

Knowledge and perceptions of doctors in a tertiary level hospital in KwaZulu-Natal towards palliative care

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Short Poem

*Strange is the visa of life...
It can be cancelled at any time*

*The duration of its validity is unknown...
And its extension is too impossible*

Hakeem Muhammad Akhtar
(Poet, philanthropist and sufi mentor)

Abstract

Background:

South Africa (RSA) was a signatory to the 2014 World Health Assembly resolution that highlighted the importance of ongoing palliative care (PC) education amongst disciplines that manage patients with life-limiting illnesses. Thereafter, policies, such as the National Policy Framework and Strategy on Palliative Care, were established that advocated for the integration of PC. PC education has also been incorporated into undergraduate curricula and the training of oncology registrars. However, except for integration of PC at a few centres in RSA, a large deficit of hospital-based PC still exists. Limited previous work has been done that investigates the knowledge and perceptions that doctors at tertiary centres in RSA possess towards PC.

Objective:

To assess the knowledge that doctors at a tertiary level hospital have regarding PC, and to determine the perceptions of these doctors towards PC.

Methods:

A prospective, observational, mixed-methods study consisting of a quantitative knowledge survey (n=65, response rate 66.32%) and qualitative semi-structured interviews (n=12) was undertaken. The survey data was analysed using statistical methods with the assistance of a biostatistician whilst, for the semi-structured interviews, thematic analysis was used.

Results:

Participants displayed an awareness of the concept of PC and its importance. There was good awareness of the role of the inclusion of patient and family preferences in decision-making. However, several knowledge deficits regarding the timing and scope of PC still prevailed. PC was largely seen as synonymous with end-of-life care, and the roles of PC beyond the physical domain were poorly understood. Some aspects regarding futile care were poorly understood. Additionally, misconceptions regarding the use of morphine were present. The majority of the knowledge deficits and incorrect perceptions prevailed regardless of level of experience or cadre. Participants admitted to knowledge gaps and to the lack of implementation of policy that underpins the need for PC. Creation of a PC service would be well received and suggestions were given on ways to integrate PC within the hospital.

Conclusion:

In KwaZulu-Natal, more education is required to improve knowledge surrounding matters related to PC and a formal PC service is much needed.

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Acronyms

ACD	Advanced chronic disease
AIDS	Acquired immunodeficiency virus
APCC	Association of Palliative Care Centres
BRICS	Brazil, Russia, India, China and South Africa
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CME	Continuing medical education
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital
COVID	Coronavirus disease
DoH	Department of Health
EAPC	European Association for Palliative Care
EOL	End-of-life
GP	General practitioner
GSH	Groote Schuur Hospital
HCP	Health care practitioner
HIV	Human immunodeficiency virus
HPCA	Hospice Palliative Care Association
ILD	Interstitial lung disease
IVF	Intravenous fluids
KAPB	Knowledge, attitude, perceptions (or practices) and beliefs
KZN	KwaZulu-Natal
LLI	Life-limiting illness
LMIC	Low and middle-income country
MDT	Multi-disciplinary team
MeSH	Medical subject headings
MBChB	Bachelor of Medicine and Bachelor of Surgery
MPhil	Masters in Philosophy
MTech	Masters in Technology
NCD	Non-communicable diseases
NGO	Non-governmental organisation
NHI	National Health Insurance
NPFPC	National policy framework for palliative care

PC	Palliative care
QOL	Quality of life
RSA	Republic of South Africa
SAMJ	South African Medical Journal
SAMRC	South African Medical Research Council
SSA	Sub-Saharan Africa
SSI	Semi-structured interviews
TB	Tuberculosis
UCT	University of Cape Town
WHA	World Health Assembly
WHO	World Health Organisation

Chapter One: Introduction

What is Palliative Care and why is it significant?

Palliative Care (PC) is defined by the World Health Organisation (WHO) as ‘an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness’.¹ It encompasses early identification of life-limiting illness (LLI), accompanied by accurate assessment, as well as effective management of pain and other physical symptoms. Additionally, one of the principles of PC is to address psychosocial and spiritual issues that may be present.

The significance of PC has been highlighted by the World Health Assembly (WHA) Resolution 67.19 of 2014, which declares that PC is a necessary component of ‘comprehensive health care delivery throughout the life course’ and ‘an ethical responsibility of health systems’.² This is especially important because, each year, approximately 56.8 million people globally suffer with LLI that requires the integration of PC services. Of this group, roughly 25.7 million are in the last year of life.¹ It is thus crucial that healthcare providers (HCP), and doctors in particular, have the correct knowledge and understanding of what PC entails, how to offer generalist-level PC services, and are able to refer patients to appropriate services.

Furthermore, The World Palliative Care Alliance³ (WPCA) has recommended that PC should be embedded within the healthcare network of any country, and that the healthcare system should integrate with the non-governmental organisation (NGO) sector to deliver effective PC services. However, as the public health situation in each country may differ significantly, PC organisation and provision ought to be tailored to the setting, prevailing cultures and patient needs.³

The Republic of South Africa (RSA) was a co-sponsor of the 2014 WHA resolution on PC. Policymakers in RSA also saw PC as an important component of patient care. As such, the National Policy Framework for Palliative Care (NPFPC) was adopted in 2017 (but has subsequently expired). Additionally, the National Health Insurance (NHI) Bill was tabled in parliament in 2019.⁴ This bill advocates for PC as part of universal health coverage. It is important that doctors, patients and families realise that PC provision to patients with LLI is a crucial and essential component of the medical care of the patients, even when patients are not terminally ill.⁵ However, until recently, PC has been associated with hospice and end-of life (EOL) care, with many HCP, and the public, solely associating PC with the care of patients with cancer.⁶

There are many well-established benefits that PC has been proven to provide. Effective PC provision can substantially reduce patient suffering, whilst enhancing quality of life, and may even prolong life.^{5, 7-10} Furthermore, PC positively impacts healthcare outcomes in patients and their families.⁸ Moreover, PC can serve as an effective adjunct to care, aiding communication with patients, and enhancing prognostic awareness.¹¹ Additionally, hospital visits and the cost of care to both the patient and the healthcare system are reduced.^{5, 9, 11-16} Furthermore, when PC approaches are implemented, the integrity of public health delivery could be enhanced, and timeous PC will likely support patients to die in a location of their choice.^{8, 10, 17-20} Lastly, when PC principles are integrated into care, families are assisted after the death of the patient, via the incorporation of bereavement care.²¹

The difference between palliative care and end-of-life care

Whilst PC and end-of-life (EOL) care are similar concepts and often intertwined, they are actually separate entities. Indeed, EOL care forms an important component of PC. PC aims to enhance a patient's quality of life from a physical, psychosocial, and spiritual perspective after being diagnosed with a LLI and should be initiated early on.^{1, 22, 23} On the other hand, EOL care involves focused care within the last portion of a patient's life.^{23, 24}

Furthermore, by the EOL stage, if PC was appropriately initiated, the patient and family should usually be aware of the prognosis and management plan. Care at this stage ought to take place at a location of the patient's choice. Additionally, hospital admissions should be minimised, and care taken to avoid futile interventions. Inevitably, an important component of this phase of patient care is to ensure that the patient dies with dignity and comfort, surrounded by loved ones, in an appropriate location.¹⁷

Unfortunately, even within the developed world where PC services are often readily available, many providers have incorrect knowledge and perceptions regarding PC, or are unsure about when to refer to these services.^{6, 14, 16, 24-28} These HCP incorrectly view PC as care provided when treatment is no longer aimed at cure, or as only EOL care and therefore only offer PC late for symptomatic management and comfort care. It is therefore important to assess what doctors know about PC, and to investigate some of the incorrect perceptions surrounding PC, so that the benefits of PC can be realised.

The role that the knowledge and perceptions of doctors plays in the provision of palliative care

The Geneva Declaration of the physician's pledge, states that a doctor should offer 'treatment he is well-versed in'.²⁹ Furthermore, the Hippocratic Oath compels doctors to 'do no harm'.²⁹ Additionally, healthcare, including PC, needs to be delivered in the right order, at the right time, in the right setting, and with delivery of the right healthcare services.³⁰ However, it may be argued that the timing of PC referral is not straightforward, and therefore 'the right order' and 'right time' are debatable. This is because interpersonal, subjective and institutional factors play a role in the decision to initiate or refer to PC.⁹ Notwithstanding this, it can be argued that the PC knowledge doctors possess and the perceptions they have of PC are likely key components leading to the 'delivery of the right healthcare services' in this context.

In addition, the European Association of Palliative Care (EAPC) recommends that all healthcare professionals should be equipped with some degree of PC skills,³¹ so that PC can be delivered in at least two tiers; with an overarching PC approach, or with specialist PC services. A third layer of care was suggested to be 'generalist' PC, provided by HCP who often care for patients suffering from LLI. Generalist PC refers to providers having undergone some sort of basic, informal PC training. Additionally, studies have emphasised the need for doctors to have good communication skills, awareness of appropriate prescribing of analgesia, competency in loss and grief counselling, and awareness of how to adopt a basic PC approach.^{6, 14, 17, 32-35} These sentiments were echoed locally in an article by Burger et al.³⁶ emphasising that, especially in RSA, doctors of any level or discipline should have at least some basic PC training when caring for patients suffering from LLI and their families. Accordingly, at tertiary hospitals, where patients with LLI are often seen, PC should be delivered at globally acceptable standards, by doctors familiar with PC approaches. Doctors without adequate PC knowledge, or incorrect perceptions, need upskilling to ensure that the provision of PC can be achieved, and to make PC an effective tool when caring for patients with LLI.^{2, 3, 37}

There are many centres globally that offer a dedicated PC service, predominantly in first-world countries. However, studies have proven that, notwithstanding this, poor knowledge regarding the timing of PC, as well as incorrect perceptions regarding PC, has led to suboptimal utilisation of these facilities.³⁸⁻⁴⁰ As such, this proves that a gap in PC education may directly lead to late referral to PC and suboptimal patient care.

PC should be aimed at the care of all patients with LLI, including patients with advanced chronic disease (ACD). Internationally, there is a growing public health burden of LLI caused by ACD (both communicable and non-communicable disease (NCD)).^{6, 34, 41, 42} Such ACD is regularly encountered at hospital level. As such, hospital doctors that manage LLI should be equipped with sound knowledge regarding the application of PC principles, and the integration of a biopsychosocial-spiritual approach to care.

For patients facing LLI, the doctor may be the first person to break bad news or the person that they trust the most with the management of their illness. Therefore, doctors need to be equipped with the awareness of how to skilfully break bad news, communicate empathetically, practice 'truth-telling', and share all information in an honest, yet sensitive manner. This requires appropriate knowledge regarding PC principles and approaches when caring for patients with LLI. PC knowledge empowers doctors to holistically explore the patient's perspective, including physical symptoms and signs, psychosocial stressors and their unique spiritual, cultural and religious beliefs and concerns. Ultimately, a PC approach will hopefully ensure that the doctor is able to offer appropriate person-centered care to these patients.

Why is a study on the 'Knowledge and perceptions of doctors in a tertiary level hospital in KwaZulu-Natal towards palliative care' needed?

Locally, approximately 30% of South African doctors are employed within the state sector, which is responsible for health services delivered to 84% of the population.⁴³ Whilst establishment of formal state sector hospital-based PC services has been realised in Gauteng¹⁷ and the Western Cape,¹² various constraints may currently hinder the creation of a similar PC service in KwaZulu-Natal (KZN). However, doctors could still equip themselves with skills to adopt a PC approach or develop 'generalist' PC knowledge. These doctors can then deliver more effective patient care, and some benefits of PC delivery could then be realised.

The researcher is of the opinion that there appears to be large gaps in PC provision in many parts of RSA and, in particular, within the state hospital setting in KZN. Reasons for this are likely multifactorial. However, the researcher questioned whether a contributing factor towards this could be poor provider knowledge of PC, or incorrect perceptions regarding PC. The data to inform this is currently insufficient.

What is known, however, is that the NPFPC was approved by the National Health Council in 2017, and thereafter work on PC in the country escalated.¹² This document clearly outlined a plan for PC in RSA and highlighted the reasons why PC is an essential component of healthcare delivery. However, as of January 2025 it appears that, in KZN, PC services have not expanded beyond the community level, despite many patients with LLI being treated at hospital level. Therefore, it could be argued that, despite the NPFPC, lack of knowledge and poor perceptions regarding PC persist, and PC delivery is thus suboptimal.

Equally important is the fact that there are examples already in place in other provinces of RSA serving as proof of the effectiveness of PC services within the state-sector.^{12, 17} However, from an observational level, it appears that the impetus to expand PC services in KZN is still deficient. This may be due to doctors, departmental heads, and institutional stakeholders not deeming PC to be essential. Additionally, based on the researcher's discussions with colleagues, it appears that the established PC research and policies were not well known. Therefore, it is likely that poor knowledge and perspectives may impact decision-making.⁴⁴ An investigation of doctors' knowledge of and perceptions towards PC will thus assist in highlighting knowledge gaps and assessing perceptual inaccuracies that need to be addressed.

Furthermore, PC forms an essential part of the management of several NCD. Locally, the need for further education of HCP regarding NCD, and the need for appropriate management of NCD, has been emphasised. For example, the South African Medical Research Council (SAMRC) stressed the need for increased investment targeting the care of NCD.⁴⁵ Mayosi et al.⁴² also argued for significant investment to tackle the 'rising epidemic' of NCD. The need to improve PC services is likely part of this. Furthermore, this would include the assessment of what is currently known regarding PC, so that education can be tailored to close the knowledge gaps regarding PC.

Additionally, research is progressively increasing on the need for PC in non-cancerous NCD,³⁹ as well as for communicable diseases⁵. As such, with the increasing burden of non-cancerous disease globally, a greater need for PC exists. Therefore, research regarding the knowledge and perceptions of doctors towards PC needs to extend beyond oncology doctors. Understanding what these doctors know can assess knowledge gaps, inform PC education and possibly used to inform decision-making regarding the creation of a formal PC service in KZN.

The researcher focused this study on doctors employed at a tertiary hospital in KZN, Grey's Hospital. This is because, in KZN, no formal full-time palliative care service exists for adults at a tertiary hospital, and only one paediatric-based palliative care post exists. It is therefore evident that, in spite of the aforementioned drives towards the escalation of PC delivery, and the position of PC as a public health priority both nationally and globally,⁴⁶ KZN is lacking in the delivery of this aspect of care. Ultimately, the identification of knowledge gaps and incorrect perceptions around PC in doctors not formally trained in PC could encourage PC education and, consequently, a stronger drive for the creation of a formal PC service within the hospital. Many doctors, as well as patients with LLI, stand to benefit from these measures.

Approach to the study

Study type

Knowledge, attitude, perceptions (or practices) and beliefs (KAPB) studies

Rationale behind the chosen study type

Knowledge, attitude, perceptions (or practices) and beliefs (KAPB) studies are a beneficial means of studying populations.⁴⁷ They provide a cost-effective, easily designable, quantifiable means of analysing data, and are reliable as a method of performing public health related studies.⁴⁷ Recognition of misunderstandings and misconceptions within the target population allow certain hypotheses to be either proven or nullified, knowledge deficits identified, myths recognised and interventional needs analysed. Gaps and socioeconomic and cultural factors are also easily assessed. The effectiveness of these studies is heightened when little, or no, previous data on the topic is available on the target population, as is the case with the current study. These studies do come with limitations, including, difficulties with accurate data interpretation and analyst biases.⁴⁷

Mixed methods studies combine quantitative and qualitative approaches in order to gain a better understanding of phenomena that are being researched.⁴⁸ As such, the researcher adopted this approach to gain a richer understanding of the knowledge and perceptions of doctors towards PC.

Rationale behind the study

A blueprint describing the rationale for the creation of a hospital-based PC service in RSA exists. Gwyther et al.¹² highlighted this in an article, entitled 'The development of hospital-based palliative

care services in public hospitals in the Western Cape, South Africa'. However, based on the researcher's discussions with colleagues, even at senior level, this article is not well known.

Furthermore, Selma Browde established the first hospital-based PC team in RSA in the Johannesburg General Hospital (now Charlotte Maxeke Johannesburg Academic Hospital (CMJAH)) in 2001.⁷ Despite this, twenty four years later, no formal hospital-based PC service exists in KZN. Therefore, the researcher questions why KZN has fallen behind with this, and questions whether the knowledge and perceptions of both doctors and policymakers towards PC has played a role in this. Consequently, the researcher argues that, with a few small educational interventions, a 'nurse-run, doctor directed PC clinic', as was created by Browde,⁷ could be incorporated into the existing service.

Based on the researcher's knowledge, this is the first mixed-methods study on this topic performed at a large center in KZN. This researcher hopes that this study can be used to enhance awareness of PC and highlight prevalent knowledge and perception shortfalls. Furthermore, this researcher endeavours to motivate doctors to study PC further formally or informally, so that PC can be embedded more effectively within their practice. Additionally, using the information gleaned in this study, the researcher wishes to advance the drive for implementation of a fully integrated PC service in KZN.

Chapter Two: Literature Review

Overview of literature review

A narrative literature review was performed to provide a synthesised look at the available literature on this topic. Multiple databases were accessed in order to increase the reliability of the findings.

Methodology of the literature review

A comprehensive search strategy was developed, in partnership with a specialist librarian at the University of Cape Town (UCT). The search was conducted using recognised academic databases. Metasearches of the literature using the UCT's Primo portal and Google Scholar were also performed. These searches incorporated combinations of the keywords 'knowledge', 'attitude', 'perceptions', 'beliefs', 'doctors', 'KZN', 'South Africa', 'palliative care' and 'palliative medicine'. Relevant medical subject headings (MeSH) terms and Boolean phrases were also incorporated, where applicable. These are further described in [Appendix A](#).

Contextually relevant literature was also sought within the UCT library resources, such as its internal repository, 'OpenUCT'. Additionally, contributions were sought from local experts in the field of PC, and suggested resources were either emailed to the researcher, or located online.

All literature from 30 years prior to development of the research protocol was included in the search (1992 to current day), however the search excluded studies that didn't involve doctors, unless specifically deemed to be critical to the requisite evidence base or setting. All non-English articles were excluded, except one article that was published in both Spanish and English. The researcher incorporated literature pertinent to the study until sufficient data was extracted to formulate the literature review.

The comprehensive search strategy is included in the appendices [\(Appendix A\)](#).

History of PC in a South African context

PC was first formally introduced to RSA in the 1970's,⁴⁹ and is now a growing discipline locally. Since then, over one million PC-based interventions to over thirty thousand patients and their loved ones have been delivered.⁵⁰ Progress made on PC in RSA was highlighted, when the second edition of the Global Atlas of Palliative Care was published in 2020.⁵¹ This atlas identified RSA as a country with level 4a status, signifying that PC is already at the preliminary state of integration within the healthcare

system.⁵¹ Such recognition brings hope that PC can progress faster in RSA, including development resources aimed at increasing PC delivery.

Policy supporting the strengthening of PC services in RSA is well established, including the NPFPC and the passing of the National Health Insurance (NHI) bill in 2019, which incorporates a comprehensive package of PC services¹⁸ and the inclusion of PC into the National Referral Policy.¹⁸ However, whilst international studies have demonstrated PC integration into hospital-based services,¹² hospital-based PC services are still lacking in RSA. A local study by Sithole⁴⁹ in 2012 emphasised that community-based hospices could not meet the PC needs of all patients. Whilst this was a qualitative study done as part of Masters' thesis (discussed later), the multi-centre study pointed towards an important gap in the PC structure locally, namely efforts to expand PC services to a hospital level. To emphasise the impact of hospital-based PC services, a small study by Kirk and Collins,⁷ reporting on the PC service at CMJAH, demonstrated that this service holistically improved patient health, including physical, functional, social and emotional well-being. This 2006, single-centre study of a small cohort of patients provided insight into the potential of hospital-based PC for patients with LLI in RSA. However, more studies of this kind are required in RSA.

After the development of the PC team at CMJAH, other PC services were developed, including the Gauteng Centre of Excellence for Palliative Care at the Chris Hani Baragwanath Academic Hospital, the Abundant Life PC program at Victoria Hospital in Cape Town and the PC Department at the Groote Schuur Hospital (GSH), also in Cape Town. However, as Gwyther et al.¹² report, PC as a hospital-based speciality in RSA is still a developing field. Despite literature from these centres highlighting the benefits of PC, more efforts are required to assess existing knowledge and perceptions towards PC nationally, and what measures can be taken to incorporate PC in RSA's resource-limited state hospital setting.

PC Education in South Africa

One of the keys to any healthcare service is the education of the HCP regarding the options of care that are available to the patient.^{12, 36, 41, 52, 53} However, in the modern era of medicine, there may be a focus on interventions aimed at cure, rather than supporting the suffering patient.^{30, 38, 52, 54-56} As such, there is a dire need for the development of education programs aimed at enhancing doctors' knowledge of PC in RSA.

