central to all these interventions is recognising the complex needs of our people, as well as respecting the rights and dignity of patients and their families at all times.”¹⁵⁷

The PC NCo is situated in the non-communicable disease (NCD) directorate in order to facilitate leadership and PC integration across all provinces. In the Western Cape, a senior director has taken the lead as an additional task to lead the provincial Palliative Care Task Team (PCTT). This task team comprises stakeholders from district health care services, hospitals, NGOs, universities, and support structures in the provincial government. Currently, two members from GSH contribute to this provincial leadership structure, together with a volunteer specialist from the university.

Accountability and financial support structures for PC are lacking both nationally and provincially.^{12,22} Donors have historically funded PC via the Non-Government Organisations service. According to the senior national manager interviewed (NM), the National Department of Health (NDoH) is responsible for policy-making and administrative duties. Provinces are responsible for applying for funding to the national treasury, and the funds are allocated according to their requests. District Coordinators are responsible for motivating for PC funding when provincial budgets are being prepared. Therefore, the provinces carry the bulk of the financing responsibility.

Goal 4 in the national PC policy is to develop a costing formula for PC.¹² It was intended to be completed by 2018, but to date, there is no national costing formula or funding track. The NM postulates that it is because PC is not perceived as a priority:

“Because they feel like palliative care is not a healthcare priority”. (NM)

Palliative Care integration in Groote Schuur Hospital in relation to provincial, national and global palliative care integration

This section presents a timeline of how PC was integrated in GSH in 2011 and grew, as a result of support from the university, through teaching and training. The construction of the timeline was informed by interviews conducted with the Professional Nurse Manager and NM, as well as a documentary review of the national and provincial policies.^{12,22} The timeline was further validated through the WHA 67.19 Assembly declaration (2014), the Kampala declaration (2016) and the National(2017) and provincial policy (2018). (See Appendix 1)

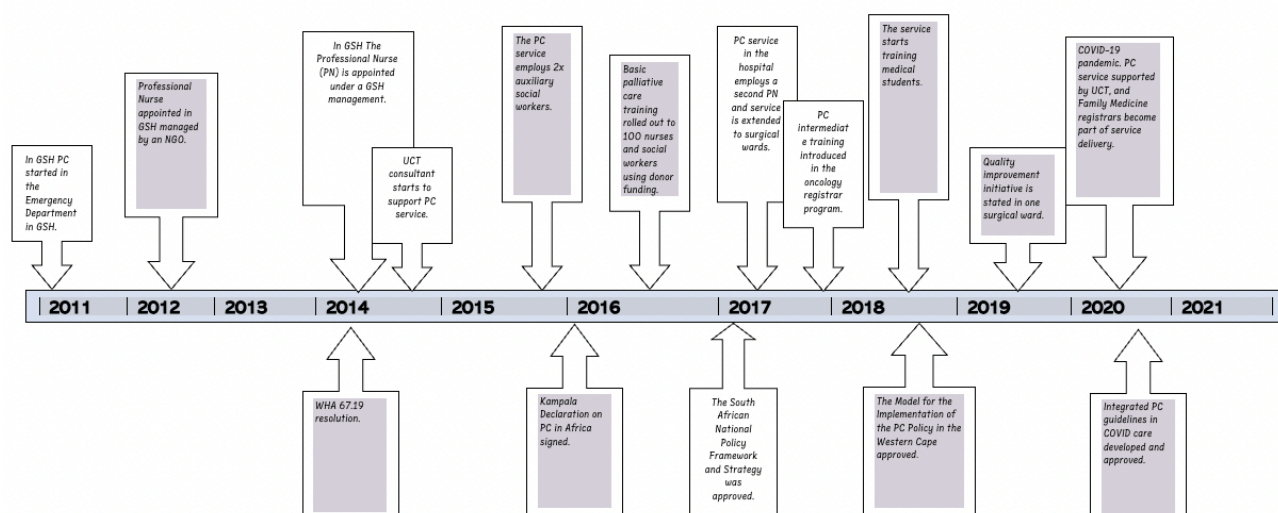


Diagram 3. 2: Timeline of Palliative Care Integration at Groote Schuur Hospital in relation to provincial, national and global Palliative Care integration

The palliative care context at a meso level in South Africa

PC integration at a meso level is influenced by the need for PC; hospital leadership; PC service delivery structure, education and training; patient profile; medication availability; documentation supporting PC; research and their interplay with normative aspects which will be elaborated below.

Table 3.1 illustrates the need for PC – showing routine hospital data from 2017-2021. For example, consider the proportion of deaths in the hospital to number of referrals to PC. The NPFSP argues that 50% of all deaths require PC.¹² Therefore, we expect a minimum of 3.15% of the admissions to be referred to PC. This was also supported by the interviewees – for example, “*The need is very big, very, very big*” (Man2).

Patient Demographics and Hospital Information

	2017	2018	2019	2020	2021	Overall
No. Palliative Care Referrals	737	593	773	931	1195	3585
No. hospital admissions	50010	51504	53956	44024	42206	241700
No. deaths in hospital	2825	3027	2741	3133	3549	15275
Proportion of admissions that died	5.7%	5.9%	5.1%	7.1%	8.4%	6.3%
Proportion of admissions that were palliative care referral	1.5%	1.2%	1.4%	2.1%	2.8%	1.8%
Proportion of deaths that were palliative care referral	26.1%	19.6%	28.2%	29.7%	38.4%	27.7%

Table 3.1: Patient demographics and hospital information (source: GSH routine hospital data)

The hospital structure in service delivery and leadership is vertical in all disciplines, with clinical leadership situated with consultants in each discipline who focus on their specific disciplinary needs and structure.

...it's a hospital that is very siloed. In fact, the whole ethos and nature of work in this hospital is that people fight for their own ... And then there are highly specialised areas who fight against others for resources, but you fight in your own, in your own lane. (Man 4)

Two managers indicated that leadership in the hospital for integrating PC lies with the executive management and or CEO as indicated. There is acknowledgement by 3 managers that the university plays a major role in providing support in integrating PC.

PC-trained staff are limited to 4 professional nurses with intermediate-level PC training (Prof Nurse Manager). However, continuous PC bedside mentoring is happening in the hospital (Prof Nurse Manager). It is acknowledged that participating and completing accredited training is contingent on training that will advance careers. (Medical Manager).

For people to do palliative care training, that doesn't advance their career and for interest, and that... no one's done that. (Man 4)

In clinical disciplines where accredited training has been introduced, there is a recommendation that intermediate-level PC training should be extended to other clinical disciplines (Man 3).

Despite limited trained staff, the presence of a vertical specialised PC service in the wards, which improves access to a PC approach, has increased awareness (Man 2, 4 and 5).

but I think that awareness better now than it was five years ago because there is a much more active, visible presence. (Man3)

Two integrated hospital PC guidelines were available. The first was a guideline incorporated as an additional chapter in the surgical guideline (authored by the university). The second, authored by the pulmonology team, asked whether patients were referred to PC when receiving home oxygen. Hospital guidelines, authored by the vertical nurse-led service, formulated Standard Operating Procedures (SOPs) for 'end-of-life' as well as for 'syringe drivers'. In addition, they authored documentation on referral criteria, PC assessment and monitoring PC patients. All the PC medications as advised by the WHO essential PC medication, are available in the hospital.

Personal experience seems to be the trigger for involvement in PC in the ATH, as confirmed by 3 managers and the NCo.

So, it's their own experience that's a main motivator for integrating palliative care. (NM)

Three participants commented that there is avoidance of working with PC patients, as well as in the field.

I was talking about it at one of our regional meetings, and one of the heads of surgery in a regional hospital outside, when I said, you know, you need to engage in palliative care processes and thinking, he said 'I don't want all those people dying in my ward. (Man 2)

The assumption that PC is only about end-of-life care among the clinical community was widely recognised by participants.

...main assumption was that when you're referring a patient for palliative care, there's nothing more that can be done for the patient. And that's why I think, in many settings, the medical team kind of withdraws from palliative care you know, because they think their job is done. (Man 1)

The palliative care context at a micro level in South Africa

As previously outlined, PC integration at the micro or individual level is influenced by the values, assumptions, vision and motivation of individuals. In addition, functional aspects such as level of training and personal need also influence the context.

It is evident from multiple managers that there is an element of moral distress associated with working with patients requiring palliative care.

I think there's a, there's a huge amount of distress. I think, uh, it depends on how close the engagement has been with the family and the patient. Uh, I think there's distress from the nursing side, , the medical staff are often very distressed by patients dying. That triggers a... a frequent desire to do stuff, to over-intervene, to check, test and administer things, uh, most of which are harmful and delay the inevitable or, or they are futile attempts that delay the inevitable. (Man2)

There is an assumption held by 2 of the participants that PC is only end-of-life care, but all the participants state that this assumption is prevalent in the hospital. The participants value PC, and dignity in death is an important aspect of care (Man 1 and 3). However, there is also avoidance of dealing with their own mortality and medicalising suffering when faced with PC situations (Man 2, 3 and 4)

Because... maybe there are things they haven't dealt with themselves about mortality and... umm... so they will stick to... when they explain things to patients, they will use scientific terms and jargon that patients don't understand because that's how they feel comfortable. (Man 4)

The managers are aligned with the vertical and horizontal PC services policy (Man 3 and 4), and emphasise the need for strengthening PC services at district-level (Man 3 and 4). There is a vision that all healthcare providers should have a basic understanding of PC (Man 5). However, there is a concern that doctors do not recognise that they need further training.

And what do you think are the biggest assumptions, umm, regarding your discipline and palliative care? The biggest assumption is that consultants know all about palliative care. (Man 4)

	Functional aspects	Normative aspects	Inference
Macro environment	Policy <ul style="list-style-type: none"> National Policy approved in 2017 and provincial model on implementation approved in 2018^{12,22} PC integrated and aligned in National Health Insurance Bill,¹⁶² the National Strategic Plan for the Prevention and Control of Non-communicable Disease (2020-2025),¹⁵⁸ and the National Cancer Strategic Framework for South Africa (2017-2022).¹⁵⁷ No M&E mechanisms in place in the NPFSPC¹² but opioid monitoring mentioned in policy for the Prevention and Control of NCD (2020-2025)¹⁵⁸ No funding formula included in the policies but PC mentioned in the proposed NHI bill¹⁶² 	Motivation <ul style="list-style-type: none"> The quadruple burden of disease in South Africa¹² Advocacy using the principle that PC is a human right (National Co-ordinator and policy) 	There is converging evidence that there is a recognised need for PC but it is not seen as a healthcare priority.
	Leadership¹² <ul style="list-style-type: none"> The Minister of Health was committed to implementing the resolution in South Africa¹² A national PC coordinator facilitates PC integration and is appointed on a contract (NM) Provincially a palliative care task team chaired by a senior provincial director (NM) <ul style="list-style-type: none"> Palliative Care Task Team developed delivery and Clinical Care guidelines during COVID pandemic^{23,41} 	Relationships <ul style="list-style-type: none"> Existing relationships in teaching, service delivery and general comradery exist between PC service delivery teams, the universities, and national and provincial leaders (NM) PC is not seen as a healthcare priority (NM) 	
	Governance <ul style="list-style-type: none"> No accountability structures included in the national nor provincial policies^{12,22} 		
	Finance <ul style="list-style-type: none"> PC was historically funded by the NGO sector Provinces motivate and apply to National Treasury for additional funding (NM) 		
Meso environment	Need <ul style="list-style-type: none"> Disease burden and complexity of diseases (database) Lack of trained PC workforce (Man 5) Assisting in HCP moral distress when dealing with end-of-life care (Man3) Lack of PC services in the district (Man 1 and 3) Research for policy development (NM) 	Motivation <ul style="list-style-type: none"> Driven by personal experience. (NM, Man 2 and Man 4) 	There is converging evidence that the hospital value specialized disease-specific care and aim to avoid patient deaths, which can be seen as treatment failures. There's a shortage of PC trained HCW to address misconceptions about PC. These values and assumptions may be the cause of the lack of aspects of functional integration.
	Structure <ul style="list-style-type: none"> Siloed structure across the hospital Vertical nurse-led PC service (Man 5) 	Assumptions <ul style="list-style-type: none"> Refer to PC when there is nothing further the treating team can do PC is only end of life care 	
	Education and training <ul style="list-style-type: none"> Four trained professional nurses at intermediate level (Man 5) Initial 100 HCP trained in PC (Man 5) 	Values <ul style="list-style-type: none"> Emphasis on curative care and bed turnaround time (Man 2) 	

	<ul style="list-style-type: none"> Continues bedside mentoring by PC team (Man 5) Limited engagement in training because current training does not advance career pathways (Man 4) 	<ul style="list-style-type: none"> PC must be visible on the clinical platform (Man2) 	
	Leadership <ul style="list-style-type: none"> Perceived leadership to integrate PC is with CEO/ executive management (Man 4 and 5) PC service is managed through a distributive leadership (Man 5) PC service supported by academic leadership from the university (Man 5) 	Norms <ul style="list-style-type: none"> Avoidance of end-of-life care Late referral to PC service (Man 1 and 5) 	
	Documentation <ul style="list-style-type: none"> Most SOP's and guidelines created by PC team Limited integrated guidelines (only 2 found) 		
	Medication <ul style="list-style-type: none"> WHO essential medicine list available¹⁶⁰ 		
	Research <ul style="list-style-type: none"> Limited in or with PC team (Man 1,2,3,4,and 5) 		
Micro	Education and training <ul style="list-style-type: none"> Limited training among HCP (Man 5) Need for basic PC training (Man 5) 	Motivation <ul style="list-style-type: none"> Personal experience (Man 2, 3)) 	There is converging evidence that moral distress among HCW is a crucial factor to consider when integrating PC. It can either hinder or facilitate the integration process.
	Need <ul style="list-style-type: none"> Assist in addressing moral distress (Man 2 and 5) 	Assumptions <ul style="list-style-type: none"> No further PC raining is required (Man 1, 3 and 4) <i>But that:</i> PC is only end-of-life care (Man 4) 	
		Vision <ul style="list-style-type: none"> Principles of PC policy supported (Man3, 4 and 5) 	
		Value <ul style="list-style-type: none"> Discomfort around own mortality (Man 2) 	
		Norms <ul style="list-style-type: none"> Dignified end-of-life care (Man 2) 	

Table 3. 2: Table of themes identified across data collection methods. Data was collected in parallel. Documents collected from the database are indicated by the word 'database', data collected from interviews are indicated by interviewee identifier, and data collected from documents are indicated by a reference to the specific document.

3.4. Discussion

This research has demonstrated the complexity of the normative and functional contextual factors and the interconnectedness between all the levels of health care involved in PC integration.² In addition, as Valentijn et al. (2015) state, it is the normative aspects that enable the interconnectedness between all the levels of health care², and in PC integration, the normative aspects are core because of the complex and emotive nature of a PC intervention.

Policy

On a macro level, it is agreed that the NPFSP and global advocacy are facilitators promoting integration of PC into the health system in South Africa. The vision of the policy is supported by managers working with patients requiring palliative care and who aim to integrate PC. It is further aligned and integrated in other national policies.^{157,158,162} Therefore, the policy is acceptable in GSH and aligned with a global and national vision.¹⁴ A shared vision is an essential normative dimension of integration and this vision has been operationalised at a macro level by appointing a national PC coordinator in a leadership role although the position is for a limited time and donor-funded. As highlighted by Valentijn et al. (2015), leadership is an enabler if the leader is senior and formally appointed.⁸⁵ Without formally appointed and vocal PC leadership, the PC agenda may not receive the attention required. This is important at all levels, especially when there is a need to advocate for appropriate resource allocation to PC.

Financial resources

One factor that requires urgent attention is allocating financial resources to PC. Highlighting the need for PC and building on the 'human rights' argument, further advocacy is needed to ensure appropriate funding is allocated to promote alignment with the WHA 67.19, the South African NHI Bill and the NPFSPC.^{12,14,162} Unfortunately, to date, limited national funding has been allocated, negatively impacting the meso and micro level of integration. For example, if there is no funding to provide the care, then the impact of the care cannot be observed and further valued. The lack of funding may be further underpinned by the normative aspect of integration that PC is not valued as a health care priority. The fact that South African health authorities are not prioritising PC further implies lack of value assigned to end-of-life care. A cross-country comparison of experts' assessments of the quality of death and dying conducted in 2021, demonstrated that South Africa was one of the lowest-ranked (73/81) countries when evaluating the quality of death and dying globally.¹⁶³ This cross-country comparison identified investment in PC and access to affordable PC as aspects that enable better care at the end of life. The poor state of how South Africans die may be linked to the limited PC resources.

Current situation

Although there are limited national resources being allocated to PC, GSH has developed a PC service in the hospital as a result of advocacy rather than policy, according to 5 managers. The passionate advocacy based on personal experience by the Emergency unit manager, staff and neurosurgery facilitated necessary resource allocation. Furthermore, this advocacy has contributed to the valuing of a PC approach and identifying the need for a PC service.^{8,164} In 2014 GSH appointed a PC nurse who provides clinical PC services and support to clinical colleagues in the medical wards, following referral of patients. Further integration will require attending to other PC needs in the hospital such as the lack of trained staff, research, standard operating procedures across the hospital and providing all staff with tools and training to manage moral injury when working with patients who are suffering.

This moral distress experienced by HCPs is a tangible but unspoken factor in ATH. It is recognized in this study and other studies that without the skills to care for patients with life-threatening illnesses, there is over-investigation, avoidance, and even hopelessness among HCPs.⁵⁷ Sallnow et al. states that conversations about death and dying are difficult and avoidance is preferred. A result is continuation of inappropriate treatments, which inevitably leads to a high-cost medicalised end-of-life care package for patients.⁵⁷ PC services and education are thus fundamental in ensuring the non-abandonment and appropriate treatment of patients with life-limiting illnesses, cost-effective care and addressing distress in HCPs, patients and families.

Palliative Care education

However, the urgency around PC education is more complex than the global and national call for PC education.^{12,14} Unfortunately, PC is still associated with only end-of-life care, a topic many HCPs, including educators, avoid.^{57,165} The research participants relate this avoidance to the complexities of HCPs facing their own mortality. Besides the emotive nature of PC education, PC is not an academic requirement in many disciplines, reinforcing misconceptions, avoidance, discomfort and ultimately limited PC provision. In an overstretched existing curriculum, PC education is not valued as an essential component of training. Refraining from integrating PC education into all medical and nursing curricula is cemented by the assumption that HCPs are already providing PC and that further education is not required, as discovered by this research. Although national and international policies highlight the need for a PC-trained health care force and recognise that additional training is required, especially in specialities who work daily with patients with life-limiting illnesses, PC has not been voluntarily integrated into training curricula.^{14,158} Sustainable and recommended PC education requires

mandatory PC education integration across curricula as indicated by global standards.^{14,166} These assumptions play out beyond the educational paradigm, including hospital and clinical leadership and may also require further mandatory interventions.

The gap in clinical leadership for palliative care and accountability structures

Many senior clinical leaders have received little to no PC training in South Africa.^{48,167} These individuals are the clinical decision-makers and leaders in the wards. Junior PC-trained colleagues have recognized that it is difficult to initiate a PC approach when the decision-makers do not support this approach.¹⁶⁸ Clinical leadership is a recognized functional dimension to enable clinical integration.⁸⁵ This lack of senior clinical leadership has a ripple effect beyond immediate clinical care as it results in absence from clinical guidelines as well as inhibiting the transformational effect of PC that is envisioned by international and national policies. South Africa has only recently recognized PC as a subspecialty, which impedes clinical leadership. A consequence, as demonstrated in this study, is that PC-related governance, training and information systems do not exist in all the departments, and many disciplines steer away from taking ownership of their PC service delivery. The reluctance of clinical leaders to embrace the PC approach may be a function of the misconception that it is only for dying patients. Traditionally a dying patient is linked with poor outcomes and perhaps even poor care. In a hospital striving for excellence, poor outcomes are not welcomed.³⁹ Therefore, if PC outcomes are not measured as an indicator of good care, the need to strive for good PC outcomes may seem unnecessary and counterproductive. Including and measuring PC outcomes as measures of excellence may strengthen accountability toward patients and families with life-threatening illnesses.

Accountability structures are not included in the National Policy and the Western Cape Model for Implementation.^{12,22} This study also found that the main guidelines, policies and management structures were created in the vertical nurse-driven service, with limited evidence of further integration in the ATH. From the above it is evident that the PC integration is being driven by a small group of people within the PC service and the university which is not fully integrated across the hospital. This finding is concerning as the long-term sustainability of PC is in jeopardy if it is driven by only a small group of individuals.¹⁰⁹

Silo'ed approach a barrier to integration

This lack of integration is not just a phenomenon experienced in PC because the hospital functions in silos, and HCPs stay focused on their discipline. Services are linked rather than integrated in the hospital.¹²⁶ In South African ATHs, different disciplines are siloed to manage a high volume of patients

with limited resources. Moreover, these patients have complex disease profiles. As the preferred method of service delivery, stakeholders may not willingly change.¹²⁶ Therefore, aiming to provide horizontal care may not align with the 'way things are done' in the ATH's prevailing vertical delivery system.¹¹³ Changing a prevailing organisational culture is labelled as a 'major' change that may be beyond a new emerging intervention.¹¹³ Furthermore, PC is not aligned with a specific academic discipline or the disease approach to care. The national recognition of PC as subspecialised care with specific skills and role is a necessary and fundamental global indicator that reflects PC development in a country.¹⁶⁶ PC in an ATH will, therefore, have to create its own unique 'silo' to align with the way the hospital functions and with global PC development to ensure a PC focus is maintained. Furthermore, PC cannot be confined to one level of care.

The alignment problem in PC is also evident in the district services, which indirectly impedes PC status and integration in the ATH. This research has demonstrated that managers value bed turnaround time because it is essential to ensure that as many patients as possible receive care with curative intent in ATH. Thus discharging patients to functional PC services in the district is fundamental to valuing PC. Patients who require long-term PC may be 'blocking beds' in ATH and would probably receive better and more appropriate care in their own homes or hospice beds.⁵⁷ The high cost, over medicalised care is known to be a negative consequence of hospitalised end of life care.⁵⁷ Unfortunately, PC is not fully integrated into district services, and there are still limited dedicated PC beds in district services with limited trained home PC providers. Whole system oblique integration, especially into communities, is thus core to the integration in ATHs to ensure patients receive excellent care and the appropriate care at the right time.¹⁶³

Palliative care diplomacy

Despite these challenges, GSH has achieved a level of PC integration. This service is supported by the university clinically and also in relationship-building outside and inside the hospital. It is linked to many hours of supporting HCPs with clinical care and sometimes assisting HCPs to cope with their own distress. PC diplomacy and steadfast relationships are required to build trust within the health care system. Factors such as being of service, being always available, being invited in, being grateful for receiving referrals, being modest and being transparent are recognised normative factors that enable integration in PC.¹⁶⁹ With limited resources, diplomacy may be core to pushing the PC agenda. However, this service will require further support, especially due to the multifaceted PC need, if we are to prevent burnout in existing services. In addition, without established PC services in ATHs there will not be sufficient research, educational and clinical support to drive national PC integration.

3.5. Conclusion

This research has highlighted the interplay between micro, meso and macro level in the integration of PC in one ATH in South Africa. This is further impacted by the interplay between functional and the normative aspects in the South African ATH context that is filled with misconceptions regarding PC, competing values, resource limitations, vertical structures and lack of PC accountability structures. Therefore, mandatory PC education, national recognition of the specialised nature of PC, national and local monitoring and evaluation, standards and guidelines and oblique integration across the health system are fundamental in PC integration but are currently not in place.

Understanding the interconnectedness of the above-mentioned normative and functional aspects in the context of PC integration may assist in developing strategies to break this repetitive negative feedback. Furthermore, understanding the specific clinical settings' context may assist in developing strategic interventions when integrating PC. This may in turn, assist in the transferability of these strategies to other settings.

3.6. Limitations

This research is situated within GSH, a relatively well-functioning ATH in the South African setting with many years of PC sensitisation. This may not be true for other ATHs in South Africa but the approach used to describe the context does provide an analytical approach for other settings. GSH is also within a province that has already launched a PC policy, and that has relatively stable primary care and secondary care. GSH is also linked to hospices across the WC, contributing to the continuity of care. This may influence the transferability within the South African context, especially in areas without well-established referral pathways.

Most of the data was obtained through interviews. Participants may not have given a true reflection of actual events and reasons for integrating PC to prevent negative impressions.

Ethics approval and consent to participate

Ethics approval was obtained from the University of Cape Town Human Ethics Committee (HREC 071/2020), and site permission was obtained from Groote Schuur Hospital. The REDCap database also has ethics approval from the UCT Human Ethics Committee (HREC R012/2016). Informed consent was obtained from the interviewees and patients or their families on the database. All consented to their

data being included. All data were anonymised, stored on a password-protected data base with secure access.

Consent for publication

Consent to publication was obtained from participants.

Author contribution(s)

Krause: 60% (conceptualization, formal analyses, methodology, project administration, resources, validation, visualisation, writing)

Gwyther: 20% (conceptualization, analyses, and review writing.)

Olivier: 20% (conceptualization, analyses, and review.)

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Nil to declare

Availability of data and materials

Anonymized data is available from the corresponding author on reasonable request.

Chapter 4: Evaluating a vertical nurse-led service in the integration of palliative care in a tertiary academic hospital

Chapter 3 described the context of the academic teaching hospital (ATH) and highlighted key factors to consider when integrating PC. Chapter 4 introduces a Vertical Nurse Led Doctor Supported (VNLDS) service, specialised PC service, as an integration strategy. This service was introduced by an NGO in 2012 and has been officially governed by the GSH since 2014. It was developed from the need to provide a dignified place of death for patients who arrive in the emergency service at the end-of-life. This service was firstly only for patients in the medical wards but has now expanded across the hospital.

This service consults with patients referred to them. They conduct an initial a bio-psycho-social and spiritual assessment using a standard evaluation form. The VNLDS will advise on medication and other management aspects. When necessary, the PC doctor will prescribe medication and adjust medication. All patients will be reviewed by the team on a daily basis while in the hospital. Families will be counselled and supported, and a follow-up message will be sent to all patients and families a week post-discharge. All patients and families also have access to a WhatsApp system to ask questions. This service is linked to the structure as recommended by the NPFSPC, that recommends a consultative palliative care service.¹²

This service is established, but how this resource contributes to integration is unknown. The aim of this chapter is to evaluate how a vertical nurse-led doctor-supported PC team served as a strategy to integrate PC into GSH. This is a theory-based evaluation that uses the conceptual framework drawing from Valentijn's Model of Integrated Care. It, therefore, evaluates both how the VNLDS contributed to the normative and the functional aspects of integration. The theory is summarised in this chapter and is aligned as discussed in the Literature review section describing [a conceptual framework for palliative care integration in ATH](#).

It is written in article style and has been published:

Krause R, Olivier J and Gwyther E. Evaluating the impact of a vertical nurse-led service in the integration of palliative care in a tertiary academic hospital. Palliative Care and Social Practice 2024; 18:26323524231224806.

The researcher in the main author (60%) who developed the methodology, assisted in data acquisition, did the data analyses with the other authors and wrote manuscript. The other two authors contributed the conception, data analyses and manuscript editing.

This was the first strategy to be evaluated and uses the theory to evaluate the integration strategy. It uses a bottom-up approach to integration. This chapter highlights how important understanding of the context([Chapter 3](#)) is to explain the findings in this chapter. Clinical-level integration was achieved as demonstrated by interviews, database, and documentation. Certain findings such as the decrease in referrals from the Emergency Department are not described in this chapter because the reasons are not explored within this research process. It used a mixed sequential design to expand and confirm findings. It deepens our understanding of how the service contributed to the cultural change in the hospital and why this occurred because we can link it to contextual knowledge.

Article: Evaluating a vertical nurse-led service in the integration of palliative care in a tertiary academic hospital

Abstract

Background:

Groote Schuur Hospital is a large Academic Hospital in South Africa that is in the process of integrating palliative care (PC) via a Vertical Nurse-Led Doctor-Supported service that was initially established to deliver clinical care. PC integration should occur across multiple dimensions and may result in variable degrees of integration between levels of the health care system. This research evaluates the VNLDS through a theory-driven evaluation to describe how the service affected integration.

Methods:

A mixed-method sequential design consisting of a narrative literature review on the theory of integration and palliative care, retrospective quantitative data from a PC service delivery database, qualitative data from semi-structured interviews and document analyses. It was structured in 3 phases which assisted in confirming and expanding the data. Statistical analyses, deductive thematic coding and documentary analyses were conducted according to the conceptual framework of PC integration.

Results:

The PC integration process was facilitated in the following ways: (i) the service provided good clinical PC; (ii) it was able to integrate on a professional level into specific diseases, such as cancer but not in all diseases; (iii) developing organisational structures within the service; (iv) the observed benefit of good clinical care increased the value stakeholders assigned to PC, thereby driving the adoption of PC. However, there are still clinicians that do not refer to PC services. This gap in referral may be grounded in assumptions and misconceptions about PC, especially at the organisational level.

Discussion

Observed PC service delivery is core to integrating PC across the health care system because it challenges the normative barriers. However, the VNLDS could not achieve integration in leadership and governance, education and hospital-wide guidelines and policies. Whole system integration, foregrounding organisational commitment to PC excellence, is core to integrating PC.

Conclusion

The VNLDS service has effectively linked PC in specific disease profiles and normalised the PC approach where healthcare workers observed the service. These integrational gaps may be grounded in assumptions and misconceptions about PC, especially at the organisational level.

Keywords

Integration, Nurse-led, Academic Teaching hospital, normative, functional

4.1. Introduction

Access to palliative care (PC) services is recognised as fundamental in the continuum of care; unfortunately, there is limited access to these services, especially in low-middle-income countries (LMIC).^{5,14,16} Multiple integration strategies are being used to integrate PC services and it is essential to evaluate how strategies work, especially in LMIC where the needs are so great.¹⁷⁰ Groote Schuur Hospital (GSH) is a large Academic Teaching Hospital (ATH) in South Africa that is in the process of integrating Palliative Care (PC).⁷ For the past 10 years, a PC service has been provided by a vertical nurse-led doctor-supported (VNLDS) service in the hospital. The provision of PC services in an ATH is aligned with the South African National Policy Framework and Strategy for Palliative Care Policy (NPFSPC) based on the World Health Assembly 67.19 palliative care resolution, which provide guidelines on PC service delivery in hospitals.^{12,14} Furthermore, this Framework describes PC in an ATH as *"a specialist palliative care service at regional and tertiary hospitals. Centres of excellence will be established at academic hospitals to support education and research in palliative care."*¹² Therefore, role of a PC service in an ATH extends beyond the provision of clinical care. The NPFSPC was adopted in 2017, and the PC service in GSH had, thus, been started without policy guidance and may provide a service different from that envisaged in the policy. Therefore, it is essential to evaluate this service to identify gaps in its integration process and establish how and why it was or was not achieved.

Gröne et al. (2001) state that integration is: *"the act of making a whole out of parts; the co-ordination of different activities to ensure harmonious functioning"*.⁹² Integration is the process, methods and tools to achieve the harmonious functioning of the different dimensions of a health care system.^{70,89} These different dimensions need to be coordinated to ensure patients and families have access to PC when they need it. These dimensions are complex, interlinked and there are a number of theories describing them. This research draws from Valentijn's so-called 'Rainbow model of Integrated Care'. Valentijn et al. (2015) linked integrated clinical health care with an integrated health system. This framework takes account of the dynamic nature of a health system and the non-linear patterns of integration.⁸⁵ It identifies six integration dimensions, namely: clinical, professional, organisational, systems' integration, functional and normative integration. According to this model, integration of services can happen at different levels, namely micro (clinical integration), meso (professional and organisational integration) and macro (system integration). In addition, Valentijn's theoretical framework also discusses that integrative care requires normative integration at all levels of care. It is the final step to integration and describes the development of mutual values, vision, trust and culture. Valentijn et al. (2013) also describe functional integration as including key support functions and

activities structured around the service to ensure accountability and decision-making. Functional and normative integration are interconnected at all levels,² and the prevailing hospital organizational culture plays a vital role across all these levels.

Organisational culture is a complex phenomenon, universal but challenging to define, dynamic and indistinct.¹¹³ Martin describes it as shared sets of understanding and meaning guiding behaviour and social interactions in a particular organisation.¹¹² *"This is the way things are done around here"*, is a layman's and easily understandable description of organisational culture.¹¹³ Therefore, formal change may be easily introduced, for example, a new policy or dress code, but the unwritten values and rituals must be tackled with sensitivity and understanding. For this reason, disruption of 'how we always do things' in an organisation is not always welcomed and can be met with the marginalisation of a new intervention.¹¹⁴ For example, PC challenges stakeholders to acknowledge the suffering and death of patients, and, sometimes, their own mortality. This produces uncomfortable feelings and may even disrupt an individual's way of thinking about their discipline. Thus, the integration of PC into the culture of an ATH and the normalisation of PC may be one of the most significant dimensions of integration. There is a need to evaluate both functional and normative integration, and especially culture when evaluating a new service, such as the VNLDS.