To address this need, the postgraduate palliative medicine program was developed at the University of Cape Town (UCT) in 2001.⁵² In 2007, Gwyther and Rawlinson⁵² reported on its progress from 2001

to 2007. This report was a comprehensive review of PC education over the period, and provided reasons to support the progression of PC education locally. The study found that enrolment in the program was due to personal interest from the doctors, and that students partook in these studies to improve patient care. However, at the time of the study, the UCT program was limited to doctors only, and there was clear evidence that PC education needed to expand beyond this.

In the early stages of this program, it was found that doctors may have had time limitations that prevented them from undertaking formal university studies.⁵² However, it was essential that HCP optimised their PC capabilities. As such, a 6 month 'Introduction to Palliative Care' distance learning course was created, available to all HCP.⁵² The timing of this program was fortuitous, as results from the Gwyther and Rawlinson⁵² study also reported that CME at a single event may not necessarily equate to conversion into practical skills. The report by Gwyther and Rawlinson⁵² did not report on universities other than UCT, however it provided important insights into the desire of HCP to improve patient QOL, and paved the way for further PC education and research.

Over time, as evidence supporting the need to improve PC education increased, some universities in RSA began integrating PC into their curricula. Most medical universities in RSA have now adopted PC modules as part of their undergraduate curricula.³⁶ Reporting on this, Burger et al.³⁶ published a position paper describing undergraduate PC education for doctors in RSA. This paper reported that, by 2021, most South African universities (seven out of eight) had positively responded to these PC education needs by integrating PC education into the undergraduate curricula. However, there was no standardisation of the course content, and the methods of delivery varied. Additionally, only one university (UCT) met the EAPC recommendation of 40 hours of undergraduate training that reflects undergraduate PC education competency. Furthermore, only three programs included practical bedside PC education. Shortage of PC education in the pre-clinical undergraduate years was described. Describe this paper extensively reporting on the status of PC education at most South African medical schools, and notwithstanding positive findings that were presented, the study did not follow up with regards to what these students, once graduated, were able to achieve in terms of PC delivery in the workplace. Further studies looking at the effects of this education on healthcare service delivery are warranted.

Furthermore, RSA's health system encompasses several academic state hospitals. The aforementioned WHA resolution stressed the need for 'intermediate level' PC training.⁵⁴ Many African countries, including RSA, agreed to this resolution, via the signing of the Kampala Declaration.⁵⁷

Therefore it is necessary to integrate PC training into the curricula of postgraduate registrar programs. However, until 2016, PC did not form a part of formal postgraduate registrar programs.⁵⁴ Additionally, little was known about what level of PC education should be delivered to registrars, and how this education should be delivered. Furthermore, as of 2023, a significant gap was still noted in PC training for South African clinicians, and PC was still not recognised as a field of medical specialisation in RSA.⁵⁸

Therefore, in 2017, a pilot project was developed by UCT, with the aim of aligning PC locally with international standards. This intermediate-level PC training program targeted radiation oncology registrars. In 2021, Krause et al.⁵⁴ published the results of this intervention, which demonstrated that, doctors appreciated the benefit of this program to their overall career growth. In addition, the doctors saw PC as an essential component of the care required by their patients. Furthermore, whilst there were some concerns regarding the course content layout, it was almost unanimous that this training provided clarity regarding the interface between curative treatments and a PC approach. The programme proved that efforts to enhance PC education can be positively received, despite busy schedules and resource constrained workplaces. While acknowledging possible biases from the study authors evaluating their own programme, the small study cohort of only 32 registrars, and despite the fact that only five training centres and one discipline were included, the study shows promise in paving the way to increase PC education at all academic levels in RSA. Furthermore, the results of this study could prompt the integration PC education can be into other registrar training programs. More research is required to assess how amenable other departments will be to PC education.

As it was important to reflect on the long-term impact of the aforementioned intermediate-level PC training program, in 2024, Krause et al.⁵⁹ published the results of a secondary analysis of data from the previous study. In this study, an important finding was made that education alone has a limited impact. It was found that, for effective, sustainable PC services, hospitals required the creation of means for policymaking, implementation and evaluation of services, dedicated PC teams, standardised service delivery protocols for and facilitation of care co-ordination. This was a smaller study, qualitative in nature, and limited to GSH. Therefore, it may not be reflective of the picture elsewhere. However, it indicated that similar work at other centres is warranted.

[Burden of disease requiring a palliative care approach](#)

Statistics reveal that, each year, approximately 56.8 million people suffer from LLI and have PC needs.¹ Of these, an estimated 25.7 million people are in the last year of life. However, a large majority of global deaths are individuals from low and middle-income countries (LMIC) and these people likely die

without access to basic PC.⁶⁰ Notwithstanding the large proportion of deaths in LMIC's, first-world countries are not spared as, even in the developed world, health systems may fail to deliver quality PC and EOL care⁶⁰. It is therefore important to note that, regardless of geographic location, people suffering from LLI likely experience significant biopsychosocial and spiritual distress; therefore adopting a PC approach is key to enhancing QOL in this difficult period.

Furthermore, the WHO emphasises that PC is required to tackle the rising burden of both communicable diseases and NCD.¹ This is important, as the scope of PC is therefore recognised as expanding beyond the borders of cancer care. A study has reported that deaths from NCD accounted for 39% of all deaths in RSA.⁴⁵ Around this time that study was performed, a publication by Mayosi et al.⁴² reported on the state of health in RSA, and described a statement by the WHO that estimated that RSA had a two to three-fold higher burden of NCD than countries in the developed world.⁴² Whilst this publication was not solely focused on PC, it shed important light on the need to appropriately address the burden of NCD, and therefore indirectly highlighted the importance of constituents of care such as PC. Furthermore, in addition to cancer care, PC is seen as an approach to care for patients with a variety of ACD, including medical, surgical, congenital and degenerative conditions, as well as chronic communicable diseases.¹ Despite the extensive scope of PC, poor PC knowledge, or incorrect perceptions regarding the scope of PC, when combined with underdeveloped healthcare systems and economic constraints, may prevent HCP from appropriately adopting a PC approach or referring patients for timely PC intervention. Additionally, whilst there may be criteria in use in other countries around the world, an expert panel coordinated by Krause et al.⁴¹ reported that RSA, with its unique socioeconomic circumstances, required its own set of criteria. Thus, this expert panel modified the British SPICT criteria to develop a unique SPICT-SA criteria, to guide referral to PC, which incorporates both communicable diseases and NCD. This publication provides user-friendly guidelines indicating patients that may benefit from PC, and could be used in the quest to achieve benefits of PC locally. However, despite the conciseness of this set of criteria, not much research has been performed on the awareness and usage of the criteria locally, and further research is warranted on the effect this criteria has had on PC referral and utilisation.

In addition to NCD, communicable diseases also contribute to the burden of LLI. However, in RSA there appears to be a disproportionate resource allocation favouring communicable diseases,⁴² such as Human Immunodeficiency Virus (HIV), Acquired Immunodeficiency Syndrome (AIDS), tuberculosis (TB) and, in the recent past, SARS-CoV-2 and the COVID-19 pandemic. Interestingly, however, despite well-documented studies on these diseases, research done has also demonstrated that the cancer

mortality exceeds the cumulative death rates from HIV/AIDS, TB and malaria.⁴⁶ Despite this, it is important to note that survivors of communicable diseases, such as TB, may have long-standing symptoms years after completion of medical treatment.⁵ A similar picture may manifest with virologically suppressed HIV patients. Moreover, the rapidly increasing rate of multi-morbidity – combinations of communicable and non-communicable diseases – underpins the need for investment of resources in both these disease spheres, including HCP education on PC principles, if we are to effectively tackle this growing epidemic.⁶¹ Future studies are needed on this matter.

Cancer has been reported to be accountable for 20% of worldwide deaths, and is often regarded as a common LLI³⁰. The global cancer burden is increasing, with a reported increase of 33% of cancer cases from 2005 to 2015.³⁰ Looking forward, cancer-related morbidity and mortality will likely continue to rise.³⁰ Cancer often manifests with severe pain, and approximately 60 – 80% of individuals affected by cancer experience moderate to severe pain.³⁵ As such, this large portion of the global population will have PC needs.

Acknowledging the rising cancer burden globally, Lubuzo et al.³⁰ published an article reviewing RSA's cancer burden and its approach towards cancer. The thematic review, reviewing online resources, identified cancer as an escalating public health issue, and highlighted that fragmented healthcare provided by multiple providers contributes towards poor patient care.³⁰ Additionally, HCP-related factors were among the main factors contributing to the burden of morbidity. Moreover, the publication reported that HCP had insufficient training to ensure delivery of timely care. Whilst this thematic analysis of the available literature highlighted important gaps in cancer care in RSA and poor co-ordination of care, further research, possibly via a cohort study or systematic review, is needed to isolate means to fill this gap within the cancer care framework. Deficiencies in education were also highlighted, however the means of achieving practical PC training to all cadres of staff at all levels of care was not addressed, and therefore requires further research. Additionally, similar studies which incorporate other LLI are required.

[Barriers to the provision of palliative care](#)

While there is an established need for the integration of PC into the care of both communicable diseases and NCD, there are factors that challenge the provision of PC. Such factors may include inadequate provider knowledge, misconceptions regarding PC poor policy implementation, socioeconomic and cultural factors, and variability of the geographic uptake of PC services across different regions.^{18, 20, 26, 30, 33, 35, 38, 58, 62-65} Failure to mitigate such barriers may result in adverse health outcomes which, ironically, may potentiate the need for PC in patients with LLI.

Both the RSA state and private health sectors work alongside the NGO sector. However, the state healthcare sector's sole reliance on government coffers may place strain on both provincial and national Departments of Health (DOH) budgets. Therefore, based on the financial benefits of effective PC, PC policy integration from an executive-level downwards may benefit the users and funders of the healthcare system alike.

Some shortfalls of policy implementation were highlighted in a Lancet review by Kreuter et al.³⁹ Such shortfalls included the presence of insufficient PC resources, limited availability of suitable treatments, poor remuneration for PC services, overburdened hospital systems and poor collaboration between HCP. An additional shortfall, in RSA, is the lack of recognition of palliative medicine as a formally recognised medical speciality.⁵² Whilst further research on this matter is warranted, it is likely that this has led to a decreased impetus by HCP to pursue a career in PC, or improve their existing PC knowledge.

Importantly, the researcher of the current study also noted that the Kreuter review³⁹ identified provider-related barriers to care. Such barriers included time constraints (that limit emotional conversations), personal barriers and differences in cultures and beliefs. The review concluded that such barriers led to poor provision of person-centred care. Whilst Kreuter et al.³⁹ focused on PC in the setting of interstitial lung disease (ILD) only, and was primarily authored by researchers from abroad (with some South African input), their findings highlight some of the barriers faced by all patients suffering from LLI, including poor knowledge and perceptions of doctors towards PC. Furthermore, these findings resonate in RSA. However, further research on these matters, potentially using superior modalities of studies, is warranted in the South African setting.

RSA can be described as a multicultural, multilingual nation. As an article by Burger et al.⁵⁸ reports, a high variability between the cultural groupings within RSA therefore exists. Consequently, healthcare seeking behaviour of patients is not uniform, and perceptions surrounding death-related matters may differ, with some even regarding death as taboo.^{39, 58} However, cultural factors affect both the patient and the HCP, as HCP also subscribe to various cultural groupings, which may influence care provision. Therefore, it is important that any cultural barriers are sensitively navigated. Additionally, the perceptions of HCP towards PC within a cultural context becomes important if the challenges of caring for patients with LLI are to be mitigated. At this stage, further research on the impacts of culture on PC attendance and provision in RSA is required.

Regarding the interface between PC and EOL (discussed elsewhere), Janah et al.⁴⁰ reported that doctors perceived PC to be for late stage disease. and were unaware of the role for PC when delivered concurrently with disease-modulating care. As an additional finding, despite the availability of PC services, the findings of this retrospective cohort study suggested that some doctors were unaware of the role of PC in non-cancerous diseases. Therefore, this study, although performed in the developed world, highlights that, as a barrier to PC, poor knowledge and perceptions towards PC transcends boundaries, finances and settings.

Due to the biopsychosocial-spiritual approach that PC warrants, doctors need to incorporate care of the physical disease, with careful incorporation of the psychosocial and spiritual aspects of care. However, a study by Tapsfield and Bates⁶² found hospital-based policymakers and doctors are currently focused on the physical aspects of disease alone. This study additionally reported that HIV positive patients carry a high psychological burden: 55% reported depressive symptoms and 49% reported anxiety-like symptoms.⁶² Whilst this retrospective case study was performed in Malawi, where PC services differ from those in RSA,¹⁸ it sheds light on the need to educate doctors on biopsychosocial aspects of care.

Another potential barrier to PC is the misperception amongst the healthcare fraternity that PC is expensive.¹³ However, local data published by DesRosiers et al.⁶⁶ reporting on the Abundant Life programme at Victoria Hospital in Cape Town has provided data to refute this. Abundant Life was created to address biopsychosocial issues, as well as to enhance continuity of care and reduce costs of care. Abundant Life regards care of the patient's support structure as part of its scope, and aims to achieve home deaths for patients with LLI.⁶⁶ DesRosiers' study found statistically significant results indicating that the PC service, even if provided on an outpatient basis, achieved these goals. Additionally, decreased hospital admissions and shorter lengths of stay were achieved, cumulative admission days were lower. Whilst this was a relatively small, single-centre retrospective file study, it was performed at a large state hospital serving a population of approximately 600 000 patients not covered by medical aid,⁶⁶ and provides hope that similar models can be adopted elsewhere in RSA to achieve similar outcomes.

[Global research reporting on knowledge and perceptions towards PC](#)

In the twenty-first century, technological advancements have increased the drive towards curative-based medicine, which may be seen to conflict with the role of PC.^{41, 54, 56, 58, 67} Carvalho et al.,⁵⁶ in a multidisciplinary qualitative study, found that knowledge and perceptions regarding PC are influenced by a multitude of factors, including poor referral systems, inadequate resources, deficient HCP education and a culture aimed at curative medicine (which they described as a 'biomedical hegemonic

model’). This was a small study, performed in Brazil. However, its findings can likely be extrapolated to other countries as well. In keeping with these findings, it is likely that the failure of HCP to gain appropriate PC knowledge regarding PC has revealed a negative consequence of modern medicine, wherein biomedical care is favoured, thus directly linking poor PC knowledge with decreased QOL.

There is a large body of literature describing the knowledge and perceptions of doctors towards PC globally. A full review is beyond the scope of this narrative review. Two salient articles from India however, will be highlighted. This is because India shares similarities with RSA. Like RSA, it is a developing country and a member of the Brazil, Russia, India, China and South Africa (BRICS) organisation. Importantly, the ‘Indian Health Policy of 2017’ was passed, which, like RSA’s NPFPC, recognised PC as an essential component of patient care. It appears, however, that India continues to face difficulty with policy implementation and shares challenges regarding doctors’ knowledge and perceptions of PC with RSA.

Firstly, an Indian paper by Atreya et al.³³, highlighted the fact that there was a definite shortfall between the need for specialist PC services and the provision of these services. This shortfall was present at all levels, due to the lack of trained professionals. Other challenges to PC provision included inadequate skilled doctors, education gaps, poor perceptions towards PC and deficient communication amongst HCP. Consequently, this led to patients with LLI often being treated by many HCP who were not PC trained. The paper mentioned that it is imperative that these physicians obtain the requisite PC knowledge, and identified a list of essential PC knowledge that doctors should possess, including the following:

- Physical symptom assessment and management
- Awareness of settings of care and ensuring continuity of care
- Psychosocial and spiritual care
- Knowledge of communication skills and breaking bad news
- Knowledge of ethical and legal aspects of care
- Bereavement care and family support

Whilst this paper was authored by experts in India, no dedicated study was performed that was directly linked to its publication. However, it provided an overview of the state of PC in India and suggested core competencies that doctors should possess with regards to PC.³³ In spite of it being an assessment from India, similar situations could possibly occur in other countries of the world. The recommendations of this study could thus lead to enhanced PC anywhere. However, if extrapolated

to RSA, the question remains regarding whether similar measures would work effectively, and future research is warranted.

Another Indian publication by Ghoshal et al.⁶⁸ reported on existing findings from other studies which demonstrated that informal training methods, can 'improve professional practice and healthcare outcomes', including PC related practices. However, the findings of this study also showed that knowledge alone is not sufficient to provide PC and that it should be coupled with positive attitudes and perceptions towards PC. This study displayed that various HCP possessed fair knowledge of PC, but had negative perceptions towards PC. Additionally, these HCP admitted to having poor skills to effectively carry out PC services. Significantly, this study reported a three to six-fold increase in PC knowledge and improved perceptions of PC after a short course in generalist PC training. Whilst this cross-sectional survey of 62 participants cannot be deemed to be an adequate reflection of the global and/or local picture of PC, and whilst the study utilised a non-validated, non-translated survey tool, results nevertheless suggest that similar issues could be occurring elsewhere. The diversity of HCP involved may also limit its applicability to the current study. However, whilst there are many courses of variable durations to train HCP in PC and optimal training is debatable, the finding of a positive outcome with such a short teaching span is reassuring.

In addition, the benefit of a shift in knowledge and perceptions after short course PC training is also demonstrated by other studies. A report on the PC training of healthcare workers who treat patients with multi-drug resistant TB by Krakauer et al.⁵ found that as little as three to six hours of PC training can enhance levels of emotional support that is provided to patients, and assist with identification of complex symptoms that require further care and attention. Whilst this cohort of patients and staff may have been small and the exact improvement from the training could not be quantified, the finding that a short period of focused training can yield positive results is encouraging. Consequently, the findings of this study can be used to help motivate other HCP who treat patients with LLI to increase their knowledge regarding PC and improve their perceptions of PC as well.

[Matters surrounding knowledge and perceptions towards PC in South Africa](#)

As the burden of communicable disease and NCD continues to rise, efforts aimed at increasing the quality of care that is provided to patients with LLI also need to increase. Included in these efforts would be assessment of the knowledge and perceptions towards PC, so that education can be tailored to the needs of the region. The study by Gwyther and Rawlinson⁵² reported that the focus of the mainstream healthcare system in RSA has traditionally been on disease-orientated care. Furthermore, they found that many doctors admitted to being uncomfortable with the management of patients

with LLI and expressed despondency when specialist PC advice or services were absent. This indicates a lack of knowledge or negative perceptions regarding PC and towards a definite need for the escalation of PC education locally. However, there is currently limited local data describing the knowledge of and perceptions towards PC in RSA.

Results extracted from existing published dissertations

Elizabeth Booth,²⁴ in her Masters in Philosophy (MPhil) thesis entitled 'An exploration of doctor's perceptions and the provision of palliative care at a private hospital in Gauteng, RSA' found that doctors had acceptable levels of knowledge regarding the WHO pain ladder, but did not adopt its suggested approach to analgesia. Additionally, doctors opted not to use morphine at all, or reserved it for EOL care. This cohort of doctors discussed the side effects of morphine with families of patients, but often not the patients directly. Furthermore, a large proportion of the study population perceived PC to be synonymous with EOL care, or an approach to be adopted when active measures had failed, and associated it solely with cancer patients. Goals of PC were only partially understood. Additionally, many doctors reflected that they did not have a role to play in providing PC, as their aim was to cure disease, and felt that PC was for 'a dying patient'.

Whilst Booth's thesis²⁴ shares some common themes with the current study, findings are not readily applicable to the setting of the current study. Booth's study was performed in a private, non-academic hospital, where patients (or medical aids) pay for services and, as such, PC may not be a readily available option from a financial perspective. Furthermore, academic training may not have been actively promoted at this centre and team-based approaches may not always have been considered. Lastly, formal PC centres are available in Gauteng, even at tertiary state hospital level, and, to the best of the researcher's knowledge, this is not yet the case in KZN.

Cornelius Loftus,⁶⁹ in his MPhil thesis entitled 'The Knowledge, Attitudes, Beliefs and Practices towards palliative care of family physicians in the Boland and Northern Suburbs of Cape Town', found that family physicians, by virtue of long-standing relationships with patients and their caregivers, play an invaluable role in the care of terminally ill patients. His study emphasised the importance of generalist PC training, which may possibly be more beneficial than specialist level training, and reiterated the important role that general practitioners (GPs) play in PC and EOL services. Respondents to his study were comfortable with EOL care as well as the emotional aspects of care, and did not find this burdensome. However, some respondents disagreed with these notions. In addition, findings from his questionnaire displayed almost unanimous agreement with the fact that GPs deemed patient involvement in decision making to be important, highlighting an important shift of care toward

patient-centered practices. Importantly, participants of his study displayed a willingness to enhance their PC skillset, and acknowledged their PC skill deficit, demonstrating a reassuring attitude towards PC. Moreover, these GPs acknowledged the need for a team-based approach, although they largely saw themselves as the team leader and primary decision maker, possibly contradicting their aforementioned positive attitudes. That said, the bulk of the participants felt that the main objective of PC would be control of physical symptoms, displaying a poor understanding of PC principles. In contrast with some of Loftus' positive findings, his results demonstrated that the concept of 'total pain' was poorly understood. He concluded that the lack of understanding of the biopsychosocial nature of PC by the GP population was concerning, and called for increased informal PC training, amongst other means of education.