The integration process may also vary in the 'intensity' thereof may vary depending on the unit of care.¹²⁶ Some stakeholders may prefer activities to be linked with an adequate referral process only with good communication between the referring service and the PC service.¹²⁶ Other stakeholders would prefer activities to be coordinated where clinical information is shared to manage the transition of patients between different units, such as a multi-disciplinary meeting. Furthermore, stakeholders will not engage in PC interventions deemed inappropriate and unresponsive to their and their patients' needs.⁶⁹ In addition, these clinical needs cannot be addressed in isolation - for example, patients cannot be referred to a unit unless the unit forms part of the hospital's standardized referral process, which requires technology, standard operating procedures, and monitoring.¹⁴⁸ This is especially true in an ATH, where functions are too complex to operate only in one domain. Therefore, achieving in-depth, appropriate, responsive, but sustainable PC health service integration may require further health system integration. Kaasa et al. (2018) recommends that PC integration in oncology needs to have both vertical and horizontal aspects as well as multi-dimensional integration.¹⁷¹

In order to manage the complexities of providing PC, a dedicated PC team works in GSH. It currently consists of two PC-trained professional nurses (one acting as a coordinator), two auxiliary social

workers, an administrator and two volunteer PC-trained medical doctors. This research evaluated the ability of a VNLDS services to strengthen the integration of PC in ATHs in South Africa. Understanding why and how things happened during the development and implementation of the VNLDS are essential to the evaluation. Principles of a theory-driven evaluation are used to gain information additional to the performance and merit of the program.¹⁷² This approach was chosen because an experimental evaluation may not reveal how and why the strategies brought about the change. Astbury and Leeuw¹⁴² state that how programmes bring about change is called ‘unpacking the black box’ to explore the inner components and logic of programmes.^{141,142} Although counterfactual evidence is important in an evaluation, the national policy implies that there should be no ATH without a PC integrated service.¹² Furthermore, PC is a complex intervention and its integration into the ATH may be influenced by multifaceted aspects, for example, individual, hospital and societal factors.¹⁴³ Most importantly, understanding causal pathways of integration may assist with identifying improvements needed as well as implementing the strategies in other settings.

A conceptual framework was developed by drawing on Valentijn’s theory on integration and its dimensions, further literature on integration as well as PC integration.⁸⁵ This was developed in the research team and speaking with PC advisors in the field. We can thus conceptualise that a VNLDS service affected on functional integration in the functional domains and dimensions, as illustrated in the table below.

Table 4.1: Domains of PC integration drawing from multiple sources

Domains	Dimension of Palliative Care Integration
The provision of patient and family centred care. ^{85,99}	<ul style="list-style-type: none"> • Pain and symptom management • Psycho-social and spiritual care • Informed and participatory decision making • Family are active members of the team • Bereavement care available • Patient and Family Education
The provision of collaborative care ^{85,99}	<ul style="list-style-type: none"> • Automatic triggers to initiate palliative care • Multidisciplinary care • Continuity of care • End of life care
Information systems ⁶⁹	<ul style="list-style-type: none"> • Monitoring and evaluation tools • Integrated reporting mechanisms

Education ^{65,85,147}	<ul style="list-style-type: none"> • Basic • Intermediate • Advanced • Multidisciplinary • Continuous Medical Education
Leadership and governance. ^{65,85,147}	<ul style="list-style-type: none"> • Strategic Plan for PC • Managerial oversight and accountability • Financial and resource support • Clinical leadership
Guidelines and policies ^{147,149}	<ul style="list-style-type: none"> • Integrated policies • Stand-alone PC policies
Palliative care workforce ¹⁴⁷	<ul style="list-style-type: none"> • The availability of a multi-disciplinary PC trained workforce. • Emotional and organisational support for the palliative care workforce
Drug availability ^{43,147}	<ul style="list-style-type: none"> • Essential medication as specified by the WHO Essential PC Medicine List
Research ¹⁴⁷	<ul style="list-style-type: none"> • PC specific research • Integrated PC research

Contextual factors include the environment it is being integrated into, such as the PC need, patient issues, existing frontline services, resources as well as governance structures. In this research, these multiple factors can be further organised into clinical care as well as professional, organisational and systems integration to distinguish the aspect of integration. Having introduced these different factors, normalising PC by addressing the organisational culture remains core.^{2,113}

In this evaluation, organisational culture refers to the norms, values, and behaviour that stakeholders have towards working with patients with life-threatening illnesses, the assumptions they have regarding PC and its role in the health system. Their vision and goals of PC integration form part of the normative process of integration.⁸⁵

The aim of the research is to evaluate how a vertical nurse-led doctor supported PC team served as a strategy to integrate PC into GSH. In order to make recommendations regarding an effective strategy for integration, it is important to evaluate current PC integration implementation strategies and how they align or do not align with contextual factors, as well as functional and normative integration.

4.2. Methodology

A mixed-method sequential design was followed, synthesizing retrospective quantitative data from a PC service delivery database (PC REDCap), qualitative data from semi-structured interviews, and document analyses. This research was conducted from March 2020 to July 2022. A narrative literature review was conducted prior to the study to understand PC integration in hospitals and how it can be achieved. The conceptual framework for the research study draws from the Rainbow Model of Integrated Care and principles of palliative care.^{38,147, 85} This research was conducted in Groote Schuur Hospital (GSH), a large tertiary/quaternary academic hospital with 975 beds, which serves the Cape metropole and attracts patients from across South Africa for specialised care. It is also a training hospital supporting both undergraduate and postgraduate education and a centre for research.

In phase 1, demographic and clinical quantitative data was extracted from a REDCap database from the period January 2017 to June 2021. It was analysed statistically to describe the profile of the referred patients, the sources and timeline of the referrals, the PC services rendered to the patients and families, as well as the discharge process. The Provincial Data centre was also approached to access the date of death.

Also, in phase 1, semi-structured interviews (n=5) were conducted with VNLDS staff to describe the services delivered in 2022. Face validity of the interview guides was ensured by presenting the questionnaire to experts in the field of normative and functional integration and experts in the field of PC. Construct validity was derived by aligning this tool with the theoretical framework. The methodological triangulation of data strengthened trustworthiness by asking permission from sources about using information obtained outside the formal research process and sharing results with participants before any publications.⁷⁶ This is embedded research, therefore, assumptions held by the researcher were explored before commencing data collection via a recorded reflective interview between the researcher and supervisors. Reflexivity was further ensured by the researcher and research assistant keeping journals with short notes on discussions, as well as after interviews.

The qualitative data from the staff interviews was analysed using the framework analysis approach using deductive coding.¹⁷³ The interviews were transcribed and imported into NVIVO version 14.23. The researcher familiarised herself with the and immersed herself in data sources. The coding framework was developed from the conceptual framework as discussed in the introduction, drawing from Valentijn's theory on integration.⁸⁵ Themes and sub-themes identified in the analysis of the interviews were coded. Codes and analyses were discussed with the supervisors and research assistant and attention was given to emerging themes not identified by the framework as not to overlook any data. Negative cases or outliers were included and discussed. Codes were also discussed

with advisors to check for bias of the researcher. These codes were applied to all the data sources and data was charted across all the data sources of the study. Selected representative data was used to illustrate the resulting themes of the analysis.^{79,80}

In phase 2, analysis from the database and the interviews with the VNLDS service were merged, and these findings were discussed with the VNLDS staff to confirm and explain the data. This assisted in connecting with organisational documentation (n=14) (see Appendix A) that explains and confirms the service delivery. The documents were thematically analysed using deductive coding and drawing from the conceptual framework as discussed in the introduction. A data extraction sheet was used to analyse documents with regard to the name of the document, how, when and why the document is used, and for themes of functional and normative integration. Where palliative care is /not in the document and how it is referred to. These factors were further supported by discussing them with research team.

The data was further expanded by identifying wards and services with distinct referral patterns. The wards with limited PC were determined by listing all wards in GSH and discussing with the PC staff the logical explanation for limited referral to PC in these wards. For example, it is understandable that there will be limited PC referrals from an ophthalmology ward. If there was incongruence between the disease profile of patients in the wards and the number of referrals, interviews were conducted with staff from those units. These sequential interviews (n=5) were conducted with purposively selected senior ward staff outside the PC service. Interviews were performed using a semi-structured interview guide drawing from the conceptual framework, analyses of the VNLDS interviews, database and PC literature.

Finally, all the data sets were integrated to evaluate the-effect of the VNLDS in both the different domains. These findings were discussed with an independent observer and with the VNLDS.

The figure below illustrates how, in Phase 1, quantitative and qualitative were merged to expand on the phenomena. Further interviews and document analyses were done to explore the findings further. If all 4 data sets were confirmed the findings, it was deemed to be strong convergent evidence and if 1 dataset did not confirm the findings, it reported as divergent evidence. The merging of the data and the inferences drawn from the data was done in discussion with the research team. The details of the merging and inferences are attached in Appendix A.

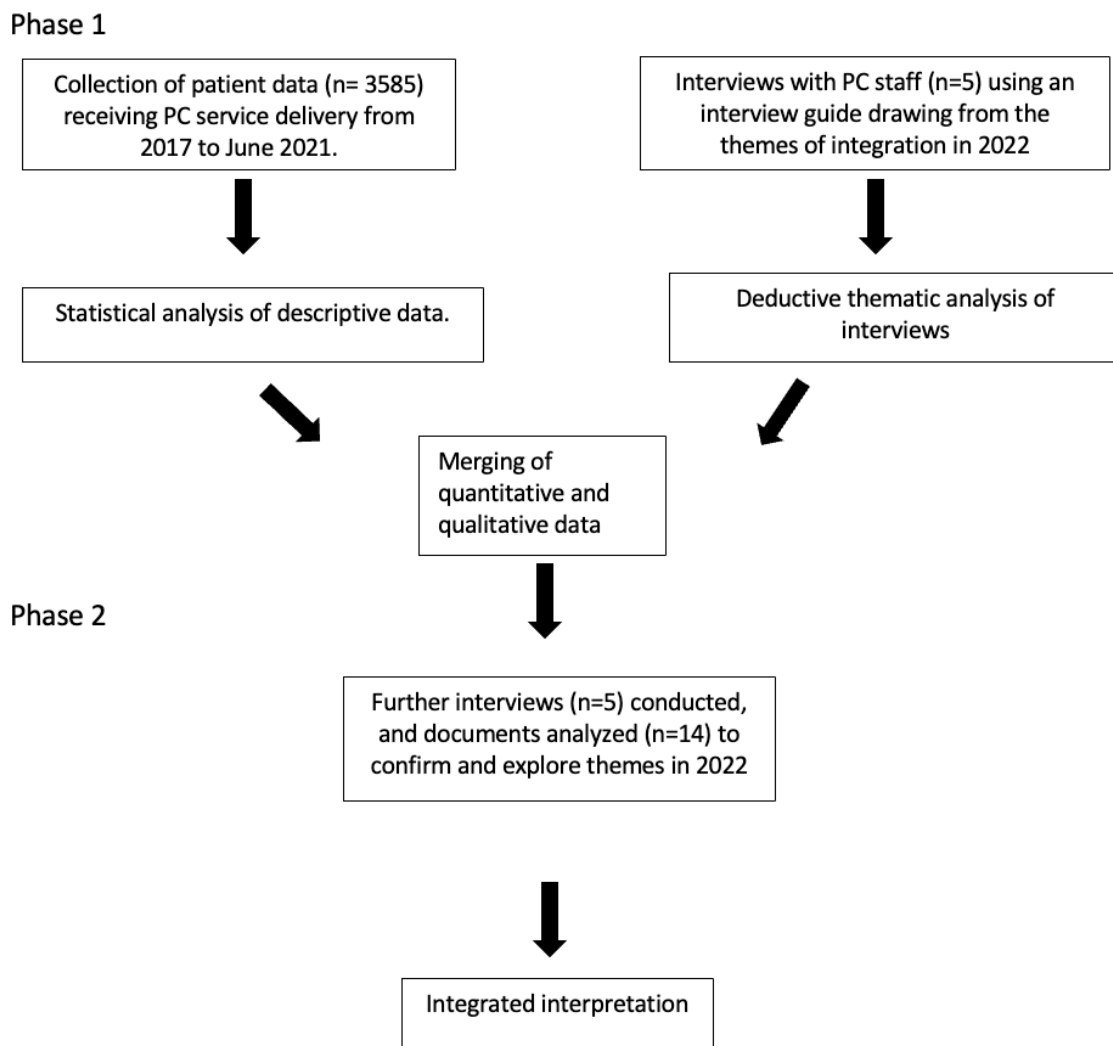


Figure 4.1 : Schematic representation of the methodology

4.4.Results

Results from the integrated findings are presented in nine main clusters concurrently, as described by the conceptual framework and the dimensions of integration.

Clinical profile of referred patients and dimensions associated with clinical integration

This dimension explores person-focused care provided by the PC service.

The provision of patient and family-centred care

The literature review found that clinical PC is provided when patients and families receive: pain and symptom control; psycho-social and spiritual care, informed participatory decision making; and families are informed and are seen as part of the care team; patient and family education is provided; and bereavement care is provided.^{43,147,171}

Clinical palliative care service delivery

Interviews with the VNLDS staff indicated that the VNLDS delivers a consultancy service across the whole hospital. There is evidence of increasing numbers of patients being referred to the VNLDS service from across the hospital with multiple conditions. The majority of patients were bedbound (43%) or required assistance (41%), with very few being fully mobile (15%). On average, 58% of PC patients were referred specifically for end-of-life care as a reason for referral. However, this decreased from 91% in 2017 to 36% in 2021 (see Table 1). Other reasons for referral are comprehensive care, including symptom control, counselling, education, social support, and placement.

Table 4.2: Referral data to the PC service from 2017 to June 2021 (REDCap Database)

	2017 (n = 737)		2018 (n = 593)		2019 (n = 773)		2020 (n = 931)		2021(until June) (n = 551)		Overall (n = 3585)	
	n	%	n	%	n	%	n	%	n	%	n	%
Referring Ward												
Surgical wards	104	14.1	120	20	190	24.6	249	26.7	159	29	822	22.9
Medical wards	283	38.4	240	40	335	43.3	313	33.6	184	33	1355	37.8
Gynaecology	11	1.5	19	3	29	3.8	48	5.2	21	4	128	3.6
Emergency Unit	175	23.7	100	17	81	10.5	63	6.8	40	7	459	12.8
Intensive Care Units	3	0.4	2	0	3	0.4	10	1.1	7	1	25	0.7
EOL beds	35	4.7	19	3	17	2.2	9	1.0	15	3	95	2.6
Out-patients	54	7.3	38	6	59	7.6	59	6.3	25	5	235	6.6
Community referral	56	7.6	45	8	40	5.2	146	15.7	42	8	329	9.2
*No data	11	1.5	10	2	5	0.6	34	3.7	58	11	118	3.3
Diseases referred												
AIDS	14	1.9	2	0.3	10	1.3	8	0.9	3	0.5	37	1.0
COVID-19	-	-	-	-	-	-	135	14.5	93	16.9	228	6.4
End stage cardiac failure	78	10.6	43	7.3	64	8.3	21	2.3	14	2.5	220	6.1
End stage COPD	20	2.7	58	9.8	32	4.1	25	2.7	19	3.4	154	4.3
End stage dementia	24	3.3	42	7.1	33	4.3	20	2.1	16	2.9	135	3.8
End stage liver failure	11	1.5	10	1.7	12	1.6	7	0.8	1	0.2	41	1.1
End stage renal failure	125	17.0	101	17.0	109	14.1	143	15.4	58	10.5	536	15.0
Major CVA	26	3.5	20	3.4	8	1.0	18	1.9	11	2.0	83	2.3
Metastatic cancer	320	43.4	234	39.5	374	48.4	447	48.0	268	48.6	1643	45.8
Progressive neurological	72	9.8	25	4.2	56	7.2	27	2.9	19	3.4	199	5.6
Tuberculosis	3	0.4	3	0.5	9	1.2	11	1.2	3	0.5	29	0.8
Other	34	4.6	55	9.3	52	6.7	54	5.8	41	7.4	236	6.6
*No data	10	1.4	-	-	14	1.8	15	1.6	5	0.9	44	1.2
Average level of functionality												
Bedbound	348	47.2	243	41.0	292	37.8	411	44.1	228	41.4	1522	42.5
Fully mobile	97	13.2	93	15.7	125	16.2	130	14.0	81	14.7	526	14.7
Requires Assistance	281	38.1	248	41.8	346	44.8	366	39.3	224	40.7	1465	40.9
*No data	11	1.5	9	1.5	10	1.3	24	2.6	18	3.3	72	2.0
Referred for End of Life Care												
Yes	644	91.3	272	46.9	578	75.6	344	37.3	197	36.1	2035	57.9
*No data	32	4.3	13	2.2	10	1.3	9	1.0	5	0.9	69	1.9

Reviewing available mortality data (n=1894) of these referred patients on the REDCap database, most patients (53%) were referred in the last week of life. See Graph 1

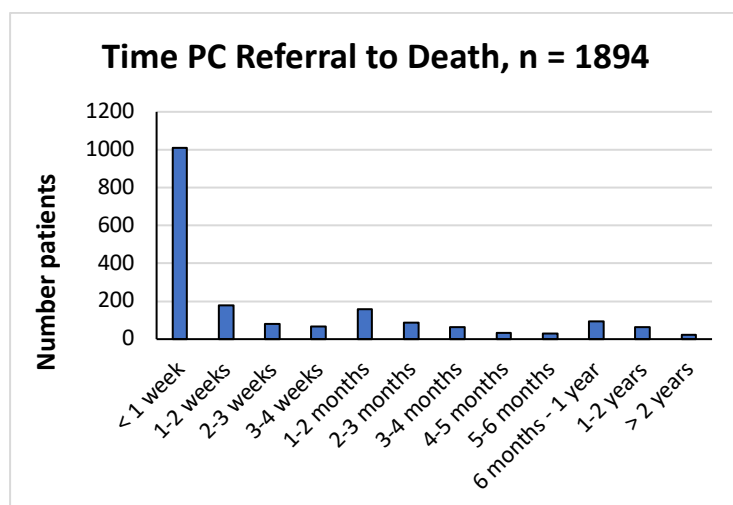


Figure 4.2: Time of PC referral to death

The data centre confirmed that place of death of (n=1188), 27% of patients died in hospitals. See Table 2. It further confirmed that 191 (16%) died at home. The data centre could only provide the death data for 33.1% of patients because home deaths are not always recorded on the provincial data system, which is not linked to the Department of Home Affairs, where deaths are recorded. All hospital death data is available; if no place of death is recorded, we can assume the place of death is home.

Table 4.3: Place of death

	2017		2018		2019		2020		2021		Overall	
	n	%	n	%	n	%	n	%	n	%	n	%
Place of death n = 1188												
Home	45	6.1	48	8.1	54	7.0	29	3.1	16	2.9	192	5.4
Hospice	3	0.4	5	0.8	4	0.5	1	0.1	5	0.9	18	0.5
Hospital	125	17.0	164	27.7	145	18.8	334	35.9	202	36.7	970	27.1
Intermediate Care	1	0.1	1	0.2	1	0.1	1	0.1	0	0.0	4	0.1
Other	2	0.3	1	0.2	0	0.0	0	0.0	1	0.2	4	0.1
*No data	561	76.1	374	63.1	569	73.6	566	60.8	327	59.3	2397	66.9

Pain and symptom control

There is strong converging evidence from the database, document review, and interviews that patients referred to the VNLDS receive pain and symptom control. The database indicated that 97% of the referred patients received pain and symptom control.

This is further supported by evidence of routine pain and symptom control in document review of the PC stationery. There is also evidence that pain and symptom are important markers by which other staff evaluate the impact of a VNLDS.

For me, it is when they come and initiate the pain control; it helps the patient a lot. The patient is then very comfortable and so. The palliative care is good, they tick all the boxes. Wardstaff

Psycho-social and spiritual referrals

The database and documentation indicate that 100% of the patients received psycho-social support. The majority (89,6%) of the patients are classified by their social circumstances by the hospital as 'poor' (family unit earns less than R100 000 per year); (51,4%) or 'very poor', which is classified as that formally unemployed, no formal income (38,2%), emphasising the need for social support.

Is the patient working? If the patient is still working, I do it. Referral to the social worker so that I, the social worker can help the patient with the work papers. Pallsocial1

Interviews with the VNLDS show that the team also links with a multifaith spiritual team who liaises with the team daily. There is evidence in the documentation of routine spiritual assessment and referral to a spiritual team.

Informed and participatory decision making

The interviews with the VNLDS indicated that the treating teams must break bad news and share prognoses. However, the VNLDS service assesses patients' understanding of the disease and prognoses and assists in deepening this understanding and exploring care options with both the patient and family. Routine data collected by the service indicates an average of 50 family meetings a month, and there is a specific family meeting stationery in the documentation analysed, including educational material provided to patients and family education of the illness, the care and medication that is and will be required.

Bereavement care

There is evidence of bereavement follow-up (28,9%), and the stationery includes a section to record a bereavement call. However, most patients are referred to community resources for PC and bereavement care after discharge.

Patient and family education

This domain is both clinically and organisationally important. Patient and family educational material in the form of pamphlets is available. Staff outside the VNLDS service identify the role of the VNLDS service in patient and family education as a positive contribution to care and empowers the family to continue on their own.

There are patients, the family members, actually, I've seen the family members before palliative team is involved and after you the PC, are involved. And there's a huge difference. There's, there's the unanswered questions, you know, the PC answer those questions. The family members feel the sense of, not so much control, but understanding, so they they've come to terms with what is to be expected, and what they can do. So, that they actually have this, this empowerment. Ward staff 3

Dimensions associated with professional integration

The provision of collaborative care

The provision of collaborative care is conceptualised as the appliance of automatic triggers, multidisciplinary care provision, ensuring continuity of care and the provision of end-of-life care across the hospital. ^{85,99}

The use of automatic triggers to initiate PC

There is divergent evidence on applying automatic triggers on when to refer to PC. There is documentation (a referral sheet and a PC indicator tool). Still, the referral patterns demonstrate that mainly cancer patients (45%) (diagram 1) are referred with few cardiac patients (6%) and HIV and TB patients(1,5%) referred, suggesting that the indicator tool is not used regularly. There is further evidence that referrals are late in the disease trajectory.

I do not know if all the patients (needing palliative care) are referred to palliative care.
Wardstaff3

Multidisciplinary care implementation

There is very little evidence of multidisciplinary care during the evaluation period at GSH. According to the VNLDS staff interviews, the PC team works and provides care as an interdisciplinary team. However, the PC is linked but not integrated into the ward teams. The VNLDS refers to rehabilitative services. This lack of multidisciplinary has not been impacted by the VNLDS.

It's more the doctors that are giving the orders. There's no multidisciplinary approach. There's no, like a combined view on the patient. So, if there's a doctor's rounds, the nurse will accompany the doctor and take the orders. Pallnurse2

Yes, so I don't; I don't think the nursing staff feel empowered enough to actually make suggestions, not only with regards to the palliative team, but I mean with any other, whether it's dietitian or, you know, if there's any social services. Wardstaff1

Ensuring continuity of care

According to the literature PC systems integration occurs when there are clinical care pathways for patients to ensure continuity of care. The VNLDS refers patients to Community Health Care and Hospices. The service also follows the patients up one week after discharge to ensure community care is in place.

Then I do a follow up with the patient to see if they got the community key services; then if not, I will follow up with the coordinator working in that specific area where the patient stays to find out the delay. AdminPC

The provision of end-of-life care

Documents provide evidence that comprehensive end-of-life care is provided for patients referred to PC but not to all dying patients in the hospital.

And it's almost like they want to push the patient to a side cubical, fine when they are dying. Wardstaff2

Dimensions associated with organisational integration

The availability of information systems

Drawing from the literature, one of the aspects of organisational integration is that there are monitoring and evaluation tools available to evaluate the PC in the hospital.⁶⁹ Currently, there are monitoring and evaluation services available in the VNLDS but no other PC monitoring and evaluation in the hospital.

There is evidence of monitoring within the service.

And yes, then also daily, weekly, monthly. I will do the stats. PCAdmin

However, outside the service, the outcomes of patients who need PC are not always known.

No, I may not always know the outcomes of those patients. Wardstaff2

Education in PC at various levels

Conceptually PC education should be provided at various levels.¹⁴ Furthermore, continuous medical education and patient and family education should be available.¹⁴⁷

Basic Education

There is evidence that 100 of the 3 400 healthcare professionals employed by GSH³⁹ from various disciplines have been trained in basic PC. From the interviews with the VNLDS staff, 100 HCP in the hospital have received basic palliative care training. The VNLDS service is involved in final year medical students training once a week and in the training of Gynaecology oncological fellows.

Intermediate Education

From the interviews, Family Physicians registrars rotate for 6 weeks through the service. There is also intermediate training for oncology registrars in the hospital linked to the university. However, neither family physicians nor oncologists refer to the VNLDS. There is no further intermediate level training in the hospital.

Advanced Training

From the interviews, there is no advanced PC training in the hospital. Both the doctors volunteering in the VNLDS service have specialised PC training.

Continuous medical education

The documentation indicated that the VNLDS provided a quarterly lecture as continuing education on PC open to the hospital, but this stopped during COVID. There is an acknowledgement that there is a need to provide further continued education in PC across the hospital.

There needs to be more empowerment of the current team in the ward and further continuous education. Pallnurse2

Leadership and governance

Data analysis included review to assess whether there is a strategic plan for PC in the hospital, managerial oversight and accountability, financial and resources support and clinical leadership.

No strategic PC plan was found. There is documentation evidence of clinical, administrative managerial oversight through minutes of meetings. Quarterly meetings are held with management as a whole team, and staff report to their clinical managers weekly. Medical clinical leadership is provided by university staff.

Guidelines and Policies

Hospital documentation was reviewed for integrated guidelines and standard operating procedures to provide evidence of organisational integration. Stand-alone guidelines and policies do exist in the VNLDS but not in other areas of the hospital.

No, I don't, I don't have any policies. I was actually going to speak to sister at palliative care because we need, not only an SOP for nursing, but also if we can actually incorporate it from doctors as well. Wardstaff1

Five documents were found as stand-alone policies or guidelines supporting the VNLDS PC service. PC was integrated into one stand-alone PC chapter in the surgical guidelines and one question in the home oxygen referral system.

PC workforce and resource support

Two professional nurses, two auxiliary social workers and a clerk are employed in PC by the hospital. The university employs medical doctors volunteering in the hospital. The professional nurses are not in dedicated PC posts. The VNLDS have a dedicated office, family meeting and teaching space. The university contributes to the resources of the service. There is a debriefing service for the PC staff. There are 2 further nurses in the hospital with intermediate PC training in other departments who work in oncology and surgery.

The availability of essential PC medication.

Essential medications, as specified by the WHO Essential PC Medicine list, are all available in the hospital.

Researching PC.

There is evidence of PC research in the VNLDS but no evidence of dedicated PC research outside the service.

Normative integration (norms, values, behaviour)

There is the assumption that PC services are only for end-of-life care. This assumption has not been changed by the VNLDS.

I think that most are walking around with the assumption or going around with the assumption that palliative care is just for patients who are going to die or are now diagnosed with cancer and they gonna die at the end of the day. Pallnurse2

The behaviour of avoidance of end-of-life care and referring when no further curative management can be done has been shifted by the VNLDS service as evidenced by more patients being referred for reasons other than end-of-life care.

The outside wards value the VNLDS service for both clinical and staff care. The PC staff has assisted the ward staff in managing their distress and has assisted in creating spaces, like a butterfly, room for reflection.

The palliative care sister assisted us in addressing the moral distress and how to manage death and dying Wardstaff3

Normalising

The VNLDS service has become part of routine care, contributing to the service's acceptability and value.

Um, you know, I think, I think what makes a big impact is to see people who do it regularly. So, I think, I think people talk about palliative care and refer to palliative care more because they see it happen, uh, and they see the clinical benefit of it. So, I think it's a bit of a chicken and egg situation, but I think the, the more active a palliative care team is in a ward with clinical decision making, uh, the more it's used and the more valuable it becomes and the more engaged with it other doctors are. Wardstaff4

4.5. Discussion

The extent of integration achieved

The VNLDS service has successfully implemented the integration of PC at a clinical level, in accordance with the recommendations outlined in the conceptual framework, across the majority of hospital wards.² There is both quantitative and qualitative evidence of pain and symptom control, family involvement, as patient and family education.^{147,171} The VNLDS has demonstrated the importance of family meetings, which empower patients and families in decision-making. Carolan et al. (2015) highlighted that family distress, may have a significant ripple effect, impacting the entire family system.¹⁷⁴ Family meetings are thus core to assessing family structure, support and educating patients and families on the required care, as essential components of a PC service.^{43,147,171} The impact of family support by the VNLDS has allowed most patients to be discharged home with referrals to support from home-based care organisations rather than dying in the hospital. Continuity of care is further strengthened by linking them with community services.¹⁴⁷ Linking hospital PC and networking beyond the hospital is essential to both clinical hospital integration and strengthened PC care in the community system.³⁸

How the service improved the valuing of palliative care and palliative care integration

The clinical service expansion is attributed to observing the positive outcomes of working with the PC team. As stated by one of the participants: *"the more you see it, the more valuable it becomes"*. Observing the positive engagement and improved outcomes of referred patients and their families ensures value is assigned to PC, which assists in integration. Patients' continuity of care is ensured;

most patients referred to the GSH PC service are discharged and receive palliative care in the community and die at home. These observed perceived benefits and compatibility with current service needs affected the adoptability of the PC approach.⁶⁹ Users are more receptive to the PC approach, which in turn provides legitimacy to the PC service.⁶⁹ For example, a senior staff member states that the VNLDS makes a “*huge difference*,” and subsequently, this unit refers to PC regularly.

The acknowledgement of the impact of the end of life is as important for staff as it is for their patients. The open engagement with the suffering and actual dying process has assisted in addressing the staff's personal moral distress, which has been an important finding of this research study. PC has provided staff outside the VNLDS with the tools to care but also to engage with their own home and work experiences openly. For example, a butterfly room was opened in a ward as a place for contemplation for families and staff. Subsequently, vulnerability around death and dying is respectfully acknowledged and managed in this ward. There is thus a realisation of the benefit of PC service through attending to the staffs' needs, which enhances the receptiveness towards PC.⁶⁹

Limitations in the extent of clinical integration

Unfortunately, most patients are referred for end-of-life care, an average of 7 days after hospital admission. In addition, most of these patients already require assistance with activities of daily living or are fully bedbound. Therefore, the fully recognised impact of early specialised PC services has yet to be reached as demonstrated in global research.³⁸ For example, Temel et al. (2010)¹⁰ demonstrated that specialised PC services early in the disease trajectory of patients with metastatic lung cancer improve quality of life, reduce anxiety and depression in patients and marginally prolong life.¹⁰ However, as indicated by this research and other studies, late referrals to PC may result from an assumption that PC is only for actively dying patients.^{16,57} This, together with observed behaviour of avoidance of patients at the end of their lives, may result limited, late referrals.¹⁷⁵ The medical world has assisted in what Sallnow et al. (2022) describe as an “unbalanced” societal approach to death, dying and grieving⁵⁷ focuses on unnecessary clinical interventions and may exclude the psycho-social and spiritual dimensions of dying. Therefore, the referral to PC services may be convenient at this stage of care to avoid the dying process and accompanying complex care and emotions. Subsequently, this behaviour of disengagement with patients at the end of their lives may also cause disengagement with the whole PC process, and not recognising the benefit of PC at an early stage of the disease trajectory. However, this behaviour is challenged by the VNLDS service by persistently stating that PC starts long before the end of life. Subsequently, one of the normative aspects of integration accomplished by the VNLDS service is the normalisation of death in accordance with WHO definition of PC and a global movement to value death and dying as an important and integral part of life.^{29,57,163}

A further limitation in the extent of integration is that VNLDS is not reaching all disease-specific populations that require PC. The incidence of metastatic cancer patients referred to the VNLDS compared to other life-threatening illnesses and the causes of mortality in South Africa are disproportionate.¹² In South Africa, TB, diabetes, cerebrovascular disease, heart disease and HIV were the leading causes of death in 2018.⁵⁶ Despite this, very few TB and HIV patients (1,5 %) were referred to the VNLDS, and of note, the cardiology outpatients were the lowest source of outpatients referrals. This disproportionate referral pattern leaves many patients with cardiac and infectious diseases without access to PC. Automatic triggers and awareness on when to initiate PC are well established within oncology, but in organ failure and infectious diseases, PC needs are not met.¹⁷⁶ The VNLDS service has initiated automatic triggers in patients with pancreatic adenocarcinoma and end-stage renal patients, which are reflected in the referral patterns. For example, all patients in GSH who are declined for dialyses are automatically referred to PC services.¹⁷⁷ This is evident in the number of patients with renal failure referred to PC. However, the PC service currently works mainly on voluntary referral and linkage has not been uniformly successful. Automatic triggers specific to the context are thus core to further integration and universal PC access.⁵³ The SPICT-SA indicator, specifically designed for South Africa, considers the unique patient burden and wide range of patients who require PC.⁵³ The assumption that PC is only for metastatic cancer or for EOL care is a significant assumption that requires further professional interaction to address this gap in access to PC.