Loftus' cohort study⁶⁹ was performed in a region of RSA that has a strong hospice support base, and at a primary healthcare level. Furthermore, the Western Cape, where the study was conducted, has formal hospital-based PC services available. As such, these findings may not necessarily reflect the situation at a tertiary hospital in KZN.

Ntombizodwa Sithole,⁴⁹ in her Masters in Technology (MTech) thesis entitled 'An assessment of the integration of palliative care in the caring of cancer patients in selected oncology clinics in the eThekweni district in KwaZulu-Natal' found that HCP were broadly aware of the holistic role that PC plays, but that knowledge regarding the scope and definition of PC was based on level of experience and training. Participants were also aware of the important role that caregivers play in the management of patients with LLI. However, participants in this 2012 study acknowledged that they applied PC principles most often at the EOL stage, indicating that, despite awareness of the holistic role of PC, perceptions towards it may be inaccurate. In addition, many of participants perceived decisions regarding PC approaches to be the domain of a doctor, saw PC as an intervention that is initiated after curative measures failed, and deemed the role of PC to be related to physical symptoms. The mindset of a hierarchical aspect to PC, and the apparent lack of knowledge regarding early PC approaches, as well as an apparent disregard for the concept of 'total pain' contradicted their awareness of the holistic role of PC, and displayed some poor PC knowledge and perceptions.

Furthermore, regarding the referral of patients to PC services, such as hospice, Sithole's study⁴⁹ found that knowledge of available options varied, and poor communication between oncology clinics and PC services was noted. Thus, continuity of care may be compromised. Additionally, concern was raised

that, despite the benefits of hospice interventions, hospices were not integrating themselves enough within the hospital structure.

To the best of the researcher of the current study's knowledge, Sithole's study is the most similar study to this one within the KZN setting. Her study provided insights into the knowledge and perceptions of HCP in KZN towards PC, but was primarily conducted with nurses. Additionally, despite its multi-centre methodology, the study was a qualitative one conducted via focus group discussions. Therefore, despite providing good foundational insight, findings may be limited by a lack of more extensive data collection methods and the exclusion of doctors. Further similar research is thus warranted in KZN.

Results extracted from other published literature

While specialist PC services should be available at all tertiary hospitals, early PC integration should encompass generalist-level PC at other levels of care. McMillan et al.⁵³ recently published results of a survey performed at state sector district hospitals in the Western Cape. Results demonstrated that, whilst participants' PC knowledge and attitudes towards PC were favourable, the role and timing of PC initiation or referral was poorly understood. Furthermore, results demonstrated that clinical experience played a role in doctors' PC knowledge. Whilst this multi-centre quantitative study involved staff in various settings, and was reportedly the first of its kind in the Western Cape, additional qualitative analysis would have been informative. Nevertheless, this study can be used as a template for investigation in similar settings within other provinces.

Prior to McMillan's work, another study by Ganca et al.³² examined PC at a tertiary hospital with an established PC service. Despite this service, results demonstrated that doctors lacked the knowledge and understanding of how to deal with LLI, that doctors lacked knowledge on how to understand patient and family care needs and expectations, and that doctors had marked difficulty with PC-related communication skills. This study delineated three categories of doctors regarding their knowledge and perceptions of PC:

- 'Those with good, clear knowledge and understanding'.
- 'Those who identified gaps in their individual knowledge and understanding of PC'.
- 'Those who had little knowledge and understanding of PC'.

Whilst this study only looked at doctors in selected clinical disciplines, and covered a small cohort of sixteen doctors, a rigorous data analysis process was used to highlight deficits in PC education. Such deficits were present even at the better-resourced state facilities, and thus suggested that that the

education and perception of doctors is potentially as equally important as the availability of resources and infrastructure. Such findings make the researcher of the current study question the situation elsewhere in the country, where PC services are still not available.

A variety of PC-related deficits in doctors were identified by Shen et al.²⁰ in a study also performed at a local tertiary centre with PC services. They and described how RSA doctors had great difficulty understanding matters related to PC and EOL communication, and highlighted the importance of communication skills. This study found that, when compared with the United States of America and China, where 37% and 60% of patients respectively had been part of a conversation on EOL matters, only 2.3% of local patients had received similar communication. Thus, a poor picture is painted regarding the knowledge and perceptions of South African doctors regarding PC, communication skills and EOL matters. Despite being a single centre study, this study of a large cohort of 221 patients raised concern about linkages to care, even in centres where PC services were available, and the barriers that incorrect knowledge and perceptions towards PC may pose.

The cascading effects of poor PC knowledge, or incorrect perceptions, of PC have also been demonstrated in a study conducted in RSA and Uganda by Selman et al.³⁴ These effects include increased caregiver stress, poorer outcomes, decreased intent for self-care and lacklustre coping mechanisms. This study recommends that all HCP that deal with patients with LLI should receive 'generalist' PC training, and enhance their communication skills, so as to improve the QOL of their patients. This was multi-centre, qualitative, 90 participant study and involving both patients and caregivers. Thus, data-rich evidence was likely gathered during the study. Additionally, findings of this study correlate with another study by Kreuter et al,³⁹ which demonstrated that patients with LLI wished their physicians had shared more information about their illness with them earlier. As such, it can be said that effective PC knowledge and training in communication skills are crucial as part of the spectrum of quality PC delivery.

To demonstrate the transitional nature of PC in RSA currently, a letter to the SAMJ editor by Lerato et al.⁷⁰ stated that, despite the absence of PC training, doctors, in RSA do attempt to provide PC . Notwithstanding the low response rate of 45%, and the fact that this as performed in 2006, this cross sectional questionnaire study found that greater than one-third doctors in the Free State provided home-based PC, despite the absence of formal PC training. Whilst this may indicate that PC delivery was likely suboptimal, it also suggests that simple measures targeted at HCP that manage LLI could improve the available PC services in RSA. Additionally, results demonstrated that doctors may possess

favourable perceptions towards PC and amenable to PC delivery despite the absence of formal PC qualifications.

Gaps identified in the literature

Whilst the aforementioned studies begin to paint a picture regarding the knowledge and perceptions of doctors in RSA towards PC, insufficient local data is available on this topic, particularly from provinces other than Gauteng and the Western Cape, such as KZN.

A large portion of the studies that have been performed on PC, both locally and internationally focus on cancer-related illness. However, particularly in RSA, additional studies are required that research the knowledge and perceptions of doctors treating noncancerous LLI, due to a paucity of data on this topic.

Furthermore, most research on this subject have focused on HCP in general, and few identified studies investigated doctors exclusively. In the resource-limited South African state sector, it is often the doctor that first investigates, diagnoses and manages LLI, and therefore a study targeted at doctors is warranted.

With regards to PC education, the available literature demonstrates reassuring findings that PC education in RSA is gradually being incorporated into both undergraduate³⁶ and postgraduate⁵⁴ education programs. Furthermore, the need for doctors to be familiar with PC approaches, have good communication skills, and competency in prescription of analgesia is well documented. However, the effects of this education, and on the current situation regarding PC knowledge 'on-the-ground', remains poorly studied.

Additionally, studies were identified on PC training for oncology registrars in RSA, notably by Krause et al.⁵⁴ However, there is a clear need for the integration of PC education into the curricula of other registrar programs, as LLI is not limited to patients with cancer. No literature was identified that explored the knowledge of other departments' registrars.

Moreover, as PC is not currently recognised as a speciality in RSA, more reviews of the PC training situation in RSA is warranted, which can examine the effect that PC training has had on the healthcare system, so as to inform policyholders on the importance of recognising PC training more formally in the country.

Importantly, there is a plethora of literature available that supports the use of morphine for patients with LLI. Morphine in its oral formulation is arguably the most important of the essential palliative care medications.⁵ However, studies in RSA are lacking on knowledge of the correct usage of morphine by doctors who care for patients with LLI and doctors' awareness of misconceptions surrounding morphine usage.

It can then be seen that there are large gaps and deficits in RSA with regards to PC literature, particularly aspects of the knowledge and perceptions of doctors towards PC. By performing this study, the researcher endeavours to fill some of these gaps, contributes positively to the PC research base in RSA.

Chapter Three: Aims and Objectives

Aim

To explore the knowledge and perceptions of doctors regarding the application of PC principles to patient care in a tertiary hospital in KZN.

Objectives

- To determine the knowledge that doctors of varying ages, clinical training and experience have regarding the discipline of PC.
- To assess if doctors are aware of when a PC approach should be introduced
- To explore perceptions that doctors working at a tertiary state hospital have regarding the application of PC principles to patient care.

Chapter Four: Methodology

Study design

A prospective, mixed-methods, cohort study that is observational in nature and not interventional.

Study site

Grey's Hospital, Pietermaritzburg, KZN

This is a 512 bed tertiary-level hospital, offering care to patients in the central and western regions of KZN.

It is also a training centre, offering internship training, as well as registrar and subspecialty-level training (as part of the University of KwaZulu-Natal training program).

Services offered at Grey's Hospital include the following:

Accident and Emergency Department, Anaesthesiology, Internal Medicine and its subspecialties, Obstetrics and Gynaecology and its subspecialties, Clinical Oncology, Paediatrics and its subspecialties, Surgery and its subspecialties and Radiology.

Allied health services available include audiology, clinical psychology, dietetics, laboratory services, occupational therapy, pharmaceutical services, physiotherapy, social work services and speech therapy.

No formal PC currently exists, and only one paediatric-specific PC post is available, but is currently vacant.

Selection criteria

Inclusion criteria

- Medical doctors, holding a Bachelor of Medicine and Bachelor of Surgery (MBChB) degree or equivalent.
- Doctors must be employed by the KZN DOH.
- Doctors must be working at Grey's Hospital at the time the study is conducted.
- Doctors at any level of the KZN DOH organogram, from medical intern to Head of Department.
- Doctors working in clinical areas that directly oversee the care of patients that present with LLI.

Exclusion criteria

- Healthcare workers that are not medical doctors, and who do not hold a MBChB or equivalent degree.
- Doctors that are not employed by the KZN DOH, including those employed by higher education institutions, for elective work, locum staff and those working at the hospital primarily for research purposes.
- Doctors not working at Grey's Hospital at the time the study is conducted.
- Doctors that have formal postgraduate PC training (Diploma level or higher).
- Doctors working in non-clinical areas.
- Doctors working in clinical areas that do not directly manage patients presenting with LLI (for example: radiology and anatomical pathology).

Sampling

Quantitative survey

Sampling method

Specific departments that care for patients suffering with LLI were approached, via a purposeful sampling method. This is an approach wherein participants are selected based on certain characteristics or knowledge, gaining focused information that better aligns the participants with the aims and objectives of the study.⁷¹

Sample size

At the time of the research protocol, 136 potential participants met the inclusion criteria, based on staff counts from departmental heads. However, at the time of data collection, which was over a year later, only 98 potential participants attended the departmental academic meetings and met the inclusion criteria, as 38 staff members had either resigned, or transferred to other posts, or were rotating at other hospitals, and they were thus excluded from participation. Recruitment was only from the potential participants that attended the academic meetings, as this was the cohort of staff that now met the inclusion criteria for the study. The survey was thus sent to the 98 attendees of these academic meetings. Additionally, out of the 12 doctors in the Oncology Department, four doctors were excluded due to formal postgraduate training in PC. The participation of the meeting attendees was entirely voluntary.

A total of 65 responses (n=65) were obtained from 98 potential participants (n=98) that the researcher met as part of recruitment. This reflects a response rate of 66.32%.

Qualitative semi-structured interviews

Sampling method

Purposeful sampling for face-to-face semi-structured interviews (SSI) was used to select appropriate participants with the aim of representing the various disciplines, level of clinical experience and cadre of staff.

Sample size

The purposeful sampling continued until data saturation was achieved. This was achieved after twelve participants were interviewed.

Ethics approval

Research approval from the University of Cape Town's Human Research Ethics Committee (HREC) was obtained, reference number 252/2023 ([Appendix B](#)). Thereafter, approval was granted by Grey's Hospital ([Appendix C](#)) and the KZN Department of Health Provincial Health Research Ethics Committee, reference number KZ_202306_015 ([Appendix D](#)).

Data collection tools

Quantitative survey

Development of tool

The literature review and expert opinion informed the expected level of knowledge regarding PC for doctors. Based on review of the literature and discussion with local PC experts, salient knowledge deficits were identified, and this was used to formulate questions aimed at assessing participants' PC knowledge. The [tool](#) comprised of two sections – the first assessing the participant's knowledge of PC concepts and the second their knowledge of some clinical aspects of PC.

Validity and reliability

As this was a custom-designed tool specifically for this study, extensive validation was not undertaken. No previously validated tool could be located in the literature that was entirely appropriate for the

setting of this research. However, once developed, the tool was discussed with both supervisors, and, after reflection, deemed to be appropriate.

Piloting

One consultant per department (assumed to be amongst those with the most clinical experience) from three departments was recruited to pilot the survey. The quantitative phase of the study commenced once the piloting process was complete, after no gaps were identified and no further changes were made.

Translation

The survey questionnaire was written and answered in English. All study material was only available in English. English is the de facto language used to communicate patient care and other matters at Grey's Hospital, despite a variety of home languages being represented. It was thus assumed that all doctors would be proficient in and comfortable with English as the language of the study. No translation was required.

Qualitative semi-structured interviews

Development of tool and trustworthiness

The [tool](#) was developed after discussion with supervisors, and trustworthiness was ensured by member-checking and feeding back to participants and peer review by the supervisors (credibility), and prolonged engagement with the data (dependability). Field notes were also made during the interviews. The tool was adapted as the interviews progressed and data was analysed.

Piloting

Two consultants from different departments were approached to pilot the SSI. These consultants did not form part of the cohort of study participants used for data collection and analysis. The tool was deemed to be appropriate after discussion and reflection with supervisors.

Translation

All SSI, transcription and analysis was done in English for reasons previously discussed. No translation was necessary.

Data collection process

Process of data collection

Quantitative survey

The researcher disseminated the questionnaire ([Appendix E](#)) to all attendees of the departmental academic meetings and allowed time to complete the questionnaire and remained available during these meetings to answer any questions that participants had whilst completing the questionnaire. Both hard and electronic copies of the questionnaire were available to make it as convenient as possible for potential participants to complete as per their choice.

After signing consent ([Appendix G](#)), electronic questionnaires were completed using the Google Forms platform and collected onto a password-protected Google account. Responses were not saved on Google Drive. Participants that opted for hard copies signed [written consent](#), and completed the questionnaire thereafter. All hard copy and electronic responses were then transferred, with the assistance of a statistician, to Microsoft Excel 2021 and coded, before being transferred to Stata Version 18 for analysis.

Once the surveys were completed, analysis of the data took place. Thereafter, a decision was taken to proceed with the qualitative phase of the study. Iterative modification of the already determined semi-structured interview guide was made based on the findings of the survey to explore why response rates were low for certain larger departments.

Qualitative semi-structured interviews

After obtaining written consent ([Appendix H](#)), the researcher conducted in-depth individual interviews using the custom-designed semi-structured interview guide ([Appendix F](#)). Interviews lasted for fifteen to thirty minutes. Audiotaped interviews were recorded on two devices, to correct for any technological failures. These interviews were then transcribed verbatim and analysed. The interview guide included the researcher addressing the following issues:

- Existing knowledge regarding the definition and roles of PC
- Relevance of PC to the domain within which the participant works
- Perceptions regarding the roles, timing and importance of PC
- The participant's reactions to patients with LLI
- Reasons why PC is not yet offered at hospital-level in KZN

- Participant's opinions on how PC can fit into the KZN state hospital sector and how this service can be supported

Field notes were made during the interviews describing significant gestures and sounds for purposes of reflection and objectivity, where appropriate and applicable to the context. Significant data that was captured was noted by the researcher during the process of data collection so that theme and code identification could proceed early on. The researcher also made notes during the interview for later reflection about any additional thoughts that arose during the interview.

Research assistants

Statistical data for the quantitative survey was analysed with the assistance of a qualified biostatistician, Ms. Anneli Hardy. No further research assistants were used during the research process.

Recruitment strategy and informed consent

Quantitative survey

The researcher attended a meeting that was earmarked and approved by the heads of the clinical units. He explained the study and answered any questions that prospective participants had. The information sheet ([Appendix I](#)) and [consent forms](#) were made available for participants to get a better picture of what the study entailed.

Participants were reassured of matters regarding confidentiality and data storage. No incentives of any form were provided and no coercion was allowed at any stage of the recruitment process. All participants signed informed consent.

If insufficient participants were recruited at the first attempt, as was the case with the Departments of Surgery and Paediatrics, the aforementioned process was repeated at a second meeting.

[Informed consent forms](#) were embedded into the Google Forms document and electronically signed at the beginning of the survey. The participants that opted for a paper-based survey received hard copies of the [participant information sheet](#) and [consent form](#). Participants were given the option to share their email addresses whilst completing the survey, otherwise the survey was fully anonymous. Participants were also informed that they may be contacted for SSI at a later stage.

Qualitative semi-structured interviews

Two to three participants per department, after participation in the knowledge survey, were purposefully recruited to participate in the SSI. Participants were selected based on their levels of experience, cadre and departments they worked in to ensure representative results. Prior to commencement of the interview, an information sheet ([Appendix J](#)) was provided in advance, so that they were informed of the need for the interview and the process of it. An [interview guide](#) was used and participants were given an identification number for the purposes of anonymisation.

Informed consent was obtained, in hard copy, from all participants recruited for the SSI prior to commencement. This consent included consent to participation and specifically included consent for the audio recording of the interviews.

Distress protocol

All participants, prior to participation, were made aware of the concepts that would be covered in the survey and the SSI and invited to ask questions regarding the study. Their agreement to participate, via signing informed consent, proved that participation was voluntary. Should any participant have indicated any signs of distress during the study, they would have immediately been offered to pause, defer or abandon the process. All their immediate questions and concerns would have been answered and addressed, to the best of the researcher's ability. The participant would then, if required, have been offered to the hospital's services that are in place to support staff members, including the occupational health clinic, the employee assistance program and the in-house clinical psychologist, as per their needs at the time. No participants, as of the time of writing of this dissertation, displayed or reported any signs of distress.

Data Analysis

Quantitative survey

Data was collected during the survey in both electronic form and hard copy. Data was then transferred onto a Microsoft Excel 2021 spreadsheet and thereafter coded for purposes of analysis. Initial analysis was performed by the researcher, who was assisted by a biostatistician, and Stata Version 18 was used. Analysed data was reviewed by both the biostatistician and the supervisor to elicit significant responses and extract further information regarding trends that would assist in meeting the aims and

objectives of the study. Data was initially analysed to describe correct and incorrect responses ([Table 6](#)).

Thereafter, with the aid of a biostatistician, tests of association between participants' responses and cadre, level of experience and discipline were performed using the aforementioned Stata program. Following this, to ascertain significant findings of these tests of association, the Chi-square (χ^2) and Cramer's V tests were used on this program ([Appendix K](#)).

The Chi-square test of independence (or Pearson Chi-square test) is an effective tool that can be used to test hypotheses in research studies that involve numerical variables.⁷² This is because it incorporates both statistical significance and data that describes which categories account for any differences. However, coupled with the statistical significance, a researcher needs to understand the strength of the association between variables. As such, the Cramer's V test was utilised by the researcher as a test of the strengths of the associations, as it is the most common test used to accompany the Chi-square test for this purpose.⁷² Further explanations of these tests is beyond the scope of this minor thesis.

Qualitative semi-structured interviews

The researcher immersed himself in the data from the outset of data collection and used field notes to complement the audiotaped recordings. Interviews were transcribed verbatim. Data was then analysed using thematic analysis, aided by the NVivo Program, version 14. Initial analysis involved inductive coding of the data via line-by-line analysis of the transcribed recordings, following which data was grouped into categories. This was performed according to the principles described by Braun and Clark.⁷³ Transcribed interviews were reviewed with the supervisors during the process of data analysis. Codes and themes were developed independently by the candidate, and then checked with the supervisors, who also analysed the data for themes, until consensus was reached. The researcher also reflected on findings using the field notes taken during and after the interviews. Using this process, the researcher sought to identify themes, subthemes and deviant cases. Transcribed interviews did not include any identifying data other than the participant identification number. After the interview process, member-checking was performed and feedback was provided to the participants regarding the findings of the study.

Data storage and confidentiality

Access to records is solely available to the researcher. Knowledge surveys were completed by participants on their personal cell phones and went directly to a password-protected account to which only the researcher had access. Hard copy responses were stored in two secure, separate lockers and/or cupboards and scanned into digital format to be stored on password protected USB drives. All consent forms and participant identifier details were also stored in the aforementioned lockers, with care taken to ensure that all identifying details were stored separately from data that was collected.

Data collected in electronic format was stored on a secure, password protected account. This account was created for the purposes of the study. Where possible, password protected USB drives were used.

Recordings of the SSI were done using a cellphone recorder as well as a second recording device, to compensate for any technological failures. The Zoom recording function was also made available for participants for who opted for online (Zoom) interviews. However, no participants opted for online interviews. Recordings were transferred to password-protected USB drives and all USB drives used for the study were stored in the aforementioned lockers. Should any technological failures have occurred, a Dropbox account was to be created for purposes of this study.

The location for the interviews was safe, mutually convenient, confidential spaces. The researcher allowed for the option of interviews taking place online via a Zoom meeting. However, no interviews took place via the online platform with all interviews being in person.

All data, whether in hard copy or on electronic format, will be stored for a period of five years. The locker used to store data will be at the researcher's home but within an area that is not visible to outsiders. Only the researcher will have access to this locker.

Workplan and study period

Table 2: Schedule of Workplan for the MPhil dissertation

Approval of protocol by UCT	April 2023
Approval of protocol by Facility	June 2023
Approval of protocol by Provincial DoH	June 2023
Permission from departmental heads	August 2023
Quantitative surveys	September 2023- January 2024
Qualitative semi-structured interviews	February 2024- May 2024
Data analysis process	June 2024- August 2024
Writing up of findings (discussion)	September 2024- November 2024
Conclusion	December 2024
Intention to submit given to UCT	December 2024
Completed document handed to UCT	February 2025

The table above tabulates the workplan for this MPhil dissertation.

Breakdown of budget for study

The research was funded by the principal researcher, Dr. J.M. Vahed, and all expenses that were incurred during the course of the research were borne by him. Participants were informed beforehand that there would be no financial compensation for participation.

Table 3: Record of budget for this MPhil study

Expense	Cost
Travel Cost	R500
Printing and related expenses	R1250
Cellphone purchase (2 nd Recorder)	R1500
Airtime for Calls	R500
Food/drinks for participants	R1000
Total expenses	R4750

This table describes the various expenses incurred by the researcher during the course of this study.

Ethical considerations

[Research approval from the University of Cape Town's Human Research Ethics Committee \(HREC\) was obtained, reference number 252/2023](#). Thereafter, [approval was granted by Grey's Hospital](#) and the [KZN Department of Health Provincial Health Research Ethics Committee, reference number KZ 202306 015](#)

This research was undertaken according to the Principles of Helsinki.⁷⁴

It was important for the researcher to ensure that participants were cognitively competent and that they understood that they were voluntarily participating in a research study. This was done at the time of the recruitment process. In order to ensure that autonomy was maintained, participants were thoroughly informed about the study via the information sheets (Appendices [I](#) and [J](#)), and signed informed consent prior to participation for the quantitative and qualitative phases of the study separately. Further information was provided to them when required.

Contact details of the researcher and supervisors were provided to accommodate any issues that arose following either the knowledge survey or the SSI.

The participants were informed clearly that participation carried no monetary or other incentives.

Beneficence was maintained by virtue of this study empowering participants to question the roles of PC as well as foster healthy debate on the benefits that a PC service would provide to Grey's Hospital. Additionally, the researcher's PC training, was leveraged to empower the participants regarding PC by answering any questions and queries that they had about PC.

In order to ensure that non-maleficence was maintained, participants were reassured that refusal to participate would carry no negative consequences and that all data collected was to be anonymised. Participants were informed of the distress protocol. They were also reminded of their ongoing consent and of the option to withdraw consent at any time.

The researcher acknowledges the potential of intrinsic vulnerability on the part of the participants: they may have felt obliged to participate as he is their colleague, or because he is a doctor that they may refer patients to. To ensure the researcher was transparent about his positionality, the information leaflet clearly stated that he was acting, for the purposes of the study, as a researcher and not in his capacity as a doctor of Grey's Hospital.

Participants were informed that their participation in the research study was valuable but voluntary and would greatly aid the drive for PC development within KZN.

Dissemination of findings

Prior to the completion of this dissertation, the researcher informed participants of the results that were obtained from data analysis of the study. The researcher will endeavour to publish the results of the study in a recognised medical journal once he has passed the MPhil degree. Additionally, the results and findings will be discussed at various academic forums, including conferences and CME

Chapter Five: Results of the study and analysis of results

Quantitative survey

A total of 65 responses (n=65) were obtained from a total of 98 meeting attendees (n=98) at the various departmental meetings as part of recruitment. This reflects a response rate of 66.32%. The table below demonstrates the response rates of the various departments:

Table 4: Summary of response rates per department

Department	Eligible meeting attendees (n=)	Responses received (n=)	Response rate (%)
Internal Medicine	28	27	96.42%
Neurology	9	8	88.88%
Obstetrics and Gynaecology	16	11	68.75%
Oncology	8	4	50.00%
Paediatrics	20	8	40.00%
Surgery	18	7	38.88%
Total	98	65	66.32%

This table demonstrates the response rates from each department after the study was explained to all potential participants at the departmental academic meetings.

At the time of data collection, 98 potential participants attended the academic meetings ([as explained previously](#)). Of the 12 staff from the Oncology Department, four potential participants were excluded due to formal postgraduate PC training. The researcher was not aware of any other meeting attendees that held formal postgraduate PC qualifications.

Table 5: Demographic data of participants in knowledge survey (n=65)

Data requested	Output options	Frequency (n =)	Percentage (%)
Gender	Male	24	36.92
	Female	40	61.54
	Prefer not to say	1	1.54
Age	20-25	8	12.31
	26-30	19	29.23
	31-40	22	33.85
	41-50	12	18.46
	>50	4	6.15
Years of experience post undergraduate qualification	</=5	27	41.54
	6-10	16	24.62
	>/= 11	22	33.85
Cadre	Intern	15	23.08
	Registrar/ MO	34	52.31
	Consultant	16	24.62
Department	Internal Medicine	27	41.54
	Neurology	8	12.31
	Obstetrics and Gynaecology	11	16.92
	Oncology	4	6.15
	Paediatrics	8	12.31
	Surgery	7	10.77

This table demonstrates the demographic data of the various participants of the knowledge survey.

A large portion of doctors were noted to be between the ages of 26 and 50 years old (81.53%, n = 53). When compared with participants from age groups <25 (12.35%, n=8) and >50 (6.15%, n=4), an unbalanced distribution was noted. Therefore, the age variable will not be considered in further analysis.

Respondents' years of experience was reasonably split: 27 had <5 years of experience post undergraduate qualification (41.54%), 16 had 6 to 10 years of experience (24.62%) and 22 had >11 years of experience (33.85%). A majority of respondents (52.31%, n = 34) were either employed as registrars or medical officers. The largest cohort was from the Internal Medicine Department (41.54%, n=27). Response rates were low from the Departments of Paediatrics (response rate 40.00%, n=8) and Surgery (response rate 33.33%, n=7).

Knowledge variables assessed are demonstrated in table 6 below:

Table 6: Frequency table of variables for the knowledge survey.

Variable	Yes (n=)	No (n=)	I don't know (n=)	Correct (n=)	Incorrect (n=)	% correct
1. I am aware of the concept of palliative care	65	0	0	65	0	100
2. I believe that palliative care is an essential clinical discipline	65	0	0	65	0	100
3. Once diagnosed with a life-limiting illness, palliative care can be commenced at any time within the disease trajectory, including early on in the disease process	61	4	0	61	4	93.85
4. Palliative care is primarily aimed at patients at the end of life	23	42	0	42	23	64.62
5. Palliative care is only concerned with patients who have been diagnosed with cancer	0	65	0	65	0	100
6. Should a palliative care clinic be established at my institution, I see myself referring patients to this clinic	64	1	0	64	1	98.46
7. Recommendations for the initiation of palliative care exist	45	5	15	45	20	69.23
8. I have heard of the SPICT Criteria	13	47	5	13	52	20.00
9. Palliative care is focused on management of physical symptoms to enhance the quality of life of patients with life threatening diseases	38	24	3	24	41	36.92
10. When planning treatment in palliative care, patient preferences should be taken into account , even when contradictory to conventional medical advice	59	2	4	59	6	90.77
11.Consideration of family or caregiver involvement is preferable for good palliative care management	63	1	1	63	2	96.92
12. Morphine cannot be titrated to high doses because it poses a danger of respiratory depression	19	41	5	41	24	63.08
13. Control of physical aspects of pain will always ensure that successful analgesia is achieved	24	38	3	38	27	58.46
14. As the doctor heads the multidisciplinary team, they have the final say with regards to decision	7	56	2	56	9	86.15

making for patients with life threatening illnesses						
15. In palliative care, addiction is a relevant concern when using high doses of morphine	18	42	5	42	23	64.62
16. If a patient with stage 4 cancer develops new vertebral metastases and lower limb weakness, there are clinical options available to address this	47	8	10	47	18	72.31
17. Initiation of intravenous fluids is warranted if a patient's oral intake at the end of life's has declined significantly	34	21	10	21	44	32.31
18. It is good clinical practice to initiate patients on laxatives if they have been prescribed with opioids	56	6	3	56	9	86.15
19. The medical team's role terminates once the patient has deceased and/or they have been removed from the institution	13	46	6	46	19	70.77

Table 6 demonstrates the questions that were asked in the knowledge survey and tabulates the responses received.

Some Important findings regarding correct responses are noted below:

- All participants (100%, n=65) were aware of the concept of PC, believed that this is an essential discipline (variable 2) and that it was not solely associated with the care of cancer patients (variable 5).
- Only one participant (1.54%, n=1) felt that he or she would not refer to a PC service should one be established at the hospital (variable 6).
- Correct responses were obtained from 90.77% of participants (n=59) when asked if patient preferences should be taken into account when planning treatment in PC, even when contradictory to conventional medical advice (variable 10).
- Almost all the participants (96.92%, n=63) agreed that consideration of family or caregiver involvement was preferable for good PC (variable 11).

- Knowledge of laxative use when prescribing opioids was high, with 86.15% of total participants (n=56) responding positively (variable 18).

Knowledge questions with a high rate of correct responses were not considered for further analysis.

Survey responses were first assessed to determine overall results, i.e. the accuracy of doctors' knowledge. Thereafter, in order to meet the objectives of the study, further tests of association were performed to determine if there were any statistically significant knowledge deficits or trends in any subgroup of participants. Where knowledge gaps were identified by low rates of correct responses, the data was further analysed and will be discussed below. Detailed breakdowns of this analysis can be found on [Appendix K](#).

When assessing respondents' knowledge of the relationship between PC and EOL care, results found that over one-third of participants (35.38%, n=23) incorrectly saw PC as EOL care (variable 4). Of these respondents, 43.48% (n=10) possessed > 10 years of experience, 39.13% (n=9) had <5 years of experience and 17.39% (n=4) had 6-10 years of experience. This was compared to respondents who did not associate PC exclusively EOL and it was found that 42.86% (n = 18) had <5 years of experience, 28.57% (n = 12) had 6-10 years of experience and 28.57% (n=12) had 10 or more years of experience. Despite the difference in proportions, no statistically significant association between the belief that PC was primarily EOL care and level of clinical experience was found ($\chi^2(df=2) = 1.7801$, $p = 0.411$) and results were of a small effect size (Cramer's $V = 0.1655$). Additionally, more than half of the incorrect responses to this question (52.17%, n=12) were from registrars or medical officers. However, when comparing all cadres of staff who responded, the association between cadre and incorrect knowledge was not statistically significant ($\chi^2(df=2) = 0.2595$, $p = 0.878$) and a very small effect size was noted (Cramer's $V = 0.0632$). Furthermore, more than half of the incorrect responses (52.17%, n=12) were received from the Internal Medicine cohort. When incorrect response and departments were correlated however, the association was not statistically significant, ($\chi^2(df=5) = 5.4035$, $p = 0.369$) despite a moderate effect size (Cramer's $V = 0.2883$). These findings, although not statistically significant or of a large effect size, demonstrate a noteworthy overall finding; that one in three doctors incorrectly conflated PC with EOL care, however no specific subgroup did so more than any other.

Regarding recommendations for the initiation of PC, the knowledge survey found that almost one third of participants (30.77%, n=20) were unaware of the existence of any such recommendations (variable 7). Of these respondents, 30% (n=6) possessed <5 years of experience, 45% (n=9) had 6-10

years of experience and 25% (n=5) had >10 years of experience. When this was compared to the participants that were aware of the recommendations 46.67% (n=21) possessed <5 years of experience, 15.56% (n=7) had 6-10 years of experience and 37.78% (n=17) had >10 years of experience. There was a higher percentage of correct vs. incorrect responses received from participants that possessed <5 years of experience (77.78% vs 22.22%) and participants with >10 years of experience (77.27% vs 22.73%), when compared with participants with 6-10 years of experience (43.75% vs 56.25%). Thus, a statistically significant association was found between knowledge regarding recommendations for the initiation of PC and level of clinical experience ($\chi^2(df=2) = 6.4706$, $p = 0.039$), with a moderate effect size (Cramer's V = 0.3155). More than half of the incorrect responses (55%, n=11) to this question were received from either registrars or medical officers. However, the association between cadre and incorrect response was not statistically significant ($\chi^2(df=2) = 1.197$, $p = 0.550$) and the effect size was very small (Cramer's V = 0.1357). Tests of association were also performed to assess the relationship between respondents' clinical department and awareness of existence of recommendations PC. A high percentage of correct vs. incorrect responses was received from participants from Paediatrics (87.50% vs 12.50%), Internal Medicine (81.48% vs 18.52%), Oncology (75.00% vs 25.00%), Obstetrics and Gynaecology (63.64% vs 36.36%) and Neurology (62.50% vs 37.50%). However, participants from Surgery performed poorly on this question (14.29% vs 85.71%). Therefore, a statistically significant association between the knowledge of recommendations and clinical department was found ($\chi^2(df=2) = 13.4706$, $p = 0.019$) with a moderate effect size (Cramer's V = 0.4552). It can thus be seen that the level of experience and the department to which the doctor belongs plays a bigger role in awareness of recommendations for the initiation of PC than staff cadre does.

The SPICT Criteria is evidently not currently well known by doctors, as almost three quarters (72.31%, n=47) had not heard of the tool (variable 8). Due to this being a very PC-specific tool, no further tests of association for analysis of this response were conducted. However, this result is indicative of the lack of awareness amongst participants of what necessitates referral to PC.

In order to assess if participants' awareness of a biopsychosocial-spiritual approach to care of PC, they were questioned regarding care beyond the physical domain. Almost two-thirds of participants (63.08%, n=41) incorrectly responded 'yes' when asked if PC focused on the management of physical symptoms to enhance QOL (variable 9). Of these participants, 41.46% (n=17) possessed <5 years of experience, 24.39% (n=10) had 6-10 years of experience and 34.15% (n=14) >11 years of experience. This can be compared to the 36.92% (n=24) of participants who acknowledged the holistic nature of

PC: 41.67% (n=10) possessed <5 years of experience, 25.00% (n=6) had 6-10 years of experience and 33.33% (n=8) had >10 years of experience. Despite differences in proportions, when comparing levels of clinical experience regarding recognition that PC is more than biomedical care, no statistically significant association was found ($\chi^2(df=2) = 0.0054$, $p = 0.997$) and results were of a small effect size (Cramer's $V = 0.0091$). More than half of the incorrect responses were received from registrars and medical officers (56.10%, n=23) however differences in knowledge between cadres of staff were not statistically significant ($\chi^2(df=2) = 0.6861$, $p = 0.710$) with a small effect size (Cramer's $V = 0.710$). Similarly, the association between clinical department and awareness of this concept was not statistically significant ($\chi^2(df=2) = 6.0463$, $p = 0.302$) and a small effect size was noted (Cramer's $V = 0.3050$). Whilst not statistically significant, this trend demonstrates that lack of knowledge regarding the scope of PC beyond the domain of physical care exists, regardless of level of experience, cadre of staff or clinical department, and that more education surrounding the psychosocial and spiritual aspects of care is required for all staff.

Related to this concept is the entity of 'total pain'. Management of total pain is critical for effective PC, therefore a question regarding the achievement of effective analgesia was included in the survey. To this question, 41.54% of participants (n=27) incorrectly indicated that control of the physical aspects of pain would ensure successful analgesia (variable 13). Of these incorrect respondents, 44.44% (n=12) possessed <5 years of experience, 22.22% (n=6) had 6-10 years of experience and 33.33% (n=9) had >11 years of experience. This was compared with participants that were aware that analgesia was not restricted to the physical domain: 39.47% (n = 15) had <5 years of experience, 26.32% (n = 10) had 6-10 years of experience and 34.21% (n=13) had 10 or more years of experience. Despite differences in absolute proportions, no statistically significant association between awareness of analgesia extending beyond physical pain management and years of clinical experience was found ($\chi^2(df=2) = 0.2049$, $p = 0.903$) and only a very small effect size (Cramer's $V = 0.0562$) was seen. Furthermore, of the 27 participants that responded incorrectly, more than half were medical officers or registrars (55.56, %n=15). However, when comparing proportion of incorrect answers between cadres of staff, the association was not found to be statistically significant ($\chi^2(df=2) = 0.9530$, $p = 0.621$) with a small effect size (Cramer's $V = 0.1211$). Additionally, no significant association between clinical department and knowledge surrounding analgesia beyond the physical domain was seen ($\chi^2(df=2) = 8.2294$, $p = 0.144$), despite a moderate effect size (Cramer's $V = 0.3558$). Thus, a large proportion of doctors do not have sufficient understanding of 'total pain'. However, there was no identifiable subgroup with greater deficits in knowledge regarding this entity, therefore signifying that there is a universal presence of this PC knowledge gap.

Care for physical symptoms, as part of PC, is not limited to pharmacological interventions. Therefore, the survey probed participants' knowledge of the non-pharmacological management of physical symptoms. Of the participants, 27.69% (n=18) incorrectly responded that patients with stage 4 disease and new vertebral metastases had no further clinical options available (variable 16). However, when tests of association for analysis of this data were performed, no statistically significant association could be identified amongst those who responded incorrectly vs. those who responded correctly.

Morphine is a commonly used opioid in PC. The survey thus looked at doctors' knowledge regarding some of the myths surrounding this drug. One such myth is that morphine leads to respiratory depression. More than one-third of the participants (n=24, 36.92%) responded incorrectly, saying that morphine could pose a risk of respiratory depression (variable 12). Of these respondents, 45.83% (n=11) possessed <5 years of experience, 25% (n=6) had 6-10 years of experience and 29.17% (n=7) had >10 years of experience. This was compared to the 41 participants that were aware that morphine did not pose a risk of respiratory depression, where 39.02% (n=16) possessed <5 years of experience, 24.39% (n=10) had 6-10 years of experience and 36.59% (n=15) had >10 years of experience. Despite the differences in proportions, knowledge surrounding whether or not morphine causes respiratory depression was not significantly associated with level of clinical experience ($\chi^2(df=2) = 0.4174$, $p = 0.812$) and results were of a very small effect size (Cramer's V = 0.0801). Furthermore, of the 24 participants that responded incorrectly, 50% (n=12) were medical officers or registrars. However, when comparing all cadres of staff, the association between cadre of respondent and morphine knowledge was not statistically significant ($\chi^2(df=2) = 1020$, $p = 0.950$) and a very small effect size was noted (Cramer's V = 0.0396). Similarly, the association between clinical department and knowledge surrounding morphine causing respiratory depression was not statistically significant ($\chi^2(df=2) = 5.0937$, $p = 0.405$), despite a moderate effect size (Cramer's V = 0.2799).

Regarding knowledge of the myth of addiction to morphine being a concern in PC, more than one-third of the participants (n=23, 35.38%) felt that morphine usage may lead to addiction when used in PC (variable 15). Of this cohort of respondents, 34.78% (n=8) possessed <5 years of experience. 39.13% (n=9) had 6-10 years of experience and 26.99% (n=6) had >10 years of experience. This was compared to the 42 participants that were aware that morphine addiction was not a concern in PC, where 45.24% (n=19) possessed <5 years of experience, 16.67% (n=7) had 6-10 years of experience and 38.10% (n=16) had >10 years of experience. Despite these differences in proportions, when comparing years

of experience, the researcher found no statistically significant association between knowledge of morphine addiction and level of clinical experience ($\chi^2(df=2) = 4.0709, p = 0.131$), despite a moderate effect size (Cramer's $V = 0.2503$). More than half of the incorrect responses were received from registrars and medical officers (60.87%, $n=14$). However, when comparing between cadres of staff, no statistically significant association was found ($\chi^2(df=2) = 1.1171, p = 0.572$) and a small effect size was noted (Cramer's $V = 0.1311$). Similarly, the association between clinical department and awareness surrounding morphine addiction in PC was not statistically significant ($\chi^2(df=2) = 3.9456, p = 0.557$), despite a moderate effect size (Cramer's $V = 0.2464$).