Enabler

This commitment and the drive to integrate PC on a professional level comes from inside the VNLDS service and the university's Faculty of Health Sciences. The VNLDS staff are passionate and committed to integrating PC. Rhee et al. (2018) identified factors affecting PC integration in Africa and named advocates and pioneers as key factors driving integration.¹⁰⁹ However, they warn that integration fuelled only by advocates is high risk as sustainability further requires other strategies and infrastructure support.¹⁰⁹ PC being driven by only a small group of passionate PC advocates, lack of commitment from organisational leadership, limited trained PC staff and lack of PC education are all factors in GSH echoing barriers experienced across the African continent.¹⁰⁹ Sustainable PC leadership in the hospital and across Africa will be important to ensure PC integration. Admittedly, moving this paradigm is beyond a clinical service and was thus not achieved by the VNLDS service.

Linking palliative care to the prevailing culture

The organisational culture of siloed service delivery results in a need for more professional integration across all disciplines, including PC. Disciplines stay in their '*own lane*' and that is the '*way things are*'

done'. Most services in the ATH are only at a level of integration where services are linked with doctors working in parallel and disciplines functioning in their siloes.¹²⁶ It may be ambitious to imagine a horizontal PC service in a hospital with limited PC-trained staff, where disciplinary excellence is core to organisational culture.⁹² Consequently, a PC service that is only linked may be appropriate, at first, within the ATH context to align with the prevailing culture of vertical excellence. However, currently, innovation and technical excellence are celebrated, an intervention that deals with death and dying may not be perceived as key. Although the VNLDS service is valued, it does not yet form part of "excellence". Labelling PC as excellent care one of the most significant paradigms shifts to normalise PC and aligning it with prevailing culture of excellence. The prevailing structure of 'how things are done' will be important as the initial pathway in integration.^{69,113} To ensure this linkage across all the appropriate disciplines will not be successful if further aspects of functional integration do not anchor it at all levels of care.³⁸

Limitations in functional integration

This lack of functional integration is evident when we observe that nurses are not in dedicated PC posts, there is no PC strategic plan, and the accountability structures are not integrated. Atun et al. (2009) advise that integrating an intervention into the broader health system governance structure will require alignment with existing regulatory mechanisms, creating unified accountability frameworks, integrating reporting, and establishing a joint performance management system.⁶⁹ All of the above integration structures mentioned by Atun require action on an organisational level. This action can be unpacked as decision-making, commitment, support, and willingness of key leaders to achieve PC integration.¹⁷² Furthermore, the current GSH team, needs to conform to the recommended staffing, especially the requirement for PC-trained nurses and medical doctors.¹² Kaasa et al. (2018)³⁸ confirms the lack of trained PC specialists is a substantial barrier to the integration of PC and hampers the confidence by which other specialists refer to PC services.³⁸ Furthermore, as stated above, this impact of limited-service delivery and specialist PC training in an ATH may impact beyond the ATH. This is evident when we review the limited research and education in the PC discipline, which impacts nationally and in the rest of Africa.¹⁷⁸ This need for whole system integration is especially evident when we evaluate the lack of PC education in South African ATHs. Physicians and surgeon trainees receive no PC training, and there are no PC mentors in these departments due to the absence of PC-trained consultants in most ATH. Overloaded curricula and services may underpin this lack of training, resulting in ATHs' workforce having very limited PC knowledge and skills. However, the Departments of Radiation Oncology across South Africa have successfully integrated a PC course into registrars' training without overburdening registrars or consultants.¹⁶⁸ This leaves the VNLDS as a small group of healthcare workers within the hospitals with PC skills.

This lack of investment in PC may be an overburdened and under-resourced healthcare system, and another new intervention may be deemed an extra burden on the healthcare system.²⁵ GSH is a well-functioning hospital in South Africa but is also overburdened by limited resources. Waddington et al. (2008) highlight that integration of new interventions is not always welcomed because, in a system where the wider health system is not functioning well (South African healthcare sector), it is questionable to change aspects of the system that are working.⁹⁶ Furthermore, a new intervention has to demonstrate a significant impact on cost containment.⁹⁶ Unfortunately, the VNLDS service has no economic evidence that it is cost-effective apart from discharging 72% of patients home for EOL care. The need for contextually specific economic evidence is paramount to enable further integration. This is further complicated by the limited research and costing models for PC in low-resource settings.^{179,180} Shifting the functional aspects of integration will require economic commitment from leaders and willingness and commitment to integrate PC.

4.6. Limitations

This is embedded research and the researcher is explicit about her support of PC, which may introduce bias with stakeholders and their responses to her. Most of the data was obtained through interviews and participants may also have recall bias. Participants not in favour of PC integration may also not want to be interviewed, which may limit counterfactual information.

Data in the databases also depend on the actual input of the records. However, as part of the database management process, data is validated regularly following set data management operating procedures. The limitation of the database was that it contained limited data on the patients' deaths.

4.7. Conclusion

The VNDL service has been able to harmoniously integrate clinical PC services in specific units and disease profiles and has brought about an organisational culture of normalising a PC approach. Observation of the service by hospital staff outside of the specific units and realising the benefits have further contributed to the adoption of PC integration. However, PC has yet to be adopted across all units nor disciplines. The context of vertical service delivery among all disciplines and the lack of organisational integration may underpin the reasons for this. In conclusion, PC integration will require an organisational commitment and economic evidence to ensure PC integration in an ATH to have an overall impact on national PC integration.

Ethics approval and consent to participate

Ethics approval was obtained from the University of Cape Town Human Ethics Committee (HREC 071/2020) and site permission was obtained from GSH. The REDCap database creation and data analyses received ethics' approval from the UCT Human ethics committee (HREC R012/2016).

Consent for publication

Consent to publication was obtained from participants.

Author contribution(s)

Krause: 60% (conceptualization, formal analyses, methodology, project administration, resources, validation, visualisation, writing)

Gwyther: 20% (conceptualization, analyses, and review writing.)

Olivier: 20% (conceptualization, analyses, and review.)

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Conflict of interest statement

Nil to declare

Availability of data and materials

Anonymized data is available from the corresponding author on reasonable request. All data is stored on a REDCap database and protected storage devices and can be accessed with permission

Chapters 5: Evaluating palliative care training in the oncology registrar programme in South Africa

The lack of education was identified in the previous chapter ([Evaluating a vertical nurse-led service in the integration of palliative care in a tertiary academic hospital](#)) as a barrier to integration, especially on a professional level. Chapter 4 has also illustrated that professional integration has not occurred across the hospital using only service delivery because referrals are voluntary and there is minimal organisation integration (documentation, database and interviews). Therefore, the way forward is to extend the specialised service beyond clinical care to teaching, research and leadership. Also, long-term sustainability requires moving beyond just clinical integration. One of the main functional gaps identified was limited PC trained HCW. This article will thus be important to evaluate how training contributes to PC integration. As discussed in [Chapter 3](#), there are very few HCP in GSH who are trained in PC. Furthermore, unfortunately, very few HCWs, want to undergo further PC training because according to them it does not assist in their career development. There is thus a need for appropriate and feasible PC training. However, is education, on its own, an effective integration strategy? PC education is a complex intervention and, therefore, the Chapter 5 looks at education in integration, to determine the feasibility and appropriateness of the tool/ resource used to train oncology registrars.

This training is situated in oncology, which is a high-burden and accepted discipline that requires PC integration, both locally ([Results](#)) and globally. The intervention/strategy is an intermediate-level education as the tool on a professional level for junior oncology trainees. Intermediate PC education is recommended for HCPs who work with patients with a high burden of palliative care but PC is not their main focus of care.¹⁴ These HCPs should be able to care for most patients but will require specialist help when managing patients with more complex PC needs. Currently the oncology team does not refer PC patients to the VNLDS service and are responsible for their own patients because of the resources. Complex patients are discussed during a weekly ward round with the specialised team. It is a top-down approach (a hierarchical approach where senior team members, make the decisions and then communicated down the hierarchy to lower-level employees), and the evaluation of an education programme is conducted in Chapter 5. Oncology registrars also cannot refer to specialised PC services because of the patient load for the VNLDS

11Chapter 5

This chapter evaluates the impact of a 1-year PC course within the training programme for specialist oncologists in SA. This chapter evaluates the programme in 5 universities. All eight university oncology centres were invited but only 5 participated. This ensured that the tool being used was feasible and appropriate; this is especially needed because the buy-in into PC training is seen by many as a non-essential skill. This evaluation follows the theory of the modified Kirkpatrick's model for programme evaluation.¹⁸¹The most widely used assessment model of educational practices is Kirkpatrick's triangle in which four levels are used to assess the impact of training¹⁸². The four levels evaluate the following:

Level 1: **Reaction**: How favourably the learners react to the instruction. Their attitude and self-efficacy.

Level 2: **Learning**: How well the learners learn the knowledge or skills imparted during the instruction.

Level 3: **Behaviour**: To what level the learners apply the new knowledge or skills in their on-the-job behaviours.

Level 4: **Results**: To what level the instruction achieves the intended impact on workplace outcomes.

There has been criticism of this model of evaluation because it is designed to measure short term and tangible outcomes and may not evaluate the "soft outcomes" of a curriculum. The 'soft outcomes' are especially important in PC education where we want to transform the health care professional to use a palliative approach when caring for patients with life limiting illness. To address these concerns the Best Evidence Medical Education collaboration (BEME) adopted a modified version of the Kirkpatrick triangle called "Kirkpatrick's hierarchy" system which evaluate:

Level 1: Participation: this evaluates the learner's experience of the teaching and learning activities.

Level 2a: Change in attitudes and perceptions.

Level 2b: Modification of knowledge and skills.

Level 3: Behavioural changes by applying newly learned knowledge.

Level 4a: Change in organisational practices.

Level 4b: Benefit to patients.¹⁸³.

This hierarchy has also been criticised in medical education for losing the soft nuances or outcomes in certain courses. Yardley *et al* suggest a mixed mode of evaluation using both quantitative and qualitative data to determine a comprehensive review of a teaching activity¹⁸³.

In order to evaluate the full impact of a course, a mixed mode of evaluation is therefore recommended which includes both qualitative and quantitative data. This study will, however, not evaluate level 4 to determine the impact in organisational practices and benefits to the patient due to funding limitations. If adequate funding can be acquired an amendment will be made to the protocol.

This follows a blended teaching model, where online material was provided for self-directed learning with face-to-face sessions with a facilitator. The facilitators were PC trained doctors working in oncology or alongside oncology at various universities. Also, important in this article is the description of how it came about and how professional integration was managed at a national level, again emphasizing the importance and the specific job of an ATH. This was thus a top-down approach.

This evaluation is answered by an article that has been published:

Krause R, Parkes J, Hartman N, et al. Evaluating palliative care training in the oncology registrar programme in South Africa. African Journal of Health Professional Education 2021; 13. <http://dx.doi.org/10.7196/ajhpe.2021.v13i2.1268>

The researcher in the main author (60%) who developed the methodology, assisted in data acquisition, did the data analyses with the other authors and wrote manuscript. The other two authors contributed the conception, data analyses and manuscript editing.

Article: Evaluating palliative care training in the oncology registrar programme in South Africa

Abstract

Background and Aim

Following a World Health Assembly call in 2014, to strengthen palliative care, the South African Department of Health approved this as part of the South African National Policy Framework and Strategy on Palliative Care. In 2016 the University of Cape Town, together with the College of Radiation Oncology of South Africa, identified the need to integrate palliative care into the oncology curriculum. In collaboration with CANSA, a research project was developed to introduce a 12 module curriculum at five teaching hospitals. The aim of this research was to evaluate the impact of a 1-year Palliative Care (PC) course within the training programme for specialist oncologists in South Africa. The objectives were to determine the reaction of the oncology registrars and their supervisors to the course to determine changes in knowledge and skills, and to determine the application in oncology practice.

Methodology

This study was a mixed-method prospective evaluation of an educational intervention. This educational programme used a blended learning method to train and support registrars (n = 32) and facilitators across (n= 5) 5 universities. Evaluation feedback was electronically collected to determine the registrars' reactions to the course materials. Pre- and post-multiple-choice questions (MCQ) were used to review their knowledge. Focus group discussions (FGDs) were used to explore their reactions, a change in knowledge and skills and how they integrated PC in their daily work.

Results

There was an overwhelmingly positive reaction towards the PC course by the oncology registrars and their supervisors. The training was found to be feasible, and the topics addressed were appropriate. Concerns, previously raised by College of Radiation Oncology of South Africa, regarding the feasibility and appropriateness of the course and material were found to be unsubstantiated. The poor MCQ results can be ascribed to poor sequencing of the execution of the question. However, the MCQs in module 7 and 8 (symptom management) demonstrated the most significant change in knowledge and skills (symptom management). The FGDs demonstrated a perceived change in knowledge and skills especially for communication skills and pain and symptom management. The FDG's also indicated that the registrars' approach to PC changed in that they were able to integrate the principles of PC into

practice, and now saw PC as an essential component of oncology. Lastly, registrars and their supervisors felt that the course addressed topics that formed part of their daily clinical work.

Conclusion

This research supports the view that PC training is an essential component of Oncology Training in the South African setting. It forms part of the daily practice of oncologists and a structured curriculum prepares clinicians to be able to integrate evidence-based palliative care into the practice of oncology if they receive appropriate training. Supervisors of the oncology training programme and registrars are confident that the training of 12 modules across one year is feasible and appropriate.

5.1. Introduction

In 2014, the World Health Assembly Resolution A67.19 called on countries to strengthen and ensure equitable access to palliative care.¹⁴ This resolution also stated that palliative care education should form an 'integral component' of ongoing education and that disciplines working routinely with patients with life-threatening illnesses should receive intermediate level palliative care training.¹⁴ The resolution was supported by African countries who signed the Kampala Declaration and by the South African Department of Health (the South African National Policy Framework and Strategy on Palliative Care).^{12,68} However, to date, no dedicated funding has been set aside to strengthen palliative care in South Africa.

The need for the integration of palliative care is never more strongly felt than in the current African cancer care situation. The burden of cancer cases is rapidly increasing in low- and middle-income countries. Although situations differ from country to country, many patients present late, and struggle to access oncology care timeously.¹⁸⁴ In Africa, long distances to oncology centres and long waiting lists to receive oncology services compound the problem of access to palliative care. The barriers to the integration of PC into the health system and oncology care are well described and some of perceived barriers that have been identified are the lack of available PC training and the misconception that PC is only for end of life care.⁴⁴

Academic cancer centres in South Africa provide training for radiation and/or clinical oncologists. These specialist trainees are not only caring for patients who require curative treatments but are frequently also serving the many patients whose care is of palliative intent. In response to the need and the importance of palliative care in oncology care, especially in Africa, the University of Cape Town (UCT) developed a palliative care curriculum at the intermediate level. The intention was to strengthen the oncology curriculum and align such curriculum with international standards and the South African National Framework and Strategy on Palliative Care.^{12,185}

The curriculum was developed after a process of consultation, drawing from a survey among trainees, exploring the knowledge and attitudes towards PC. A focus group discussion among experts was also conducted in cancer care including both academic and private oncology and palliative care experts considering the international recommendations on PC training.^{47,59} The conclusions drawn from this process included that palliative care should indeed form part of all oncology services; that palliative care is a critical part of oncology training; that palliative care training should be delivered in a structured curriculum with well-defined outcomes; that palliative care training should be provided early in the training; that palliative care should form part of the summative academic assessment and that communication skills should be a critical component of the course.

These findings were presented to the South African College of Radiation Oncology of South Africa at the examiners' meeting held on October 2016. A general agreement was reached that a PC course should be delivered to new registrars in oncology over a one-year programme which should include 12 modules. Concerns were raised around the feasibility of such a course in an already full curriculum and, therefore, not all the universities participated in this pilot project. The course used a mixed-mode of teaching, with online content and monthly facilitation sessions. The main modules would include principles of PC (5%); communication skills (40%); pain and symptom control (30%); ethical and legal aspects around end-of-life care (5%); the implementation of advanced directives (5%); bereavement and interdisciplinary teamwork (5%); burnout and compassion fatigue (5%). It was also agreed that such a course should demonstrate evidence of improvement in teaching and learning outcomes in order to justify implementation and that this would be best shown as part of a research project.

Problem statement

Before the introduction of this course, there was no structured PC curriculum within the South African oncology specialist training programme. Additions to an already full curriculum should not overburden trainees, it should be appropriate for the South African setting, and it should demonstrate improvement in teaching and learning outcomes of oncology trainees. The rationale for this study was to evaluate a one-year palliative care training module within the oncology curriculum.

5.2. Methodology

All the oncology training centres across South Africa were invited to participate in the course but due to logistical constraints, only five universities participated (UCT, Stellenbosch University, Walter Sisulu University, University of KwaZulu Natal (Pietermaritzburg) and the University of the Free State). The main reason cited for not participating was resource constraints. Facilitators were trained at a 2-day workshop at the beginning of the course. During the workshop, the training team familiarised the facilitators with the Vula e-learning website, training materials and upskilled them in communication skills and in providing student feedback. The modules were developed via a collaborative approach between oncology and palliative care. The final modules addressed concepts around self-care and were developed with the help of psychologists.

Module	Topic
1	Principles of Palliative Medicine in Oncology
2	Communication skills: Basic Principles

3	Communication skills: Breaking Bad News
4	Communications skills: Conversations around Serious Illness and Care Planning
5	Communication Skills: Managing Conflict
6	Pain Management
7	Gastrointestinal Symptoms
8	Dyspnoea and Delirium
9	Constitutional and Treatment-Related Symptoms
10	End of Life Care
11	The Role of the Oncologist providing Comprehensive Care
12	Self-Care

Fig 5.1: Modules and content

Five pre and five post-multiple-choice questions (MCQs) were developed for each assessment. Communication skills were assessed using a modified Calgary-Cambridge method.¹⁸⁶ The communication skill assessment formed part of the formative assessment and provided an opportunity for registrars to receive feedback on their communication skills.

The facilitators also met monthly online to discuss the new learning material and to reflect on the previous month's lectures. Each site had a monthly meeting in which the material was discussed, and a task was completed to apply new theory learned. The participating universities invited all specialist trainees to participate in the research project and assured them that their training would not be affected if they decided not to participate. Thirty-two oncology trainees from the five universities participated. These trainees included South African and international registrars. Although the course was geared towards adult palliative care, a paediatric oncology trainee also participated.

Continuous evaluation of the course was made essential and was used to demonstrate whether there was evidence of improvement in the identified proficiencies. The course was evaluated using the theory of the adapted version of the Kirkpatrick triangle.¹⁸³ The Best Evidence Medical Education collaboration (BEME) adopted an adapted version of the Kirkpatrick triangle called "Kirkpatrick's hierarchy" system to higher education for evaluation.^{183,187} The modified version was adopted to also

measure 'soft outcomes' of the course together with short-term and tangible outcomes. A mixed-mode of evaluation was used to measure both quantitative and qualitative data to determine a comprehensive review of teaching activity.¹⁸³ This enabled the researcher to capture the softer nuances of the impact of the course. One of the objectives of the course was to evaluate the oncology trainees' reaction to teaching and learning by trainees completing anonymous online evaluations. These evaluations evaluated the structure of the course, the relevance of the discussion groups, the course material and the applicability of the material in daily clinical practise. FGDs were conducted to determine their perceived change in attitudes and perceptions towards PC. The second objective was to determine the trainees change in knowledge and skills by asking the trainees to complete pre and post MCQ after each module. The third objective was to determine the application of knowledge and skills of PC in oncology practice by interviewing the supervisors of trainees. Change in organisational practise and benefit to the patients were not included in this study.

The quantitative data gathered was statistically analysed and the qualitative data team was analysed by the research team using thematic analysis. The researchers familiarised themselves with the transcripts collected. Through inductive and iterative process themes were identified. In the research group themes were adjusted and or confirmed. Confirmation bias was limited by using a multi-disciplinary research team, by using an anonymous evaluation platform and by including the feedback from senior supervisors.

Ethics approval was obtained from the UCT Human Research Ethics Committee. Ethics approval was also obtained from the ethics departments of all the universities who participated in this study. Twelve online modules were developed with MCQs.

5.3.Results

Feedback from the five sites indicated that trainees participated enthusiastically, and that the material resonated with their daily experiences. The Vula e-learning site provided researchers with the amount of time the site was visited (see fig 2) and data on resources most used (fig 3). Videos were the most used resources and the site was most visited when communication skills were addressed. The videos that were the most watched were the videos on pain management (174 views) and breaking bad news video (125 views). The written resource the registrars used the most was: *A guide to the treatment of cancer pain.*¹⁸⁸

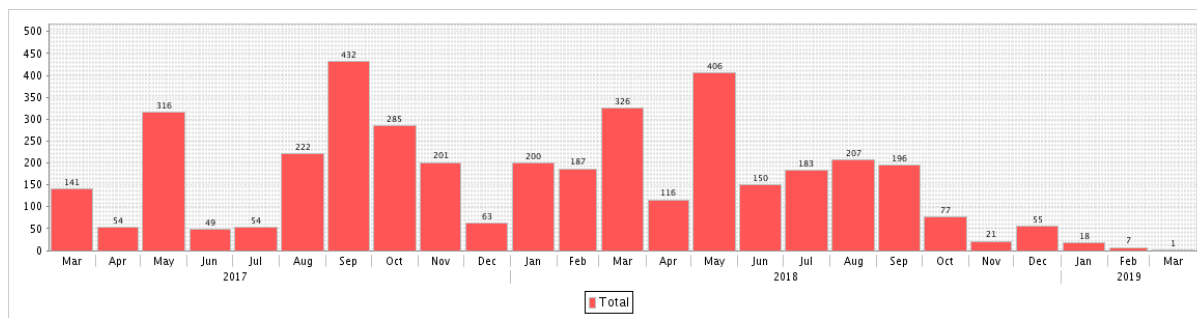


Fig 5.2: Vula visits over time illustrating the use of the site over time

Resources	Amount of Vula visits
Pain module mp4	174
Breaking bad news mp4	125
Serious illness conversation mp4	91
Dyspnoea in end-stage cancer mp4	89
The oncologist providing comprehensive care	81
End of Life Care	74

Fig 5.3: Resources most opened

There was an excellent attendance at the monthly meetings. Although not all registrars completed the required online preparation, there was active participation by all at the meetings themselves. Unfortunately, due to the workload restrictions only a one-hour meeting was allocated per module. This would ideally be longer as each module generated enthusiastic discussions which had to be cut short. The modules which generated the most discussion were the communication, self-care, end of life care and comprehensive care modules. This may be due to these subjects not being part of any formal oncology training in the past. These modules are also very emotive, and the meetings allowed the registrars to express and debate ideas that would be difficult to do on a forum or chat room. The registrars often incorporated real-life cases into these meetings which helped add a valuable practical side to the course. The structure (see fig 4), the relevance of the discussion groups (see fig 5), the appropriateness course material (see fig 6) and of the applicability of the material in daily clinical practise (see fig 7) were anonymously evaluate. Modules 7 and 8 received 100% positive feedback. This evaluation also assisted in reviewing modules for further courses.

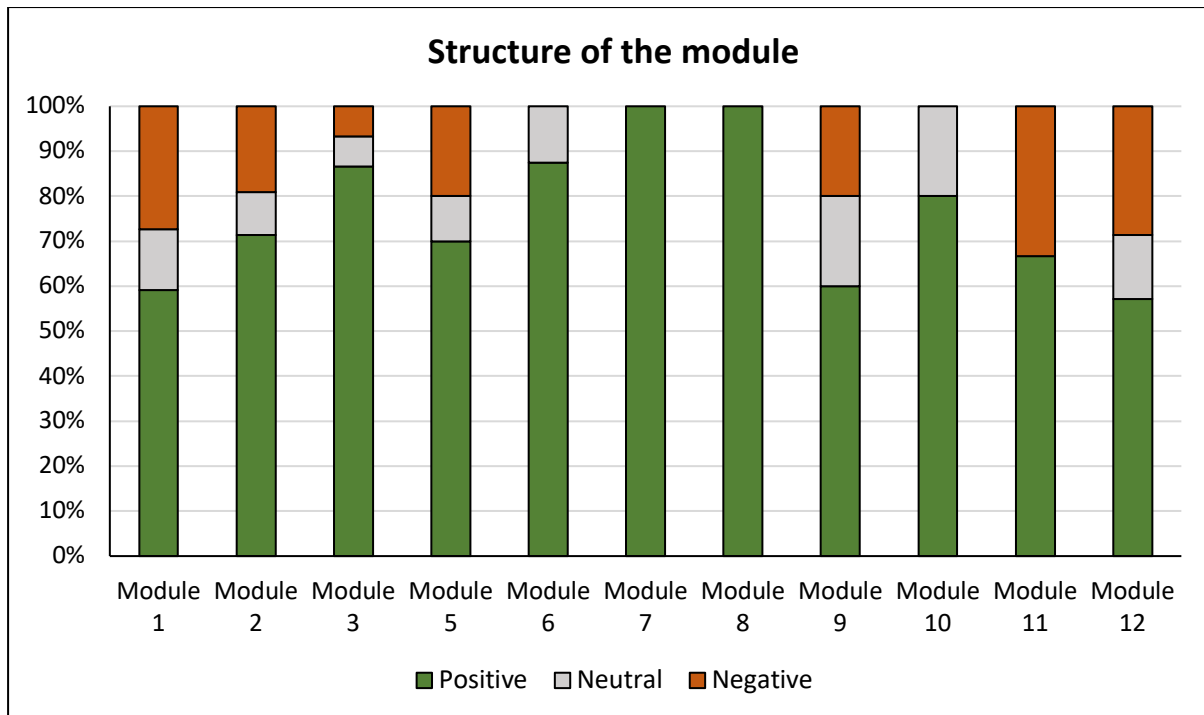


Fig 5.4: Evaluation of participants on the structure of the module

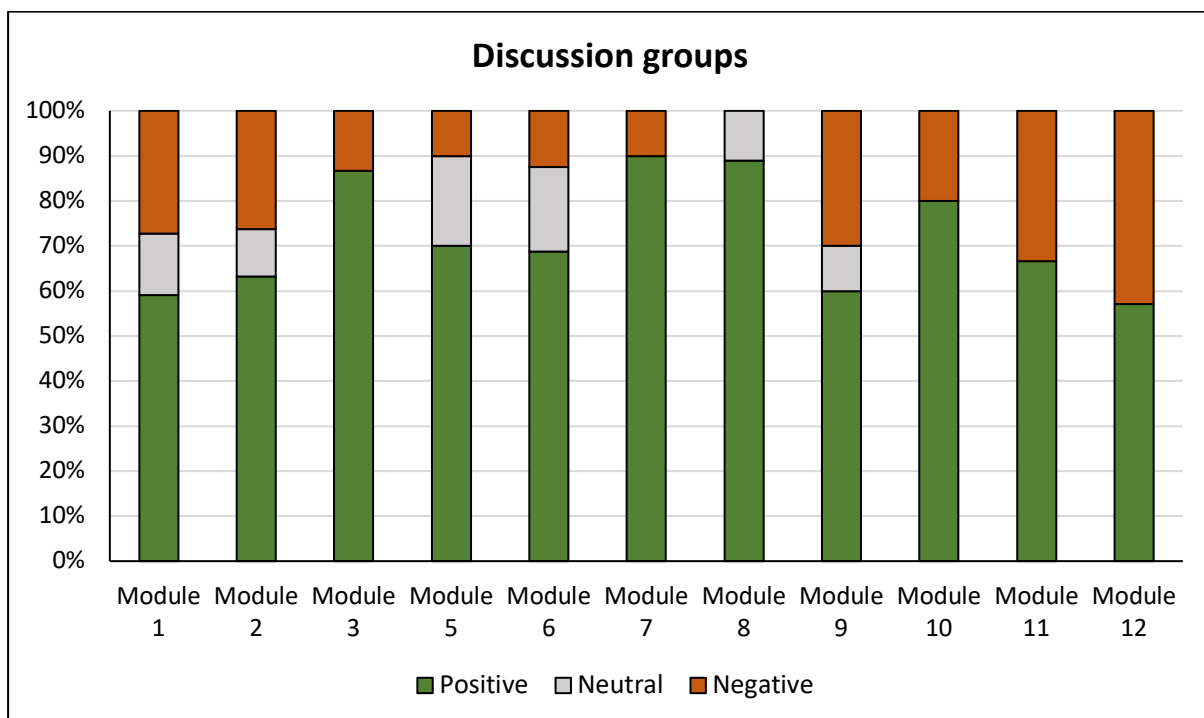


Fig 5.5: Evaluation of the participants on the relevance of the discussion groups

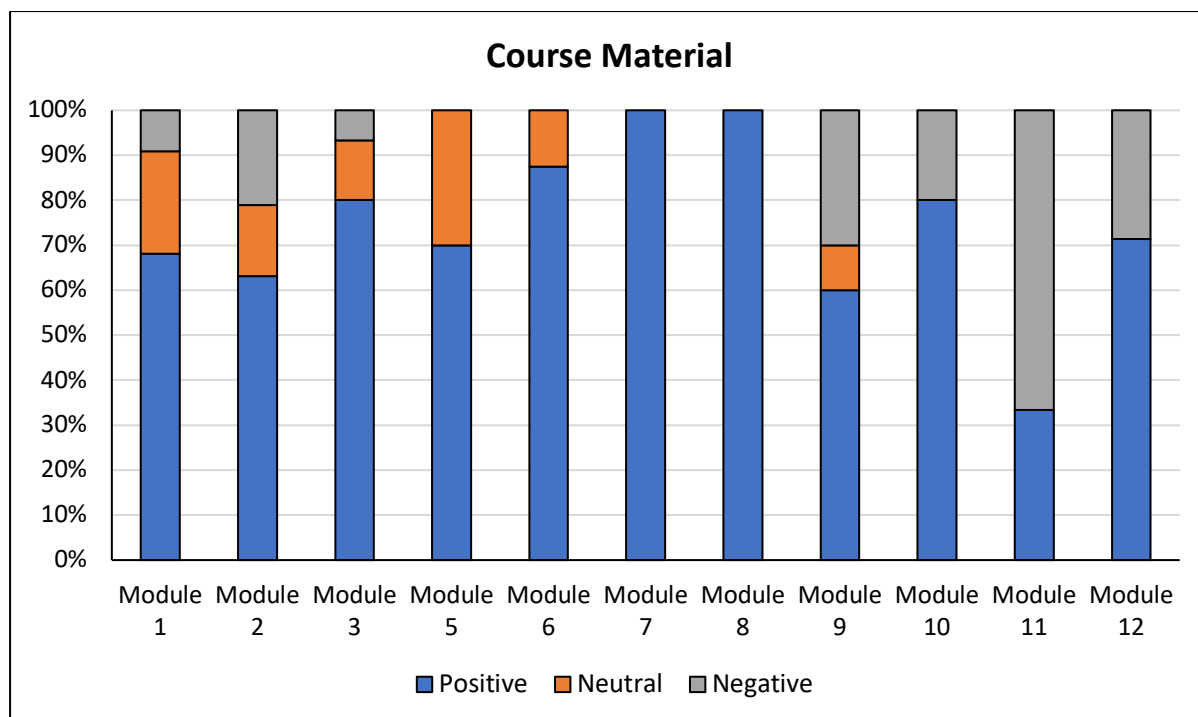


Fig 5.6: the appropriateness of the course material

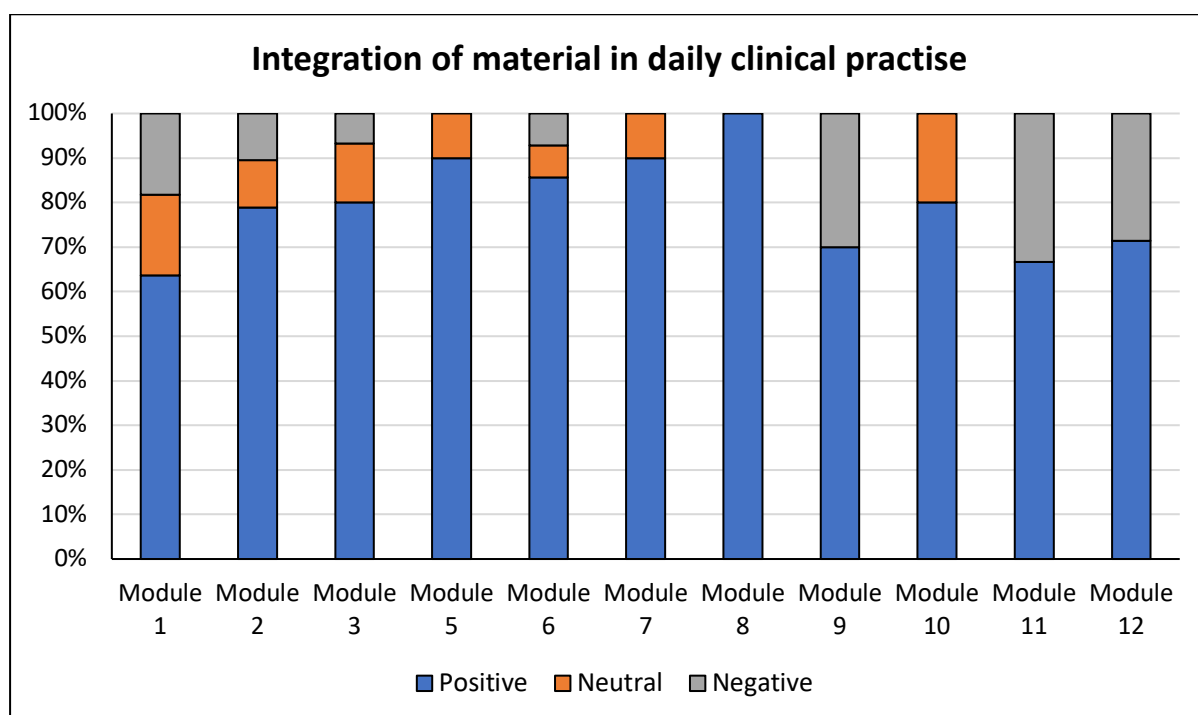


Fig 5.7: An evaluation of the ability of the material to assist the registrars in daily practise

The changes between the pre and post-test of the MCQs were analysed by running repeated sample t-tests on each module. The difference between the pre and post-tests are generally not statistically significant except for module 1 and module 7 which demonstrated negative (module 1) and positive

(module 7) outcomes in terms of a change of knowledge. In modules 5 and 8 the sample size was small (5), tending to significance (0.099 and 0.089 respectively). This may require further exploration in a larger group to determine if the effect is real. The small number of participants completing the MCQs were the main reason why the statistical tests were not of any value. The problem was not the construction of the MCQ but rather the way the MCQ was situated within the programme and that it was not enforced. The online assessment might not be the best form of assessment if it is not rigorously enforced.