The trend reflected in the previous two paragraphs demonstrates a lack of knowledge regarding myths surrounding morphine causing respiratory depression and addiction. As the findings were not statistically significant or of large effect size when compared between demographic characteristics, it shows a universal knowledge deficit that may hinder appropriate use of morphine for patients with LLI and PC needs.

Administration of intravenous fluids (IVF) for patients who are at the EOL may amount to futile care for the dying patient. The survey aimed to determine if participants were cognizant of this fact. More than two-thirds of participants (67.69%, $n=44$) responded incorrectly, stating that IVF should be initiated at the EOL in the presence of decreased oral intake (variable 17). Of these participants, 47.73% ($n=21$) possessed <5 years of experience, 29.55% ($n=13$) had 6-10 years of experience and 22.73% ($n=10$) >11 years of experience. This contrasted with the remaining one-third of participants (32.31%, $n=21$) who displayed knowledge that the administration of intravenous fluid at the EOL is unnecessary, of whom 28.5% ($n=6$) possessed <5 years of experience, 14.29% ($n=3$) had 6-10 years of experience and 57.14% ($n=12$) had >10 years of experience. There was a higher percentage of correct vs. incorrect responses received from participants with >10 years of experience (54.55% vs 45.45%), when compared with participants with <5 years of experience (22.22% vs 77.78%) and participants with 6-10 years of experience (18.75% vs 81.25%). Thus, tests of association revealed a statistically significant association between knowledge surrounding use of IVF at the EOL and level of clinical experience ($\chi^2(df=2) = 7.5752, p = 0.023$), with a moderate effect size (Cramer's $V = 0.3414$). However, no statistical significance was noted when the associations between cadre or clinical department and knowledge surrounding use of IVF for patients who are at the EOL were assessed, with tests of association yielding results of ($\chi^2(df=2) = 30.0380, p = 0.219$) and ($\chi^2(df=2) = 9.2905, p = 0.098$) respectively and moderate effect sizes (Cramers $V = 0.2162$ and 0.3721 respectively) for these

parameters. Therefore, results demonstrated that clinical experience is a significant factor that results in in greater knowledge surrounding the use of IVF at the EOL.

When it comes to palliative and EOL care, the holistic care plan should ideally extend beyond the death of the patient, as bereavement care is also essential. When questioned regarding this in the survey, almost one-third of the participants (29.23%, n=19) felt that the medical team's role terminated with the death of the patient (variable 19). When tests of association were performed for analysis of the data based on years of experience, no statistically significant association between knowledge surrounding the role of bereavement care and level of clinical experience was found ($\chi^2(df=2) = 5.5433$, $p = 0.063$), despite a moderate effect size (Cramer's $V = 0.2920$). However, there was a higher percentage of correct vs. incorrect responses received from interns (93.33% vs. 6.67%) and consultants (75.00% vs. 25.00%) when compared with the cohort of registrars and medical officers (58.82% vs. 41.18). Therefore, when responses from staff of varying cadres was analysed, tests of association revealed a statistically significant association at a 5% level of significance ($\chi^2(df=2) = 6.1757$, $p = 0.046$) with a moderate effect size (Cramer's $V = 0.3082$). Similarly, there was a higher percentage of correct vs. incorrect responses received from participants from Paediatrics (100.00% vs. 0.00%), Internal Medicine (81.48% vs. 18.52%) and Oncology (75.00% vs. 25.00%), when compared with participants from Obstetrics and Gynaecology (63.64% vs. 36.36%), Surgery (57.14% vs. 42.86%) and Neurology (25.00% vs. 75.00%). Thus, tests of association for analysis of responses by department revealed a statistically significant association ($\chi^2(df=5) = 13.8368$, $p = 0.017$) with a large effect size (Cramer's $V = 0.4614$). These results therefore demonstrate that, while level of experience is not significant, cadre of staff and clinical department plays a role in the knowledge surrounding the role of bereavement care in PC.

Qualitative semi-structured interviews

This chapter presents the results of the semi-structured interviews (n=12) that were conducted with doctors of varying cadres and departments. Demographic data of participants is listed below:

Table Seven: Demographic data of participants in the semi-structured interviews

Cadre of Staff	Consultant	3
	Medical Intern	2
	Medical Officer/ Registrar	7
Department	Internal Medicine	1
	Neurology	2
	Obstetrics and Gynaecology	2
	Oncology	2
	Paediatrics	3
	Surgery	2
Sex	Male	6
	Female	6

This table illustrates the demographic characteristics of the participants of the semi-structured interviews.

After all data was analysed, four main themes and several sub-themes emerged. These are summarised in the table below:

Table Eight: Themes and sub-themes identified during semi-structured interviews

	THEME ONE	THEME TWO	THEME THREE	THEME FOUR
SUB-THEME	The scope of palliative care	Need for PC is beyond the patient need	Reasons for absence of a PC service	Future PC at Grey's Hospital
1	Definition and initiation of PC	Patient need	Absence of adequate provider knowledge	Enhancement of education to doctors
2	PC as means of analgesia	HCP need	Oversight of policy implementation	Enhancement of available infrastructure
3	PC as a means of increasing understanding of disease and family involvement in care	Family's need	Attitudes and perceptions unfavourable towards PC implementation	Enhancement of human resources

4	PC as a means of integration of a MDT approach for holistic care	The need for MDT integration into care	Uncertainty regarding the lack of services	Enhancement of finances
5	Structure of the PC team	The need for PC to be introduced as part of the hospital services	PC seen as a domain external to hospital-based care	
6	PC as a means of bereavement care		Time and workload constraints	

This table reflects the themes and sub-themes that were identified during the data analysis process of the semi-structured interviews.

Theme 1: The scope of palliative care

1.1 Definition and initiation of PC

Most participants expressed that PC involved care at EOL. However, the exact timing of initiation of this care was ambiguous, as a large majority of participants simultaneously stated that PC should be initiated at diagnosis of a LLI. This conflict is described in the following quotes:

Regarding what PC is a participant responded, *'...involves, umm, I'd say, end-of-life care...'* and regarding its timing, *'it starts at the diagnosis of any dreaded illness'* (SSI009)

Another participant who described PC as care for *'terminally ill patients'* went on to explain that it involves *'the whole journey of diagnosis to treatment to end-of-life care'* (SSI006)

Some participants incorrectly perceived that PC could not be offered alongside disease-modulating treatments. As one participant stated:

'...a team identifies that the patient can no longer, umm, benefit, umm, from treatment or can no longer get adequate improvement on certain treatments, then they may move on to palliative medicine...' (SSI005)

However, participants who had graduated more recently from university, such as interns and medical officers, appeared to express the role and timing of PC more clearly. One intern described PC as:

'...care for people with, umm, life-limiting or life-threatening...conditions' and stated that *'It should commence once the diagnosis is made... Not necessarily if we are even in the terminal phase. You want to start as early as possible...'* (SSI008)

One participant (SSI007) incorrectly perceived PC to be a means of ‘conservative’ and ‘non-pharmacological’ care.

Seven participants stated that PC was responsible for the management of patients with ‘non-curative’ illness. (SSI002/3/5/6/7/8/9)

1.2 Palliative care as means of analgesia

It was unanimously expressed that PC can achieve appropriate physical pain control, to improve QOL. All participants saw this as one of the main reasons that PC is required. Some participants saw this as the main goal of PC. Examples of a response included the following:

‘...we want to make whatever time this patient has left, you know, as easy as possible, as pain-free as possible...to have a better state of mind...’ (SSI003)

Some participants alluded to the concept of ‘total pain’ and its management, which can be achieved with PC, but did not know how to clearly express this. An example would include:

‘...you want to make sure that your patient is pain-free, umm.... and taken care of holistically, so emotionally, physically, and also some sort of...rehabilitation, umm, but just to try, umm, and maintain a dignified standard of life or living’ (SSI010)

1.3 PC as a means of increasing understanding of disease and family involvement in care

Participants saw PC as an important tool to assist counselling both the patient and the family, to break bad news and guide them on the road ahead. Participants also displayed positive perceptions regarding the role PC plays in involving the family in care of the patient, by bridging the communication gap or by allowing the family to be part of decision-making. The views verbalised included:

‘...important point is to always remember that you're empowering patients as well...’ (SSI004)

‘...we need to understand their side versus the family, the patient, and the surroundings, and then we build a care plan that can work...also be very practical to conduct for the family as well...’ (SSI007)

1.4 PC as a means of integration of a multidisciplinary team (MDT) approach for holistic care:

Whilst participants’ responses regarding the members of the PC team differed, it was unanimously expressed that PC included a MDT approach to patient care. Comments made included:

'...So having people who understand holistic care, as well as caring for the psychosocial...OTs (occupational therapists)...because at that point they're still developing...I think it's very important...' (SSI008)

1.5 Structure of the PC Team

Participants in the SSI agreed that the PC Team was a MDT. However, views regarding the leader of the MDT differed. The majority of participants (n=9, SSI002/3/4/5/6/7/8 and SSI010/12) were of the opinion that the doctor should lead the PC team as evidenced by the following statements:

'...So obviously the doctor... uhh, of the patient...' (SSI012)

There were participants who understood that the MDT approach did not necessarily require a doctor to lead the PC team. One remarked:

'...so I think in my mind and ideal setting would be somebody who's done work in palliative medicine...' (SSI001)

1.6 PC as a means of bereavement care

Participants appeared to understand that part of the scope of PC was bereavement care. However, most participants did not spontaneously offer their perspective on this and had to be prompted regarding when the PC service terminates.

One consultant, when prompted on the matter of bereavement care, responded:

'...I never thought about that but that's actually very true... umm... beyond death... it will become more important with the family... with the patients support structure... Actually I didn't think about that' (SSI001)

Only three participants spontaneously thought about bereavement care. One such response was:

'Some people feel that once the patient is no longer there or has gone, it should end... but I feel that it should continue. There should be a certain level of support that the family should be offered as well to cope with either the loss of a loved one or give them the support that they need' (SSI004)

Theme 2: The need for PC is beyond the patient need

2.1 Patient need

Positive attitudes towards PC is indicative of 'palliphilic' perceptions towards PC and an understanding that PC would ensure that patient needs are met, as indicated by:

'...it's important just... for our patients to feel like they are taken care of not only just as a diagnosis...' (SSI010)

Five participants alluded to the dynamic nature of PC to create an environment that is suited to 'person-centered' care (SSI 001/8/7/9 and SSI 010). A participant stated:

'...I think if somebody is pain-free, motivated to engage in rehab, and it feels like they have some sort of, like, umm, of support with their mental state and their emotions, then they'd be more willing to engage in the, umm, in the treatment course...' (SSI010)

Another participant commented, regarding the role of PC in meeting patient's needs:

'...we are unable to achieve cure, but we are able to treat whatever we are able to treat...' (SSI009)

2.2 HCP need

Results analysed demonstrated both educational and emotional needs. Predominantly negative emotions when faced with patients at the EOL were evident and lack of educational preparedness played a significant role. Participants acknowledged the limitations of their skills and knowledge, expressing despondence when disease-modulating treatments were no longer available. Various statements were made including:

'Part of you feels a bit despondent... an irrational guilt or feeling that you have potentially failed the patient' (SSI002)

Some participants, however, displayed more confidence with regards to their outlook when faced with patients at the EOL:

'...I do try to communicate clear and fairly so that I don't omit important information, but I give important information in the right way...' (SSI007)

2.3 Family need

Participants often expressed that families form a significant part of PC but that the families may feel hopeless or uncertainty. Eight participants (SSI004/5/6/7/8 and SSI010/11/12) mentioned directly that PC helps comfort the family. Comments made included:

'...it's very important, umm, especially with the aspect of caregivers or relatives that may not understand what is going on. I think it really pulls them in (to care and decision making) and (this in turn) assists the patient' (SSI012)

2.4 The need for MDT integration into care

PC, due to its MDT approach, was almost unanimously seen as a necessity and as something that would benefit the KZN state sector. The MDT approach to patient care was seen as a beneficial and positive approach to care for patients with LLI One participant aptly remarked:

'...there's a lot of psychosocial issues that burden them, religious issues... So there are a lot of things that just conventional medicine and pharmacological medicine, I should say, does not address, and that's where palliative care exists' (SSI009)

Participants were aware of members of the MDT that would be required with various combinations of doctors, nurses, social workers, physiotherapists, psychologists, occupational therapists and spiritual chaplains being named as members that they would incorporate as part of the MDT.

2.5 The need for PC to be introduced as part of the hospital services

All twelve participants felt that PC was definitely important and PC services were required at Grey's Hospital, with some unsure as to why this service was not be offered at the hospital, as expressed by:

'...I'm not sure if it's been done before or whether it has been tried or somebody has attempted to implement it, I have no idea, but it's definitely something we need...' (SSI011)

Theme 3: Reasons for the absence of a PC service:

3.1 Absence of adequate provider knowledge:

Participants appeared to simultaneously acknowledge both the importance of PC and their definite lack of PC knowledge. This is supported by the following statement:

'...it's just a concept that we don't fully understand...' (SSI010) Additionally, when probed regarding the low response rate to the survey from paediatrics, one participant (SSI007) felt that there may be an existing knowledge deficit that prevented staff from participating.

When probed regarding the low response rate to the knowledge survey from the surgery department, participants SSI009 and SSI010 expressed conflicting views: one stated that it was likely lack of knowledge and awareness regarding PC on the part of their staff while the other stated that it was definitely not lack of awareness.

3.2 Oversight of policy implementation

A majority of participants felt that managerial decisions guiding the integration of PC were lacking or that PC was not seen as a priority. Some felt this was due to PC being viewed as an area of low priority. This can be illustrated by the comment below:

'...palliative care is not a priority according to the policymakers currently, even though it might be in all the documents like the WHO...' (SSI004)

3.3 Attitudes and perceptions unfavourable towards PC implementation

The majority of the participants (SSI 004/5/6/7/8/9 and SSI 010/11/12) identified this as a key factor that hindered the creation of a PC service. Suggestions for this included the perception that 'supportive care' was within the ambit of care at lower level hospitals, the attitude that a tertiary hospital should favour curative treatments and poor understanding regarding the role the PC. Remarks made included:

'...So I think Greys has gotten away...they've always been able to say...we've done everything we could... Send to base ...we're done...we fix ...whatever we can't fix we send back...' (SSI007)

Junior participants, highlighted their perception that senior staff were possibly more averse to PC approaches were not part of the PC process. PC was often left to the interns who did not feel adequately equipped to cope with the PC need. They expressed this:

'actually we are often left alone to give the news to the family or to give the news to the patients themselves... it's quite tough...' (SSI008)

3.4 Uncertainty regarding the lack of services

Participants acknowledged that PC was important and expressed confusion or uncertainty as to why services were not yet offered at the hospital. For example, when probed regarding the lack of services, one participant exclaimed:

'I have no idea...' (SSI006)

3.5 PC seen as a domain external to hospital-based care

It was highlighted by participants that, whilst PC is important, there are limitations regarding what can be done within the hospital and it is possibly more realistic to offer PC at community level. The concept of the role of initiation of PC in hospital was not clearly understood. This was displayed by one statement:

'...I feel like palliation is not going to happen within the hospital... we are seeing patients every three to six months in our clinics... in between that, we don't know what is happening to patients...' (SSI002)

3.6 Time and workload constraints

It became apparent that participants felt they did not have the time to provide PC themselves, even if they were to have some PC knowledge. Comments that were made include:

'...essentially, us, as doctors, we don't really have time to spend with the family or spend time outside the ten-minute clinical interaction with our patients...' (SSI007)

and

'...we are so overburdened with patients that PC is considered like a luxury service...' (SSI002)

When probed regarding the low response rates to the survey from the surgery and paediatrics departments, participants from the Department of Paediatrics (SSI004/7/8) all felt that members of their department knew that PC was important but staff were most likely too busy. Suggestions from participants in the Department of Surgery were that staff were too burdened by work constraints. In contrast to participants from paediatrics acknowledging the importance of PC, those from surgery expressed that surgeons were inclined to focus on acute issues only.

Theme 4: Future PC at Grey's Hospital

4.1 Enhancement of education to doctors

Eight participants felt that education of doctors through informal training would help. Participant SSI009 stated:

'...you need to have in-service training, basically for every person in this hospital'

4.2 Enhancement of available infrastructure

Participants acknowledged that, for PC services to be effectively initiated at the hospital, infrastructure would be key. However, some felt that a PC service should be integrated into the existing layout, whilst others felt that investment is required to develop a dedicated PC department. Opinions included:

'need your own designated space that you can actually see these patients in, have, you know, you have your clinics, have a place where you can meet and discuss patients' (SSI008)

'... (PC should be) integrated to disciplines where they see the majority of patients requiring palliative care...' (SSI003)

4.3 Enhancement of human resources

Participants discussed the creation of a dedicated PC team responsible for creating PC goals, visions and an initial PC structure. Participants remarked:

'...If we start with a team, we can easily establish the vision and the goals. And the mission, what are we trying to achieve... If the vision is clear to everyone in the room, it's easy to chase it..' (SSI007)

However, given resource constraints, doctors also felt that it would be more realistic to create a 'flagship' department' before a fully integrated service can be created with a new complement of staff:

'... (for now) every other department that needs to refer to palliative services can go through us as oncology because we might be giving them a bit more...' (SSI011)

4.4 Enhancement of finances

Restricted finances and competition for budget was deemed to be an important hurdle in the quest for PC services at the hospital. However, there seemed to be concerns that PC is seen as a luxury service and therefore is not allocated the resources that it should be. Participant SSI003 remarked:

'I can only imagine it's quite a costly and lengthy process... attaining all of those doctors (and) allied healthcare workers that need to be a part of that team...Then adding a lot of admin... because a team will need an administrator, a legal support, a clerk, etc...'

Corroboration of findings

Table 9: Corroboration of findings between knowledge survey and semi-structured interviews

Subject matter	Knowledge survey	Semi-structured interview	Inference
Awareness of PC and its importance	100% of participants (n=65) were aware of the concept of PC and see it as an essential discipline.	No participant mentioned that they did not know what PC was and all doctors agreed that PC was important when asked.	Converging evidence: participants are aware of PC and see it as important.
PC being aimed solely at physical symptoms	63% of participants (n=41) responded that PC is focused on management of physical symptoms.	All 12 participants alluded to care that extended beyond the physical symptoms of the patient.	Diverging evidence: The knowledge survey showed a clear gap in understanding while the interviews illustrated an awareness of PC extending beyond the spectrum of physical symptoms.
The role of PC in analgesia	41.54% (n=27) of participants felt that pain medication would definitely achieve analgesia.	All 12 participants saw analgesia as one of the main roles and goals of PC. Not all participants were able to link the psychosocial aspect of care with analgesia (poor awareness of the concept of 'total pain').	Converging evidence: PC can achieve analgesia. and Converging evidence: Participants lacked the ability to see pain beyond its physical aspect.
Patient involvement in decision making and family involvement in PC	90.77% of participants (n=59) expressed that patient preferences were important. 96.92% of participants (n=63) regarded family or caregiver input as preferable.	Most participants expressed that PC can increase patient understanding and improve healthcare related decision making. All participants mentioned that PC	Converging evidence: Participants had knowledge of the role of PC to include patient and family wishes and perspectives into decisions.

		incorporates the patient's support structure and assists with family communication.	
Is PC synonymous with EOL and cancer care?	35.38% of participants (n=23) indicated that PC is primarily aimed at patients at EOL. All participants were aware that PC is not solely associated with cancer care.	Responses conflicted as some participants expressed both that PC should begin at diagnosis of a LLI and that PC is for patients that are at the EOL.	Data indicated neutral results on this matter.
Running of the PC team structure	86.15% of participants (n=56) knew that the doctor need not necessarily be the head of the PC team.	9 out of the 12 participants indicated that the doctor was the leader of the PC team	Diverging evidence with no correlation between the knowledge survey and the semi-structured interviews.
Bereavement care as part of the spectrum of PC delivery	29.23% of participants (n=19) were of the opinion that the role of the PC team terminates when the patient passes away.	All participants agreed that bereavement care was within the framework of PC. However, the majority of participants (9/12) required prompting to discuss bereavement care.	Converging evidence: Bereavement care is part of PC. and Converging evidence: A knowledge gap, regarding the role of bereavement care in PC is present.

This table demonstrates where diverging and converging evidence that was gathered during the data collection process.

Chapter Six: Discussion

Demographic characteristics and some implications

This study was performed at Grey's Hospital in Pietermaritzburg, KZN, a tertiary healthcare centre servicing the western parts of this province. With this research, the researcher endeavoured to assess the level of knowledge that doctors caring for patients with LLI at this institution possessed regarding matters related to PC. Additionally, the researcher wanted to assess whether levels of experience, cadre or department in which they worked affected this knowledge. The researcher also wished to explore these doctors' perceptions surrounding the application of PC principles to patient care. Participants were questioned regarding deficits in PC services in the KZN state sector and asked for suggestions to improve PC services at Grey's Hospital to assess if perceptions regarding PC affected their support for PC at the hospital.