Focus groups

In general, better feedback information was obtained from the focus groups than from the assessment documents. Data was analysed using systematic thematic analysis using inductive coding. The focus groups notes were read and reread and were discussed with the research team. The following themes emerged.

Theme 1: Attitude towards the course

Positive

Negative

Theme 2: Workload and structure of the course

feasibility of the course

Structure of the course

The modules

Theme 3: Application in workplace

Theme 4: Integration of palliative care principles into oncology

Focus group table

Theme 1

Positive feedback

It was clear that the registrars deal with palliative care on a daily basis. The course has introduced topics that form part of their daily work. There was an overwhelmingly positive attitude towards the course and all registrars felt that they wanted to continue with the course. This course had changed

their approach to palliative care (PC) and most stated that PC is part of oncology care. Many felt that the course highlighted that PC is an essential component of oncology training not only for palliative patients but for better management of all oncology patients.

“It is actually part of the bread and butter of oncology in my experience and there is so much that we’ve learnt throughout the module with regards to palliative care.” StUK ref 3

“For palliative care is, even in the non-metastatic setting, in patients with curable intent or radical intent, there is still so much that you can learn from palliative care in terms of communication skills, breaking bad news and so I found it extremely important in the oncology setting.” StUK ref 4

Negative feedback:

It was an adjustment for the registrars to become online students. There was also variability in the facilitators which affected registrars’ attitude towards the course. Registrars also felt that many of the skills were not mentored to them by their teachers because supervisors had no training in palliative care. This lack of comprehensive training affected integration into the daily care of patients.

“...that one is just an IT challenge, where sometimes every time you needed to log in,” StUS ref 3

“I think, I know is probably idealistic thinking but I do think that not, maybe if you could have like a crash course version for even consultantsI also think it will be good for them to understand what it is that we are learning in the curriculum and it would help them support us when we try to apply these things in the day-to-day dealing with patients in clinic and all of these.” StUU Ref 3

Theme 2: Workload and structure of the course

Feasibility

The registrars felt that the workload was achievable and that the course was feasible in their own setting. The supervisors' concern was that some registrars did not prepare for lectures beforehand. There were some concerns about how to better train communication skills and the actual mentoring and using it in current clinical practice.

“I have to just generalize I would say that the curriculum is quite comprehensive and that the pace at which the curriculum was presented was a good, manageable for the students and for the facilitator and that the variety of faculty brought depth and richness to the curriculum.”

SupUS ref 1

"I know this is not the question but am, probably the communication part is something that is still struggling to, you know, kind of apply practically just because of the kind of feasibility of it in our setting." StUU ref 1

"I think a negative thing for me was that during the course, most of the time, most of the students did not, you know, did not prepare beforehand." SupUF ref 1

Structure of course

Registrars wanted short, precise and very practical material. They enjoyed the video material and group interactions. However, supervisors still felt that the course needed to be academic with journal articles and assessments built-in, in order to engage registrars in their capacity as postgraduate registrars.

"I think it will be nice to be, maybe interactive with the other groups in other parts of the country." StSuRef1

"...felt that the videos were very, very nice." StUUref 4

"I also feel that way and I do think that it sometimes takes the academics out of it. We mustn't take the academics out of it." SupUUref 7

Modules

The modules that contributed most to registrars learning was communication skills. The registrars felt that this assisted them in the learning and development beyond working with PC patients.

"I also think that communication and breaking bad news is the main thing." StUFref5

"...will improve my way of relating to patients. And I found it very valuable when I was doing my exams because it helped me really communicate very well during the oral exams. Communications were very key both to the question, in taking history and also to the examiners." StUUref6

Pain management was a vital component to the course and this was supported by supervisors and by registrars.

"I can say that I have seen changes and it will mostly be around pain management,"

SupUSref1

"I think the module on pain control and it was more I think the practical advice that you as a palliative care physician could actually offer, that you can't really get in textbooks which were very, very useful." STuUref1

Self-care was a new topic introduced into oncology as a formal component in the curriculum.

"...think for me probably the one module that stood out the most for me was the self-care. I think at the end of the day as a clinician in order for you to be able to manage your patient well, you have to be physically, mentally, you have to be mentally, you know, in the right space to be able to treat with, to deal with your patient" StUEref1

Theme 3: Application in workplace

The registrars indicated that the course contributed to their daily practice and that it gave them the confidence to manage situations that they confronted regularly and in which they did not previously receive training in. The training also contributed their approach to deal with patients for curative intent and that they could use the skills in activities other than patient interactions.

"It gave us a bit more confidence to approach a lot of the topics. So we were able to manage our patients a bit more confidently with good backing and theoretical knowledge of each subject matter." StUKref2

"I can say that I have seen changes and it will mostly be around pain management," SUSUref1

Theme 4 Integration of palliative care into oncology

This course enabled registrars to integrate key concepts of PC: Palliative Care starts at diagnosis; holistic care; teamwork; pain and symptom control and the involvement of the family. This course also enabled registrars to see the role of a palliative care team in the care of oncology patients.

"I feel is very important because we deal with a lot of patients that require palliative care and palliative care being not just for the end-stage patients, at beginning, right from the beginning from the"STUSref1

"We generally tend to focus more towards chemotherapy and radiation not forgetting the more important biopsychosocial, the psychosocial part of it. So it made us more aware of trying to address those problems providing us with insight into an approach to these problems and enable us to provide holistic management in all aspect of care "StUKref6

"I think also is good to also be aware of your own limitations. You know to be aware that there are palliative care facilities and the team of palliative care specialists. To know when your role, you know, I have done all I can and I need to call someone else in" STUFref1

5.3. Discussion

The course was developed using minimal resources but strong collaboration. The collaborators were Palliative Medicine (UCT), Radiation Oncology (UCT), Health Professional Education (UCT); Radiation Oncology (US), a private palliative care physician and the Cancer Association of South Africa (CANSAs). It used blended learning to enable facilitation in different oncology settings and to support facilitators across South Africa. The facilitators were from five universities which enabled a community of trainers to develop.

Blended learning is a new method of learning and assessment for many registrars and supervisors and some registrars did find this challenging. In the future, more time needs to be spent in the beginning familiarising registrars and supervisors to an online teaching platform. Although blended learning does have its challenges, it does support and develop more sites in integrating PC into a curriculum using minimal resources.

The first objective of this research was to determine the reaction of oncology registrars and their supervisors to a PC course. There was an overwhelmingly positive reaction towards the course. The course "surpassed" its expectations. Concerns from supervisors like the feasibility and appropriateness of the course and material were found to be unsubstantiated. PC training in oncology is feasible and the topics addressed were appropriate. This was supported by both anonymous evaluation forms and qualitative data from the FGDs.

Communication skills and pain and symptom management were found to be the most valuable components of the course for the registrars. This was supported by evaluation forms, data from the Vula site and FGDs. Self-care was found to be a valuable component of the course and may be included in more programmes according to comments received from the focus group.

The second objective was to determine changes in knowledge and skills in PC. The negative aspect of this study was that there were generally no statistically significant changes in pre- and post-tests and that there was poor completion of the online assessment. Knowledge in practical aspects like pain and symptom control improved. The FGD demonstrated that the registrars' knowledge of what palliative care is and could integrate the principles in daily work.

The third objective was to determine the application of knowledge and skills of PC in oncology practice. The registrars felt the course made oncology 'more fluid' which enabled registrars to move between the disease-specific care to a patient-centred approach and between a curative and palliative approach more easily. The course addressed topics that formed part of their daily work. The skills and knowledge most applicable in the oncology setting are communication skills and pain and symptom

management. These skills thus need to be core components that must be included in all oncology curricula. However, these competencies do not stand alone and are best managed if the principles of PC are integrated into all components of care.

5.4. Conclusion

Internationally, PC training is an essential component in oncology training and should be incorporated in the South African specialist oncology training programme.¹⁴ PC forms part of the daily practice of oncologists and a structured curriculum enables clinicians to practise using an evidence-based approach. This provides registrars with confidence when managing a patient with PC needs. Supervisors of the oncology training and registrars are confident that the training of 12 modules across one year is feasible and appropriate. These skills are part of daily practise and support the WHA 67.19 resolution that PC training is an integral component of oncologist training.¹⁴

"...intermediate training should be offered to all health care workers who routinely work with patients with life-threatening illnesses, including those working in oncology, infectious diseases, paediatrics, geriatrics, and internal medicine;"

Sustainability of this course can only be ensured by advocating for strong collaboration between academic oncology units and academic palliative care units. PC training must also become available to the oncologist who has not been previously exposed to palliative care training through short courses. This may serve as a module to integrate PC in other disciplines.

Declaration.

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Author contributions.

RK: data collection; RK and LG: analysis; all authors: manuscript writing; all authors: scientific input.

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Conflicts of interest.

None.

Chapter 6: A description of how registrar palliative care training affected palliative care integration in South African oncology

Education at all levels have been advocated as an important integration strategy. As previously mentioned in chapter 3, there are very few HCP in GSH trained in PC. Wrongfully, many HCP still take PC competencies for granted and do not see the need for further training. In chapter 5, we demonstrated that training oncology registrars in a using blended learning was feasible and appropriate. The research supports this strong statement of feasibility. It is also very important to underscore that limited resources were used but did require strong collaboration between PC experts and oncology leadership. This is also a small department and only 3 supervisors were not involved in the training. In Chapter 6 will describe how this programme contributed to integration after 5 years of implementation. It will follow the same conceptual framework, that was applied in chapter 4, drawing from Valentijn's Model of Integrated Care in Chapter 2 ([2.14.A conceptual framework for palliative care integration in relation to ATHs.](#)) This conceptual framework assisted in developing the themes and the subthemes as described in Chapter 1([Data analyses](#)).

This qualitative descriptive study combines secondary analysis of existing data from a previous evaluation of the registrar training. The analysis framework is discussed in Chapter 1 ([Data analyses](#))

This is written in article style and the article is currently under review in the South African Journal of Oncology.

Krause, R., Mohamed, Z., Olivier, J., & Gwyther, E. A description of how registrar palliative care training affected palliative care integration in South African oncology. [in review stage in the South African Journal of Oncology]

The researcher is the main author, conceptualised the research, the development of the methodology, data acquisition, analysed the data and wrote the article. The rest of the research team assisted in analyses, supervision, and editing it.

Key findings of chapters 5 and 6 are summarised in appendix T

Article: A description of how registrar palliative care training affected palliative care integration in South African oncology

Abstract

Background

The current state of cancer care in Africa necessitates immediate intervention to enhance accessible cancer prevention, treatment, rehabilitation, and integrated palliative care services. Achieving effective integration of palliative care within oncology requires both functional and normative integration. Decisive strategies are required to address persistent misconceptions, lack of awareness and comprehension regarding integrated PC services.

Aim

This research aims to describe how intermediate level palliative training affected PC integration in Oncology at Groote Schuur Hospital in South Africa.

Setting

Groote Schuur Hospital is a tertiary, quaternary academic hospital with 975 beds. The oncology unit sees approximately 2 800 new patients per year and qualifies an average of 3-4 registrars annually.

Methods

This is a qualitative study combining secondary thematic analyses of qualitative data from focus group discussions (n=2) from a previous study, with new interviews (n=3) and document analysis.

Results

Including PC education seems to enhance patient and family-centred care, contributing to improvements in the normative aspects of integration. Nevertheless, focusing solely on training registrars has proven insufficient in achieving crucial functional aspects of integration. The

misalignment between policies, guidelines, and registrar education constrains effective integration of a PC approach. In addition, consultants' lack of training in palliative care poses difficulties in implementing comprehensive patient care. Complete 'functional integration' is inhibited by palliative care clinical- leadership remaining outside of oncology. Addressing these shortcomings is vital to successfully integrating palliative care within cancer care settings.

Conclusion

Training registrars in PC is undoubtedly necessary but insufficient. Clinical palliative care leadership within oncology in Africa is essential for integration.

Key Words: Palliative care; Palliative Medicine; Education; registrars; integration

6.1. Background

An increasing cancer burden, failing health systems, the COVID pandemic and limited resources have moved advocacy groups, patients, and healthcare workers to call for better and more accessible cancer prevention, treatment, and rehabilitation across the African continent. In Africa, oncological services, such as radiotherapy and chemotherapy, are limited, with even less access to PC.^{189,190} Access to palliative care (PC) in oncology is equally important, hence the necessity of its inclusion into strategic plans for comprehensive cancer care. The integration of PC into African health systems, especially cancer care, therefore, requires urgent action.¹⁶ This article will describe how educating registrars (trainee oncologists) is used as a strategy to integrate PC into cancer care in an Academic Teaching Hospital (ATH) in South Africa.

Palliative care is vital in the African setting, especially in oncology, as most patients present with advanced cancer, causing severe suffering.¹⁹⁰ Many patients are also far from health services and have limited access to radiotherapy and chemotherapy.^{191,192} In addition, culturally competent and effective psycho-social and spiritual care are necessary in the context of traditional beliefs and the poverty burden in Africa.⁹³ Delivering care in overburdened healthcare systems also causes distress to healthcare providers. The retention of HCWs is feasible if they have the skills to navigate comprehensive care, as well as the knowledge and support to look after themselves. PC, with its biopsychosocial and spiritual approach, thus needs to be integrated to relieve this immense health-related suffering in oncology.¹⁶

An integrated healthcare approach is usually followed when complex long-term problems are addressed which require a multiplicity of services, service levels and providers.⁸⁷ Functional integration implies the key support function and activities structured around the support service delivery to ensure accountability and decision-making between the organisation and the professionals⁸⁵. Drawing from the literature on integration and PC, this research suggests that the following 9 domains are required to achieve 'functional integration' of PC in an ATH: The provision of patient and family centred care;^{38,85,99} The provision of collaborative care;^{85,99} Information systems;⁶⁹ Education;^{65,85,147} Leadership and governance;^{65,85,147} Guidelines and policies;^{147,149} Palliative care workforce;¹⁴⁷ Drug availability;^{43,147} and Research.¹⁴⁷

Functional integration of all aspects within the domains depends on their being interconnected, which can only be achieved within an organisational culture that values and believes that a PC approach is critical to the health care system, and is an essential element of basic oncological care.² According to Valentijn et al. (2015), mutual values, vision, trust and culture, which are core aspects of normative integration, are essential to ensuring an integrated approach.⁸⁵ Thus, we can theorise that PC integration is dependent on functional and normative integration being achieved.

Education as an integration strategy

A comprehensive palliative care education programme was developed for oncology registrars, in ATHs in South Africa. The programme was based on the assumption that successful integration of palliative care into oncology practice requires strategic actions, such as effective teaching and training.

After multi-stakeholder engagements and following a curriculum development approach, a one-year PC training course was developed for radiation oncology registrars across five universities in South Africa.⁴⁷ The programme was designed at intermediate level as per the World Health Assembly resolution 67.19, which stated that intermediate-level training should be integrated into disciplines that work routinely with PC patients.¹⁴ The programme aims to equip oncology registrars with the necessary knowledge, skills, and attitudes to provide holistic care for patients with advanced cancer and improve their quality of life. It emphasises both functional and normative integration of palliative care within the oncology setting.¹⁶⁸ This strategy was adopted because many health care professionals' attitude was that PC skills were already acquired, and PC is seen globally and locally as an essential component but not included in oncology training in South Africa.^{47,165} These paradigmatic assumptions were reflected in the South African Radiation Oncology curriculum before 2016 with minimal emphasis on communication skills, pain and symptom control, teamwork and self-care, despite their global recognition as essential in oncology training and service delivery.^{47,193}

The first cohort of students completed the course in 2017. An evaluation of this course itself aimed to determine the appropriateness and change in the teaching and learning outcomes of registrars. It concluded that it was feasible, and appropriate and PC training is an essential component of oncologist training.¹⁶⁸ This programme has continued across many universities for the past 5 years. PC education is currently an important and examinable component of oncology training. In GSH, although there are specialised PC services, the oncology team does not refer to these specialised services. This study aims

to describe how intermediate-level PC training affected PC integration in an ATH in South Africa, drawing from the theoretical framework of integrated PC

6.2. Methodology

This qualitative descriptive study combines secondary analysis of existing data from a previous evaluation of the registrar training (2019),¹⁶⁸ with primary interviews of supervisors (2022) and documentary analysis. The study site was the oncology unit in GSH, which sees approximately 2 800 new patients annually and qualifies an average of 3-4 registrars annually. Registrars are trained from across Africa, and approximately 50% per cent of the registrars are from countries outside of South Africa.

Ethical approval for this study was obtained from the University of Cape Town Human Ethics Committee (HREC 071/2020).

Firstly, data from the 2019 Training Evaluation pertaining only to UCT registrars and supervisors were extracted. Data was obtained via two Focus Group Discussions (FGD) informed by a semi-structured interview guide. The first was with 10 registrars (This group is identified as *FGD reg*) and the second FGD with 2 supervisors (this group is identified as *FGD sup*). Written consent was obtained from all the participants.

Secondly, individual interviews were conducted with supervisors (n=3) who had not been involved in the Training Evaluation but who had been involved in the training of registrars before and after the programme in 2021. They are identified in the result as *Sup 1,2 or 3*. Recruitment was purposively done, and all interviews were anonymised. Face validity of the interview guide was ensured by presenting the questionnaire to experts in the fields of normative and functional integration and PC. Construct validity was derived by aligning this tool with the theoretical framework described in the introduction. Reliability of the tool was established by piloting it with consultants who were involved in the PC training and the evaluation, but who were outside of GSH. All interviews were conducted in English by a single research assistant trained to conduct them.

All the transcripts were imported into NVIVO version 14.23.0 for deductive thematic analyses. Coding was informed by literature on the theory of functional integration, aspects of normative integration, barriers, facilitators and processes in the integration process. The research team familiarised themselves with the data within transcripts (two FGDs and three new interviews). The group discussed the existing themes, and subthemes and developed a coding framework, which was discussed and agreed upon with the research team. As the agreed frame was applied to the full dataset, additional subthemes were identified and incorporated into the coding frame. Selected representative data was used to illustrate the resulting themes of the analysis.

Lastly, document analysis was done on purposively sampled guidelines and policies within the oncology department, as guided by the interviews, policies, and guidelines on key conditions where a PC approach is needed. One guideline and two standard operating procedures were identified and analysed. This was done by importing the transcripts into NVIVO14.23.0. The documents were analysed to identify the extent of PC content information as to where, how PC had been integrated into GSH oncology care and identifying gaps. All the documents had been created after 2021.

Rigour was ensured by using multiple data sources, member checking of transcripts and discussion within the research team. This was embedded research as the primary researcher (RK) works within this setting and also led the implementation and training of registrars. To limit bias, key training and service delivery participants were consulted.

6.3.Results

The deductive analysis produced the themes and sub-themes tabled below.

Themes	Normative integration	The provision of patient and family-centred care	The provision of collaborative care	The presence of information systems to monitor PC.	Education in PC	Leadership and governance specific for PC	Guidelines and policies in the oncology service	Availability of a palliative care workforce	Drug availability for PC	Research in PC	Barriers to integrating PC
Sub-themes	Normalising and valuing a PC approach. [Sup2, Sup 1, FGD reg]	Pain and symptom management. [Both FGDs, Sup1 and 2 and importance mentioned 2 documents]	The expansion of multidisciplinary care. [all the interview sources and 1 document highlight the importance of multidisciplinary care]	Monitoring and evaluation tools for PC. [sup 1 and mentioned in documents but not specific to PC]	Limited to intermediate-level training in the department. [FGD reg, sup 2 and 1]	The need for collaborative leadership. [Sup 1]	Integrated policies [Protocol for managing adenocarcinoma of the colon, the Standard Operating Procedure for non-small cell lung cancer and the Protocol for Treatment of Gynaecological Malignancies]	The availability of a multi-disciplinary PC trained workforce. [FGD sup and Reg]	Essential medication as specified by the WHO Essential PC Medicine List. [as per hospital documents]	No PC specific research. [Sup 1]	The resources are too limited to provide PC. [Sup 2]
	Assumptions about the nature of PC. [FGD reg]	Psycho-social and spiritual care. [FGD reg, Sup 2 and importance mentioned 2 documents]	Continuity of care beyond the hospital. [all the sources highlight the importance of continuity of care]			The importance of mentorship. [Sup 1]	Stand-alone PC policies. [nil found]	Emotional and organisational support for the palliative care workforce. [sup1]		Integrated PC research in registrar portfolios. [Sup2]	
	Strengthening positive resilience through training. [Sup 1]	The family are active members of the team. [FGD reg, Sup 2 and importance mentioned 2 documents]				Limited clinical leadership within oncology. [FGD reg]					

Table 6.1: This diagram represents the themes and the subthemes identified together with the sources of the information.

Normative integration

As discussed in the background, PC was seen as separate from oncology care before the integration of training and was not seen as a fundamental component of oncology care. Normalising PC in oncology is a core component of PC integration.

Normalising and valuing a PC approach

All interviewees from the FGD's and individual interviews acknowledged the need for PC and its importance in oncology. The supervisors in the FGD observed that the registrars also identified the shift in mindset to recognise that PC is an integral component of the job. Furthermore, registrars are more confident to stop aggressive care and are more at peace with stopping interventions at the end-of-life.

It is easier always to give more like chemo regulation, etc, but now I have started noticing, especially at end-of-life care, people seem to have more confidence in terms of.... stopping.
(FGD Sup 1)

Assumptions about the nature of PC

Multiple assumptions of PC were challenged with this programme. The first assumption that was challenged was that PC was not an important part of oncology care. It is now recognised as important in oncology care and is now examinable as part of the final exit exam. Secondly, registrars did not recognise their own role in delivering PC and only saw their role in curing cancer. Thirdly, that PC is only for end-of-life care.

Biggest one (assumption), of course, is the fact that you should only implement PC when the person's dying. (FGD Reg6)

So I think that one of the things that is common when we go to medical school and it happens a lot in a lot of the other specialties as well, is that we have this notion that patients are here for us to fix things. (FGD Reg3)

Strengthening positive resilience through training

Self-care and building positive resilience are core components of a PC curriculum. These skills were not previously taught in the oncology curriculum. The education programme pro-actively addressed this in order for registrars to gain with better understanding of the concept of suffering and resilience skills in dealing with health-related suffering.

I think that we've, you know, we've actually done reasonably well, in terms of resilience. And some of that is probably due to the skills that are in the PC module. (Sup 1)

The need for and importance of these skills is better appreciated when interviewing a supervisor with no PC training who indicates that the mechanism to deal with suffering is detachment from the situation.

So, I'm old. And I've been doing this for many years. And so, to a certain extent, one has to become, sounds harsh, but blunted. And I don't mean that to sound harsh, but if when, you know, if I were to get emotionally involved or upset about all the patients that I see that, you know, are going to be managed with palliative intent, I, I wouldn't, I probably wouldn't be able to function. (Sup2)

The provision of patient and family-centred care

The programme undoubtedly provided the registrars with the competencies in comprehensive care for patients, especially in communication skills, pain management and symptom control. The registrars were able to identify Total Pain, and a more comprehensive approach was valued. Families are also recognised as important care team members and valued as being core in the patient's care.

registrars have got a framework in terms of how to deal with palliative patients in terms of symptom management but also holistic care. (FGD Sup 2))

and now, you know, I have learnt to tell myself that's what the family wants, that's not in my hands, that's, it's something you need to accept.(FGD Reg 5)

The provision of collaborative care

Oncologists are used to working in multidisciplinary teams, but the PC programme has expanded these teams to look outside the hospital to hospices and to include more of the health and rehabilitation workers. Previously, referring to a social worker within oncology was the extent of collaborative care.

And that's not only the teams within oncology, we also rely quite heavily on our multidisciplinary teams. (Sup 1 FGD)

We've, we've tried to implement a more community-centric approach to palliative care. (Sup 1)

The presence of information systems to monitor PC

There are no palliative-specific monitoring and evaluation nor integrated reporting systems in which PC outcomes are measured.

there's no formal monitoring and evaluation of these patients. (Sup1)

Education in PC

PC educational activities for the registrars are limited to this programme and a mentorship ward round once a week. The programme focuses only on registrars in the team as indicated by both the registrars in the focus group and the individual interviews with sup 1.

Leadership and governance specific to PC

The programme assisted oncologists in taking ownership of developing a PC programme for oncology in the hospital, but they admit that a PC consultant is pivotal to PC integration in a hospital as indicated both supervisors. Collaborative leadership assisted in making the programme successful.

And we've always had her (PC consultant) working together with one of the oncologists. (Sup 1)

The importance of mentorship

So having her(PC consultant) in the hospital for several hours a day and available to our registrars and our patients or for teaching and also for the continuous care ward round has made an absolutely massive difference. (Sup 1)

However, consultants need to be trained as there can be discord around decision-making.

I think, I know it is probably idealistic thinking but I do think that maybe if you could have like a crash course version for even consultants because sometimes you find that we learn these very good principles and then you want to apply them, but you know if the head is not in sync with the neck, then there is a problem you know. (FGD Reg 4 UCT)

Guidelines and Policies in the Oncology Service

The protocol for managing adenocarcinoma of the colon [PCC], the Standard Operating Procedure for non-small cell lung cancer [SOPNSLC] and the Protocol for Treatment of Gynaecological Malignancies [PGM] were evaluated. Only one of the authors of one of the documents had PC training. Multidisciplinary is recommended in 1 document but not seen as core. PC is integrated into protocols for the management of cancers in 3 specific ways:

- As a palliative chemotherapy or radiotherapy intervention [SOPNSLC]
- A separate section as an addendum.[PGM]
- The use of Supportive Care vs. PC is not clearly defined [PCC, SOPNSLC]

Patients with performance status ≥ 3 should be managed supportively. (PCC)

A multi-disciplinary team and home support are strongly recommended. (PGM)

The clinical protocols that are specific for each disease site, certainly in GIT oncology going to the, you know, the chemotherapy regimens, the side effects to look out for and how to manage them and when to... in which situations you would get other team members involved, you know, when to get a surgeon involved. (Sup2)

Availability of a palliative care workforce

There are no dedicated PC personnel in the oncology services. One oncology consultant works with the PC consultant to deliver the training and lead the mentorship ward rounds per the researcher's observations.

Drug availability for PC

All the medications advised by the WHO as essential PC medicines are available in the hospital as per the Essential Medicine List and Standard Treatment Guidelines.¹⁹⁴

I think what the course has done is made a better awareness in what drugs can be used for which symptoms and made sure that they are, you know, available, routinely in our pharmacy in our block. (Sup2 FGD)

Research in PC

There is very limited PC research. It tends to be confined to case studies in registrars' portfolios and to research led by PC consultants, as indicated by Sup2.

Barriers to integrating PC

Sup 2 indicated that barriers such as too many patients with limited staff and time constraints, particularly to provide holistic care, remain universal barriers.

Part of the challenge is that these are really busy clinics. They have... they... basically too many patients and too few doctors, so we don't have adequate time to spend with the patients once we introduce them to PC, whether it includes chemotherapy or radiation or not. (Sup 2)

6.4. Discussion

The oncology service at GSH has used the education of registrars for the past 5 years as a strategy to achieve integration of PC. This has normalised a PC approach among registrars and is moving towards patients receiving the right care at the right time for example they know when to stop aggressive care. According to Kaasa et al., PC integration in oncology is based on both organisational structure and patient-centred care plans. Education assists the registrars to have the tools to provide better patient and family-centred care and also ensures that the culture in oncology changes so that the PC approach is valued.^{2,38} Furthermore, the PC training programme challenged registrars and addressed embedded assumptions, for example, that PC is only for dying patients.¹⁶⁸ These are essential components of integrating PC in oncology services. However, this research study has demonstrated that educating

young trainees is insufficient to ensure PC is fully integrated into oncology services because PC is still not integrated in important documentation as a clear and uniform element of care. Furthermore, no research dedicated to PC is done in the unit, although most of the patients are for palliative intent.

Knowing when to integrate a PC approach and knowing when to stop chemotherapy or radiation therapy are core skills all oncologists need to have. There are well-known normative reasons why these skills are hard to practice, for example, fear that PC provision may be seen as giving up on patients.¹⁹⁵ In the African setting, these complex decisions are further amplified because there are many patients presenting late with advanced disease hoping for a cure.⁹³ In addition, there are few PC services to refer and also not enough time to develop comprehensive care plans for patients and families.¹⁹⁶ It may be easier and quicker to give another dose of chemo/radiotherapy than to have a complex conversation, especially if the treating team does not have advanced communication skills or is not equipped to provide culturally appropriate care needed when making decisions. This programme assisted the registrars in becoming better skilled in rationalising care and when to stop aggressive care and use the wider multidisciplinary team to care for patients. In addition, the training impacted their own resilience and confidence in managing difficult decisions.

The resilience needed to be compassionately present during suffering is a disposition that requires proactive skills with targeted actions to address distressing situations.¹⁹⁷ These skills come in the form of communication skills, debriefing sessions, knowing when to integrate psycho-social actions, working with colleagues in the multidisciplinary team, understanding spirituality and culture in patient care and exploring how to determine what is needed by patients and their families. These skills are known to assist with preventing burnout and managing the moral distress experienced by the oncologist.¹⁵⁵ This course created a structured programme where these skills were taught and openly discussed to ensure they were relevant to their own African setting.¹⁶⁸ Unfortunately, these competencies are newly taught and have yet to be part of the expected competencies of many senior healthcare workers. Previously, oncology training was rooted in mainstream medicine, focusing on acute care.³⁸ Most senior oncologists did not receive the above-mentioned training, which may have contributed to a situation where they did not have the competencies to manage complex situations requiring PC and “blunted” them to suffering. Depersonalisation of these situations often causes inner distress and may affect their long-term commitment to the profession.

The moral distress experienced by healthcare workers and the subsequent loss of healthcare workers leaving the public sector or the profession is a major concern in Africa. Connel et al. evaluated this massive exodus of trained South African health professionals to other countries, naming the toll of HIV with emotional exhaustion compounded by limited resources within the health system causing healthcare professionals to leave the country.¹⁹⁸ These factors resonate with the moral exhaustion and lack of resources evident in African oncology practice. In low-to-middle-income countries where the need for PC is the highest, access to PC is at its lowest.¹⁷¹ Limited resources, the high incidence of patients presenting with incurable cancers and limited access to trained PC specialists are some of the main reasons why PC training is even more essential to oncology training in Africa than elsewhere. The training of oncologists needs to change to ensure that oncologists have both the emotional and clinical competencies to care for their patients.

To ensure the full impact of PC on the health care system, the training must extend beyond junior trainees. The training must include the whole team, which includes surgeons, senior oncologists, social workers, and rehabilitation professionals, to ensure *“head is in sync with the neck”* (ref from FGD Reg interviews). This may assist in integrating the PC approach in every aspect of cancer care. This is, also, important to ensure cost-effective PC is experienced along the whole continuum of care. The economic value of including PC is undoubtedly one of the main reasons for its inclusion in a health care system, besides improved quality of life of patients and families.^{16,152} However, the benefit goes beyond the cost effect on the health system but extends to household poverty prevention. In low- to middle income countries many of the direct and indirect costs of care are the families' responsibility and the cost of futile care can have devastating effects on households.¹⁷⁹ The consequences of not providing comprehensive training to the entire team in order to incorporate a PC approach become even more apparent when we examine the additional components required for the successful integration of PC.

The findings suggest that the strategy of training registrars for the past five years has had limited impact on integrating PC in core functional aspects of integration beyond the clinical service provided. Although the training may be an investment in the future for PC integration. More extended integration is needed to ensure inputs, delivery, management and organisation of services are aligned to achieve greater access, better quality, user satisfaction and efficiency.⁸⁷ Currently, the hospital needs the following PC inputs: policies, monitoring and evaluation tools and dedicated PC teams in

the oncology services. Training registrars have thus led to better linkage with PC services but no standardised care pathways have been created.⁷⁰

The lack of standardization is evident, especially in guidelines, for example, the absence of uniformity in the meaning of PC vs Supportive Care.¹⁹⁹ The result of using different words is that no action or different actions are linked with these words. Furthermore, in the guidelines, the initiation of PC chemotherapy and radiotherapy are seen as the action required to initiate PC, a further indication of the lack of the understanding of the comprehensive nature of PC. A misalignment between clinical guidelines, standard operating procedures, and the training provided can lead to confusion among young trainees. It is also a concern that PC outcomes are not monitored and evaluated to provide outcomes data. Monitoring and evaluating outcomes and service delivery is generally not well done because of the lack of automatic systems but it is even worse when it comes to PC. Currently, in South Africa, it is not integrated as an essential component of hospital reporting.

Leaders in oncology have been at the forefront of recognizing the need to integrate PC and being supportive in the process.¹⁶⁸ However, in GSH, the day-to-day leadership for the integration of PC comes from outside oncology. Most research on PC integration identifies a PC specialist as an enabler for PC integration.^{147,171} The lack of recognized PC leadership within oncology contributes to the absence of a PC strategic plan and many other functional aspects of PC integration that need to be actualised. The recognition of PC as a subspecialty of oncology is a recent development. Consequently, there is a scarcity of these subspecialists within the country. While establishing a career pathway for oncologists in PC is a positive advancement, there is a pressing need to train more leaders in this subspecialty from oncology. The limited number of subspecialist leaders, combined with the already limited number of oncologists in mainstream oncology, presents a significant barrier to oncologists being able to devote time to PC. Although PC is aligned with oncology, it possesses a distinct body of knowledge. Therefore, successful integration requires more dedicated and recognised leadership to ensure long-term sustainability.

The lack of many functional aspects of integration is evident in GSH oncology. However, the culture of including PC as a fundamental aspect of cancer care is now recognised. These young trainees are the leaders of tomorrow and will also work across Africa and hopefully will integrate PC more sustainably.

6.5.Conclusion

PC education and training is currently a recognised element in the oncology curriculum. This training has contributed to registrars delivering better patient and family-centred care, assisting with their distress in managing complex situations and valuing PC. However, to achieve full PC integration in oncology, a strategic plan has to be developed to include all the aspects of integration. Ideally, this strategic plan must be led from within oncology.

6.6.Limitations

This is embedded research, and the researcher also plays a role in service delivery and PC programme development. This was done in one hospital in South Africa. Furthermore, the number of interviews is limited.

Contribution:

Rene Krause (author); Zainab Mohamed (analysis and conceptualisation); Jill Olivier (supervision and editing); Liz Gwyther (supervision, analysis and editing)

Chapter 7: Quality Improvement as a strategy to integrate palliative care early in pancreatic adenocarcinoma surgical care in a South African Teaching Hospital

This chapter draws from what was learned from the context, the specialist service and training to evaluate how Quality Improvement (QI) as a strategy for early palliative care integration in pancreatic adenocarcinoma surgical care. Education (Article: Evaluating, [Chapter 6: A description of how registrar palliative care training affected palliative care integration in South African oncology](#)) and resources (Article: Evaluating) are described as integration strategies in these earlier chapters. These chapter have shown that limited professional integration was reached and multiple barrier but also facilitators have been highlighted that may linked to the context as discussed in Chapter 3. Chapter 7 reviews process change using an audit tool to assist with collaboration. This intervention recognised that it will be important to move palliative care from mainly an end-of-life care service to a service providing earlier PC. This draws from Chapter 4, where PC services demonstrated fewer end-of-life care referrals as time as the service grew. This study aims to evaluate how a quality improvement cycle using audit influenced the integration of PC in patients with PDAC care.

The audit ([Appendix U](#)) is situated in firstly an area with a recognised high PC burden and secondly in an area where the contextual barriers to PC are visible such as the fact that in this setting the service is siloed, highly technical and there is avoidance of death and dying by health care workers as described in ([Article:The Influence of context on the implementation of integrated palliative care in an Academic Teaching Hospital in South Africa](#)).This approach uses both a top-down and bottom-up strategy. Recognising that the VNLDS provides quality clinical care and combining the specialised skills with dual PC and surgical leadership to develop standards of care for both groups. The tool offers a platform to be mutually curious about what is happening in both disciplines. It further aligns with the current structure of siloed care and creates a linkage between the structures. This iterative approach also assisted in both services providing continuous support to each other during weekly rounds. There is also staff hospital psycho-social support available.

This approach considers how to address misconceptions about PC is by firstly, trying to understand how a specific discipline makes sense of PC and secondly, of death and dying. The research aimed to describe 'what they think they were doing' as a key aspect of the normative integration and organisational culture. Being explicit and curious about values may assist mutual growth, responsibility, and gain.

Furthermore, this approach aligns with a contextual aspect of accepting that PC provision is not for everybody but through understanding that we can still ensure the patient receives the required care as described in chapter 3 when considering [the palliative care context at a micro level in South Africa](#). [Therefore, this research was developed drawing from the insiders' perspective, the need for an iterative approach, the need to address misconceptions about PC and the vertical nature of the hospital.](#)

Integration extends beyond patient and family outcomes but considers what HCWs gain from PC integration.

This chapter is written as a chapter but the researcher is explicit about the contributions of other researchers in the research process.

Quality Improvement as a strategy to integrate palliative care early in pancreatic adenocarcinoma surgical care in a South African Teaching Hospital

This chapter investigates how a quality improvement cycle was used to integrate PC in patients with pancreatic ductal adenocarcinoma. The research uses a mixed method approach to explore how and why a quality-improved cycle assisted in integrating palliative care into the surgical care of patients with PDAC.

7.1. Introduction and background

The integration of palliative care (PC) is considered a basic human right and a cost-effective component in caring for patients with life-threatening illnesses.^{94,152,200} PC is a recommended fundamental aspect of the overall treatment and support of patients with life-threatening illnesses.¹⁴ Based on these principles, the Hepatopancreatic-biliary (HPB) surgical service and the PC service at an Academic Hospital (ATH) in South Africa are collaborating to improve the Quality of Life (QOL) of patients treated for Pancreatic Ductal Adenocarcinoma (PDAC). This required a strategy that was acceptable, practical, and viable in the context of a busy, limited resource setting. In addition, effective integration of these two services required an understanding of the interaction between the people, resources and processes.⁹⁹ A Quality Improvement (QI) cycle was used as a strategy to facilitate the integration process. This study aimed to evaluate how QI assisted in the integration of PC in the care of PDAC patients.

Palliative care focuses on improving the QOL of patients and their families, based on a team approach, providing comprehensive care in conjunction with other therapies that are intended to prolong life, such as chemotherapy and interventions such as biliary drainage, and includes investigations needed to improve understanding and managing of distressing clinical complications.²⁹ There is an urgency to integrate PC into health care services both internationally and locally to alleviate the unnecessary suffering of patients and their families.^{14,157,16} Early PC has shown to improve quality of life of cancer patients and their families, reducing emergency care admissions and re-admissions to the hospital.¹⁷⁶ It is cost-effective and also impacts on the financial burden of families.^{10,94,152,201} These benefits are especially needed when caring for patients with PDAC.

PDAC is often diagnosed at an advanced stage, and even in first-world health systems, only about 20% of patients are treated with curative intent.²⁰² For patients who undergo a surgical resection, the 5-year overall survival (OS) is about 10%, and patients receiving palliative treatment have a median survival of around three months. Palliative chemotherapy gives a very modest increase in OS. In addition, PDAC is associated with a high symptom burden, including jaundice, pain, nausea and vomiting, fatigue and weight loss, that require specific palliative measures.²⁰² PDAC patients receiving PC have less aggressive care – less chemotherapy, fewer ICU admissions, fewer emergency department (ED) and hospital visits close to the time of death.²⁰¹ Aggressive care is linked to poorer QOL for patients and worse bereavement outcomes for families without improving the outcome.²⁰³ In the South African setting, these issues are amplified because patients present late with advanced disease, travel from far from rural areas and may have limited access to continuous PC once discharged from the hospital.⁹³ Access to PC should, therefore, be seen as a fundamental element of care for patients with PDAC and their families.

Although PC is a fundamental element of care, the enabling of this collaborative care is met with many barriers. As previously discussed, integration of PC is complex because PC is an emotive topic, it requires close teamwork, there are few trained PC health care professionals, it is poorly understood, and finally, it is not financially well supported by the South African health care system.^{7,29,48} Equally important, it is well known that integrating any new service component, such as PC, into an established and well-structured service may be met with resistance. In a demanding, overstretched healthcare system, collaborative care may seem like an additional burden and shared decision-making may not always be acceptable or feasible.⁷⁰ The known complexities of integration were evident in the local setting; however, the need for PC in patients with PDAC became an imperative. This was brought to the foreground by re-admissions and complaints by patients and families. Senior leadership in both services and hospital management agreed that a plan was needed to ensure access to PC. Therefore, to ensure the process of integration was acceptable, a Quality Improvement (QI) cycle was decided among the stakeholders (senior leadership in both services and hospital management) to facilitate the process of integration.

Quality improvement in public health is an iterative, defined, and deliberate process of planning, doing, checking and finally acting. It is an ongoing process and focuses on the system rather than

individuals and ideally should be viewed as an integral element of service delivery.²⁰⁴ Although elements of quality PC have been internationally defined, it was important to develop a local tool to assess local care.⁸⁰

This research aimed to evaluate how a quality improvement cycle using auditing impacted on the integration of PC in patients with PDAC care.

7.2. Methodology

Study design

This was a mixed-method study that was sequentially conducted, consisting of a focus group discussion, a quality improvement audit, and semi-structured interviews (Figure 1). This approach was used to inform the consecutive steps and to expand on the phenomena identified.

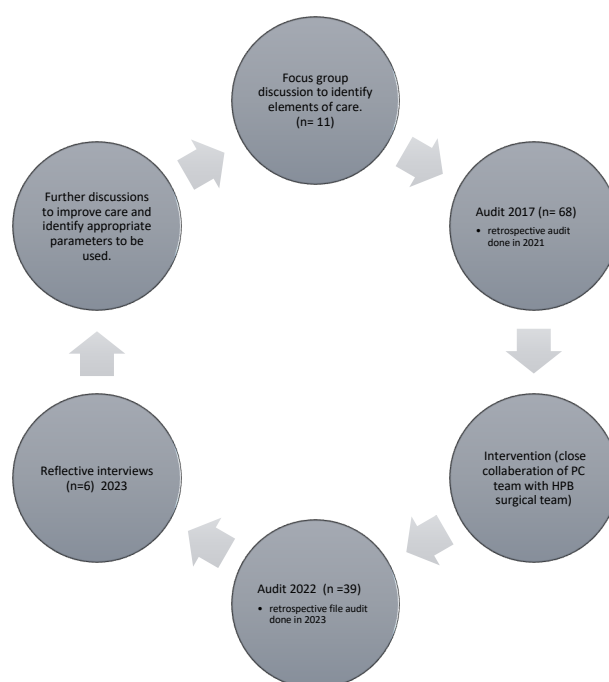


Figure 6.1: Methodology of the quality improvement cycle. A schematic representation of the steps and dates of the research steps. This demonstrates the sequential process and an iterative approach. The steps of data collection were: 1) the FGD, which informed the audit process; 2) the intervention; 3) the re-audit and finally 4) the post-audit interviews.

Study site

The study was conducted at Groote Schuur Hospital, Cape Town, South Africa. GSH is a teaching hospital, with a PC unit and a HPB unit where approximately 80 newly diagnosed PDCA patients are seen annually. This unit was chosen because of the poor prognoses of most patients with a PDAC diagnosis and because of previous complaints from patients and families about pain and symptom control.

Study Population

Experts in PC, oncology, HPB surgery, nursing and social work; with more than five years of experience and who are involved in the care of PDAC patients formed part of the FGD. The participants were purposefully sampled using the above criteria. All patients diagnosed with PDAC, who were for palliative intent and who were entered into the databases in 2017 and 2022 were audited. Experts in nursing and HPB surgery (n=6) were purposively sampled and interviewed to reflect on how the auditing process contributed to integration. They all had more than five years of experience and were directly involved in caring for patients in the HPB unit in GSH.

Data Collection tools

Interview guide for the FGD

An interview guide was developed by the researcher and refined in discussion with supervisors, drawing from the literature on PC integration and PDAC. The participants were asked to explain their roles and functions in the hospital, opportunities, what they see as essential care when PC and barriers and enablers they have experienced in working with patients with PDAC for palliative intent. Factors that the participants considered would be measurable and what could improve care were also explored. Face validity of the interview guide was ensured by presenting the questionnaire to the HPB unit head, experts in the field of normative and functional integration, and experts in the field of PC.

Interview guide for the reflective interviews

An interview guide was developed by the researcher and refined in discussion with supervisors, drawing from the literature on integration. The participants were asked to explain their roles and

functions in the hospital and in the integration of PC in the unit. Furthermore, opportunities, barriers and enablers that they experienced in working with patients with PDAC for palliative intent were explored to better understand the intervention.

Face validity of the interview guide was ensured by presenting the questionnaire to experts in the field of normative and functional integration and experts in the field of PC. Construct validity was derived by aligning this tool with the theoretical framework presented in diagram as per the conceptual framework ([2.14.A conceptual framework for palliative care integration in relation to ATHs.](#)) Reliability of the tool was ensured by piloting the tool with HCP in GSH. The interviews were by the same research assistant who was trained in conducting these interviews. The recruitment and training of the research assistant was done as discussed in chapter 1 ([Training of research assistant](#)).

REDCap Databases

This research uses REDCap, a web-based password-protected database available for use by UCT staff. Two databases were used: the PC database and the HPB database. Both these databases collect routine data such as date of admission, date of interventions and date of discharge. These databases are hosted by the University of Cape Town and have UCT HREC approval (HREC R016/2016 and HREC R012/2016) for use in research studies, with updated ethics approval. Patients provide verbal consent to be added to the database and data to be used in research, and all data is anonymised. The REDCap database does provide internal checks to ensure the validity of reports. Data was further verified by doing individual file spot checks and verifying the data with the PC and HPB staff. Data is collected on a weekly basis routinely on the REDCap database by the teams.

The audit tool

An audit tool was developed in REDCap using the information from the FGD.

Data collection

After HREC approval, site permission and individual managers' permission a sequential approach was followed. The steps of data collection were: 1) the FGD, which informed the audit process; 2) the intervention; 3) the re-audit and finally 4) the post-audit interviews.

The recruitment and consent process was done as described in chapter 1 ([Recruitment](#)). The focus group discussion was conducted in 2020, and the study population consisted of local experts (n=11)

in the above-mentioned disciplines. The research assistant and the researcher completed the following steps:

FGD

The focus group discussion was conducted online in 2020 using the interview guide and chaired by the researcher. All information sheets and consent were obtained prior to the meeting and the research team was explicit that confidentiality should be respected because confidentiality cannot be guaranteed during a FGD.

Audit process

All patients diagnosed with PDAC, who were for palliative intent and who were entered into the databases were audited in 2021 (patients from 2017) and again in 2023 (patients from 2022). Both databases use the REDCap platform hosted by the University of Cape Town and have UCT HREC approval (HREC R016/2016 and HREC R012/2016) for use in research studies. In 2017 68 patients (n=68) met the inclusion criteria and in 2022, 39 patients (n=39) met the inclusion criteria. Two audits were thus performed.

Data was pulled from both databases and merged. The parameters are the dates of admission, referral, discharge, and a checklist of whether certain actions were performed, for example, a hospice referral. This was further checked when the folders were reviewed. The folder reviews were conducted in the record section of GSH by the researcher and the research assistant. The parameters are displayed in the result section.

The intervention

The intervention, drawing from the FGD, included the PC team working more closely with the HPB surgeons, weekly PC ward rounds with the junior surgeon in training and regular discussions with the senior PC and surgical teams.

Post audit interviews

Late in 2023 reflective interviews were conducted by the researcher on an individual basis with the participants as described above. Recruitment and consent followed as described in chapter 1. All interviews were conducted in private room and recorded before. Interviews were transcribed by a research assistant and checked with the participants.

Experts in nursing and HPB surgery (n=6) were purposively sampled and interviewed in 2022 to reflect on how the auditing process contributed to integration. They all had more than five years of experience and were directly involved in caring for patients in the HPB unit in GSH.

Data analyses

FGD

The interviews were transcribed verbatim, and the transcripts were imported into NVIVO version 14.23.0 for inductive thematic analysis by the research team. The participants in this research are identified by number as *focus participants 1, 2, 3*. Following familiarisation with the data of the focus group transcript, emerging themes were identified. This is further explained in chapter 1 ([Qualitative analyses](#)). The research group discussed these themes and developed a coding framework. The agreed framework was applied to the full dataset and additional subthemes were identified. This was discussed and agreed upon with the members of the focus group to identify parameters to be audited. Quotes from FGD participants were used to illustrate the resulting themes of the analysis. Using the available results, an audit tool was developed in consultation with the members of the focus group.

Audit

Following the entry of data by the researcher and research assistant into the audit tool, spot checks were implemented. Data was extracted from REDCap, and the statistical analyses were performed using SPSS software (IBM® SPSS® Statistics27; SPSS, Inc., Chicago, IL, USA). For the descriptive statistics, mean and range, median and standard deviation or percentages were used as appropriate. A comparison between the two cohorts was conducted using an unpaired t-test for continuous variables and Fisher's exact test for categorical variables to determine statistical significance. The evaluation was performed within a 95% confidence interval, and a P-value less than 0.05 was considered statistically significant. Survival was calculated from the date of the index hospital admission.

To access the date of death, the Provincial Data Centre was approached to access data to include date of death data. If the data centre did not have the date of death, then the patients ID numbers from the Data Centre was used to access date of death from Home Affairs as held by the Medical Research Council. The patients did assent to their data being collected as per the database protocol.

Reflective interviews

The interviews were transcribed verbatim, and the transcripts were imported into NVIVO version 14.23.0 for inductive thematic analysis by the research team. The researcher familiarised herself with the data of the study being analysed. The researcher also immerse herself the data sources such as fieldnotes and interview notes taken by the research assistant. She reflected on the data with the research assistant and compared it with field notes of her own and that from the research assistant. Themes and subthemes were identified. Negative cases or outliers were included and discussed. Themes and sub-themes that emerged from the analysis of the interviews were coded. Codes and analyses were discussed with the supervisor and research assistant. Codes were also discussed with advisors to check for bias of the researcher. These codes were applied to all the data sources and data was charted across all the data sources of a study. Selected quotes were used to illustrate the resulting themes of the analysis. Finally, data was collated.^{79,80}

7.3.Results

Focus Group Discussion:

Participants of FG consisted of 4 professional nurses, 3 HPB surgeons, 1 oncologist, 1 social worker and 2 PC consultants. Five main themes were identified in the focus group discussion and converted to measurable outcomes.

Table 7.1: The themes and measurable audit outcomes

Themes	The need for early Palliative Care	The need for pain and symptom control.	The importance of shared decision-making	The importance of collaborative care.	The importance of ensuring continuity of care.
Subthemes: Measurable outcomes	<ul style="list-style-type: none"> Dates of referral to unit and PC service Dates of interventions Patient performance status Patient date of death 	<ul style="list-style-type: none"> Documented pain and symptom control assessment. Documented management. Documented reassessment. 	<ul style="list-style-type: none"> Documented breaking bad news discussions. Documented Advanced Care discussions. Documented family discussions 	<ul style="list-style-type: none"> Number of Palliative Care Referrals Number of MDT Meeting Number of Social Worker Referrals Number of Social Grant Application 	<ul style="list-style-type: none"> Number of hospice referrals. Number of home-base care referrals.

			<ul style="list-style-type: none"> • Documented Do-Not-Resuscitate instructions. 	(Financial support) <ul style="list-style-type: none"> • Number of Spiritual Care Referrals • Number of Dietician Referrals 	
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Theme 1: The need for early Palliative Care

The focus group identified early PC involvement as an important overall care component, and not just at the end of life. There was an agreement that aggressive interventions in the last- month-of- life were seen as a poor outcome.

And I think one of our problems is 80% of these patients are palliative, and I feel that it really would be helpful to get palliative care involved in the decision-making earlier on, for a lot of these patients. (Focus participant 4)

Theme 2: Pain and symptom control

Pain and symptom control were identified as the main concerns for the patients due to the debilitating effects and impact on quality of life. Prompt management during the hospital admission was necessary as patients experienced difficulties such as accessing scheduled pain medication in a primary health care setting. Repeated interventional endoscopic and radiological treatments for obstructive jaundice should be avoided.

Uncontrolled symptoms, specifically pain, are reasons for unplanned admissions (focus participant 8)

Theme 3: Shared decision-making

The need to have discussions and involve patients and their families in treatment decisions was identified important early intervention. However, some team members expressed that these discussions were difficult, and required extra support. An additional challenge related to patients from rural areas where complex discussions had to take place without family members being present. Group members identified the process of accepting the poor prognosis of PDCA as complex, which requires time.

*For me, a big problem is the communication around the family. It is difficult to fill in a Do-Not-Resuscitate form that you put in a folder in front and you say this patient is **not** for resuscitation and not for organ support if you haven't engaged with that conversation. One, you need to confront the patient about it, and you need to have a frank conversation with the family, and obviously, that's what we can do with some guidance from people who have expertise on it – because I find it difficult. (Focus Participant 5)*

This was seen as measurable by reviewing the files for documented discussions with patients and evidence of family meetings held.

Theme 4: Collaborative care

There was consensus that the comprehensive needs of the patients and families required a multidisciplinary team approach that extended beyond the medical team. These services are all available within the hospital and require a referral, which was not previously done routinely. Social workers, nurses, dieticians and spiritual carers were identified as core to the care.

I think social workers can help but the doctors are the experts in the patient's physical situation But if there is pressure on the doctors then social workers can help and sit in with the doctor. (Focus participant 11)

a nurse get involved from the beginning and is the contact person throughout the oncology process, or the palliative process for the patient. (Focus participant 10)

Theme 5: Continuity of Care

Many participants voiced their concerns about poor follow-up and access to PC once patients were discharged from the hospital. This was especially distressing for patients who were from rural areas with limited access to palliative care and pain control. The frustration around patients returning to specialised centres just for follow-up pain medication contributed to specialised staff's burden of work, poor use of the health care system resources and unnecessary suffering of patients and their families.

crisis presentation – that's something I see quite regularly; hearing [indistinct] this process is not well in place or the palliative induction was done too late and these people present after hours, or to a clinic in a wheelchair or on a trolley, really in a bad state. (Focus Participant 5)

Audit Outcomes:

Audit

Audit period: 01/01/2017 to 31/12/2017

Initial number of PDAC patients identified from the PC and Pancreatic Cancer REDCap registries n = 105. From the above 105 patients, 37 were excluded from the audit. The reasons were: Curative intended surgery (n=17); not PDAC (n=9); seen only in OPD / procedure only / short stay in ward (n=4); records incomplete or unavailable (n=7)

Audit period: 01/01/2023 to 31/12/2023

Initial number of patient records identified from the PC and Pancreatic Cancer REDCap registries n = 72. From the above 72 patients, 33 patients were excluded from the audit. The reasons were: Curative intent surgery (n=7); not PDAC (n=6); seen in OPD / procedure only / short stay in ward (n=20). The reason for the increase for the increase in the short stay ward is due to more patients receiving care in the peripheral hospitals.

To assess the need for early PC intervention we compared the PDCA patient records of 2017 in the pre-intervention stage (n=68) to 2022 (n=39) after PC integration. The majority of patients, 70% in 2017 and 56.4% in 2022, had a symptom burden for than 30 days before seeking medical assistance. On admission in 2017, 16.2% had an ECOG performance status of 3 or 4, and in 2022, it was 25.6%. In 2017, only 37 (54.4%) of patients were referred for PC after admission to the HPB unit, while in 2022, 32 (82.1%) were referred for PC, this was statistically significant ($p = 0.0059$). Median duration of referral delay was seven days in both 2017 and 2022. Ten patients (14.7%) died in 2017 during the index admission, and eight (20.5%) in 2022. Of the 58 patients who were discharged in 2017, 28 (48.3%) were readmitted to hospital in the final 30 days of life, and in 2022 14 (48.3%) of 31 patients. The audit indicated that more than 80% of these readmissions were deemed unavoidable. Overall survival from date of admission to death was a median of 75 days (range 3-466) in 2017 and median 48 (range 2-400) in 2022. Survival from date of invasive intervention or invasive diagnostic testing was a median of 73 days (range 2-465) in 2017 and 42 days (range 1-389) in 2022.

Pain and PDAC specific symptom burden assessment indicated that malignant obstructive jaundice was present in 79.5% of patients in 2017 and in 76.9% in 2022, while 48.5% (n=33) reported moderate or severe pain in 2017 and 61.5% (n=24) in 2022 (Table 2). Reassessment of symptoms was more often recorded in the 2022 cohort.

Documented shared decision-making, collaborative and continuity of care yielded several statistically significant differences, with improvements most domains when comparing the 2017 and 2022 cohorts (Tables 4, 5, 6). Documenting a DNR instruction demonstrated a small improvement from 10.2% in 2017 to 25.6% and remains a challenge. There were notably fewer referrals to Oncology in the 2022 cohort.

Table 7.2. Basic demography and pre-admission data

	2017 n=68	2022 n=39	P value
Male	32 (47%)	18 (46.2%)	1.000
Female	36 (53%)	21 (53.8%)	
Age			0.3540
Median (Range)	63 (27-89)	64 (35-84)	
Mean (SD)	62.2 (11.18)	64.3 (11.32)	
Number of symptomatic days before referral			
Not recorded	1 (1.5%)	4 (10.3%)	0.0580
≤ 14 days	10 (14.7%)	7 (17.9%)	0.7845
14-30 days	9 (13.2%)	6 (15.4%)	0.7780
≥ 31 days	48 (70.6%)	22 (56.4%)	0.1466
Delay from time of referral to HPB admission			

Median (Range)			
Mean (SD)	0 (0-37)	2 (0-28)	
	3.5 (7.38)	3.2 (4.82)	0.8206

Table 7.3. Clinical Findings on Admission

	2017 n=68	2022 n=39	P value
ECOG performance status			
0	0	0	
1	29 (42.6%)	18 (46.2%)	0.8400
2	28 (41.2%)	11 (28.2%)	0.2139
3	9 (13.2%)	9 (23.1%)	0.2823
4	2 (2.9%)	1 (2.6%)	1.000
Pain Complaint			
Yes	44 (64.7%)	32 (82.1%)	0.0765
No	17 (25%)	6 (15.4%)	0.3297

Not recorded	7 (10.3%)	1 (2.6%)	0.2534
Pain Intensity			
Mild	9 (20.5%)	7 (21.9%)	0.5776
Moderate	18 (40.9%)	13 (40.6%)	0.5095
Severe	15 (34.1%)	11 (34.4%)	0.4910
Not recorded	2 (4.5%)	1 (3.1%)	1.000
Obstructive Jaundice	54 (79.4%)	30 (76.9%)	0.8093

Table 7.4. Pain and symptom control

	Present		Treatment		Reassessed		Improved		Unchanged		Worsened	
	2017	2022	2017	2022	2017	2022	2017	2022	2017	2022	2017	2022
Pain	44	32	44	32	6	17	3	17	3	-	-	-
Jaundice	53	30	50	28	11	28	11	25	-	2	-	1
Pruritus	19	14	11	10	0	12	-	11	-	-	-	1
Constipation	14	13	11	11	1	9	1	9	-	-	-	-

Diarrhoea	6	0	3	-	4	-	4	-	-	-	-	-
Nausea	19	13	13	9	6	10	5	9	1	1	-	-
Vomiting	13	9	7	5	7	7	6	7	1	-	-	-

Table 7.5. Documented shared decision-making outcomes.

	2017 Cohort n=68	2022 Cohort n=39	P value
BBN Conversation	8 (11.7%)	27 (69.2%)	0.0001 ss
Advanced Care Discussion	18 (26.4%)	27 (69.2%)	0.0001 ss
Family Discussion	34 (50%)	31 (79.4%)	0.0037 ss
Do Not Resuscitate (DNR)	7 (10.2%)	10 (25.6%)	0.0534

Table 7.6. Documented collaborative care referrals.

	2017 Cohort	2022 Cohort	P Value
	n=68	n=39	
Palliative Care Referral	37 (54.4%)	32 (82.1%)	0.0059
MDT Meeting	58 (85.3%)	22 (56.4%)	0.0022
Social Worker Referral	20 (29%)	29 (74.4%)	<0.001
Social Grant Application (Financial support)	12 (18%)	27 (69.2%)	<0.001
Spiritual Care Referral	1 (1.5%)	25 (64.1%)	<0.001
Dietician	31 (45.6%)	13 (33.3%)	0.2291

Table 7.7. Documented continuity of care referrals

	2017 Cohort	2022 Cohort	P Value
	n=68	n=39	
Hospice	28 (41.7%)	29 (74.3%)	0.0012
Home Based Care	28 (41.7%)	29 (74.3%)	0.0012
Oncology Appointment	25 (36.7%)	4 (10.3%)	0.0031

Table 7.8: Post-discharge outcomes

	2017	2022	P value
	58/68 (85.3%)	31/39 (79.5%)	0.4365
Duration of Hospitalisation			
Median (Range)	8 (1-46)	11 (1-38)	
Mean (SD)	10.7 (9.41)	12.5 (9.6)	0.3956
Lost to follow-up	1 (1.7%)	-	1.000
Known Alive	0	2 (6.5%)	0.1187
Number of Deaths	57 (98.3%)	29 (93.5%)	0.2771
Days alive			
Median (Range)	96 (5-466)	69 (6-400)	
Mean (SD)	116.9 (95.58)	113.2 (110.64)	0.8696
Readmissions during final 30 days of life	28 (48.3%)	14 (45.2%)	0.8263
Unavoidable	23 (82.1%)	12 (85.7%)	1.000
Avoidable / Inappropriate	5 (17.6%)	2 (14.3%)	1.000

Post-integration interviews:

Three HPB surgeons and three nurses working in HPB were interviewed. These interviews were conducted after the integration plan was well established and served as a reflective process to identify shortcomings that needed to be addressed.

Table 7.9. Emerging post-integration interview themes

Themes	The need for PC extends beyond the patient's need.	The importance of having a whole (comprehensive) system structure for patients who need PC	The voice of the whole multi-disciplinary team.
Sub-Themes	<ul style="list-style-type: none"> • Palliative care for other patients in the wards. • Palliative care to assist (alleviate) with the workload. • Palliative care to support families. • Palliative care to support HCW when making complex decisions. 	<ul style="list-style-type: none"> • Aligning the system with current services and ways of thinking. • Developing a context specific system for the palliative care approach • Systems way of thinking is needed because of lack of PC 	<ul style="list-style-type: none"> • Members of the multidisciplinary team feel overlooked.

Theme 1: The need for PC extends beyond the patient's need.

When the audit commenced, the focus was on improving the care of pancreatic adenocarcinoma patients. However, on reflection, it has become evident that the needs extend to the family and also to the HCWs. The HCWs appreciate the shared decision-making and assisting with managing PC situations like shared decision making and symptom control.

And we needed the family to actually get involved. We needed them to, to become, to have counselling, to realise where were we going, which part is going to be taken. [P3]

we sometimes ask you (PC team) beforehand if you think it's appropriate to try and drain these, so that's, that's the one thing. [P1]

Palliative care to assist (alleviate) with the workload.

If palliative care is not there, we're going to work, we're going to have more load, stress load, the workload is going to be more. [P5]

The need is also with other patients in the ward who require palliative with a ripple effect of the extension of care.

And that thinking is not reserved for pancreatic cancer patients, it's for everybody.. [P2]

Theme 2: The importance of having a systems structure for patients who need palliative care.

The surgical team is very accepting of early PC, but it requires a structure which aligns with their structures to make sense of what is happening in their wards. They confirmed that PC training was not part of their previous training and that copying a care approach from a different context is not applicable in this hospital context. There is a need for a context specific approach to formalise a PC structure for these patients.

Ja, so you cannot copy an American or an English model, or for that matter, any model and try to apply it here. I mean, our situation is even more complex. [P2]

The system also has to align with the current system and needs to be regularly adjusted to align with the current system.

So, this was kind of something you had to acquire afterwards and usually by observing people how they do it and they could have been good or bad examples. [P2]

we look at the need and we look at innovative ways to get to the point where we want to get. And I think that is the process - sort of to add on, add on, add on, modify, add on, modify. [P2]

Theme 3: Members of the multidisciplinary team feel overlooked.