Doctors understood what PC was and recognised its necessity. However, the timing of PC initiation, as well as the place for EOL care, were poorly understood. The involvement of the patient and family as part of PC was well recognised. Additionally, and the priority of symptom control was understood, despite shortfalls on knowledge and perceptions regarding the holistic nature of PC. Overall, despite knowledge gaps were undoubtedly evident, there was a relatively positive attitude towards PC in general. Specific areas for increased training include the use of morphine, issues surrounding the timing of initiation of PC, management of total pain and bereavement care. Fortunately, doctors were open to furthering their PC knowledge and willing to work with PC services if this becomes available.

Of the cohort of 65 survey respondents, 41.54% (n=27) had less than 5 years of experience post undergraduate qualification. The majority of these doctors would have received some sort of formal undergraduate PC training.³⁶ However, this analysis showed that, overall, neither more nor fewer years of clinical experience correlated with significantly increased PC knowledge. One can then deduce that, regardless of pre-existing undergraduate PC education, based on these results, postgraduate CME training may possibly be of equal benefit as formal undergraduate training, albeit with undergraduate training creating PC awareness earlier in a doctor's career.

The largest cohort of respondents to the survey was from Internal Medicine (n=27, 41.54%). This may be indicative of a 'palliphilic' atmosphere within this department. The researcher considers this to be an important finding as there appears to be a great need for integration of PC into the Department of Internal Medicine. This is a department which sees a large number of patients with both communicable disease and NCD (including HIV/AIDS, TB, cardiac, respiratory and haematological

illnesses). The literature emphasises that the burden of these illnesses may outweigh the burden of acute illnesses⁴², and that management of NCD is key to the overall health of patients in South-Africa.^{42, 45, 61} Part of the care of these diseases would include appropriate PC provision. Therefore, doctors working within this discipline ought to have appropriate PC knowledge and positive perceptions regarding PC. The need for PC in some LLI managed by this department is highlighted by a 2017 article by Kreuter et al.³⁹ which highlighted the pivotal role that PC plays for patients with interstitial lung disease, and another article by Singh et al.⁷⁵ assessing PC needs in patients with cardiovascular disease. Despite the knowledge survey not specifically confining knowledge deficits to this discipline, PC education to these doctors, as well as a PC service at Grey's Hospital, may improve health outcomes in patients treated by this department due to the variety of patients with LLI that present to this department.

Other non-oncology departments including Obstetrics and Gynaecology, Paediatrics and Surgery also have a heavy burden of patients with LLI, and have similar staff counts to Internal Medicine (as per the research protocol of this study). However, the low response rates from some of these departments could indicate that doctors in these departments could possibly be overburdened with patient care, or have little time to participate in surveys and other academic activities. Importantly, though, lack of participation by doctors from these departments could reflect perceptions that PC is an insignificant component of care for their patients and that they do not want to dedicate time to PC. However, these poor response rates were concerning for the researcher, as LLI does likely form a fair portion of the patients that some of these departments care for. The literature on PC in non-cancer patients is largely published in the developed world, where resources and time commitments are different. However, it does illustrate collaboration between other specialists and PC. As an example, a study by Hay et al¹¹ concluded that gynaecologic oncologists used specialist PC services to aid effective communication with patients and treatment planning. If low participation rates by these specialities do reflect a suboptimal attitude towards PC, a finding which in itself deserves further study, it stands to reason that if their PC knowledge can be enhanced and perceptions reshaped. Thereafter, these doctors may be able to manage their patients with PC needs more effectively. This may be easily achievable, considering the research by Krakauer et al⁵, which demonstrated that minimal time input is required to educate doctors on basic PC provision.

[Matters surrounding knowledge of PC and perceptions of PC based on data analysis](#)

Analysis of both the knowledge survey and the SSI revealed fair or good knowledge of some aspects of PC and other PC areas with definite knowledge deficits. The need for education and knowledge regarding PC is emphasized in the local literature. A recent paper by Burger et al.³⁶ highlighted the

need for PC training commencing at the undergraduate level and the benefits of this, as well as a paper by Krause et al.⁵⁴ demonstrating the benefits of PC training to registrars in RSA. Internationally, basic or generalist PC education to doctors to enhance knowledge in PC was emphasized in a white paper by the EAPC,³¹ which recommended that all HCW should be equipped with some degree of PC skills so that PC can be delivered at all levels of care. The knowledge deficits highlighted by the study are indicative of the need for further PC education for doctors, especially those who treat patients suffering from LLI.

The finding that 100% of the participants were aware of the concept of PC and believed that this is an essential clinical discipline is important. It demonstrates that participants of diverse demographic characteristics (table 5) all felt that PC should be part of the care that is offered to patients. Results also showed a strong desire to refer patients from these disciplines to PC services, with only one participant expressing that they would not refer to a PC service should one be established. Furthermore, the awareness that PC was an option available beyond the spectrum of cancer care demonstrated that doctors clearly saw a role for PC within their disciplines. Corroboration of findings demonstrated convergence on this matter, as all participants in the SSI were also aware of PC and saw it as an important part of patient care. Despite this, the exact role of PC was not clearly defined by most participants, with confusion persisting regarding specific details and practices, thus indicating suboptimal knowledge. This correlates with findings in the literature, where multiple articles^{9, 14, 15} report that, while specialist PC and early PC referral are important, knowledge used to guide clinicians towards referral is potentially poorly understood. It was, however, reassuring to note a study in the Free State done by Lerato et al.⁷⁰ that found that many GP's were already attempting to provide PC to their patients, even in the absence of PC training. The researcher agrees with the findings of Coym et al.²⁵ that PC education would assist doctors to address pertinent knowledge gaps. Achievable interventions, such as CME meetings and clinical mentorship, could be integrated into Grey's Hospital to assist with filling these knowledge gaps.

More than 90% of doctors responding to the survey felt patient and family/caregiver participation in decision-making was crucial. In a resource-limited setting, due to various factors, this may not always be possible. However, it was reassuring that data reflected good knowledge regarding these aspects of PC. This corroborated with findings of the SSI, wherein positive perceptions were also expressed regarding the involvement of the patient and family in PC. Research, including an article by Lubuzo et al.³⁰, indicates that LLI not only affects the patient but also impacts the family and support structure from physical, psychological and economic perspectives. The findings of the current study are

reassuring as it displays that that the person- and family-centered nature of PC is so well recognised by non-PC trained doctors.

Despite participants being aware of PC and how essential it is, the study found that the definitions of PC and of EOL care appeared to be poorly understood. Furthermore, there was uncertainty regarding how to approach patients at the EOL. In both the survey and the SSI, despite the awareness of PC in general, lack of adequate knowledge of the relationship between PC and EOL care was apparent, with some participants seeing PC and EOL care as synonymous. The survey demonstrated that clinical experience, cadre and clinical department did not correlate with knowledge of the role that PC plays in the spectrum of patient care and that the timing of PC initiation was not fully understood. Research on this matter, particularly an article by Bell et al.,⁷⁶ identified that decisions around EOL care are amongst the most difficult decisions that doctors need to make. Furthermore, Gwyther and Rawlinson⁵² reported that doctors were uncomfortable caring for patients with LLI. As such, this poor understanding of the relationship between PC and EOL is in keeping with the findings of the literature and is indicative of poor knowledge regarding this aspect of PC.^{52, 60, 77} Consequently, this shortfall is likely to have direct implications on patient care, as management of patients with LLI could be delayed. Such aspects of care that are likely to be delayed in patients with LLI, as indicated by Kellehear et al.⁷⁸ include issues around mental health, social isolation, stigmas, family and financial issues and spiritual stress. Consequently, patient QOL and holistic health will be compromised. Interventions are thus required to fill the gap identified by this study to educate doctors regarding the role of PC, the differences between living with LLI and EOL and how to optimally care for patients at EOL. Furthermore, fears doctors have regarding addressing matters surrounding EOL care need to be addressed.

This study demonstrated a knowledge gap regarding the existence of recommendations for the initiation of PC and the SPICT Criteria. This gap persisted across all levels of experience, cadre and department. Importantly, results showed statistically significant results demonstrating that doctors with greater clinical experience, as well as doctors from certain departments, were more aware of the existence of some sort of recommendations. Whilst participants were not directly questioned about these criteria in the SSI, participants in the SSI appeared conflicted on the timing of PC initiation, indicating again that the criteria is likely not readily known. Participants of the SSI also expressed that there is a lack of education amongst doctors regarding when to initiate or refer to PC, and suggested the creation of PC education in the form of CME meetings and via other academic forums, and possibly strengthening of undergraduate PC curricula. The expression of this sentiment was reassuring,

especially as The WHO advocates for PC integration early in the course of illness.² Positively, perceptions towards education aimed at enhancing knowledge regarding PC referral was favourable. As such, measures aimed at enhancing the knowledge of doctors on this matter will likely be well-received at Grey's Hospital.

It was unanimous in both the knowledge survey and the SSI that PC is an effective means of achieving analgesia and that this is one of the main goals of PC. However, many survey participants (63.08 %, n=41) replied that PC was primarily associated with management of physical symptoms, highlighting a knowledge gap that is present with regards to the entity of 'total pain'. Participants were thus less cognisant of the biopsychosocial-spiritual approach to care. Other feedback supported this, with 41.54% of survey participants (n=27) responding that control of physical pain would ensure successful analgesia. This could indicate that, even when patients are prescribed appropriate analgesics, management may still be suboptimal. Convergence was noted with the SSI results, wherein participants appeared to focus on role the PC plays in targeting physical pain. However, some of the SSI participants did allude to the 'total pain' approach indirectly, albeit as an afterthought. The importance of non-pharmacological approaches to care is emphasized in the literature. Hui et al.⁷⁹ mentioned that supportive care (a synonym for PC in some locations) is essential for the management of the holistic needs of the patient. Such needs would include addressing 'total pain'. Additionally, Coym et al.²⁵ highlighted how, inter alia, effective communication with the patient and offering of spiritual care improved patient QOL. As such, appropriate knowledge regarding the biopsychosocial and spiritual aspects of care, as well as correct perceptions regarding these aspects of care is crucial for improved healthcare services. A clear knowledge gap is demonstrated by this research and intervention is warranted.

Findings of the quantitative survey revealed that above one-third of doctors either felt that morphine posed a risk of respiratory depression or were unsure about this. Likewise, over one-third of doctors felt that its use may lead to addiction. Morphine has been proven to be an effective medication to treat acute and chronic pain, as well as dyspnea, in patients with LLI.⁵ Thus, the finding that more than one-third of participants incorrectly believed myths surrounding morphine highlights an important knowledge gap. Use of this opioid, so crucial in PC, would be compromised if this knowledge gap is not addressed. This is especially true in state sector, where access to other opioids is severely restricted.⁸⁰ Doctors may be reluctant to initiate or escalate doses of morphine to achieve analgesia. Further exploration of the data revealed a paradox: many participants in the SSI stated that pain

control was crucial to PC, yet doctors were reluctant to use morphine as part of their management 'toolbox'. This finding echoes the results of a publication by Knaul et al.¹³ that reported that poor use of this inexpensive, accessible drug is now indicative of a public health failure. An important question thus arises, not covered by the current research, regarding medications current used to achieve analgesia for patients with PC needs.

To continue to explore strong opioid use, there was good awareness regarding the need for concurrent usage of laxatives. This reflects positively on the knowledge and adoption of certain PC concepts in patient care, as patients may default opioid analgesia if QOL is hindered by constipation.⁸¹

The majority of survey participants felt that IVF should be administered to patients at the end of life when oral intake is decreased, with statistically significant results that greater clinical experience (>10 years) played a role in doctors' awareness that IVF is not required at the EOL. This suggests that patients at the EOL in the hospital may be receiving futile care. This is important, as studies, such as one by Lokker et al.,⁸² have reported that provision of IVF at the EOL does not result in improved outcomes or QOL. Thus, the perception that artificial hydration at the EOL is beneficial to patients needs to be addressed, in order to prevent unnecessary hospitalisations in these patients.

Nearly one third of the survey participants (29.23%, n=19) appeared to lack the knowledge that PC continues after the patient dies as PC includes grief and bereavement care. Whilst this aspect of care may be challenging in a resource-limited setting, ignorance regarding this aspect of care highlights a gap within the South African state sector health system. Loss of a loved one could potentially trigger mental health pathologies, social stressors and other health conditions in the bereaved. Work by Drenth et al.²¹ emphasised the need for appropriate bereavement care by demonstrating that 10-20% of families experience prolonged or complicated grief. The current study found statistically significant evidence that doctors' cadre and department affected their knowledge regarding the relationship between PC and bereavement care, however it was concerning to note that doctors with greater clinical experience were not the most aware of this. Additionally, findings correlated with those of the SSI, where some participants did not mention bereavement care at all until they were prompted whilst others mentioned it only as an afterthought. There is still no guarantee that the presence of established PC services will improve bereavement care. As Kellhear⁷⁸ reports, many centres that offered PC services fell short of following this up with bereavement care. Thus, while the current study found the role of family and caregivers to be recognised during the patient's life, the recognition of the patient's social context was unfortunately not found to be persistent after their death. Therefore,

future training programmes to improve doctors' PC skills should include the bereavement needs of families.

Participants of the SSI expressed sentiments suggesting that, at managerial or DOH level, there may be lack of impetus to create a PC service. Most of these participants indicated that this was most likely because of competing resources, or because PC was not seen a priority. However, participants simultaneously reflected on the fact that, coupled with those at these levels, the staff on the ground likely had the incorrect attitudes and perceptions towards PC, and this may also hinder the creation of an appropriate service. This finding was in keeping with the study by McMillan⁵³ that demonstrated poor attitudes of doctors towards PC. Additionally, this finding proves the case for the need on increased PC education amongst doctors. Consequently, as Dlamini and colleagues⁶³ report, once doctors have the correct knowledge and attitudes towards PC, a collaboration can be created with the DOH that can lead to the creation of a much-needed PC service. The identified knowledge gaps of this study can be used to empower doctors with focused training and through this training their confidence in providing care with a PC paradigm will likely improve. Should this training occur in a scrutinised manner, with post-intervention assessment, the effect on care can be assessed and remaining gaps appropriately filled.

Results of the interviews further revealed evidence of doctors' sentiments regarding the financial burden of PC. Furthermore, participants expressed concerns regarding the additional investments into infrastructure and human resources that would be required for the realisation of PC service creation. However, there are existing examples of effective, feasible PC services currently in RSA. There is evidence in the literature regarding the creation of a hospital-based PC service,¹² as well as regarding the effectiveness and sustainability of context-appropriate services within the state sector.⁶⁶ However, doctors and stakeholders outside the Western Cape need to be empowered with the knowledge of this, so that this perception can be corrected, with a view to increase the chance of a hospital-based PC service being realised. It was reassuring, however, to note the surprise expressed by some participants that PC services are absent. As Lerato and colleagues⁷⁰ reported, doctors that are treating patients with LLI in the absence of PC education would likely be amenable to enhancing their PC knowledge and skills. Findings of the current study therefore supported the view that these participants saw PC as an essential service, would be willing to rather than a luxury, and provides hope that these doctors consider may PC in the future and motivate for increased PC services.

Strengths and limitations of the study

To the best of the researcher's knowledge, this is the first, multi-departmental study at a tertiary hospital in KZN that investigates the knowledge and perceptions of doctors towards PC. This study included doctors of all cadres and levels of experience to gain a broader understanding of the factors that may affect this knowledge and perceptions. The researcher was able to perform purposeful sampling and select the most appropriate participants. As such, the researcher is hopeful that the findings of this study reflect a clear picture of the sentiment towards PC in the hospital currently. The benefits of KABP studies and mixed methods research has [previously been discussed](#) in the introduction of this study.

Study limitations may impact the results that have been presented. Despite the responding participants representing a diverse population from all demographic sub-groups, response rate of 66.32% was noted. Additionally, due to the questionnaire nature of the knowledge survey, there is potential for non-response bias and selection bias, whereby only those who deemed PC to be important or who had an idea what is participated, with others potentially not seeing this an important field of study. Response bias may have also been present in those who did respond whereby their answers reflected what they thought the researcher wanted to hear, rather than true opinions. Furthermore, this study was performed at one tertiary hospital only. While this allowed for an in-depth assessment of the situation, there may be staff at elsewhere with differing knowledge and perceptions. As such, further studies are warranted at other centres. Lastly, the researcher focused the study on doctors that treat patients with LLI and policymakers were not part of this study. However, there may be administrative and other issues that impact the development of avenues for PC education or the creation of a service. Therefore, there is room for future studies that investigate this.

Chapter Seven: Conclusion

RSA is a sub-Saharan upper middle-income nation. However, despite being a signatory to the WHA Resolution of 2014 and the adoption of NPFPC locally, large gaps in PC service delivery currently exist. Notwithstanding the presence of these gaps, the WHPCA has recognised RSA as a nation where PC is at a preliminary state of integration within the healthcare system.

There is a need to determine the effectiveness of local policies on PC services within RSA and, in particular, within KZN. As such the researcher undertook this study at Grey's Hospital in Pietermaritzburg, KZN. This large, tertiary state hospital was chosen as it serves as a referral centre for a substantial portion of KZN and is a site where large numbers of patients with LLI are diagnosed and managed.

The researcher undertook the study in order to determine the knowledge that doctors employed at this hospital possessed regarding PC. Additionally, the researcher endeavoured to explore the perceptions of these doctors towards PC and the application of PC principles. Doctors from six departments of varying ages, levels of experience and cadres were deemed to be eligible to participate.

Overall, the survey found that doctors possessed overarching knowledge of the concept of PC and recognised its importance. Knowledge of PC concepts did not significantly differ based on years of experience or cadre. However, the role, scope and timing of PC seemed to be poorly understood. PC was incorrectly perceived to be synonymous with EOL care by a large proportion of the participants. Furthermore, whilst there was an awareness of the multi-disciplinary nature of PC, roles of the members of this MDT still appeared to be unclear to the participants and many participants erroneously perceived the doctor to be the leader of the MDT.

Participants were amenable to referring patients to PC, however, there was poor knowledge of referral criteria, such as the SPICT and SPICT-SA criteria. As such, there was no consensus on when PC approaches should be initiated. Participants displayed conflicting knowledge, as many acknowledged the role of early PC initiation, whilst simultaneously expressing sentiments that PC was aimed at EOL care. Furthermore, bereavement care was generally acknowledged as important in PC, but most participants only mentioned this as part of the provided package of PC after being specifically prompted.

Regarding knowledge of management in PC, it was noted that, even amongst senior staff, the role of morphine within PC was poorly understood. Morphine is a cornerstone of PC pharmacology, and is also cheap and readily available. This finding pointed to the fact that more education is required about the role that medications can play within PC. In particular, education on the use of morphine for patients with LLI should be high up on the PC training agenda for doctors of all cadres. Furthermore, as part of PC, participants focused on the management of physical symptoms, and often forgot about the role PC plays in psychosocial and spiritual aspects of care. The psychosocial and spiritual aspects of care are crucial parts of the PC plan of any patient, and doctors need to be enlightened regarding this.

Despite awareness of the need for PC in their patients, participants expressed concern regarding the place for it within an already resource-constrained busy hospital setting. Additionally, some participants perceived PC to be care that ought to be delivered at other centres or at community level. However, it was suggested that small-scale services at focally appropriate points should be started within the hospital. For example, the department of oncology was suggested as a pilot department for the initiation of PC services.

Additionally, the notion was expressed that, although needed, PC may not receive the resources and time that it requires due to competition for resources and infrastructure. Furthermore, PC was incorrectly perceived by some to be a 'luxury' service. However, positive feedback was received that, if established, a formal PC service would be well received by most departments and that PC services could potentially be incorporated into the existing resources and infrastructure. Participants also suggested that if policymakers opened up avenues for PC education at the hospital, such as CME and other programs, they would be willing to engage with these programs, in order to enhance their PC awareness and adopt PC approaches within the hospital.

With this in mind, the researcher concludes that there is a definite need for enhancement of PC education to all doctors, particularly those that manage patients with LLI. An increase in the current PC knowledge of doctors will open up the way for the provision of dignified treatment to those suffering with LLI, with less provision of futile care, and could result in enhanced healthcare delivery and outcomes. Furthermore, modification of some of the current perceptions towards PC can prove to be vital in ensuring that patients receive appropriate person-centred care, and maintain an acceptable QOL, despite an existing LLI.

The researcher is hopeful that the results of this study can ignite efforts from doctors to increase their PC knowledge and encourage supervisors to invest in the PC training of their staff. The knowledge gaps and uncertainties detailed in this study can inform both formal and informal PC training platforms. Furthermore, the existence of these deficits at all levels of experience, and in all cadres of staff highlights the need for the incorporation or expansion of PC training at both undergraduate and postgraduate level, including intermediate-level PC training for registrars in all disciplines dealing with patients with LLI. The receptive attitude towards PC in general, as well as the willingness to undergo further training (that was found by this study), supports these endeavours as potentially well-received and impactful.