On reflection about the care of PDAC patients and the integration of PC, the nursing staff often felt excluded. Their knowledge of the patients and their interaction with families were viewed as very important to care plans and decision-making for PDAC patients. This lack of empowerment was iterated by three senior nursing staff.

This patient is not talking about active resuscitation and the decision has been made, we've been informed, that sort of the most senior clinician should speak to nursing staff and say 'Okay, what do you think?'. Because sometimes we're not involved in that decision-making. I will sometimes ask like, so, what is the treatment plan? Then they will tell me and then I will tell nursing staff, that's how nursing is involved in that decision. [p4]

7.4. Discussion:

PDAC is a disease that presents late, with a high symptom burden, poor outcomes and, thus, patients are predictably in need of PC services.²⁰² It was evident in this study that most of the patients were symptomatic with pain and other symptoms, and presented after more than a month of symptoms. At first glance the audit results show that the introduction of an in-patient PC QI improvement programme does not alter the patient outcome and course of PDAC. This is contrary to a recent study from Finland where the overall survival significantly improved after PC intervention.²⁰⁵ An important finding in our two cohorts were the unavoidable readmissions during the last 30 days of life as a result of severe cholangitis, sepsis, and gastric outlet obstruction. This result is comparable to the findings of a study from Australia where 61.2% of patients were readmitted despite PC, and 71% of patients who visited the Emergency Department in a study from the United States in the final 30 days of

life.^{206,207} Most patients who are investigated or treated for PDAC will be cared for by a surgical team.²⁰⁸ These outcomes and symptom burden highlight the need to integrate PC in this surgical unit.

1 The normalisation of palliative care as discussed in chapter 4, is an important part of the integration of PC. The disruption of previous routine care happened because of patient and family complaints, which were followed by difficult conversations between the PC unit and the HPB unit and has initiated PC surgical integration in HPB surgery. This major cultural shift within the surgical care of HPB patients at GSH was enhanced by a quality improvement cycle, which allowed for an iterative approach between all the role-players to improve care. It has thus become an evolving systems improvement project which addressed many of the known barriers to PC integration in surgery. The reasoning behind how a disease-specific quality improvement cycle assisted in improved access to PC for patients and PC integration has worked is better understood by highlighting some important points.

Firstly, it is important to recognise that PC integration addresses many unmet needs in the hospital. The first unmet need it aimed to improve was access to palliative care for patients with PDAC, which was evident by using patient outcome data. However, response to this unmet need was extended in the audit not only for patients but also for families. The importance of family care is also a well-recognised PC principle.²⁹ Although, per definition, PC aims to improve the quality of life of patients and families, it is seldom that we acknowledge another need for PC in the health system, which is the role of a PC team in supporting other HCWs. The post-audit interviews underlined that most of the HCWs in the ward had received no previous PC training and valued the PC input in the ward. A senior PC team can assist with difficult decisions, end-of-life care decision-making, symptom management, communicating a change of goals of care, assisting with processes of care and assisting with carrying the workload of containing patients and families when facing a life-threatening illness.²⁰⁹ In a busy surgical ward, with limited resources and conflicting priorities, skilled PC can be a major asset in optimising healthcare resources.²⁰⁹ This study has demonstrated that PC input assists with breaking bad news, advance care discussions, pain and symptom control, and ensuring continuity of care. The results demonstrate better collaborative care and better documentation of discussions which have a positive effect on patient experience.

This QI process has exposed the complex needs of PDAC care in the health system which include the high number of deaths during the index admission, as well as unavoidable readmissions in the final thirty days of life.

The role-players themselves best understand these complex needs. Becerril et al. calls this 'tacit knowledge' and states that tacit knowledge, rigorously organised, is a useful and feasible tool to prioritise an implementation process.²¹⁰ Thus secondly, the QI process, allowed the role-players to organise the parameters of good care that were relevant to this context. This achieved achievable and appropriate goal setting, fostering collective responsibility to provide continuous, comprehensive, and coordinated care, and these functions are all needed for professional integration, as described by Valentijn.⁸⁵

Thirdly, the way of understanding and measurement or 'sense making' of context-specific parameters of quality of care was aligned with the way the current PDAC care system measures outcomes. As discussed in Chapter 2, sense-making and reasoning are important components of implementation and aligning the sense making about PC with how the HPB reason assisted in the explicit comprehension of PC.⁴ An audit process is a quantified, formal and systematic approach and can assist in 'making sense' of non-numerical information.²¹¹ This audit focused specifically on a particular disease, distinguishing it as pancreatic adenocarcinoma rather than general pancreatic cancer. This is aligned with the current culture of care delivery in the hospital, which is siloed, highly technical, very structured and depends on strong systems to manage a large number of patients, especially because of the limited resources. This alignment has created an 'easy entry point', allowing for the integration to be feasible.⁹⁶ Strong clinical leadership assisted in identifying this entry point.

However, this audit has demonstrated not all the patients diagnosed with PDAC receive the team's recommended care. Using the QI process, an important barrier. This barrier identified in the reflective interview was that professional nurses still did not feel empowered to express their concerns or suggest changes in patient care. Nurses spend intimate time with the patients in the wards; they are mostly the first line when interacting with families, they co-ordinate care, and finally, they are the professionals who most probably are the first to recognise when a patient is deteriorating.²¹² The nurse's role thus extends beyond care but also on planning the care for all patients who require PC. This role of the nurse has been well validated in the palliative care culture, and a strong PC service should encourage the nurse's voice to be equitable in the decision-making.²¹² In a surgical ward, this is not always the prevailing culture. However, embedding a strong palliative care culture in the ward may be one of the mechanisms to empower the nurses and the rest of the MDT.

Introducing a culture of PC within a ward has had a far-reaching impact. This integration process started as clinical integration that focussed on the coordination of care in a single process across time, place and discipline.² However, it has extended to professional integration, where there is coordination of care across various disciplines and specific disease care.² For instance, consider a junior surgeon responsible for caring for a patient with PDAC in an environment with established PC processes. Over time, this surgeon begins to integrate the concept of PC as the norm. Later, if the same surgeon transitions to a different surgical speciality, such as vascular surgery, they continue to emphasise PC. This, in turn, prompts them to question the presence of PC processes within vascular surgery. This is evident when we review the referral data to PC from surgical wards across the surgical pavilion in GSH, which doubled from 2017 to 2021 as demonstrated in chapter 4.

The increasing normalisation of palliative care practices does result in more referrals for palliative care and an increased demand for palliative care services. More resources have not accompanied this increase in demand and provision of palliative care. Higher demands lead to less physical time spent in the ward with PDAC patients and the senior PC doctors not attending decision-making ward rounds. This places the onus back on PC services to become more systems-orientated and learn from existing disciplines to ensure effective care is provided to the large number of patients needing palliative care. This expansion is where clinical and professional integration will require organisational integration to allow for a structured hospital-wide system.

7.5. Conclusion

Organising tacit knowledge using locally accepted methods of 'sense making' in an iterative approach has contributed to PC integration in the surgical PDAC wards. The audit results comparing outcomes before and after the invention confirm the effectiveness of this process. There was improved pain and symptom assessment and management, shared decision-making, improved collaborative care and continuity of care. Integrating PC principles, such as strong nurse participation in decision-making in patient care may strengthen the care further. This QI process will have benefits beyond the HPB unit expanding across the surgical wards and into surgical care. The next step may be to use the principles learned in this QI process and apply them at the organisational level.

7.6.Limitation

A major limitation of this study is that the perception of patients and their families of integrated PC were not included. This was omitted because of limited research resources. Future studies should include patient-reported outcome measures as parameters in quality improvement cycles.

Members of the research team were also healthcare providers to the PDAC patients which may introduced bias.

Author Contributions:

RK: study design; gathering, analysis and interpretation of data; writing and editing.

Urda Kotze: study design; gathering, analysis and interpretation of data; writing and editing.

Eduard Jonas: study design; analysis and interpretation of data; writing and editing.

Marc Bernon: study design; gathering, analysis and interpretation of data; writing and editing.

Jill Olivier: study design, interpretation of data; writing and editing.

Liz Gwyther: study design, interpretation of data; writing and editing.

Chapter 8: Conclusion

How, why and to what extent palliative care integration occurred at Groote Schuur Teaching Hospital

8.1. Introduction

Valentijn et al. reminded us that integration is an art form with a colourful pallet of values and perceptions.⁶ This research not only showcases the artistry of integration, saturated with the colours of the rainbow, but also filled with emotions and meaning-making. In the previous chapters, this thesis explored three strategies: 1) a specialised palliative care (PC) service, 2) education and training of oncology registrars, and 3) process change in protocol as a quality improvement process for managing patients with pancreatic cancer, using minimal resources to partially integrate PC into an Academic Teaching Hospital (ATH) setting. This was preceded by describing the current context (chapter 3) within an ATH in South Africa.

The importance of this research is situated in the reality that statisticians and researchers are estimating that there will be an increasing need for PC.¹⁶ It is further estimated that 83% of deaths with health-related severe suffering will occur in low-middle-income countries (LMICs), such as South Africa.¹⁷⁰ In addition, the World Health Assembly (WHA) resolution on PC describes PC as an ethical responsibility of health systems. Unfortunately, the recognition of this increasing need has not been accompanied by the allocation of resources for PC services. This leaves many patients and families suffering unnecessarily and places increased pressure on the health system.¹⁶ Therefore, understanding how, why and to what extent these strategies worked within this specific context may assist in refining current strategies for the integration of PC and developing further effective, cost-effective, contextually relevant strategies within the hospital and beyond the hospital in other LMICs. This chapter aims to answer how effective the current palliative care integration strategies are at implementing PC into an ATH, how they worked and why they worked /not. Furthermore, it will briefly describe how the COVID-19 pandemic affected integration. This may assist in gaining an in-depth understanding of the multiple real barriers and facilitators and what mechanisms can be used to integrate PC. This is especially relevant because this interaction between the context and strategy may assist in the transferability of the findings to other low-resource regions.²¹³

These strategies aimed to motivate or enable Health Care Professionals (HCP) to make different choices when caring for patients with palliative care needs by changing their understanding and reasoning about PC. This was conducted in an ATH context as described in Chapter 3. How the context

of GSH interacts with Valentijn's Model on Integration, the reasoning about PC, and the new resources, provides us with a new understanding of how, why and to what extent integration occurred.²¹⁴ Astbury states that programmes work (have successful "outcomes") only in so far as they introduce appropriate ideas and opportunities ("mechanisms") to groups in the appropriate social and cultural conditions.^{135,141} These mechanisms were referred to by Suchman¹⁴² 'as unpacking of the 'black box,' which gives implementors an understanding of what actually happens in the real world.¹⁴² How strategies work or do not work depends on how stakeholders interpret and act on the interventions.¹⁴³ Knowing the reasoning for integrating PCs or how people make sense of PC is core to integrating PC. Sense-making is the process of turning a new unknown situation into an explicitly understandable situation, which further assists in meaning-making and the actions to follow.⁴ Knowing what action followed the reasoning may assist us in firstly alleviating misconceptions around PC and integration, and planning future integration strategies around driving forces and activities that are successful.¹⁴⁶ Appendix S ([Appendix S: The interaction between the theory of integration, the strategy, the context, the mechanism, the outcome and the output](#)) maps and demonstrates the linkage between context, mechanisms and outcomes. This is also further linked to Valentijn's theory on integration to explain the level of integration or effectiveness as an output.²

8.2. How, why, and to what extent did the VNLDS integrate PC?

A resource that was introduced in 2014 is a specialised team consisting of two PC-trained professional nurses, two auxiliary social workers, a clerk, and two university-employed PC consultants on a part-time base to address the PC clinical need in the hospital. This specialised team works across the hospital in the context described in Chapter 3. This PC service demonstrated effectiveness in achieving clinical integration in the areas it serves. Four main factors have been identified in how and why they brought about clinical integration.

Firstly, by delivering good clinical palliative care in a context with a high burden of patients with palliative care needs. Therefore, addressing patient and family clinical needs. This need was identified by the managers in the hospital, and because it addressed their identified need, initial funding was provided to employ the nurses.⁸

Secondly, this good clinical care was an observed benefit by HCPs in the hospital, which in turn created confidence in the PC approach. According to the literature, interactive methods are recommended for

integration, which aligns with these research's findings.^{136,138} A specialised team being visible on a ward interacting with doctors, nurses and social workers, discussing ideas, and concerns with the PC team are core to changing the perception of PC and about death and dying in the hospital. This interaction around the bed has disrupted the 'way things were done' to assist in wider clinical integration.¹¹⁴ We can, therefore, say that positive, constructive interaction on a daily basis is one of the reasons why the service contributed to integration. This constructive interaction is a core aspect that may be generalisable to other settings as well.

Thirdly, the service offers service delivery and support to healthcare workers who prefer to steer clear of the difficult and emotional aspects related to end-of-life care, death and dying.¹⁷⁵ The availability to sometimes assist them with their own personal experiences and feelings is valued by HCP. This further assisted in integration because it assisted HCPs with personal and professional distress when working with death and dying.

Fourthly, clinical integration was achieved because the service demonstrated effective palliative care and normalised PC as a clinical service. Observing PC in action influenced the hospital's approach to end-of-life care. Addressing and normalising death and dying is an important aspect of why aspects of PC integration was achieved. Assisting in providing patient care, assisting with HCPs' own personal grief on the wards, and assisting them in making sense of what is happening to themselves when encountering death in the wards, and at home has been a new important aspect explored of integration of PC. This was further illustrated during the COVID pandemic when the palliative care team not only provided direct patient care but also met with clinical teams regularly to provide emotional containment of HCPs in the wards, leading from an avoidance approach to PC at the beginning of 2020 to a much more welcoming approach towards the middle of 2021. As we have learned from Schein, stories about a topic, values and assumptions are core aspects of an organisational culture.¹¹⁹ Therefore, inserting PC in the story of GSH, disrupting the normal way of reasoning and what is valued, and challenging assumptions about PC were some of the reasons why PC has become part of the way things are done in GSH. This has slowly changed some HCP's reasoning about palliative care, assisted them in 'making sense' of what PC is about, and changed their culture of cure for all cases, accepting that death is a natural part of life. It has also influenced some HCPs' avoidance of personal or professional views of death. This, in turn, has developed trust in the PC approach when managing serious illness. The implication is, therefore, that clinical integration was

achieved by ensuring an interactive specialised PC team is in the hospital. Changing how people reason about PCs is thus a core new aspect of ensuring PC integration in other settings.

The role of PC teams in integration is not only evident in GSH but also across the province. The team in 2024 consists of an additional doctor and is involved in multiple other integration strategies, such as the improvement of PC in the Intensive Care Unit. Reviewing the use of oral morphine, an important indicator for PC integration, the link between PC integration and specialised teams can be further proven.²¹⁵ Hofmeyer et al. analysed the use of morphine in the metro of the Western Cape. Higher morphine use was demonstrated in hospitals with established PC services.²¹⁶ We can argue that the visibility and interaction with PC teams assist in highlighting the need to provide PC to patients and the positive outcomes of PC. Therefore, *'if you see it, you believe it'*. The WCDOH financially supports the PC team and additional nurses have been appointed across the province, despite the financial constraints. The lack of specialised teams in ATHs in South Africa and other LMICs is, therefore, a major barrier to integrating PC in ATHs. The argument of cost is often provided as a reason for not employing teams, and we know that initial investment is required to achieve integration.⁷⁰ Furthermore, study in Cape Town has shown that PC services reduce cost by reducing the number of days in hospital and increasing the rate of home deaths.¹⁷⁶ The cost of the specialised PC service at Chris Hani Baragwanath Hospital was estimated in 2020 to be R 11 million per annum and the cost of the GSH PC service was, with minimal staff, costed at R 2.4 million. However, the actual requirement in GSH for the PC team to function optimally was costed at R 4.4 million per annum.²¹⁷ However, these costs are low in comparison to other affordable services and contribute to adding value to the services. This research has demonstrated that most patients were referred in the last week of life, and only 27% of these referred patients passed away in the hospital. As discussed in Chapter 4, patients were referred to appropriate home care services where they received appropriate treatment for this part of their life. Although this implies a cost-saving implication for the hospital because patients died outside of the hospital, further rigorous studies on the cost-saving implications of a specialised PC team in South Africa and costs for patients and families need to be done to gain deeper insights. The economic benefit of integrating palliative care into the hospital setting may further change the reasoning at a macro level about PC where it is not seen as a priority.

Further implications of the understanding of the role of specialised PC teams are that these teams need the skills to have interactive sessions on the wards. The importance of the interactive sessions is discussed above. These interactive sessions may be initiated because of clinical care, but the PC must

extend these sessions to include further reflections on the emotive aspects of caring for patients with PC needs and knowledge transfer of PC. The ability of PC teams to contain colleagues' fears, anxiety and misconceptions about PCs may not yet be part of PC training and should be recommended to be included in all specialised PC training. These sessions include coaching, mentorship, and time to listen and validate people's experiences and feelings. These functions will be essential in the integration process and should be included in job descriptions for PC team members and acknowledged as one of the roles of a PC team by other clinical teams. There is an additional task of specialised PC providers to impart further PC skills to HCPs on the wards because of the increasing demand for PC services. This role is supported in a study by Jacobson et al. in which basic PC skills were taught to internal medicine interns through coaching consultations.²¹⁸ It was found to be an appropriate teaching method for those who requested it.²¹⁸ These findings also have an implication on how we review outcomes in PC. Valentijn names 'care experiences' as an important measure of outcomes in integration. In PC, these experiences of care are those of patients and families. However, from this research and looking at PC integration, the HCPs experience of working with patients with palliative care needs is also a key measurement when evaluating PC integration.

The extent of integration was limited. Clinical integration was achieved, but full professional and systems integration was not. The reasons for not achieving full integration are grounded in the same reasons for its clinical success, visibility and normalisation. Therefore, PC was not delivered in clinical areas/disciplines where PC was not normalised nor seen as an effective strategy. Globally, PC is normalised in cancer care, and the improved outcomes described and inevitably, as demonstrated by this research, mainly cancer patients are referred to PC.²¹⁹ However, in areas such as trauma, PC has not been normalised, and very few patients were referred from the trauma areas. Thus, a recognised need, a demonstratable benefit and a process of normalising PCs is thus core concepts to ensure further integration of PC in all settings.

8.3. How, why, and to what extent did the oncology registrar training integrate PC?

An intermediate-level oncology trainee programme was developed following research into PC training requirements in the oncology registrar training programme. This discipline was chosen because of the recognised high burden of patients who require PC. PC training is a recommended method to promote the integration of PC.¹⁴ However, oncology is a contextually siloed and protocol-driven discipline, and despite the training, PC is still not fully integrated into oncology protocols and clinical spaces. The training programme addressed the knowledge gap and misconceptions about PC among those who

were trained. Research findings showed that these registrars were also more resilient in observing suffering and valued PC more.¹⁶⁸ This clinical and professional gap in integration, as described in chapters 5 and 6, was because the decision makers were not trained in PC. The registrars, therefore, could not fully implement what they were taught and did not see it being practised by their seniors.

This lack of observed PC practice can be grounded in the fact that in this context, PC skills are perceived by oncologists as skills that they have already obtained (chapter 3). Many oncologists are under the impression that they are providing PC, although they only provide the chemotherapy and radiotherapy components. PC education was recommended by the WHA 67.19 in the declaration in 2014, especially in high-burden areas like oncology. However, these recommendations are relatively new, and it will take years before the trained registrars influence integration. Therefore, although PC training is core to see long-term improvement, it will take many years before PC becomes fully integrated into oncology. Furthermore, because PC is still perceived as 'taken for granted and not needed,' (chapter 3) training will have to be mandatory as a long-term investment in the health care system.

Focused foundational training will always be essential for providing and integrating palliative care.^{14,148} There are expectations that educating clinicians in palliative care will result in a 'bottom-up' integration of palliative care. However, if training is used as an integration measure, it will have to be supported by further professional and organisational integration measures, such as training management staff and mentorship of clinicians trained in PC. In addition, to facilitate professional and organisational integration, it will be necessary to provide specific training to individuals who are the leaders and decision-makers at specific levels of integration. It will be important to train those who write the guidelines and not only the junior doctors looking after the patients. Junior doctors will not make decisions that are not supported by senior support and appropriate guidelines or Standard Operating Procedures (SOPs).

As discussed in Chapter 6 and internationally recommended, leadership in palliative care oncology may be key to achieving integration more quickly and ensuring sustainability.³⁸ In-depth understanding of the specific discipline of PC is needed to fully integrate PC in high-burden, highly specialised areas like oncology. It is by ensuring that PC approach is integrated at the point of the decision-making, whether it is at the bedside or in a protocol, that will enable further integration to

be achieved. This integration at the point of decision-making requires leadership to change all levels of integration and integration at the point of decision making should be recommended in all settings.

Furthermore, knowing that interactive teaching, coaching, and mentorship methods are key facilitators of PC clinical integration and imparting skills, it becomes essential to include this approach in structuring teaching within the PC discipline. In an educational study at Harvard Medical School, skill adoption was only 20% in well-structured workshops, while with structured coaching, skills adoption was 90%.²¹⁸ Much of the PC training at the University of Cape Town (UCT) is currently online. It is recommended that PC providers ensure PC training becomes more transformative to include interactive, case-based questioning and more opportunities for personal reflection.²²⁰ Thus, the oncology registrar training assists in initiating the process of professional integration and holds promise for future integration. However, the extent of integration of PC into the oncology service is limited and did not demonstrate full clinical nor professional integration. Findings from this thesis can be applied to broader fields of PC education such as training in Internal Medicine and Surgery

8.4. How, why, and to what extent did a quality improvement cycle in PDAC surgical care integrate PC?

The quality improvement cycle is an interactive process and was used as a tool to integrate PC. This process demonstrated effectiveness in achieving both clinical and professional integration. It achieved this by combining two specialised services to ensure a platform where the two services can make collaborative decisions. This was also an iterative process, which is continuing. Creating a process of interaction between specialised services ensured a context-specific integration process for PC and EOL care. Constructive interaction is, therefore, more productive than presentations at CME lectures or conferences to enable professional-level integration, especially for PC. This may be because sense-making and meaning-making about EOL is a personal experience.¹³⁶ However, openly providing a structured process to explore the profession's integration of the concept of caring for people who are dying in a trusted and safe space allowed for the change in culture in the profession - from a culture of cure to inclusion of a culture of care. Furthermore, as stated by Atun et al., understanding, and using the understanding of people, available resources, and processes are facilitators of effective and appropriate integration.⁶⁹

These levels of integration were, also achieved because there were mutual gains and responsibility. Surgery received assistance with the care of families, complex decision-making, better pain and symptom control for patients and a sharing of the workload. PC services had fewer late referrals and the ability to provide early PC. As a result, the PC approach was integrated at both clinical and professional levels of decision-making. As observed in the education strategy, no effective integration can be achieved without integration at the point of decision-making. However, in the quality improvement study, leadership was engaged and PC was integrated at the point of decision-making, and integration was more effective.

This Quality Improvement (QI) process also used a sense-making process known to the PDAC services (auditing, databases), which assisted in the buy-in and understanding of the PC approach. Quantitative outcome data, like the number of hospice referrals, follow the same numerical process used in other processes, like the number of operations done. Making sense of PC is a very important aspect of PC integration because PC is an emotive topic and, inevitably, impacts and is impacted upon how a person makes sense of life itself. As observed in the VNLDS integration strategy sense-making at the bedside is an important aspect of PC integration. In QI strategy the audit cycle, which is a recognised quantitative tool, was used because most surgical decisions and actions are based on quantitative evidence. Understanding how disciplines make sense of PC can allow for more effective integration. Understanding how managers make sense of important aspects of their job may also assist in more effective organisational integration.

The renowned anthropologist Geertz stated: *“The trick is to figure out what the devil they think they are up to”*.¹¹⁷ Most disciplines in the hospital have a specific culture with specific disciplinary knowledge and specific technical skills. In Hepato pancreaticobiliary services, HPB surgeons only operate on patients with liver, gallbladder and pancreatic conditions, and these operations are highly technical, at a sub-specialist level. These surgeons will spend approximately 20 years in training before they can do these highly skilled procedures. Thus, understanding who the stakeholders are, as well as their skills and knowledge, is an essential entrance point when it comes to integrating a complex intervention into specific disciplines. Trying to figure out what is important to them personally and professionally, and how they view their actions are core to enable integration. A collaborative approach enabled this disciplinary curiosity in this research because it provided a platform to be mutually curious and ask questions.

It is notable that the other two contextual mechanisms used to integrate PC were driven from inside the specialised PC team. Other integration strategies within the hospital, not researched in this study, are also supported within the specialised PC service, such as the weekly renal PC clinic. The research team is not aware of other integration strategies for PC in the hospital.¹⁴⁷ Hui et al. emphasised that of all the resources, the presence of a specialised PC team was a major indicator of PC integration in oncology.¹⁴⁷ However, Hui's study was conducted in the oncology setting and as we have seen in this research PC is currently well accepted within the framework of cancer care. Furthermore, Hui suggests that the function of the PC team is to provide clinical care for in-patients and out-patients. This research, which was conducted across the hospital, suggests that the role of a specialised PC team in a hospital has contributed to integration beyond oncology and clinical care to include HCPs' emotional care. A specialised team is an important tool to change the reasoning about PC and to further acceptance of PC as discussed above, not only in hospitals but in all settings. However, in low-resource areas with a huge burden of care, specialised PC teams will need to work smartly to ensure basic skills are imparted to more HCPs. Thus, integration of palliative care into surgical care is evident at clinical and professional levels and is influencing integration at the organisational level.

8.4. The influence of the COVID-19 pandemic

When describing these strategies, it is crucial to consider the dynamic nature of a healthcare system as a whole. The healthcare system is a dynamic system, not isolated and there is an interplay between the strategies investigated in this study and the context.⁶⁴ This contextual, dynamic interplay is evident when reviewing the impact of COVID-19 on PC integration in GSH. The strategies described in this study were initiated before the COVID pandemic and evaluated after the COVID pandemic. The COVID pandemic has been a global revelation of the need for PC services.²²¹ The COVID pandemic has highlighted the suffering and need for care when facing death and dying for everybody. The Lancet states that the oversight of not being explicit about PC services at the beginning of the pandemic caused unnecessary suffering.²²² Fortunately, in the Western Cape, the need for PC was identified early, and an official response was developed.²³ The COVID-19 pandemic also revealed the health system's unpreparedness to cope with this PC response. In established PC centres, PC was delivered during the pandemic, but many places across South Africa lacked the infrastructure and the understanding of PC, increasing the level of distress.⁴⁰ The gap in PC services evident during the COVID pandemic led to decisions to appoint nurses and a doctor to deliver PC services in the Western Cape post-COVID in hospitals with no previous PC services.

In addition, the financial support for PC also changed how PC is valued at clinical but also at managerial level. The impact of COVID-19 was not part of this research but understanding the mechanism of the integration of PC during COVID-19 highlights that the presence of a PC service assisted both the patients, families, and HCPs in managing the physical, psychosocial and spiritual aspects of the COVID pandemic. In addition, the provision of PC was rapidly supported by functional aspects, such as dedicated staff, PC guidelines and SOPs. However, many hospitals did not have the advantage of specialised PC services, and although guidelines and SOPs were available, the actual support and expertise to provide these services were not used. This, in spite of the fact that a palliative care doctor was identified to support each hospital as a volunteer. The lack of understanding of the need for and benefit of this resource was a barrier to providing palliative care in these hospitals and as discussed these are important elements of successful integration.

8.5. Changing the culture of PC to align with the culture of an ATH

As argued above normalising PC is an important part of integrating PC, or differently stating '*the way things are done*' here is to follow a PC approach when caring for patients with life-threatening illnesses.¹¹³ This implies PC becomes part of the organisational culture of the ATH which is core element of integration. However, this will require introspective work for PC providers to align with this fast paced centre of excellence as an ATH and the increasing need for PC services.^{170,223} PC teams have been known internationally and locally to have a specific culture built on the foundations of interdisciplinary teams.¹¹⁰ Diane Meier, a global palliative care leader, highlights how these teams are built on an ethos of shared decision-making, which is needed to manage the complex job requirements and the emotions that accompany it.¹¹⁰ It is this researcher's experience and, as confirmed by Meier, that this work requires a certain culture, which is patient and family-centred, actively practising self-awareness, openly sharing personal and professional successes and failures, focussing on care, not cure and openly talking about death. This is, perhaps broadly speaking, a non-corporate, non-disease-specific culture. As observed by the researcher, most team members in the South African setting are women, quietly doing the hard work and being softly diplomatic. As stated in this research, this characteristic of soft diplomacy is an important mechanism employed to integrate PC.¹⁰⁹ However, with the current need and the current prevailing culture of excellence and effectiveness in the hospital, PC teams will have to be culturally aligned to ensure further access to PC because it is so different from the current cultures in the hospital.¹¹⁶

Furthermore, the all PC teams will have to become more knowledgeable in disease-specific knowledge to be able to integrate in a highly specialised disease specific centre of care. This disease specific knowledge is needed to be able to advocate for specific care diplomatically but also strongly. Secondly, teams must be more interactive and clearly state what they are doing to empower other HCPs in providing basic PC. This empowerment often focuses on junior doctors and nurses. However, to be truly successful, as indicated in the training of oncology registrars, this interaction needs to be on a much more senior level.

There are many centres of excellence in the hospital which increase the status of the hospital and creates agency for the HCPs working in these centres to integrate disease-specific changes across the country. This is evident in the renal service in GSH. This renal centre is a centre of excellence, which is valued and contributes to increasing the status of the hospital and will always be included nationally to contribute to renal care in South Africa. Therefore, there is a perception that excellent care is provided at GSH. GSH is thus recognised as a centre of health care excellence.³⁹ Excellence, as discussed in Chapter 3 is also part of the hospital culture. As the only ATH with a PC team in the Western Cape, GSH must ensure that they are recognised as a centre of healthcare excellence because it provides excellent PC. It will be important that all regions have local PC centres of excellence. This has to be supported by documenting the excellent PC service. However, to achieve this, the hospital will have to implement the reporting and evaluation tools aligned with current tools as discussed in chapter 4 and 6 such as length-of-stay and mortality data This can only be achieved if the PC governance is supported at an organisational level.

Some may argue that we need to change the culture in hospitals to align more with a PC culture. It is important to focus more on a caring culture than a curing culture. However, as repeatedly explored in this research and what we know about organisational culture and laws of integration, as an initial step, it is important to figure out what they think they are doing and to realise that integration is not for everybody.^{70,118} Knowing the culture and reasoning about PC and then aligning integration strategies with the current culture and reasoning may be more of an effective measure than to try and change beliefs and values as a first point of integration.

8.6. Changing PC to align with the organisational structure of ATH

As discussed in chapters 4,5 and 6, all three strategies contributed minimally to organisational integration. Drawing from Valentijn's Rainbow Model on Integration, integration will require a common governance mechanism for all PC across the hospital.⁸⁵ Thus, a PC strategy is needed for all the patients with PC needs in the hospital, not just isolated SOPs guiding referral to the specialised team. It is clear from the data in Chapter 3 that the PC team is not even seeing all the patients that die in the hospital (the PC team is seeing 27% of deaths), and many patients are discharged or die in the hospital, receiving no PC input. Furthermore, all the documentation regarding PC is within the PC team. Topp et al. argue that high-level support is needed to ensure information systems, tools, such as SOPs and guidelines and coordinated services to prepare the system for integration.⁶³ Therefore, to achieve integration across hospitals' organisational level, additional aspects of integration are needed as described in the conceptual framework. Drawing on what we have learned about clinical integration and professional integration, we thus conclude that a managerial strategy must be developed to change the reasoning regarding PC at the managerial level to ensure managerial integration. This will have to be aligned with an interactive method using the 'sense making' of managers, like the financial impact of PC services, the culture of how hospital excellence is defined, and patient feedback mechanisms.

Furthermore, generalist PC training should become core competencies of all HCW.²¹ Relying only on specialised services with a few champions will be unsustainable in the long run because of the patient numbers. With limited PC resources a consultative service remains the most viable options in an ATH.¹⁰¹

8.7. Implication for organisational Integration

The research underscores that although South Africa possesses adequate policies conducive to PC integration, the current policies and strategies, as examined in this study, have not effectively realised PC integration using the research's conceptual framework and the NPFSPC itself.¹²

This research recommends aspects that may assist in organisational integration are as follows. Firstly, in high-functioning institutions like ATHs, fostering change must also originate internally. Internally, there will have to be demonstrated context-specific value of PC, whether this is for the health system, for HCPs or for patients or for all three. This context-specific value is key to normative integration. Secondly, developing a structure to facilitate interdisciplinary governance will be key to support functional integration in all hospitals. Currently, all the disciplines in the PC service report to their disciplinary heads, the nurses will report to the nursing manager, and social workers to the social

worker manager. There is, therefore, no consolidated interdisciplinary managerial approach to integrate PC. Changing management structures to interdisciplinary supervision and outcomes in delivering PC will change the culture from a siloed approach to a more oblique approach across disciplines.

Thirdly, organisation integration will also require interdisciplinary PC organisational research, which can only be conducted effectively if there are established interdisciplinary PC teams providing services. Furthermore, this research should align with the sense-making mechanisms employed in management, potentially incorporating financial impact studies and patient feedback mechanisms. Ultimately, the saying 'seeing is believing' holds true, underscoring the need for a specialised team to catalyse organisational integration across all PC integration.

In summary, while South Africa's policy framework supports PC integration in ATHs, the practical realisation requires a concerted effort enabled by specialised PC interdisciplinary teams, contextually specific benefit and value demonstration, and strategic alignment with governance structures to allow for integration.

8.8. Implications for health systems integration

This research consistently highlights the interconnectedness between macro-level factors that exert influence, meso-level factors, and individual factors, collectively impacting integration dynamics. This research recommends that centres of PC excellence are important on macro, meso and micro level to integrate PC. These centres are necessary for newly established teams in other hospitals and facilities to observe how services are delivered and how teams' function. These centres are needed to ensure there are clinical training centres for undergraduate and postgraduate students. Furthermore, the centres must create and integrate context-specific evidence gathered through research. For example, SPICT-SA tool to identify patients needing palliative care was generated at an ATH through recognised research procedures and is now being applied across the health system.⁵³

South Africa's rich diversity extends to its unique and context-specific needs in various settings. Currently, the presence of only three established specialised PC services in major ATHs limits the representation of the full spectrum of needs across the country in ATHs, especially those ATHs serving

more rural communities. It is in these areas where centres of excellence are required not only for service delivery but also for advocacy, leadership, mentorship and exploring context-specific care. The training needs across various disciplines also require urgent leadership and mentorship to ensure training is integrated. This research, therefore, recommends the establishment of specialised PC teams to achieve micro, meso and macro-level integration. This further requires the training of specialised doctors, nurses, social workers, psychologists and spiritual care workers to build these services. These specialised services will also not become a reality without dedicated funding set aside for PC integration. As we are frequently reminded by Leutz integration does require initial funding to save money in the long run.⁷⁰

8.9.Valentijn's model of integration

As discussed in Chapter 2, Valentijn's model of integration was developed for the primary setting and highlighted the importance of the normative and functional aspects of integration at all levels of the healthcare system.⁸⁵ This has been a useful framework for evaluating PC integration because of the equal focus on the normative aspects. Distinguishing between clinical, professional, and organisational integration has further assisted in determining where the gaps are at the different levels, which can assist in developing further integration strategies, especially at the organisational level, as illustrated in this research. However, in PC integration, a deeper level of integration may need exploration, which is how individuals personally integrate a PC approach into their own thinking in the care of patients and families and their own lives.

Furthermore, PC does have different features that need to be considered, as demonstrated in the conceptual framework, that are different from primary care.⁸⁵ In PC, more emphasis is placed on the factors that are described in the definition of PC, such as pain and symptom control and family care and less on aspect needed to run primary care centres.

This research has also demonstrated that reasoning and how people make sense of PC are important when exploring PC integration. The outcome measures in PC integration also have to extend to the experience of care by HCP. Furthermore, understanding Valentijn's measurement of outcomes helps us focus on outcome measurements that need further exploration in PC, like cost.

Furthermore, the mechanism needed to link functional and normative integration needs to be explicitly explored in evaluating integration. This is especially important because PC is a complex intervention.³ This will require a deep understanding of the contextual aspects and how they are linked to the normative and functional domains of integration. The bridge that links normative, functional and contextual aspects is in the why integration happened in a certain way which in turn can assist in the transferability to other settings.

8.10. Recommended further research

As indicated in the preceding section, a notable gap in research pertains to the economic impact of PC within South African hospitals. Such studies could influence the organisation in the implementation of PC services. Financial reasoning about PC is especially important in low-resource settings with many competing interests in core other services. This financial research needs to explore funding sources in existing budgets and financial reasons why and may even extend to minimal amounts to invest. PC care packages across various settings need to be costed within LMIC. This costing research must further extend to link how services in one setting impact the costing of services in other settings. For example, how good community PC services impact on PC services in a hospital setting.

In addition, there is a need for disease-specific research that substantiates the role and efficacy of PC within disease-specific treatment algorithms. Such research not only instils confidence among junior colleagues to initiate PC but also facilitates the transferability of integration strategies to all disciplines. This research has demonstrated the high number of cancer patients referred to PC services, and as discussed, this may be linked to PC globally normalised in PC. However, PC is not normalised in some South African disease-specific care and spaces, such as trauma and infectious diseases. In which circumstances, how and what specific aspects need to be considered in specific diseases are important aspects to explore for many conditions in South Africa. This is also important in South Africa with different contextual aspects and limited universal access to curative care. Therefore, many guidelines developed in more developed healthcare systems do not consider the PC approach in certain conditions.

Furthermore, exploring the intricacies of interdisciplinary PC teams in the African context, marked by constraints such as limited time, diverse cultures, and a shortage of specialised team members, is of paramount importance. Conducting research in this area is essential for improving the delivery of PC

services and addressing the unique challenges posed by the African healthcare landscape. PC teams may need a diverse representation, may have access to fewer trained staff and may need to use communities in a much more participatory way to ensure the need is addressed.

8.11. Limitations

A limitation of this study was that this research was, situated within GSH which is a relative well-functioning ATH in the South African setting with many years of PC sensitisation and a main clinical care centre with a palliative care service during the COVID-19 pandemic. This may not be true for other ATH in South Africa, where resources and other basic services are not available. The university with an established PC training centre is also linked to GSH which is not available at other ATHs.

This research was also conducted during a time with a lot of PC activity globally and nationally which makes PC popular, but this may lead to over-enthusiastic responses, which may not be sustainable in a burdened health system. As also explained, these strategies have been impacted by the COVID pandemic, which may have increased some of the reported distress in this research.

The integration of PC is a very dynamic process and by the time the data was collected, analysed and reported, things may have changed. Another data limitation was that the data was obtained through interviews. Participants may have yet to give a true reflection of actual events and reasons for integrating PC. Two managers, who were invited to take part in the research also declined interviews, which may limit counterfactual information.

An additional study limitation is that this research also did not research all the strategies employed in PC integration in GSH. These other strategies may have impacted or can be impacted by the researched strategies. These confounding strategies require further enquiry to determine their impact on the research strategies. There are also limitations to the individual researched strategies that make up this thesis

Another limiting factor is the generalisability of this study. GSH is within a province that has already launched a PC policy, so a PC implementation plan was developed during the COVID pandemic, with specific PC wards being opened during the COVID pandemic. The Western Cape also has relatively effective primary care and secondary care. GSH is also linked to hospices across the WC, which also

contribute to continuity of care. This may influence the generalisability within the South African context, especially in areas without well-established referral pathways. Although this research is only in one hospital, misinterpretation was minimised by rich description, contextualising, triangulation and reflexivity of all findings.

Finally, another limitation is the researcher herself, who is explicit about her profound belief in PC, and this may introduce bias in the value of PC when discussing this with stakeholders and their responses to her. This position was explained in detail in Chapter 1 with measures to mitigate the bias.

Despite these limitations this research can contribute to the integration in other ATHs drawing from the mechanism used to integrate PC in GSH and the recommendations as discussed in the sections above. Furthermore, limited resources were used to integrate PC, which makes these findings even more relevant in LMICs.

8.12. Conclusion

This research has shown that VNLDS services has demonstrated effectiveness in achieving clinical integration when operating independently as a separate entity. When the VNLDS service collaborated strategically in an area with a high burden of patients with life-threatening illnesses using an interactive quality improvement strategy, was effective in achieving professional and clinical integration. An educational strategy targeting junior HCP did not demonstrate effectiveness in achieving full clinical integration or professional integration. While none of the strategies resulted in the desired organisational integration, the presence of a PC team has had a notable impact on the hospital's organisational culture, triggering a ripple effect throughout the institution. An interactive approach, whether it is at a personal level, at the bedside or on a professional platform, is an effective mechanism of integration. These mechanisms become the transferable entity and can assist in gaining a deep understanding how to develop an effective strategy in other settings.

This research has assisted us in highlighting the importance and diverse roles of a specialised PC service. Specialised teams should be advocated for as an essential element of PC integration. Furthermore, this research has highlighted who and how educators can better educate HCPs in PC, as

discussed above. Finally, using an interactive approach exploring reasoning, beliefs, and values will assist in integrating into very specific disciplines.

Besides, the three researched strategies and the COVID-19 impact, the PC team has been involved in various other strategies to enable integration. Some of these strategies have been: 1) developing ICU PC guidelines, 2) starting a PC Renal Clinic, 3) information sessions with consultants, and 4) training of nursing staff. The common thread in these integration strategies has been that the specialised PC team are leading in all these attempts. The specialised PC team is the structure which develops and enables the interactive processes. This interactive process led by specialised teams are core to integration because PC is a complex intervention, which addresses one of life's most complex mysteries: death and dying. These interactions must be softly, strategically, and compassionately held to in a safe and trusted environment.

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Appendices

Appendices for this research

A	Corroboration of findings of a VNLD service
B	Participant information PC managers and National PC co-ordinator.
C	Participant consent form PC managers and chair of steering committee.
D	Interview guide: PC managers and National PC co-ordinator
E	Data extraction sheet documentation analysis
F	REDCap variables and statistical measurements
G	Participant information sheet: supervisors of implementation mechanisms
H	Participant consent form: supervisors of implementation mechanisms
I	Interview guide supervisors of implementation mechanism
J	Participant information: PC staff and HCP
K	Participant consent: PC staff and HCP
L	Distress protocol
M	Interview guide: PC staff and HCP
N	Approvals from Groote Schuur Hospital
O	Ethics approval for overall study and updated ethics
P	Ethics approval evaluating PC training in the oncology registrar programme
Q	Ethics approval and update of REDCap database
R	Ethics approvals and update PDAC study
S	The interaction between the theory of integration, the strategy, the context, the mechanism, the outcome and the output

Appendix A: Chapter 4: Corroboration of findings of a VNLD service
Clinical integration

Subthemes	Database	Documents	Thematic analysis	Inference
Pain and symptom control	97% of patients received symptom control. 83% of patients referred are bedbound or require assistance.	Evidence of routine pain and symptom control in PC stationery (assessment form)	Nurses in the VNLDs and in the wards indicated that the VNLDs service play a valuable role in managing pain and symptoms.	There is strong converging evidence that patients who are referred to PC receive pain and symptom control
Psycho-social and spiritual care	100% of patients or families received psychosocial support. 89,6 % of patients referred to PC are from poor to very poor backgrounds	Evidence of routine assessment of psychosocial and spiritual needs in stationery. Evidence routine spiritual care assessment.	Social auxiliary workers do an assessment and if need be refer to social workers.	Psycho-social support forms a large part of the PC services because patients are from poor backgrounds. The PC team also sees the patient at the point of diagnoses where patients have to adapt to the new reality of living with a life-threatening illness and families need to be informed.
Informed participatory decision making	An average of 50 family meetings per month	Family meeting stationery used in service	This is a core role of the VNLDs.	Resources demonstrate convergent results of patients and families being part of the decision-making process.
Bereavement call	Evidence of only 5% of patients receiving bereavement care.	Evidence of stationery including bereavement calls	No reference to bereavement care	Divergent evidence. This may be because there is no permanent social worker attached to the service and most patients are referred to community care after

				discharge. This is thus an identified need but not delivered in the hospital.
Patient and family education		Patient and family education material available	Staff in and outside the VNLDS identify the role of the VNLDS in patient and family education, and places value on this service.	There is convergent data that patients and families who are referred to PC receive education

Professional integration

	Data	documentation	interviews	
Automatic triggers	Referral patterns: Metastatic cancer 45% End-stage renal failure 15% End-stage cardiac failure 6% HIV and TB 1,5%	Referral sheet to PC has indicators and local PC indicator tool available but not applied	VNLDS have automatic triggers but staff outside the service not aware.	Divergent evidence that HCP do not know when to refer to PC services across all diseases. Triggers across all illnesses are not used.
Multidisciplinary care provided		Evidence of routine assessment for rehabilitative care and if needed referral rehab services.	The VNLDS functions as an IDT but have minimal MDT involvement. In the wards the decisions are made by the doctors.	Divergent results. The PC team works as an interdisciplinary team and provides care in an interdisciplinary fashion. However, the PC is linked but not integrated to the ward teams. The

		Attendance register of daily ward rounds.		VNLDS will refer to rehabilitative services.
Clinical care pathways to ensure continuity of care	An average 61% of patients are referred to Home Base Care organisations. An average of 28% of patients are referred for Hospice Care	Hospice referral and Home base care referrals form part of the routine assessment. Follow up call form part of the routine care	Follow up care is supported by multiple PC staff and ward staff	This is a fundamental aspect of the services provided by the ATH is to link care across the clinical platform.
Integrated EOL care	56,6 % of patients received EOL care delivered by the PC team	There is a SOP for end of life in the hospital	Ward staff identify that not all dying patients are referred to the VNLDS and that there is no application of the end of life SOP.	The PC does deliver EOL care but not all the dying patients are referred to the PC team. The integrated approach to all deaths is missing

Organisational integration

Themes	Database	Documents	Interviews	Explain
Information systems		PC report includes: <ul style="list-style-type: none"> • Number of new patients • Number of PC visits 	Inside the service	The results demonstrate the service is linked and not integrated

		<ul style="list-style-type: none"> • Home base care referrals • Hospice referrals • Number of deaths • Number of re-admissions • Number of follow up phone calls • Number of bereavement calls 	<p><i>"And yes, then also daily on a daily basis, weekly, monthly. I will do the stats." APC</i></p> <p>Outside the service</p> <p><i>No, I may not also know the outcomes of those patients. OPN2</i></p>	
Basic education		<p>100 HCP received basic PC education</p> <p>1 Gynaecologist trained per year.</p> <p>All final year medical students spend one morning with the PC service in GSH (48 hours in total across the whole 6 years)</p>	The VNLDS identify that people are poorly informed about PC.	Limited amount of permanent staff trained in basic PC
Continuous Education		<p>There was a 105 staff members trained to use Syringe Driver in 2021.</p> <p>Attendance registers of journal club meetings before COVID.</p>	A need is identified for CEU in the wards	<p>Divergent evidence</p> <p>The need for CEU</p>

Intermediate education		Learning plan and online material for the registrars.	3 Family Physicians trained per year. Weekly teaching ward round with oncology team. (Combined Care Ward Round)	The Family Physicians and the oncologist do not refer to PC team and are expected to deliver most of their own PC. There is evidence of inadequate multidisciplinary education.
Leadership and governance		Meeting minutes Quarterly meetings with hospital managers. Staff report to own managers (nursing reports to nursing No strategic plan	No mention	The lack of a strategic plan agreed upon across the hospital
Financial and resource support			Two professional nurses, 2 auxiliary social workers and a clerk staff are employed in PC by the hospital. The university employs the medical doctors. The professional nurses are not in dedicated PC posts.	

			The university contributes to the resources and support of the service	
Integrated guidelines		One stand-alone PC chapter in the surgical guidelines and one integrated question in the home oxygen referral system.	No PC policies or SOP identified	Limited integrated guidelines.
Stand-alone PC guidelines and policies	5 stand-alone standard operating procedures available	<ul style="list-style-type: none"> • End of Life SOP • Syringe Driver SOP • Standard assessment guideline • Standard Family meeting documentation Referral processes to outside organisations.	Multiple forms and SOP identified.	There is convergent evidence of guidelines and policies supporting PC service delivery
Essential PC drugs available		Treatment guidelines and essential medicine list Hospital adults	All the drugs are available	There are no limitations on drugs
Support for staff			Debriefing For PC staff sessions with an outside organisation. PC staff involved in debriefing staff	There are debriefing services available for PC staff, and the PC staff are involved in debriefing staff.

Appendix B: Participant information: Phase 2a: Palliative care managers and Palliative care co-ordinator committee

An Impact Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration

PRINCIPAL INVESTIGATORS: Dr René Krause (Department of Family Medicine), University of Cape Town. rene.kraus@uct.ac.za. Tel 083 4452304 and Prof Jill Olivier (Division of Health Policy and Systems Research) and Prof Liz Gwyther (Department of Family Medicine)

We are collecting information in order to describe the process, timeline, barriers and facilitators that led to implementing Palliative Care in South Africa and in Groote Schuur Hospitals. This will assist us in doing a realist evaluation on the implementation of Palliative Care in academic teaching hospitals in South Africa. This realist evaluation aims to make provisional recommendations on the reasons why some methods used to implement palliative care work in certain conditions and not in others. It will seek to provide a provisional recommendation on implementation strategies for the South African context.

This research hypothesises that for a Palliative Care to be successfully integrated into existing services it has to be aligned with current international trends and national requirements; it should be acceptable for local stakeholders and their clinical context, it should be feasible using local resources, be sustainable and add value to current services.

In order to make provisional recommendation on an acceptable, appropriate and sustainable implementation strategies, it is important to evaluate current PC integration implementation strategies and how they interplay with contextual factors. It is therefore important to understand your perspective on the process, timeline, barriers and facilitators that played a role in implementing palliative care. All recommendations will be provisional. This research is important in order to assist other academic hospitals in South Africa to develop palliative care programs and to learn how to strengthen palliative care in Groote Schuur Hospital.

We will always request approval from the University of Cape Town Faculty of Health Sciences Human Research ethics and from the management of Groote Schuur Hospital before we conduct any studies using the information and samples that we have collected.

What information will be collected?

We will use an interview guide that is attached to ask you questions regarding the implementation of palliative care in South Africa and in Groote Schuur Hospital. If there are any questions you do not

want to answer we will remove them before the interview. The interview will be recorded and transcribed by a member of the research group. We will also ask you to guide us to any relevant guidelines in your departments used to include palliative care. This transcriber will sign a letter to state that all information will be confidential and may not be shared. The transcribed document will be sent back to you to edit before and analyses is conducted on the interview transcription. All the data will be anonymised and all analysed data will be shared with you before it is made public. This will be achieved by sending you an electronic copy of the data before any presentation is done.

What are the benefits of allowing information to be collected?

This data may assist you in developing effective strategies to implement palliative care in your setting.

How will information about me be used and stored?

All data will be stored on a password protected cloud. Once the interviews have been transcribed and edited they will be destroyed. The transcriptions will be kept for 5 years and then destroyed.

What will happen if I decide that I do not want to participate?

You are free to choose not to participate. **Your decision will not affect your interaction with the palliative care community at all.**

Important contacts

The committee approving the collection of data is the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town. You can contact Dr René Krause at 083 445 2304. You can contact the Ethics Committee directly at 021 4066492.

Appendix C: Participant consent form: Palliative care managers and chair of the national Palliative Care steering committee

An Impact Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration

PRINCIPAL INVESTIGATORS: Dr René Krause (Department of Family Medicine), University of Cape Town. rene.kraus@uct.ac.za. Tel 083 4452304 and Prof Jill Olivier (Division of Health Policy and Systems Research) and Prof Liz Gwyther (Department of Family Medicine)

I have fully understood the above description of information collection, which I have read, or which has been read. I understand what will take place if I agree to allow my information to be used.

My questions concerning the collection of information have been answered by

..... (name of study staff member)

I consent to the collection of information about me: **YES / NO** (circle answer)

I understand that I may withdraw consent at any time without giving a reason and without affecting my normal relationships.

Participant's signature:

Participant's name:.....

Date:

If the participant gave verbal consent, please enter the name of the person who **witnessed** the consent here and their signature:

Witness' signature:

Witness' name:

Date:

Name and signature of person **taking consent**

Name:

Signature

Date:

Appendix D: Interview guide: Palliative care managers and chair of the national Palliative Care steering committee

You have formed part of the implementation of PC in _____. Can you please assist in discussing the process and answering the following questions.

- Can you describe the typical people who work in this discipline
- What do you think the biggest assumptions there are regarding your discipline
- What is the biggest mistake people can make in your discipline
- Can you describe how you understand PC

Working with patients with life threatening illnesses and dying patients can cause mixed reactions and emotions. Can we discuss these.

- Can you tell me what is the typical behaviour you have noticed when a patient is diagnosed with a life-threatening illness?
- What is the typical behaviour you have noticed when a patient is dying?
- How are decisions made when dealing with patients with life threatening illnesses?
- How do you debrief staff in your discipline after a death?
- What are the biggest challenges staff face in your discipline when dealing with dying patients/ life-threatening illness ?
- What are the biggest assumptions staff have regarding PC?
- How important do you think PC integration is?
 - How do you envisage PC integration in your discipline?
- How do you think we should integrate PC?
- How big is the PC need in your discipline?
- Do you have any structures in place to include PC in your discipline?
- Do you report on PC outcomes in your discipline?
- How many people in your discipline are trained in PC?
- Is there any research being conducted on patients with life threatening illnesses and does the research include PC outcome?
- Can you advise on any documentation regarding the care of patients with life threatening illness or end of life care?
- Can you advise on any documentation on where PC has been integrated in your discipline?
- Can you advise on any documentation where you think it should be integrated in regarding the care of patients with life threatening illness or end of life care?

Process

- 1) Can you describe why PC was started in GSH?
- 2) Can you give a timeline of what happened when and why?
- 3) Can you explain the process?
- 4) Where does the power lie in order to integrate PC?
- 5) Did you experience barriers and what were they?

Appendix E: Data extraction sheet

Document name	How/when and why document is used	Provision of patient centred care		Y/N and description
			Pain and symptom control	
			Psycho-social and spiritual care	
			Information sharing	
			Family involvement	
			Bereavement care	
		Provision of collaborative care	Automatic triggers to initiate PC	
			Multidisciplinary care	
			Continuity of care	
			End of life care	
		Information	PC M&E	
			Integrated PC M&E	
		Education	basic	
			intermediate	
			Advanced	
			multidisciplinary	
			CME	
			Patient and family education	
		Governance and leadership	Strategic plan	
			Financial and resources	
		Guidelines and policies	Integrated guidelines	
			Stand-alone guidelines	
		PC trained workforce	Availability of PC trained staff	
			Emotional support	
		Research	Stand alone	
			Integrated	

Appendix F: RedCap variables and statistical measurements

Area	Measure	Statistic
Patient Demographics	Average age of patients	Average, range
	Average income as determined by housing type	Average
	Distribution of patients as per demographic area	Frequency distribution
Referral Source and Timeline	Distribution of wards referring to PC	Frequency distribution
Admission Type	Average and variance of days from admission to seen by PC	Average, range
	The main reason for referral	Frequency distribution
	Main diagnoses of patients	Frequency distribution
	The main PC condition	Frequency distribution
	The average level of functionality	Frequency distribution
Service Rendered	# of Encounters with PC team	Average, range
	Type of Encounters	Frequency distribution
	Reason for encounters	Frequency distribution
	Staff category at an encounter	Frequency distribution
	Patient Condition at encounter	Frequency distribution
	Areas Addressed at Encounters	Frequency distribution
	# Family member counselled	Average, Frequency Distribution
	Multidisciplinary Team Involvement	Frequency distribution
	Duration of Encounter (min)	Average, range
	Length of stay	Average, range
Discharge	Place discharged to	Frequency distribution
	Intermediate Care	Frequency distribution
	Referral to Home Base Care	Proportion
	Provision of Assistive Devices	Proportion
	Provision of medication for symptoms	Proportion
	Provision of syringe drivers	Proportion
Re-admission	Re-admitted?	Proportion
	Re-admission reason	Frequency distribution
	Action to Address Re-Admission	Frequency distribution
	Re-admission discharge to	Frequency distribution

Area	Measure	Statistic
	Discharged to HBC?	Proportion
Death	Patient Died?	Proportion
	Age at Death	Average, range
	Place of death	Frequency distribution
Exit	Bereavement Call Made?	Proportion
	Referred for further bereavement care?	Proportion

Appendix G: Participant information: Supervisors of implementation mechanisms

An Impact Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration

PRINCIPAL INVESTIGATORS: Dr René Krause (Department of Family Medicine), University of Cape Town. rene.kraus@uct.ac.za. Tel 083 4452304 and Prof Jill Olivier (Division of Health Policy and Systems Research) and Prof Liz Gwyther (Department of Family Medicine)

We are collecting information about how the implementation strategy: _____ (name the strategy) used in your setting assisted in implementing palliative care in Groote Schuur hospital. We would like to understand what worked, when and how did it work, for whom did it work and under what circumstances did it work.

This is will assist us in doing a realist evaluation on the implementation of Palliative Care in academic teaching hospitals in South Africa. This realist evaluation aims to make provisional recommendations on the reasons why some methods used to implement palliative care work in certain conditions and not in others. It will seek to provide a provisional recommendation on implementation strategies for the South African context.

This research hypothesis that for a Palliative Care to be successfully integrated into existing services it has to be aligned with current international trends and national requirements; it should be acceptable for local stakeholders and their clinical context, it should be feasible using local resources, be sustainable and add value to current services.

In order to make provisional recommendation on an acceptable, appropriate and sustainable implementation strategies, it is important to evaluate current PC integration implementation strategies and how they interplay with contextual factors. It is therefore important to understand your perspective on the mechanism used to implement PC in your setting. All recommendations will be provisional. This research is important in order to assist other academic hospitals in South Africa to develop palliative care programs and to learn how to strengthen palliative care in Groote Schuur Hospital.

We will always request approval from the University of Cape Town Faculty of Health Sciences Human Research ethics and from the management of Groote Schuur Hospital before we conduct any studies using the information and samples that we have collected.

What information will be collected?

We will use an interview guide that is attached to ask you questions regarding the implementation of palliative care in South Africa and in Groote Schuur Hospital. If there are any questions you do not want to answer we will remove them before the interview. The interview will be recorded and transcribed by a member of the research group. We will also ask you to guide us to any relevant guidelines in your departments used to include palliative care. This transcriber will sign a letter to state that all information will be confidential and may not be shared. The transcribed document will be sent back to you to edit before and analyses is conducted on the interview transcription. All the data will be anonymised and all analysed data will be shared with you before it is made public. This will be achieved by sending you an electronic copy of the data before any presentation is done.

What are the benefits of allowing information to be collected?

This data may assist you in developing effective strategies to implement palliative care in your setting.

How will information about me be used and stored?

All data will be stored on a password protected cloud. Once the interviews have been transcribed and edited they will be destroyed. The transcriptions will be kept for 5 years and then destroyed.

What will happen if I decide that I do not want to participate?

You are free to choose not to participate. **Your decision will not affect your interaction with the palliative care community at all.**

Important contacts

The committee approving the collection of data is the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town. You can contact Dr René Krause at 083 445 2304 or by email: rene.krause@uct.ac.za. You can also contact the Ethics Committee directly at 021 4066492 or by email: lamees.emjedi@uct.ac.za

Appendix H: Participant consent form: Supervisors of implementation mechanisms

An Impact Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration

PRINCIPAL INVESTIGATORS: Dr René Krause (Department of Family Medicine), University of Cape Town. rene.kraus@uct.ac.za. Tel 083 4452304 and Prof Jill Olivier (Division of Health Policy and Systems Research) and Prof Liz Gwyther (Department of Family Medicine)

I have fully understood the above description of information collection, which I have read, or which has been read. I understand what will take place if I agree to allow my information to be used.

My questions concerning the collection of information have been answered by

..... (name of study staff member)

I consent to the collection of information about me: **YES / NO** (circle answer)

I understand that I may withdraw consent at any time without giving a reason and without affecting my normal relationships.

Participant's signature:

Participant's name:.....

Date:

If the participant gave verbal consent, please enter the name of the person who **witnessed** the consent here and their signature:

Witness' signature:

Witness' name:

Date:

Name and signature of person **taking consent**

Name:

Signature

Date:

Appendix I: Interview guide: Supervisors of implementation mechanisms

You have formed part of the implementation of PC through _____ (name the strategy) Can you please assist in discussing the process and answering the following questions. We would like to understand what worked, when and how did it work.

- 1) Can you give a timeline of what happened when and why?
- 2) What worked and why did it work?
- 3) What did not work and why did it not work?
- 4) How did it work?
- 5) What were the challenges in this process?
- 6) For who did it not work and why?

Working with patients with life threatening illnesses and dying patients can cause mixed reactions and emotions. Can we discuss these.

- Can you tell me what is the typical behaviour you have noticed when a patient is diagnosed with a life threatening illness?
- What is the typical behaviour you have noticed when a patient is dying?
- How are decisions made when dealing with patients with life threatening illnesses?
- How do you debrief staff in your discipline after a death?
- Can you tell me has this changed since the training and how?
- What are the biggest challenges staff face in your discipline when dealing with dying patients/ life threatening illness ?
- What are the biggest assumptions staff have regarding PC.
- Has this changed since the intervention(name the intervention) and how?
- How has the intervention contributed/ not to:
 - Patient centred care
 - Collaborative care
 - Monitoring and evaluation
 - Education
 - Leadership in PC
 - Guidelines and policies

- Drug availability
 - Research
- Do you have any documents to support this?
- How do you envisage PC integration in the future in your discipline?

Appendix J: Participant information: Palliative Care staff

An Impact Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration

PRINCIPAL INVESTIGATORS: Dr René Krause (Department of Family Medicine), University of Cape Town. rene.kraus@uct.ac.za. Tel 083 4452304 and Prof Jill Olivier (Division of Health Policy and Systems Research) and Prof Liz Gwyther (Department of Family Medicine)

We are collecting information about the palliative care service in Groote Schuur Hospital. We are collecting information in order to describe the process, timeline, barriers and facilitators that led to implementing Palliative Care in South Africa and in Groote Schuur Hospitals. We would like to understand what worked, when and how did it work, for whom did it work and under what circumstances did it work. In order to do all of this we would like to understand the PC service delivery.

This will assist us in doing a realist evaluation on the implementation of Palliative Care in academic teaching hospitals in South Africa. This realist evaluation aims to make provisional recommendations on the reasons why some methods used to implement palliative care work in certain conditions and not in others. It will seek to provide a provisional recommendation on implementation strategies for the South African context.

This research hypothesises that for a Palliative Care to be successfully integrated into existing services it has to be aligned with current international trends and national requirements; it should be acceptable for local stakeholders and their clinical context, it should be feasible using local resources, be sustainable and add value to current services.

In order to make provisional recommendation on an acceptable, appropriate and sustainable implementation strategies, it is important to evaluate current PC integration implementation strategies and how they interplay with contextual factors. It is therefore important to understand your perspective on the mechanism used to implement PC in your setting. All recommendations will be provisional. This research is important in order to assist other academic hospitals in South Africa to develop palliative care programs and to learn how to strengthen palliative care in Groote Schuur Hospital.

We will always request approval from the University of Cape Town Faculty of Health Sciences Human Research ethics and from the management of Groote Schuur Hospital before we conduct any studies using the information and samples that we have collected.

What information will be collected?

We will use an interview guide that is attached to ask you questions regarding the service you deliver. If there are any questions you do not want to answer we will remove them before the interview. The interview will be recorded and transcribed by a member of the research group. We will also ask you to guide us to any relevant guidelines in your departments used to include palliative care. This transcriber will sign a letter to state that all information will be confidential and may not be shared. The transcribed document will be sent back to you to edit before and analyses is conducted on the interview transcription. All the data will be anonymised and all analysed data will be shared with you before it is made public. This will be achieved by sending you an electronic copy of the data before any presentation is done.

What are the benefits of allowing information to be collected?

This data may assist you in developing effective strategies to implement palliative care in your setting.

How will information about me be used and stored?

All data will be stored on a password protected cloud. Once the interviews have been transcribed and edited they will be destroyed. The transcriptions will be kept for 5 years and then destroyed.

What will happen if I decide that I do not want to participate?

You are free to choose not to participate. **Your decision will not affect your interaction with the palliative care community at all.**

Important contacts

The committee approving the collection of data is the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town. You can contact Dr René Krause at 083 445 2304 or by email: rene.krause@uct.ac.za. You can also contact the Ethics Committee directly at 021 4066492 or by email: lamees.emjedi@uct.ac.za

Appendix K: Participant consent form: PC staff and HCP

An Impact Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital

How effective are the current palliative care integration strategies implemented in the South African Academic Teaching Hospital context (Groote Schuur Hospital) in reaching the goal of integration

PRINCIPAL INVESTIGATORS: Dr René Krause (Department of Family Medicine), University of Cape Town. rene.kraus@uct.ac.za. Tel 083 4452304 and Prof Jill Olivier (Division of Health Policy and Systems Research) and Prof Liz Gwyther (Department of Family Medicine)

I have fully understood the above description of information collection, which I have read, or which has been read. I understand what will take place if I agree to allow my information to be used.

My questions concerning the collection of information have been answered by

..... (name of study staff member)

I consent to the collection of information about me: **YES / NO** (circle answer)

I understand that I may withdraw consent at any time without giving a reason and without affecting my normal relationships.

Participant's signature:

Participant's name:.....