Moreover, the results of this study confirm that a PC service at tertiary hospital in KZN should be developed and would be well received. Even a small-scale service is predicted to make positive change, and could be used as a pilot project to monitor the effects of a PC service on patient and health system outcomes in KZN. It is hoped that the positivity towards a formal PC service these results reflect will motivate policymakers and other stakeholders to create such services at Grey's Hospital and in KZN as a whole. Establishment of a PC service will align KZN more closely with the WHA Resolution 67.19 of 2014 and with the goals outlined the NPFPC of 2017.

Despite the knowledge deficits highlighted by this study, as well as some incorrect perceptions regarding PC, the researcher is hopeful that the picture of PC in KZN will change over the coming years. The increased drive for undergraduate PC education in RSA, as well as recent moves towards embedding PC training within the postgraduate training of registrars has provided hope that this is achievable. Furthermore, the creation of formal PC services in state sector hospitals in the Western cape and Gauteng provides hope that similar measures can be implemented within KZN.

This research provides a foundation for further research on the state of PC in KZN. This will ensure appropriate resource expenditure on PC needs in the province. Should the knowledge gaps highlighted by this study be addressed, the impact on patient care could be monitored and audited, and subsequently inform future PC training and service. This may then additionally contribute to the motivation for the creation of formal PC services in KZN. Continued monitoring and evaluation of PC programs as well as additional PC research in KZN will ensure that such resources can become available timeously and precisely to the patients and services that require them. This then ensures that the benefits of palliative care for both the patient and the healthcare system can be realised.

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Appendices

- A) Process of Literature Search
- B) Ethics Approval from UCT HREC
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- D) Ethics Approval from KZN PHREC
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- F) Semi structured interview Guide
- G) Participant Consent Form- Knowledge survey
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Appendix A: Process of Literature Search

Metasearches and seeking of expert opinion

In order to gain a general overview of the literature, the researcher first conducted a meta search of the literature using the University of Cape Town's Primo portal. On this portal, the keywords 'knowledge', attitude', 'perceptions', 'beliefs', 'palliative care' and 'palliative medicine' were used. The search was then narrowed down by only filtering literature that was produced or published after 1992 (the last 30 years preceding the drafting of the research protocol), and that was in the English language. The researcher excluded articles that related to any other healthcare worker that was not a doctor, unless specifically deemed by the researcher to be critical to the requisite evidence base or the setting (KwaZulu-Natal).

The researcher then conducted a similar metasearch using the Google Scholar platform.

Expert opinion was also sought from supervisors and local experts in the field of palliative medicine, who advised on some resources that should be referred to. Some of these were emailed to the researcher, or accessed via the University of Cape Town's library resources, such as its internal repository, 'OpenUCT'.

As this is a minor dissertation is not a systematic review, the researcher extracted articles were from the aforementioned metasearch platforms that pertained to the study, and all other articles were excluded, until the researcher felt that sufficient data was extracted to formulate the literature review.

Thereafter, the researcher commenced a phase of focused literature collection and review. This was performed using recognized, academically accepted, renowned medical databases, including Pubmed, Scopus, and three databases from the EBSCOhost platform (Africawide, CINAHL and Medline).

Pubmed

Using the Pubmed database, a combination of keywords and MeSH (medical subject headings) data was utilised. On this platform, the researcher utilised the advanced search option. Keywords were input into the search bar, and the added to a search history. The researcher then utilised the MeSH menu to find similar options to add to his search history. Once the search history was fully collated,

the 'search builder' option was selected to combine variations of keywords and MeSH data output to scan the literature pertaining to the research topic.

Keywords used on the Pubmed platform included the following:

- knowledge OR perception OR perceptions OR attitude OR attitudes
- tertiary hospital OR tertiary hospitals OR teaching hospital OR teaching hospitals OR quaternary hospital OR quaternary hospitals
- hospital OR hospitals
- palliative care OR palliative medicine OR supportive care OR end-of-life care OR "end of life care"
- doctor OR doctors OR clinician OR clinicians OR physician OR physicians
- Natal OR KwaZulu-Natal OR KZN
- "south africa"

The MeSH terms used on Pubmed to broaden the keywords used were as follows:

- "Health Knowledge, Attitudes, Practice"[Mesh]
- "Attitude of Health Personnel"[Mesh]
- "Tertiary Care Centers"[Mesh]
- "Academic Medical Centers"[Mesh] OR "Hospitals, Teaching"[Mesh]
- "Physicians"[Mesh]
- "Palliative Care"[Mesh] OR "Palliative Medicine"[Mesh]

The best possible combinations of these keywords and MeSH options were utilised. However, on the Pubmed platform only 12 applicable references that met the inclusion criteria were found, out of the 307 results that were picked up.

Scopus

Using the Scopus database, keywords were utilised. Keywords were input into the search option, and an asterix was used at the end of these keywords to allow for variations of the words. For some keywords, if they were phrases, they had to be put into quotation marks or a hyphen was used to break up the phrases. Variation of spelling had to be taken into account, and thus words were spelled in both American and British spellings, where applicable. Once all the individual keywords and phrases were searched for, the 'combine queries' option was selected, and the 'and' option was selected.

Keywords and phrases used on the Scopus platform, using various combinations' included the following:

- "palliative care" OR "palliative medicine" OR "end of life" OR end-of-life OR "supportive care"
- knowledge OR perception* OR attitude* OR belief* OR practice*
- "tertiary hospital*" OR "quaternary hospital*" OR "academic hospital*" OR hospital* OR "tertiary care center*" OR "tertiary care centre*" OR "academic medical centre*" OR "academic medical center*"
- doctor* OR clinician* OR physician* OR "health personnel"
- "South Africa"

Using this search strategy, 20 results were found. A similar search was performed with 'South Africa' being replaced with 'KwaZulu-Natal' (in various variations of spelling), and only 3 results were found. Of the 23 combined results, 16 significant articles were extracted. However, articles were duplicates from the aforementioned PubMed search and, thus 14 results were extracted for review.

EBSCOhost

A similar search strategy to that performed using the Scopus database was performed using the EBSCOhost database.

On this platform, using various combinations of keywords, 69 references were identified. Of these 69 references, 17 references were deemed by the researcher to be significant for study being undertaken. However, of these, 5 references were already identified on the aforementioned PubMed and Scopus database searches. Thus, 12 new references were identified for review for purposes of the study.

Appendix B: Ethics Approval from UCT HREC



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room 45 E-52-E-Floor- Old Main Building
 Groote Schuur Hospital
 Observatory 7925
 Telephone [021] 406 6492
 Email: hrec-submissions@uct.ac.za
 Website: www.health.uct.ac.za/home/human-research-ethics

25 April 2023

HREC REF: 252/2023

Dr R Krause

FaCe-Division of Interdisciplinary Palliative Care & Medicine
 Falmouth Building-FHS
 Email: rene.krause@uct.ac.za
 Student: junzzzz@gmail.com

Dear Dr Krause

PROJECT TITLE: KNOWLEDGE AND PERCEPTIONS OF DOCTORS IN A TERTIARY LEVEL HOSPITAL IN KWAZULU-NATAL TOWARDS PALLIATIVE CARE- (MASTERS CANDIDATE-DR JUNAID M VAHED)

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, subject to all KZN ethics and Provincial approvals.

Approval is granted for one year until the 30 April 2024.

Please submit a progress form, using the standardised Annual Report Form (FHS016) if the study continues beyond the approval period. Please submit a Standard Closure form 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 Junaid Vahed will also be involved in this study.

Please quote HREC REF 252/2023 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 BLOKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007

HREC/ref 252.2023



FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee



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	30.4.2025
<input type="checkbox"/> Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	12/5/2024

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to: hrec-enquiries@uct.ac.za.

Please use the latest form found on our website:
<http://www.health.uct.ac.za/fhs/research/humanethics/forms>

UNIVERSITY OF CAPE TOWN
FACULTY OF HEALTH SCIENCES
HUMAN RESEARCH
ETHICS COMMITTEE
- 7 MAY 2024

Appendix C: Approval from Grey's Hospital to conduct study



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Private bag x9001, Northern Park, Pietermaritzburg, 3200
201 Town bush Road, Northern Park, Pietermaritzburg, 3200
Tel: 033 397 3317 Fax: 033 6973396 Email: Nhlakanipho.Gumede@kznhealth.gov.za
www.kznhealth.gov.za

DIRECTORATE: GREY'S HOSPITAL
OFFICE OF THE SENIOR
MANAGER MEDICAL SERVICES

Date: 02/06/2023
Enquiries: Dr NMT Gumede
Extension No: 3317

Attention: Dr. J. M. Vahed

RE: PERMISSION TO CONDUCT RESEARCH AT GREY'S HOSPITAL

I have pleasure in informing you that permission has been granted to you by Grey's Hospital to conduct research on: **Knowledge and perceptions of doctors in a tertiary level hospital in KwaZulu-Natal towards palliative care.**

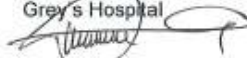
Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received approval of your study from the Provincial Health Research and Ethics Committee (PHREC) in the KZN Department of Health.
3. Application to PHREC is done online via the National Health Research Database (NHRD): <http://nhrd.hst.org.za>
4. Please ensure this office is informed before you commence your research.
5. Greys Hospital will not provide any resources for this research.
6. You will be expected to provide feedback on your findings to the Clinical HOD of the department where research is being conducted.
7. You are required to contact this office regarding dates for providing feedback when the research has been completed.

Thanking you sincerely

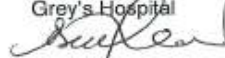
Recommended / Not recommended by:

Dr NMT Gumede
Senior Medical Manager
Grey's Hospital



Approved / Not approved by:

Mr B Shezi
Chief Executive Officer
Grey's Hospital



Appendix D: Ethics Approval from KZN PHREC



KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: hrkm@kznhealth.gov.za

Health Research & Knowledge
Management

NHRD Ref: KZ_202306_015

Dear Dr J M Vahed
(UKZN)

Approval of research

1. The research proposal titled '**Knowledge and perceptions of doctors in a tertiary level hospital in KwaZulu-Natal towards palliative care**' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

The proposal is hereby **approved** for research to be undertaken at Grey's hospital.

2. You are requested to take note of the following:
 - a. **Kindly liaise with the facility manager BEFORE your research begins.**
This is to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
 - b. All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.
 - c. Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
 - d. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za
 - e. Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.

For any additional information please contact Dr. G Khumalo on 033-395 3189.

Yours Sincerely

Dr E Lutge

Chairperson, Provincial Health Research Committee

Date: 30/06/2023

Appendix E: Knowledge survey

Survey

Section A - Demographic/Biographical information

This section of the questionnaire refers to background or biographical information. Although we are aware of the sensitivity of these questions in this section, the information allows us to compare groups of respondents. We assure you that your response will remain anonymous.

What is your gender?

Male/ Female/ Prefer not to say

What is your age group (in years)?

20-25, 26-30, 31-40, 41-50, >50

How many years of clinical experience do you have post undergraduate qualification?

<5, 6-10, >11

What post do you currently hold?

Intern, Registrar/medical officer, Consultant/ Specialist

Department?

Internal Medicine/ Surgery/ Neurology/ Obstetrics and Gynaecology/ Oncology/ Paediatrics

Section B: Palliative care

This section of the survey explores your knowledge regarding palliative care. **Please indicate your answer to each question as Yes, No or I don't know.**

1. I am aware of the concept of palliative care
2. I believe that palliative care is an essential clinical discipline
3. Once diagnosed with a life-limiting illness, palliative care can be commenced at any time within the disease trajectory, including early on in the disease process
4. Palliative care is primarily aimed at patients at the end of life
5. Palliative care is only concerned with patients who have been diagnosed with cancer
6. Should a palliative care clinic be established at my institution, I see myself referring patients to this clinic, based on the discipline that I currently work in
7. Recommendations for the initiation of palliative care exist.
8. I have heard of the SPICT Criteria

9. Palliative care is focused on management of physical symptoms to enhance the quality of life of patients with life threatening diseases
10. When planning treatment in palliative care, patient preferences should take precedence, even when contradictory to conventional medical advice
11. Consideration of family or caregiver involvement is preferable for good palliative care management
12. Morphine cannot be titrated to high doses because it poses a danger of respiratory depression
13. Control of physical aspects of pain will always ensure that successful analgesia is achieved
14. As the doctor heads the multidisciplinary team, they have the final say with regards to decision making for patients with life threatening illnesses
15. In palliative care, addiction is a relevant concern when using high doses of morphine
16. If a patient with stage 4 cancer develops new vertebral metastases and lower limb weakness, there are clinical options available to address this
17. Initiation of intravenous fluids is warranted if a patient's oral intake at the end of life's has declined significantly
18. It is good clinical practice to initiate patients on laxatives if they have been prescribed with opioids
19. The medical team's role terminates once the patient has deceased and/or they have been removed from the institution

Thank you for your willingness to participate

Appendix F: Semi structured Interview Guide

To the best of your knowledge, what is Palliative Care?

How would you describe the roles that palliative care plays in the care of patients?

How is Palliative Care relevant in the domain that you currently work?

Please describe some clinical conditions that warrant palliative care

Who would you say belongs to the palliative care team?

According to your understanding, what are some of the main goals of palliative care?

When, in your opinion, should palliative care commence and terminate?

Why do you think Palliative Care is important, or not important?

How do you react when you are faced with a patient who is at the 'end of life'?

Why do you think Grey's Hospital does not currently offer Palliative Care services?

How do you think established Palliative Care services will benefit Kwazulu natal?

How can Palliative Care be integrated into the hospital system at Grey's Hospital?

How much investment, would you think, is needed towards Palliative Care?

Appendix G: Participant Consent form: Survey

Knowledge and perceptions of doctors in a tertiary level hospital in KwaZulu-Natal towards palliative care

Consent Form:**Consent of participant:**

By virtue of signing this consent form, I hereby declare that I have studied the information leaflet for the study, and that I understand what participation will involve, including the time that is needed to participate. I understand that participation will not impact my relationship with the researcher in any way whatsoever, nor any future interactions that I will have with the researcher. I further state that I have been afforded an opportunity to ask questions, and raise any issue and concerns that I have. I declare that I am aware that no incentives are offered for participation, and that no coercion took place to result in my participation. I am aware that I am allowed to suspend, or withdraw, my participation at any stage if it becomes too upsetting for me.

I would like to voluntarily proceed with participation in the study.

Name of participant:

Signature of participant:

Contact number of participant:

Date:

Witness 1 signature and date:

Witness 2 signature and date:

Appendix H: Participant Consent form: Semi structured interview

Knowledge and perceptions of doctors in a tertiary level hospital
in KwaZulu-Natal towards palliative care

Consent Form:**Questions or queries raised by the potential participant pre-interview:**

Affidavit by researcher:

I hereby declare that I have furnished the potential participant of the aforementioned research study with the relevant information sheet, and the he or she has been provided with an opportunity to ask questions, raise comments, and to clarify any issues and concerns. The potential participant is fully aware of what participation will involve and, to my best knowledge, has no language or cognitive deficit that will hinder their understanding and effective communication. Thus, to my best knowledge, the potential participant is competent to sign informed consent and proceed with participation in the study.

Name of Researcher: _____

Signature of Researcher: _____

Date: _____

Consent of participant:

By virtue of signing this consent form, I hereby declare that I have studied the information leaflet for the study, and that I understand what participation will involve, including the time that is needed to participate. I understand that participation will not impact my relationship with the researcher in any way whatsoever, nor any future interactions that I will have with the researcher. I further state that I have been afforded an opportunity to ask questions, and raise any issue and concerns that I have. I declare that I am aware that no incentives are offered for participation, and that no coercion took place to result in my participation. I am aware that I am allowed to suspend, or withdraw, my participation at any stage if it becomes too upsetting for me.

I would like to voluntarily proceed with participation in the study.

Name of participant: _____

Signature of participant: _____

Contact number of participant: _____

Date: _____

Witness 1 signature and date: _____

Witness 2 signature and date: _____

Appendix I: Participant Information Sheet: Knowledge survey

Information Sheet:
Knowledge and perceptions of doctors in a tertiary level hospital in KwaZulu-Natal towards palliative care

PRINCIPAL INVESTIGATORS:

Dr Junaid Mohamed Vahed
 MPhil Palliative Medicine Candidate
 Division of Interdisciplinary Palliative Care and Medicine
 Dept. of Family, Community and Emergency Care
 University of Cape Town
 Email: VHDJUN001@uct.ac.za
 Contact Number: 0739786074

Dr Rene Krause
 Acting Head of Department
 Division of Interdisciplinary Palliative Care and Medicine
 Dept. of Family, Community and Emergency Care
 University of Cape Town
 Email: rene.krause@uct.ac.za
 Phone number: 0216501475

Dr Louise Walker
 Oncology Registrar
 University of Kwazulu Natal
 Email: louise.s.walker@gmail.com
 Phone number: 0338973222

This information sheet serves to inform you about a study that you may wish to participate in. Should you have any further questions that may help you decide whether you would like to participate or not, you are welcome to contact the researcher using the details provided above.

What is the purpose of the study?

This study aims to explore the knowledge and perceptions of doctors working at Grey's Hospital, Pietermaritzburg, regarding the application of palliative care principles to patient care.

Is participating in the study mandatory?

No, you do not need to participate. Should you agree to participate, the option to withdraw at any stage remains available, with no need for justification. Agreement to, or refusal of, participation will not influence the relationship that you currently maintain with the researcher, or his department (Grey's Hospital Oncology Department), as he is acting in his capacity as a researcher for this study, and not as a doctor of the hospital. Should you agree to participate, you will be requested to sign a consent form, confirming that you have agreed to do so. You may take some time to decide whether you wish to participate or not, should you be unsure about this.

What will happen if I choose to participate?

You will be requested to complete a short, online survey. If you prefer a hard copy, this can also be provided to you. It should not take more than 10 to 15 minutes to complete.

What are the benefits of the study?

There are no direct benefits of the study to participants. However, findings from the study may impact care provided to, and quality of life of, the patients that are managed by the study participants.

What are the risks of the study?

Answering some questions may lead to an emotional response by the participants. The researcher is trained to deal with this, should it occur, and a distress protocol is in place to ensure that the risk is managed appropriately.

How will your confidentiality be maintained?

All information provided in the survey will be kept strictly confidential. All surveys are anonymous. During the process of data storage and analysis, as well as during the research process and thereafter, strict measures will be adopted to safeguard confidentiality. All participants will be allocated a participant number by the researcher. No one outside the study will be granted access to study-related data.

What happens if I feel distressed during or following participation in the study?

Once the researcher becomes aware of this, you will be referred to the 'distress team' for the study, as outlined in the research protocol, and will be cared for until the distress resolves or stabilizes.

How will I find out about the results of the study?

A report back will be provided to all participating departments and the hospital via an update leaflet

Who is organizing the research?

Should you require any information regarding the research, you may contact the principal researcher, Dr Junaid Vahed, via email or telephone via the contact details listed above.

Questions regarding your human rights, or ethical queries, may be directed to:

University of Cape Town Human Research Ethics Committee Administration Supervisor
E52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Cape Town
021- 4066338. Email: hrec-enquiries@uct.ac.za

Appendix J: Participant Information Sheet- Semi structured interviews

Information Sheet:

Knowledge and perceptions of doctors in a tertiary level hospital in KwaZulu-Natal towards palliative care

PRINCIPAL INVESTIGATORS:

Dr Junaid Mohamed Vahed
 MPhil Palliative Medicine Candidate
 Division of Interdisciplinary Palliative Care and Medicine
 Dept. of Family, Community and Emergency Care
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 Contact Number: 0739786074

Dr Rene Krause
 Acting Head of Department
 Division of Interdisciplinary Palliative Care and Medicine
 Dept. of Family, Community and Emergency Care
 University of Cape Town
 Email: rene.krause@uct.ac.za
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Dr Louise Walker
 Oncology Registrar
 University of Kwazulu Natal
 Email: louise.s.walker@gmail.com
 Phone number: 0338973222

This information sheet serves to inform you about a study that you may wish to participate in. Should you have any further questions that may help you decide whether you would like to participate or not, you are welcome to contact the researcher using the details provided above.

What is the purpose of the study?

This study aims to explore the knowledge and perceptions of doctors working at Grey's Hospital, Pietermaritzburg, regarding the application of palliative care principles to patient care.

Is participating in the study mandatory?

No, you do not need to participate. Should you agree to participate, the option to withdraw at any stage remains available, with no need for justification. Agreement to, or refusal of, participation will not influence the relationship that you currently maintain with the researcher, or his department (Grey's Hospital Oncology Department), as he is acting in his capacity as a researcher for this study, and not as a doctor of the hospital. Should you agree to participate, you will be requested to sign a consent form, confirming that you have agreed to do so. You may take some time to decide whether you wish to participate or not, should you be unsure about this.