Date:

If the participant gave verbal consent, please enter the name of the person who **witnessed** the consent here and their signature:

Witness' signature:

Witness' name:

Date:

Name and signature of person **taking consent**

Name:

Signature

Date:

Appendix Distress Protocol

The following process will be followed to support an interviewee who shows signs of emotional stress during the data collection process:

1. All participants will be fully informed as to the nature of the issues to be covered in the interview.
2. Any interviewee who appears to become distressed will be offered the opportunity to stop the interview and either abandon or restart when they are comfortable.
3. The interviewer will pass on any information or request to the medical professionals at the patient's/family's request.
4. All information will be treated as confidential except in the situation of the patient's family's safety being at risk, in which case the information may be acted upon.
5. The participant will be offered support and counselling by the Groote Schuur Palliative Care team counselling staff.

Appendix M: Interview guide: PC staff and HCP

You have formed part of the implementation of Palliative Care in Groote Schuur Hospital. Can you please assist in discussing the process and answering the following questions.

- 1) Can you describe your job in patient care?
- 2) Can you describe your job in the hospital?
- 3) Where is nurse led PC services working and why?
- 4) How does it work?
- 5) Have you experienced any barriers?
- 6) What opportunities can be used to integrate PC?
- 7) Can you give a timeline of what happened when and why?
- 8) What were the circumstances that enabled it to work?
- 9) For who did it not work and why?
- 10) What were the circumstances in which it did not work?
- 11) How do you think we can improve the integration process?

Appendix N : Approval from Groote Schuur Hospital



Western Cape
Government



GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bernadette Eick

e-mail: GSHResearch.Request@westerncape.gov.za

Professor Liz Gwyther
Palliative Care and Medicine

E-mail: liz.gwyther@uct.ac.za

Dear Dr Gwyther

RESEARCH PROJECT: Palliative Care Audit on Pancreatic Adenocarcinoma Cancer Patients in Groote Schuur Hospital

Your recent letter to the hospital refers.

You are granted permission to proceed with your research, which is valid until **30 May 2024**

Please note the following:

- a) Your research may not interfere with normal patient care.
- b) Hospital staff may not be asked to assist with the research.
- c) Confidentiality must always be maintained.**
- d) No additional costs to the hospital should be incurred as indicated in your Annexure 2 i.e. Lab, consumables or stationery. **If access to TRACK Care/NHLS is required, kindly attach our letter of approval to the application form and approach Information Management to assist with data.**
- e) **No patient folders may be removed from the premises or be inaccessible.**
- f) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
- g) Should you at any time require photographs of your subjects, please obtain the necessary indemnity forms from our Public Relations Office (E45 OMB or ext. 2187/2188).**
- h) Should you require additional research time beyond the stipulated expiry date, please apply for an extension.
- i) Please discuss the study with the HOD before commencing.
- j) Please introduce yourself to the person in charge of an area before commencing.
- k) On completion of your research, please forward any recommendations/findings that can be beneficial to use to take further action that may inform redevelopment of future policy / review guidelines.
- l) If the researcher is not GSH staff member, a supernumerary contract is required before commencement of the research.
- m) Please contact Michelle Riley (Patient Fees) at ext. 2276 to ascertain if there will be charges for conducting the Research and to obtain a quote or to discuss charges
- n) Kindly submit a copy of the publication or report to this office on completion of the research.**
- o) At no time should any posters encouraging patients to partake in research, be displayed within a clinical area.**
- p) Please adhere to ALL COVID-19 regulations and Groote Schuur Hospital policies.**
- q) All Clinical Trials to be registered on Clinicom with Michelle Riley.**
michelle.riley@westerncape.gov.za

I would like to wish you every success with the project.

Yours sincerely

pp
DR BERNADETTE EICK
CHIEF OPERATIONAL OFFICER

Date: 20 July 2023

C.C. Mr. L. Naidoo, Mr. A. Mohamed, Dr N. Khumalo, Professor N. Ntusi

G46 Management Suite, Old Main Building,
Observatory 7925
Tel: +27 21 404 6288 fax: +27 21 404 6125

Private Bag X,
Observatory, 7935
www.westerncape.gov.za/health


GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bernadette Eick
e-mail: Bernadette.Eick@westerncape.gov.za

Professor Liz Gwyther
FAMILY MEDINE

E-mail: liz.gwyther@uct.ac.za / rene.krause@uct.ac.za

Dear Professor Gwyther,

RESEARCH PROJECT: An Impact of Implementing Integrated Palliative Care At An Academic Teaching Hospital (Sub-study 012/2016 & 750/2018) (PhD Dr S. Rene Krause)

Your recent letter to the hospital refers.

You are granted permission to proceed with your research, which is valid until **30 March 2021**, subject to **the approval of Professor Ntusi and Mr. Mohamed, if nursing staff are to be interviewed.**

Please note the following:

- a) Your research may not interfere with normal patient care.
- b) Hospital staff may not be asked to assist with the research.
- c) No additional costs to the hospital should be incurred i.e. Lab, consumables or stationary. **If access to TRACK Care/NHLS is required, kindly attach our letter of approval to the application form.**
- d) **No patient folders may be removed from the premises or be inaccessible.**
- e) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
- f) Confidentiality must always be maintained.
- g) **Should you at any time require photographs of your subjects, please obtain the necessary indemnity forms from our Public Relations Office (E45 OMB or ext. 2187/2188).**
- h) Should you require additional research time beyond the stipulated expiry date, please apply for an extension.
- i) Please discuss the study with the HOD before commencing.
- j) Please introduce yourself to the person in charge of an area before commencing.
- k) On completion of your research, please forward any recommendations/findings that can be beneficial to use to take further action that may inform redevelopment of future policy / review guidelines.
- l) Please contact Michelle Riley (Patient Fees) at ext. 2276 to ascertain if there will be charges for conducting the Research and to obtain a quote or to discuss charges
- m) **Kindly submit a copy of the publication or report to this office on completion of the research.**
- n) **At no time should any posters encouraging patients to partake in research, be displayed within a clinical area.**

I would like to wish you every success with the project.

Yours sincerely

DR BERNADETTE EICK
CHIEF OPERATIONAL OFFICER

Date: 13 July 2020

C.C. Mr. L. Naidoo, Dr L. Booyens, Professor N. Ntusi, Mr. A. Mohamed

G46 Management Suite, Old Main Building,
Observatory 7925
Tel: +27 21 404 6288 fax: +27 21 404 6125

Private Bag X,
Observatory, 7935
www.westerncape.gov.za/health

Appendix O: Ethics approval for overall study and updated ethics



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 406 6492
Email: hrec-enquiries@uct.ac.za

Website: www.health.uct.ac.za/fhs/research/humanethics/forms

05 March 2020

HREC REF:071/2020

Prof L Gwyther
Family Medicine
Room 2.28 Entrance 5 Falmouth Building
FHS

Dear Prof Gwyther

PROJECT TITLE: AN IMPACT EVALUATION OF IMPLEMENTING INTERGRATED PALLIATIVE CARE AT AN ACADEMIC TEACHING HOSPITAL (SUB-STUDY -012/2016 & 750/2018) (PHD DEGREE - DR S R KRAUSE)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

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

Approval is granted for one year until the 30 March 2021.

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)

The HREC acknowledge that the student: Dr S Krause will also be involved in this study.

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.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

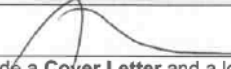
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 071/2020sa

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.


Form FHS006: Protocol Amendment

HREC office use only (FWA00001637; IRB00001938)			
<input checked="" type="checkbox"/> Approved	<input checked="" type="checkbox"/> Type of review: Expedited	<input type="checkbox"/> Full committee	
This serves as notification that all changes and documentation described below are approved.			
Signature HREC Chairperson / Designee		Date	7/12/2023
<p>Note: All Major amendments must include a Cover Letter and a local PI Synopsis justifying the changes for the amendment. Please note that incomplete amendment submissions will not be reviewed.</p> <p>Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za with subject line: FHS006 + (HREC Reference number).</p> <p>The latest forms are found on our website. http://www.health.uct.ac.za/fhs/research/humanethics/forms</p> <p>Please also clarify your plan for research-related activities during COVID-19 lockdown.</p>			
<div style="border: 1px solid black; padding: 5px; text-align: center;"> HUMAN RESEARCH ETHICS COMMITTEE - 7 DEC 2023 HEALTH SCIENCES FACULTY UNIVERSITY OF CAPE TOWN </div>			
Comments from the HREC to the Principal Investigator:			
<p>Note: The approval of this protocol amendment does not grant annual approval. Please complete the FHS016 / FHS017 form for annual approval at least one month before study expiration.</p>			

Principal Investigator to complete the following:
1. Protocol information

Date (when submitting this form)	07/12/2023		
HREC REF Number	071/2020		
Protocol Title	An Impact Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital		
Protocol Number (if applicable)			
Principal Investigator	Ass Prof Liz Gwyther		
Department / Office Internal Mail Address	FaCE		
1.1 Is this a major or a minor amendment? (see FHS006hlp) Major (tick box) Minor (tick box)	<input type="checkbox"/> Major	<input checked="" type="checkbox"/> Minor	



1.2 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> <input checked="" type="checkbox"/> <input checked="" type="checkbox"/> No
1.3 If the amendment is a major amendment <u>and</u> receives US Federal Funding, does the amendment require full committee approval? Note: Any protocol amendments for Full Committee Review MUST be submitted on the monthly HREC submission dates. (Please email an electronic copy to hrec-enquiries@uct.ac.za)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
1.4 Did the initial study require UCT No-Fault Insurance	<input type="checkbox"/> Yes	<input type="checkbox"/> No

2. List of Proposed Amendments with Revised Version Numbers and Dates

Please itemise on the page below, all amendments with revised version numbers and dates, which need approval.

This page will be detached, signed and returned to the PI as notification of approval. Please add extra pages if necessary.

It became apparent during the study that an impact evaluation was not a suitable approach to answer the research question. The research team thought that an alternative evaluation process was needed because we focused more on answering the how and why questions. We, therefore, would like to change the approach to evaluation and change this across the research study. Places where this will be changed are:

- To change the title to:
An Evaluation of Implementing Integrated Palliative Care at an Academic Teaching Hospital
- Phase 2: all the strategies have focused on evaluating the process and how and why they brought about change. The descriptions stating impact evaluation have been changed to evaluation to better align with the methodology.
- Phase 3: Phase 3 also focuses on describing how and why the strategies investigated brought about change and the term impact evaluation has been changed to evaluation.

3. Protocol status (tick ✓)

<input type="checkbox"/>	Open to enrolment
<input type="checkbox"/>	No participants have been enrolled
	Closed to enrolment (tick ✓)
<input type="checkbox"/>	Research-related activities are ongoing
<input type="checkbox"/>	Research-related activities are complete, long-term follow-up only
<input checked="" type="checkbox"/>	Research-related activities are complete, data analysis only

4. Proposed changes will affect: (tick ✓ all the categories that apply)

Protocol	
<input type="checkbox"/>	Study objectives, design (including investigator's brochure, clinical activities, study length)
<input type="checkbox"/>	Study instruments, questionnaires, interview schedules



<input type="checkbox"/>	Sample size
<input type="checkbox"/>	Recruitment methods
<input type="checkbox"/>	Eligibility criteria (inclusion and exclusion criteria)
<input type="checkbox"/>	Drug/device (composition, amount, schedule, route of administration, combination with other drugs/devices, safety information)
<input checked="" type="checkbox"/>	Data collection/ analysis
<input type="checkbox"/>	Principal Investigator. (Please attach revised conflict of interest and PI declaration statements. Refer: sections 7 and 8.4 in the New Protocol Application Form FHS013)
<input type="checkbox"/>	Consent form and information sheet
<input type="checkbox"/>	Recruitment materials (e.g. advertisements)
<input checked="" type="checkbox"/>	Administrative (e.g. change in sponsor's name, change in contact information)
<input type="checkbox"/>	Other. Please specify:
<p><i>*Note: Amendment changes involving study length, sample size, additional sites and eligibility criteria (i.e. inclusion of minors and /or pregnant woman) need to be declared to the Insurance office. Please liaise via fhs.sponsorship@uct.ac.za regarding the required documentation and information to be submitted to obtain an updated UCT No-fault Insurance Certificate- it should be included herewith</i></p>	
4.1 In your opinion, will there be any increase in risk, discomfort or inconvenience to participants?	
<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	
If yes, please provide a detailed justification/explanation:	

4.2 What follow-up action do you propose for participants who are already enrolled in the study?	
<input type="checkbox"/>	Inform current participants as soon as possible
<input type="checkbox"/>	Re-consent current participants with revised consent/assent forms (append)
<input checked="" type="checkbox"/>	No action required
<input type="checkbox"/>	Other. Please describe:

5. Detailed description of the change(s)



Please attach, for each amendment, a summary of all changes which clearly indicates:

- i. Old wording (e.g. ~~strikethrough~~ text, CHANGED FROM and CHANGED TO)
- ii. New wording (e.g. *italicized*, **bold**, tracked)
- iii. Detailed rationale/ justification/ explanation for each change

6. Ethics Review for Amendment Levy – cost including vat

Amendment Review Costs including VAT

Please tick amount to be billed:

Submission Type	Description	New fee (Vat Incl.)	tick ✓
Research funded solely from UCT departmental/ divisional/group budget	Major/ Minor Amendments	R0,00	<input checked="" type="checkbox"/>
Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges	Major/ Minor Amendments	R0,00	<input type="checkbox"/>
Protocol amendment - Major (FHS006 Form)	Clinical Trial & International Grant Funded Research - Any changes to the protocol that requires Full Committee review	R8 000,00	<input type="checkbox"/>
Protocol amendment - Major (FHS006 Form)	Clinical Trial & International Grant Funded Research - Any change to the protocol that requires Expedited review that does not require Full Committee Review	R5 000,00	<input type="checkbox"/>
Protocol amendment - Minor (FHS006 Form)	Clinical Trial & International Grant Funded Research - Minor amendments, administrative changes that do not affect study design e.g. changes to informed consent form, changes in study staff, etc.	R2 250,00	<input type="checkbox"/>
Protocol amendment - Major (FHS006 Form)	National grant funded research - Any change to the protocol that requires Full Committee review	R7 000,00	<input type="checkbox"/>
Protocol amendment - Major (FHS006 Form)	National grant funded research - Any change to the protocol that requires Expedited review that does not require Full Committee review	R2 500,00	<input type="checkbox"/>
Protocol amendment - Minor (FHS006 Form)	National grant funded research - Minor amendments, administrative changes that do not affect study design e.g. changes to informed consent form, changes in study staff, etc.	R1 000,00	<input type="checkbox"/>

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for invoicing, either complete section 1 or 2 :

1. Invoice billing – Directly to Sponsor

Sponsor's name	
Billing Address of Sponsor:	
Vat Number:	
Contact person:	
Telephone number:	
Email Address:	




2. Internal Journal Billing:	
Fund Number:	
Cost Centre Number:	
Account Holder Name:	
Division of Account Holder:	

7. Amendment Submission checklist (tick ✓)

7.1 Please tick that all the documents are attached before submitting to the HREC. NB: Incomplete submissions will not be processed	
<input checked="" type="checkbox"/>	Latest FHS006 form completed with all sections completed as per our website
<input checked="" type="checkbox"/>	Cover Letter
<input checked="" type="checkbox"/>	PI Justification/ Summary for the reasons for the amendment
<input checked="" type="checkbox"/>	Protocol - Track changes & Clean Copy (where necessary)
<input checked="" type="checkbox"/>	Informed Consent Forms (ICF), if applicable (Any changes made to ICF tracked & clean copy)
<input type="checkbox"/>	Any other additional documentation in support of amendment
<input type="checkbox"/>	Updated no fault insurance certificate (if applicable)


Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za with subject line: FHS006 + (HREC Reference number). The latest forms are found on our website.

8. Signature


My signature certifies that I will maintain the anonymity and/ or confidentiality of information collected in this research. If at any time I want to share or re-use the information for purposes other than those disclosed in the original approval, I will seek further approval from the HREC.			
Signature of PI		Date	7 December 2023

Appendix P: Ethics approval evaluating PC training in the oncology registrar programme

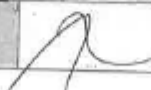
HUMAN RESEARCH ETHICS COMMITTEE
 11 DEC 2018
 HEALTH & LIFE SCIENCES FACULTY OF HEALTH SCIENCES
 UNIVERSITY OF CAPE TOWN



UNIVERSITY OF CAPE TOWN
ALERE MENTIS, CREARE ANIMAS



FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)		
This serves as notification of annual approval, including any documentation described below.		
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/maxi renewal date 30/12/2019
<input type="checkbox"/> Not approved	See attached comments	
Signature Chairperson of the HREC: 		Date Signed: 12/12/18

Comments to/from the HREC

The evaluation of the in palliative care training in the oncology registrar program was delayed because:

- Delay in obtaining ethics approval from all the sites.
- Registrars and supervisors requesting breaks during exams and national holidays.
- Supervisors leaving the country

The modules have all been completed and the focus group discussions will be completed by the end of the month.
 Data analysis will continue until March 2019.
 The course has been a success and the need to continue without a research component has been requested.

Principal Investigator to complete the following:

1. Protocol Information

Date (when submitting this form)	11/12/2018	
HREC REF Number	861/2018	Current Ethics Approval was granted until Feb 2018
Protocol title	Evaluation of the in palliative care training in the oncology registrar program	
Protocol number (if applicable)		
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes - <input checked="" type="checkbox"/> No	

Appendix Q: Ethics approval and update of REDCap database



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
Email: nosi.tsama@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

07 April 2016

REF NO: R012/2016

Dr R Krause
 Family Medicine
 Room 2.28
 Entrance 5, Level 2
 Falmouth Building

Dear Dr Krause

PROJECT TITLE: EVALUATION OF THE PALLIATIVE CARE PROGRAM IN GROOTE SCHUUR HOSPITAL

Thank you submitting your registry to the Faculty of Health Sciences Human Research Ethics Committee for review.

The HREC has **approved** the registration of your database.

Please Note: All research, including that undertaken for a master's or doctoral degree, using registered databases, registries and repositories, requires submission as a new study. It requires an application form ([FHS013](#)) and a protocol which has undergone departmental review. The study will receive its own HREC REF number which will be linked to the main database or repository.

The registration of this database is valid until **30 April 2019**.


Please quote the HREC reference number in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

HUMAN RESEARCH ETHICS COMMITTEE	
09 MAY 2022	
 UNIVERSITY OF CAPE TOWN <small>UNIBESITHI YASENZA UNIVERSITHI YOKAPETOWN</small>	FACULTY OF HEALTH SCIENCES <small>Human Research Ethics Committee</small>

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30.5.23
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee			Date Signed
			9/5/22

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website:
<http://www.health.uct.ac.za/fhs/research/humanethics/forms>

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	3/5/2022		
HREC REF Number	071/2020	Current Ethics Approval was granted until	30/5/2022
Protocol title	An Impact Evaluation of implementing integrated palliative care at an academic teaching hospital		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No	
If yes, could you please provide the HREC Reference number for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	A/Prof Llz Gwyther		

FHS017: Annual Progress Report / Renewal
Record Reviews/Audits/Collection of Biological Specimens/Repositories/Databases/Registries

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30/4/2026
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	15/5/23

Note: Please note that incomplete submissions will not be reviewed.

Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please clarify your plan for research-related activities during COVID-19 lockdown

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	8 May 2023		
HREC REF Number	R012/2016	Current Ethics Approval was granted until	30/4/2023
Protocol title	Groote Schuur Palliative Care RedCap database		
Principal Investigator	Rene Krause		
Department / Office Internal Mail Address	Family Community and Emergency Care Room 2.28; Falmouth Building; UCT		
1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No	


2. Protocol status (tick ✓)

<input checked="" type="checkbox"/>	Research-related activities are ongoing
<input type="checkbox"/>	Data collection is complete, data analysis only
Please indicate (in the block below) the titles and HREC reference numbers of any projects currently making use of the Database/registry/repository.	
017/2020	

3. Protocol summary

Total number of records or specimens collected, reviewed or stored since the original approval	6622
Total number of records or specimens collected, reviewed or stored since last progress report	2000
Have any research-related outputs (e.g. publications, abstracts, conference presentations) resulted from this research? If yes, please list and attach with this report.	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No

4. Signature

Appendix R: Ethics approvals and update PDAC study



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room G50- Old Main Building
 Groote Schuur Hospital
 Observatory 7925
 Telephone [021] 406 6492
 Email: hrec-enquiries@uct.ac.za
 Website: www.health.uct.ac.za/fhs/research/humanethics/forms

29 May 2020

HREC REF: 175/2020

A/Prof L Gwyther
 Department of Family Medicine
 Room 2.28, Falmouth Building FHS
 Email: liz.gwyther@uct.ac.za
 Student: Rene.krause@uct.ac.za

Dear A/Prof Gwyther

PROJECT TITLE: PALLIATIVE CARE AUDIT ON PANCREATIC ADENOCARCINOMA CANCER PATIENTS IN GROOTE SCHUUR HOSPITAL (PhD CANDIDATE- Dr Rene Krause)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

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

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020.

Approval is granted for one year until the 30 May 2021.

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)

We acknowledge that the student: Dr Rene Krause will also be involved in this study.

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.

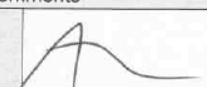
Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

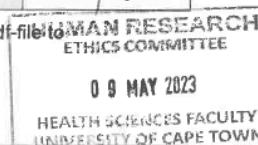
PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

HREC 175/2020sa


FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
<input checked="" type="checkbox"/> Approved	Annual progress report	Approved until/next renewal date	30/5/2024
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee			Date Signed 11/5/2023

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za
 Please clarify your plan for research-related activities during COVID-19 lockdown.
 Please use the latest form found on our website:
<http://www.health.uct.ac.za/fhs/research/humanethics/forms>



Comments to PI from the HREC

Principal Investigator to complete the following:
1. Protocol information

Date (when submitting this form)	2/5/2023		
HREC REF Number	175/2020	Current Ethics Approval was granted until	30/5/2023
Protocol title	Palliative care audit on pancreatic adenocarcinoma cancer patients in Groote Schuur Hospital		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No	
If yes, could you please provide the HREC Reference number for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	A/Prof Liz Gwyther		

Appendix S: The interaction between the theory of integration, the strategy, the context, the mechanism, the outcome and the output


Conceptual framework	Programme or strategy	Context	Mechanism (not an on off switch but a dimmer ²¹⁴)		Outcome (how effective) The changes in behaviour that result from how people respond to the intervention and contextual mechanisms.				Level of integration reached.
			<p>Interventional mechanism.</p> <p>The mechanisms contained in interventions which are designed to change the behaviour of those at whom they are targeted</p>	<p>Contextual mechanism.</p> <p>The resources and restrictions embedded in the social and organizational context may inhibit or promote the effectiveness of intervention mechanisms.¹⁴⁴</p>	What worked	For whom did work	What did not work	For whom did it not work	
		Macro:							


		<ul style="list-style-type: none"> • Appropriate policies. ^{157,159} • Not a healthcare priority. (NM) • Not funded. ¹² 							
<p><i>How a VNLDS impacted on integration</i></p> <p>A VNLDS will integrate PC in an ATH.</p>	<p>Two professional nurses, two auxiliary social workers and a clerk are employed in PC by the hospital. The university employs medical doctors volunteering in the hospital.</p> <p>They work across the hospital but</p>	<ul style="list-style-type: none"> • Large disease burden of disease ¹², limited trained staff(Man 5) HCW (Man 1,2,3,5) • Siloed structures between disciplines and disease-specific within disciplines (Man 4). • Limited PC trained staff. Man4) • Driven by personal experience Man 4). • Assumptions: <i>Only for end-of-life care</i> (Man 4). 	<p>Observing PC being delivered (ward staff 4).</p> <p>Assist in looking after patients who at the end of their life (interviews with PC team and data from REDCap database).</p>	<p>Specialized PC team in the clinical space. (interviews with PC team).</p>	<p>Referred patients and their families received PC, continuity of care and may die at home. These are mainly cancer patients outside oncology. Selected disease-specific patients</p> <p>Assisted in addressing moral distress</p>	<p>Mostly, Cancer patients outside the oncology service received PC services (REDCap database)</p> <p>HCW who observed the care had less misconceptions</p>	<p>Limited use of automatic triggers care thus PC mostly at the end of life and for limited diseases (REDCap database).</p> <p>M&E and Information systems limited to VNLDS (interviews with PC staff and ward staff)</p> <p>Clinical leadership outside.(Interviews PC staff)</p>	<p>Those who do not observe it.</p>	<p>Clinical integration</p> <p>A VNLDS achieved clinical integration, mostly in cancer patients, PC in an ATH by providing specialized skills and physical presence because they assisted in carrying the burden of care on a micro and meso level.</p>

	not in the oncology wards.	<ul style="list-style-type: none"> Avoidance of end-of-life care (Man 2). <p>Micro:</p> <ul style="list-style-type: none"> Own distress and discomfort talking about own mortality (Man 2,4) Assumptions: <i>do not require further training (man 4).</i> Supportive and wish for dignified care (sample bias) (Man2). Value excellence.³⁹ 			in staff who acknowledged distress.	about PC.(Referral patterns in REDCap database, Ward Staff 4)	Limited organizational functional integration. (ward staff 1)	leaders	
A description of how registrar palliative care training affected palliative care integration in South African oncology.	An intermediate level palliative care education programme was developed for	<ul style="list-style-type: none"> As above but only sees confirmed cancers (referral criteria) Driven by disease specific 	Addressing registrars' knowledge of PC (MCQ results in Chapter 5.2)	Mandatory examinable education for registrars (Chapter 5.1)	Registrars know how and want to provide PC (chapter 5.1) Registrars demonstrate	Registrars (Chapter 5.1)	Registrars are not always able to deliver PC services (FGD Reg 4)	Registrars and patients	Educating registrars aimed to achieve organizational level integration but did not achieve clinical functional integration because of limited clinical PC

<p>Educating registrars will impact on the integration of PC in oncology services</p>	<p>oncology registrars across South Africa.</p> <p>In GSH it is followed with limited mentorship on a combined care ward round with specialised PC services.</p>	<p>Protocol (sup 2).</p> <ul style="list-style-type: none"> • Macro level oncology leadership. Chapter 5.1. 	<p>Addressing registrars' misconceptions about PC (FGD Reg 3).</p>	<p>Senior oncologist has limited or no PC training FGD Reg 4)</p>	<p>positive resilience when exposed to suffering (sup1).</p>		<p>Confusing and limited PC oncological resources (Protocol for managing adenocarcinoma of the colon, the Standard Operating Procedure for non-small cell lung cancer and the Protocol for Treatment of Gynaecological Malignancies)</p> <p>Clinical leaders in oncology.</p>	<p>Clinical leaders in oncology</p>	<p>resources in the clinical setting. The developers of the resources are not trained.</p>

<p>Evaluate how a quality improvement cycle using audit impacted on the integration of PC in patients with PDAC care.</p> <p>Using the defined process of Qaudit impacts on the integration of PC in PDAC patients.</p>	<p>Using a QI process specifically for PDAC patients.</p>	<ul style="list-style-type: none"> As above In surgery with well described barriers. More technical and more specific. 	<p>Collaborative decision making. (Focus group discussion)</p>	<p>Structured indicators and care pathways (audit parameters)</p>	<p>Most Patients diagnosed with PDAC disease received PC services early (Audit outcome)</p> <p>Supporting HCW in carrying the burden of care (P5)</p> <p>Non PDAC patients in the ward also had more access to PC services. (REDCap database.,P2)</p>	<p>Patients and families (Audit outcomes)</p> <p>HCW</p> <p>PC patients in the same ward.</p>	<p>Nurses not included in the decision making (P4)</p>	<p>Patients and families</p>	<p>Using QI achieved clinical and professional integration because it aligned with the context of being very specific and participant orientated.</p>
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<p>Conceptual framework</p>	<p>Programme or strategy</p>	<p>context</p>	<p>Mechanism (not an on off switch but a dimmer²¹⁴)</p>	<p>Outcome (how effective)</p> <p>The changes in behaviour that result from how people respond to the intervention and contextual mechanisms.</p>	<p>Level of integration</p> 
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			<p>Interventional mechanism.</p> <p>The mechanisms contained in interventions which are designed to change the behaviour of those at whom they are targeted</p>	<p>Contextual mechanism.</p> <p>The resources and restrictions embedded in the social and organizational context may inhibit or promote the effectiveness of intervention mechanisms.¹⁴⁴</p>	<p>What worked</p>	<p>For who did work</p>	<p>What did not work</p>	<p>For whom did it not work</p>	
	<p>A pandemic with a high death burden is an enabler of PC integration</p>	<p>As above but also 10x death rate of patients</p>	<p>Awareness of the best care did not change the outcomes of patients and the real risk of own death.</p>	<p>PC teams on the wards.</p> <p>Practical guideline and approved SOP for the patients</p>	<p>Clinical and emotional support</p>	<p>HCWs on the wards.</p>	<p>Managerial support in the hospital.</p>	<p>PC teams</p>	<p>Assisted in providing clinical, professional and systems integration.</p> <p>Not organizational integration.</p>

				developed by provincial management.					
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Appendix T: Key aspects of the methodology in chapter 5 and 6

	Chapter 5	Chapter 6
Aim	To determine the reaction of the oncology registrars and their supervisors to the course to determine changes in knowledge and skills, and to determine the application in oncology practice.	To describe how intermediate level palliative training affected PC integration in Oncology at Groote Schuur Hospital in South Africa.
Sample population	<ul style="list-style-type: none"> registrars (n = 32) from all 5 universities facilitators across (n= 5) from all 5 universities. 	<ul style="list-style-type: none"> Secondary data analyses from the focus group discussions held with only the UCT registrars (n=7) and supervisors (n=3) Interviews with supervisors not involved in the Training Evaluation described in chapter 5 (n=3) Document analyses of guidelines and policies within the oncology department, as guided by the interviews, policies, and guidelines on key conditions where a PC approach is needed.
Outcomes	<ul style="list-style-type: none"> A positive reaction towards the PC course by the oncology registrars and their supervisors. The training was found to be feasible, and the topics addressed were appropriate. Concerns, previously raised by College of Radiation Oncology of South Africa, regarding the feasibility and appropriateness of the course and material were found to be unsubstantiated. The poor MCQ results can be ascribed to poor sequencing of the execution of the question. However, the MCQs in module 7 and 8 (symptom management) demonstrated the most significant change in knowledge and skills (symptom management). The FGDs demonstrated a perceived change in knowledge and skills especially for communication skills and pain and symptom management. 	<ul style="list-style-type: none"> PC education seems to enhance patient and family-centred care, contributing to improvements in the normative aspects of integration. Focusing solely on training registrars has proven insufficient in achieving crucial functional aspects of integration. The misalignment between policies, guidelines, and registrar education constrains effective integration of a PC approach. Consultants' lack of training in palliative care poses difficulties in implementing comprehensive patient care.

	<ul style="list-style-type: none">• The FDG's also indicated that the registrars' approach to PC changed in that they were able to integrate the principles of PC into practice, and now saw PC as an essential component of oncology.	Complete 'functional integration' is inhibited by palliative care clinical- leadership remaining outside of oncology.
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Appendix U: Elements of the audit in Chapter 7

Audit Outcomes

Folder No	_____
Record logged on both PDAC and PC registry	<input type="radio"/> Yes <input type="radio"/> No
Delay: referral to GSH admission	_____
Delay: admission to diagnostic / investigative procedure	_____
Delay: admission to 1st invasive therapeutic intervention	_____
Delay: admission to 2nd invasive therapeutic intervention	_____
Delay: admission to BBN	_____
Delay: BBN to PC referral	_____
Delay: Admission to PC referral	_____
Delay from discharge-ready to actual discharge	_____
Index Hospitalisation Duration	_____
Delay: Discharge to Oncology Appt.	_____
Number of days from last chemoradiation to death	_____
Hospital admission during final 30 days of life?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown (LTFU)
Reason for hospital admission during final 30 days of life	<input type="radio"/> Unavoidable <input type="radio"/> Avoidable / Inappropriate
Complaints from patient or family	<input type="radio"/> Documented <input type="radio"/> None documented
Any comments	_____

Audit Outcomes

Folder No	_____
Record logged on both PDAC and PC registry	<input type="radio"/> Yes <input type="radio"/> No
Delay: referral to GSH admission	_____
Delay: admission to diagnostic / investigative procedure	_____
Delay: admission to 1st invasive therapeutic intervention	_____
Delay: admission to 2nd invasive therapeutic intervention	_____
Delay: admission to BBN	_____
Delay: BBN to PC referral	_____
Delay: Admission to PC referral	_____
Delay from discharge-ready to actual discharge	_____
Index Hospitalisation Duration	_____
Delay: Discharge to Oncology Appt.	_____
Number of days from last chemoradiation to death	_____
Hospital admission during final 30 days of life?	<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown (LTFU)
Reason for hospital admission during final 30 days of life	<input type="radio"/> Unavoidable <input type="radio"/> Avoidable / Inappropriate
Complaints from patient or family	<input type="radio"/> Documented <input type="radio"/> None documented
Any comments	_____

The end