What will happen if I choose to participate?

The researcher will contact you to arrange an interview, at a mutually acceptable time, and you will be asked some questions regarding palliative care. It should take no more than 30 minutes to complete

What are the benefits of the study?

There are no direct benefits of the study to participants. However, findings from the study may impact care provided to, and quality of life of, the patients that are managed by the study participants.

What are the risks of the study?

Answering some questions may lead to an emotional response by the participants. The researcher is trained to deal with this, should it occur, and a distress protocol is in place to ensure that the risk is managed appropriately.

How will your confidentiality be maintained?

All information provided in the interview process will be kept strictly confidential. During the process of data storage and analysis, as well as during the research process and thereafter, strict measures will be adopted to safeguard confidentiality. All participants will be allocated a participant number by the researcher. No one outside the study will be granted access to study-related data.

What happens if I feel distressed during or following participation in the study?

Once the researcher becomes aware of this, you will be referred to the 'distress team' for the study, as outlined in the research protocol, and will be cared for until the distress resolves or stabilizes.

How will I find out about the results of the study?

A report back will be provided to all participating departments and the hospital via an update leaflet

Who is organizing the research?

Should you require any information regarding the research, you may contact the principal researcher, Dr Junaid Vahed, via email or telephone via the contact details listed above.

Questions regarding your human rights, or ethical queries, may be directed to:

University of Cape Town Human Research Ethics Committee Administration Supervisor
E52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory, Cape Town
021- 4066338. Email: hrec-enquiries@uct.ac.za

Appendix K: Results of statistical tests of association for quantitative survey

Variable 4. Palliative care is primarily aimed at patients at the end of life

RECODE of EG_end_of life (Palliative care is primarily aimed at patients at the	How many years of clinical experience do you have with undergraduate qualifications			Total
	<= 5	6-10	>= 11	
0	9 9.6 39.13 33.33	4 5.7 17.39 25.00	10 7.8 43.48 45.45	23 23.0 100.00 35.38
1	18 17.4 42.86 66.67	12 10.3 28.57 75.00	12 14.2 28.57 54.55	42 42.0 100.00 64.62
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 1.7801 Ex = 0.411
 Cramer's V = 0.1655
 Fisher's exact = 0.456

RECODE of EG_end_of life (Palliative care is primarily aimed at patients at the	What post do you currently hold?			Total
	Intern	Registrar	Consultant	
0	6 5.3 26.09 40.00	12 12.0 52.17 35.29	5 5.7 21.74 31.25	23 23.0 100.00 35.38
1	9 9.7 21.43 60.00	22 22.0 52.38 64.71	11 10.3 26.19 68.75	42 42.0 100.00 64.62
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 0.2595 Ex = 0.878
 Cramer's V = 0.0632
 Fisher's exact = 0.888

RECODE of EG_end_of life (Palliative care is primarily aimed at patients at the	What department are you currently part of?						Total
	Internal	Neurology	Obstetric	Oncology	Paediatrics	Surgery	
0	12 9.6 52.17 44.44	3 2.8 13.04 37.50	5 3.9 21.74 45.45	0 1.4 0.00 0.00	2 2.8 8.70 25.00	1 2.5 4.35 14.29	23 23.0 100.00 35.38
1	15 17.4 35.71 55.56	5 5.2 11.90 62.50	6 7.1 14.29 54.55	4 2.6 9.52 100.00	6 5.2 14.29 75.00	6 4.5 14.29 85.71	42 42.0 100.00 64.62
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00

Pearson chi2(5) = 5.4035 Ex = 0.369
 Cramer's V = 0.2883
 Fisher's exact = 0.434

Variable 7. Recommendations for the initiation of palliative care exist

RECODE of RC_RECOSMRE ndations (Recommend ations for the initiation of palliative c	How many years of clinical experience do you have post undergraduate qualificati			Total
	</= 5	6-10	>= 11	
0	6 8.3 30.00 22.22	9 4.9 45.00 56.25	5 6.8 25.00 22.73	20 20.0 100.00 30.77
1	21 18.7 46.67 77.78	7 11.1 15.56 43.75	17 15.2 37.78 77.27	45 45.0 100.00 69.23
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 6.4706 Ex = 0.039
Cramer's V = 0.3155
Fisher's exact = 0.052

RECODE of RC_RECOSMRE ndations (Recommend ations for the initiation of palliative c	What post do you currently hold?			Total
	Intern	Registrar	Consultan	
0	3 4.6 15.00 20.00	11 10.5 55.00 32.35	6 4.9 30.00 37.50	20 20.0 100.00 30.77
1	12 10.4 26.67 80.00	23 23.5 51.11 67.65	10 11.1 22.22 62.50	45 45.0 100.00 69.23
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 1.1970 Ex = 0.550
Cramer's V = 0.1357
Fisher's exact = 0.560

RECODE of RC_RECOSMRE ndations (Recommend ations for the initiation of palliative c	What department are you currently part of?						Total
	Internal	Neurology	Obstetric	Oncology	Radiatri	Surgery	
0	5 8.3 25.00 18.52	3 2.5 15.00 37.50	4 3.4 20.00 36.36	1 1.2 5.00 25.00	1 2.5 5.00 12.50	6 2.2 30.00 85.71	20 20.0 100.00 30.77
1	22 18.7 48.89 81.48	5 5.5 11.11 62.50	7 7.6 15.56 63.64	3 2.8 6.67 75.00	7 5.5 15.56 87.50	1 4.8 2.22 14.29	45 45.0 100.00 69.23
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00

Pearson chi2(5) = 13.4706 Ex = 0.019
Cramer's V = 0.4552
Fisher's exact = 0.019

Variable 9. Palliative care is focused on management of physical symptoms to enhance the quality of life of patients with life threatening diseases

RECODE of PG_MANAGER SXX (Palliative care is focused on management of physical symptoms)	How many years of clinical experience do you have			Total
	undergraduate <= 5	6-10	graduate >= 11	
0	17 17.0 41.46 62.96	10 10.1 24.39 62.50	14 13.9 34.15 63.64	41 41.0 100.00 63.08
1	10 10.0 41.67 37.04	6 5.9 25.00 37.50	8 8.1 33.33 36.36	24 24.0 100.00 36.92
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 0.0054 Ex = 0.997
Cramér's V = 0.0091
Fisher's exact = 1.000

RECODE of PG_MANAGER SXX (Palliative care is focused on management of physical symptoms)	What post do you currently hold?			Total
	Intern	Registrar	Consultant	
0	9 9.5 21.95 60.00	23 21.4 56.10 67.65	9 10.1 21.95 56.25	41 41.0 100.00 63.08
1	6 5.5 25.00 40.00	11 12.6 45.83 32.35	7 5.9 29.17 43.75	24 24.0 100.00 36.92
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 0.6861 Ex = 0.710
Cramér's V = 0.1027
Fisher's exact = 0.744

RECODE of PG_MANAGER SXX (Palliative care is focused on management of physical symptoms)	What department are you currently part of?						Total
	Internal	Neurology	Obstetric	Oncology	Paediatric	Surgery	
0	19 17.0 46.34 70.37	5 5.0 12.20 62.50	9 6.9 21.95 81.82	2 2.5 4.88 50.00	3 5.0 7.32 37.50	3 4.4 7.32 42.86	41 41.0 100.00 63.08
1	8 10.0 33.33 29.63	3 3.0 12.50 37.50	2 4.1 8.33 18.18	2 1.5 8.33 50.00	5 3.0 20.83 62.50	4 2.6 16.67 57.14	24 24.0 100.00 36.92
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00

Pearson chi2(5) = 6.0463 Ex = 0.302
Cramér's V = 0.3050
Fisher's exact = 0.294

Variable 12. Morphine cannot be titrated to high doses because it poses a danger of respiratory depression

RECODE of EC_MORPHIN e (Morphine cannot be titrated to high doses because it pose	How many years of clinical experience do you have POST undergraduate qualificati /<= 5 6-10 >= 11			Total
	0	11 10.0 45.83 40.74	6 5.9 25.00 37.50	
1	16 17.0 39.02 59.26	10 10.1 24.39 62.50	15 13.9 36.59 68.18	41 41.0 100.00 63.08
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 0.4174 Ex = 0.812
~~Cramer's V~~ = 0.0801
 Fisher's exact = 0.807

RECODE of EC_MORPHIN e (Morphine cannot be titrated to high doses because it pose	What post do you currently hold? Intern Registrar Consultan			Total
	0	6 5.5 25.00 40.00	12 12.6 50.00 35.29	
1	9 9.5 21.95 60.00	22 21.4 53.66 64.71	10 10.1 24.39 62.50	41 41.0 100.00 63.08
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 0.1020 Ex = 0.950
~~Cramer's V~~ = 0.0396
 Fisher's exact = 0.944

RECODE of EC_MORPHIN e (Morphine cannot be titrated to high doses because it pose	What department are you currently part of? Internal Neurology Obstetric Oncology Paediatric Surgery						Total
	0	10 10.0 41.67 37.04	5 3.0 20.83 62.50	5 4.1 20.83 45.45	1 1.5 4.17 25.00	1 3.0 4.17 12.50	
1	17 17.0 41.46 62.96	3 5.0 7.32 37.50	6 6.9 14.63 54.55	3 2.5 7.32 75.00	7 5.0 17.07 87.50	5 4.4 12.20 71.43	41 41.0 100.00 63.08
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00

Pearson chi2(5) = 5.0937 Ex = 0.405
~~Cramer's V~~ = 0.2799
 Fisher's exact = 0.432

Variable 13. Control of physical aspects of pain will always ensure that successful analgesia is achieved

RECODE of EC_Physica 1_pain (Control of physical aspects of pain will always ensure)	How many years of clinical experience do you have post- undergraduate qualificati			Total
	</= 5	6-10	>/= 11	
0	12 11.2 44.44 44.44	6 6.6 22.22 37.50	9 9.1 33.33 40.91	27 27.0 100.00 41.54
1	15 15.8 39.47 55.56	10 9.4 26.32 62.50	13 12.9 34.21 59.09	38 38.0 100.00 58.46
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 0.2049 Ex = 0.903
Cramer's V = 0.0562
Fisher's exact = 0.949

RECODE of EC_Physica 1_pain (Control of physical aspects of pain will always ensure)	What post do you currently hold?			Total
	Intern	Registrar	Consultan	
0	7 6.2 25.93 46.67	15 14.1 55.56 44.12	5 6.6 18.52 31.25	27 27.0 100.00 41.54
1	8 8.8 21.05 53.33	19 19.9 50.00 55.88	11 9.4 28.95 68.75	38 38.0 100.00 58.46
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 0.9530 Ex = 0.621
Cramer's V = 0.1211
Fisher's exact = 0.638

RECODE of EC_Physica 1_pain (Control of physical aspects of pain will always ensure)	What department are you currently part of?							Total
	Internal	Neurology	Obstetric	Oncology	Paediatric	Surgery		
0	13 11.2 48.15 48.15	3 3.3 11.11 37.50	7 4.6 25.93 63.64	1 1.7 3.70 25.00	3 3.3 11.11 37.50	0 2.9 0.00 0.00	27 27.0 100.00 41.54	
1	14 15.8 36.84 51.85	5 4.7 13.16 62.50	4 6.4 10.53 36.36	3 2.3 7.89 75.00	5 4.7 13.16 62.50	7 4.1 18.42 100.00	38 38.0 100.00 58.46	
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00	

Pearson chi2(5) = 8.2294 Ex = 0.144
Cramer's V = 0.3558
Fisher's exact = 0.125

Variable 15. In palliative care, addiction is a relevant concern when using high doses of morphine

RECODE of PC_MORPHIN S_ADDICTIO n (In palliative care, addiction is a relevant con	How many years of clinical experience do you have PC_MORPHIN undergraduate qualifications			Total
	<= 5	6-10	>= 11	
0	8	9	6	23
	9.6	5.7	7.8	23.0
	34.78	39.13	26.09	100.00
	29.63	56.25	27.27	35.38
1	19	7	16	42
	17.4	10.3	14.2	42.0
	45.24	16.67	38.10	100.00
	70.37	43.75	72.73	64.62
Total	27	16	22	65
	27.0	16.0	22.0	65.0
	41.54	24.62	33.85	100.00
	100.00	100.00	100.00	100.00

Pearson chi2(2) = 4.0709 Ex = 0.131
 Cramer's V = 0.2503
 Fisher's exact = 0.154

RECODE of PC_MORPHIN S_ADDICTIO n (In palliative care, addiction is a relevant con	What post do you currently hold?			Total
	Intern	Registrar	Consultan	
0	4	14	5	23
	5.3	12.0	5.7	23.0
	17.39	60.87	21.74	100.00
	26.67	41.18	31.25	35.38
1	11	20	11	42
	9.7	22.0	10.3	42.0
	26.19	47.62	26.19	100.00
	73.33	58.82	68.75	64.62
Total	15	34	16	65
	15.0	34.0	16.0	65.0
	23.08	52.31	24.62	100.00
	100.00	100.00	100.00	100.00

Pearson chi2(2) = 1.1171 Ex = 0.572
 Cramer's V = 0.1311
 Fisher's exact = 0.622

RECODE of PC_MORPHIN S_ADDICTIO n (In palliative care, addiction is a relevant con	What department are you currently part of?						Total
	Internal	Neurology	Obstetric	Oncology	Paediatric	Surgery	
0	9	3	6	2	2	1	23
	9.6	2.8	3.9	1.4	2.8	2.5	23.0
	39.13	13.04	26.09	8.70	8.70	4.35	100.00
	33.33	37.50	54.55	50.00	25.00	14.29	35.38
1	18	5	5	2	6	6	42
	17.4	5.2	7.1	2.6	5.2	4.5	42.0
	42.86	11.90	11.90	4.76	14.29	14.29	100.00
	66.67	62.50	45.45	50.00	75.00	85.71	64.62
Total	27	8	11	4	8	7	65
	27.0	8.0	11.0	4.0	8.0	7.0	65.0
	41.54	12.31	16.92	6.15	12.31	10.77	100.00
	100.00	100.00	100.00	100.00	100.00	100.00	100.00

Pearson chi2(5) = 3.9456 Ex = 0.557
 Cramer's V = 0.2464
 Fisher's exact = 0.576

Variable 16. If a patient with stage 4 cancer develops new vertebral metastases and lower limb weakness, there are clinical options available to address this

RECODE of
~~EG_SABOSE~~
stage4_cli
nical (If
a patient
with stage
4 cancer
develops n

How many years of clinical
experience do you have ~~EGSE~~
undergraduate ~~qualificati~~
</= 5 6-10 >= 11 Total

0	11 7.5 61.11 40.74	4 4.4 22.22 25.00	3 6.1 16.67 13.64	18 18.0 100.00 27.69
1	16 19.5 34.04 59.26	12 11.6 25.53 75.00	19 15.9 40.43 86.36	47 47.0 100.00 72.31
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 4.5244 Ex = 0.104
Cramer's V = 0.2638
Fisher's exact = 0.109

RECODE of
~~EG_SABOSE~~
stage4_cli
nical (If
a patient
with stage
4 cancer
develops n

What post do you currently hold?
Intern Registrar Consultant Total

0	6 4.2 33.33 40.00	11 9.4 61.11 32.35	1 4.4 5.56 6.25	18 18.0 100.00 27.69
1	9 10.8 19.15 60.00	23 24.6 48.94 67.65	15 11.6 31.91 93.75	47 47.0 100.00 72.31
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 5.1774 Ex = 0.075
Cramer's V = 0.2822
Fisher's exact = 0.064

RECODE of
~~EG_SABOSE~~
stage4_cli
nical (If
a patient
with stage
4 cancer
develops n

What department are you currently part of?
Internal Neurology Obstetric Oncology ~~Radiat~~ Surgery Total

0	9 7.5 50.00 33.33	1 2.2 5.56 12.50	6 3.0 33.33 54.55	0 1.1 0.00 0.00	2 2.2 11.11 25.00	0 1.9 0.00 0.00	18 18.0 100.00 27.69
1	18 19.5 38.30 66.67	7 5.8 14.89 87.50	5 8.0 10.64 45.45	4 2.9 8.51 100.00	6 5.8 12.77 75.00	7 5.1 14.89 100.00	47 47.0 100.00 72.31
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00

Pearson chi2(5) = 9.5543 Ex = 0.089
Cramer's V = 0.3834
Fisher's exact = 0.111

Variable 17. Initiation of intravenous fluids is warranted if a patient's oral intake at the end of life's has declined significantly

RECODE of EC_INTRAVENOUS (Initiation of intravenous fluids is warranted if a pat	How many years of clinical experience do you have with undergraduate qualifications			Total
	<= 5	6-10	>= 11	
0	21 18.3 47.73 77.78	13 10.8 29.55 81.25	10 14.9 22.73 45.45	44 44.0 100.00 67.69
1	6 8.7 28.57 22.22	3 5.2 14.29 18.75	12 7.1 57.14 54.55	21 21.0 100.00 32.31
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 7.5752 Ex = 0.023
Cramer's V = 0.3414
Fisher's exact = 0.032

RECODE of EC_INTRAVENOUS (Initiation of intravenous fluids is warranted if a pat	What post do you currently hold?			Total
	Intern	Registrar	Consultant	
0	11 10.2 25.00 73.33	25 23.0 56.82 73.53	8 10.8 18.18 50.00	44 44.0 100.00 67.69
1	4 4.8 19.05 26.67	9 11.0 42.86 26.47	8 5.2 38.10 50.00	21 21.0 100.00 32.31
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 3.0380 Ex = 0.219
Cramer's V = 0.2162
Fisher's exact = 0.231

RECODE of EC_INTRAVENOUS (Initiation of intravenous fluids is warranted if a pat	What department are you currently part of?							Total
	Internal	Neurology	Obstetric	Oncology	Paediatrics	Surgery		
0	20 18.3 45.45 74.07	6 5.4 13.64 75.00	10 7.4 22.73 90.91	2 2.7 4.55 50.00	3 5.4 6.82 37.50	3 4.7 6.82 42.86	44 44.0 100.00 67.69	
1	7 8.7 33.33 25.93	2 2.6 9.52 25.00	1 3.6 4.76 9.09	2 1.3 9.52 50.00	5 2.6 23.81 62.50	4 2.3 19.05 57.14	21 21.0 100.00 32.31	
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00	

Pearson chi2(5) = 9.2905 Ex = 0.098
Cramer's V = 0.3781
Fisher's exact = 0.085

Variable 19. The medical team's role terminates once the patient has deceased and/or they have been removed from the institution

RECODE of EG_ROLE_ES terminates (The medical team's role terminates once the patient deceases)	How many years of clinical experience do you have post undergraduate qualifications			Total
	<= 5	6-10	>= 11	
0	4 7.9 21.05 14.81	5 4.7 26.32 31.25	10 6.4 52.63 45.45	19 19.0 100.00 29.23
1	23 19.1 50.00 85.19	11 11.3 23.91 68.75	12 15.6 26.09 54.55	46 46.0 100.00 70.77
Total	27 27.0 41.54 100.00	16 16.0 24.62 100.00	22 22.0 33.85 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 5.5433 Ex = 0.063
Cramer's V = 0.2920
Fisher's exact = 0.065

RECODE of EG_ROLE_ES terminates (The medical team's role terminates once the patient deceases)	What post do you currently hold?			Total
	Intern	Registrar	Consultant	
0	1 4.4 5.26 6.67	14 9.9 73.68 41.18	4 4.7 21.05 25.00	19 19.0 100.00 29.23
1	14 10.6 30.43 93.33	20 24.1 43.48 58.82	12 11.3 26.09 75.00	46 46.0 100.00 70.77
Total	15 15.0 23.08 100.00	34 34.0 52.31 100.00	16 16.0 24.62 100.00	65 65.0 100.00 100.00

Pearson chi2(2) = 6.1757 Ex = 0.046
Cramer's V = 0.3082
Fisher's exact = 0.042

RECODE of EG_ROLE_ES terminates (The medical team's role terminates once the patient deceases)	What department are you currently part of?						Total
	Internal	Neurology	Obstetric	Oncology	Paediatric	Surgery	
0	5 7.9 26.32 18.52	6 2.3 31.58 75.00	4 3.2 21.05 36.36	1 1.2 5.26 25.00	0 2.3 0.00 0.00	3 2.0 15.79 42.86	19 19.0 100.00 29.23
1	22 19.1 47.83 81.48	2 5.7 4.35 25.00	7 7.8 15.22 63.64	3 2.8 6.52 75.00	8 5.7 17.39 100.00	4 5.0 8.70 57.14	46 46.0 100.00 70.77
Total	27 27.0 41.54 100.00	8 8.0 12.31 100.00	11 11.0 16.92 100.00	4 4.0 6.15 100.00	8 8.0 12.31 100.00	7 7.0 10.77 100.00	65 65.0 100.00 100.00

Pearson chi2(5) = 13.8368 Ex = 0.017
Cramer's V = 0.4614
Fisher's exact = 0.012