A determination of the prevalence of palliative care patients admitted to the Groote Schuur Hospital Emergency Centre and their Presenting Complaints

By Radha Govender

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Supervisors: Dr René Krause
Dr Patryk Szymanski

University of Cape Town
Faculty of Health Science
School of Public Health and Family Medicine
Division of Palliative Medicine

PLAGIARISM DECLARATION

I, ***Radha Govender***, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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ABBREVIATIONS / ACRONYMS

PC	Palliative Care
WHO	World Health Organisation
COPD	Chronic Obstructive Pulmonary Disease
HIV	Human Immunodeficiency Virus

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The staff of the Groote Schuur Medical Emergency Centre were awe-inspiring to watch. Amidst the busy-ness, high patient volumes, and need to act with speed, patients were well taken care of.

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ABSTRACT

Background: The Emergency Centre is often an entry point to health services and is, therefore, well positioned to identify patients with palliative care needs. It is also the place of care sought by the families of palliative care patients when their loved ones are seriously ill or terminal. It becomes important to understand the numbers of palliative care patients presenting to Emergency Centres and the reasons why they present there, in order to strengthen the care provided to these patients in the Emergency Centre.

Objectives: This study aimed to determine the prevalence of palliative care patients in a tertiary academic hospital Medical Emergency Centre, and to establish their presenting complaints.

Method: The study was an exploratory and descriptive quantitative study based on a review of folders of admitted patients. Non-random sampling with a convenience sampling method was used. Data collection was carried out from 01-11 August 2019. Folders of patients admitted to the Emergency Centre were reviewed, data was collected onto an excel workbook, and analysed. Data collected included patient demographics, symptoms, diagnoses, reasons for presentation, and previous history of palliative care services.

Results: Over the data collection period, 383 patients were admitted to the Emergency Centre. 124 of these patients were found to have palliative care needs. Palliative care prevalence over the measured period in the Emergency Centre was therefore 32.4%. Forty-eight percent (48%) of the palliative care patients were male, 52% were female. The most frequent reasons for admission to the Emergency Centre were pain (14% of patients), shortness of breath (7%), loss of/reduced levels of consciousness (6%), and heart disease (5%). 35% of patients presented during business hours (8am-4pm), 62% presented after hours (4pm- 8am). The most frequent reason for admission after hours was pain (18% of palliative care patients admitted after hours). There were no pain- related reasons for admission during business hours. Shortness of breath and heart disease were the most frequent reasons for admission during business hours – forming 6.8% each of all palliative care related business hour admissions. The most frequent symptoms noted for palliative care patients were pain (32.0%), loss of/reduced level of consciousness (30.6%), shortness of breath (24.2%). The most common palliative care related diagnoses were heart/vascular disease (29,0%), cancer progressive and/or metastatic (26.6%) and neurological disease/stroke (19.4%). The top 3 diagnoses in both females and males were hypertension, heart disease and cancer. The most frequent symptom presented by cancer patients was pain. Hospice services are available in the vast majority (96%) of the suburbs in which the patients reside. Only 5.6% of the palliative care patients had been referred to palliative care services.

Conclusion: The Emergency Centre is an important catchment zone for the identification and management of palliative patients. Understanding the expected volume of palliative care patients in an Emergency Centre will allow staff to plan for their special needs. The prevalence of palliative care patients presenting to an Emergency Centre is 32.4%.
To better support palliative care patients, it is important to understand why patients with palliative

care needs present to an Emergency Centre. Pain, shortness of breath and loss of/reduced levels of consciousness are driving patients to the Emergency Centre.

While South Africa has a preliminary level of integration of palliative care services with health services, palliative care services are not available to patients and their families on weekends and after hours. Until this has been remedied and other sources of care are in place, Emergency Centres remain an important site of access to care for distressed patients. This therefore requires that a palliative care approach be followed to meet patient needs, and that palliative care training is prioritised for healthcare professionals working in an Emergency Centre.

1. INTRODUCTION

In 2002, the World Health Organisation (WHO) formally defined palliative care (PC), and in doing so, identified the spectrum of the population that needs palliative care viz. patients with life-threatening illnesses. In the early years of the modern hospice movement, it was cancer patients who were primarily regarded as requiring palliative services. The updated formalised definition from the WHO broadened the base, emphasising that PC services should be provided to all people facing suffering due to life-threatening diseases, those who are approaching the end of their lives, and that this should include the families of these patients(1). This was an acknowledgement of the fact that patients with life-threatening illnesses present across the entire health system with varied diagnoses. A PC identification tool including a wide list of life-threatening illnesses and indicators of deteriorating health has been developed in response to this affirmation (2). The enhanced WHO definition also acknowledges that patients with life-threatening illnesses will present at various entry points in the health system. The Emergency Centre serves as one such point of entry. The suffering of PC patients and their families is never more acute than when they present to an Emergency Centre. While PC services and research in PC is growing in South Africa, the palliative care experience in the Emergency Centre is still relatively unknown.

The Emergency Centre is often an entry point to health services and is, therefore, well positioned to identify patients with PC needs. It is also the place of care sought by the families of PC patients when their loved ones who are seriously ill or terminal, show distressing symptoms, and the family members do not have the knowledge or skill to take care of their ill member(3-5). Research outcomes have shown that patients with life-threatening illnesses have improved outcomes if a PC approach (bio-psycho-social and spiritual) is included in their care(6). The key point of concern if whether medical staff in an Emergency Centre are geared to address palliative care patients and their needs. Medical staff working in an Emergency Centre, however, are required to be decisive and to respond briskly to rapidly changing medical situations. They are trained to treat acute illnesses, injuries and distressing symptoms, with a focus on stabilising a patient and preserving life for ongoing treatment elsewhere(7). They are not trained in longitudinal care. This is often at odds with PC goals that seek to relieve pain and suffering in line with a patient's goals of care, to avoid futile care and to provide comfort care – timeously as required by the patient and family(8). Patients with life-threatening illnesses and PC needs presenting to an Emergency Centre are therefore at risk of being side-lined, not being identified as having PC needs, and therefore not having their PC needs attended to.

Keeping in mind the potential unmet needs of this vulnerable group, it becomes important to understand the numbers of PC patients presenting to Emergency Centres and the reasons why they present there, in order to strengthen the care provided to these patients in the Emergency Centre. This information will affect the following two areas:

- It will allow a review of the changes that need to be made to accommodate the urgent and distressing needs of these patients and their carers in an Emergency Centre
- It will also support an analysis of what proportion of their visits are better dealt with in an alternative PC setting.

Palliative care is a relatively new discipline in South Africa and was mainly reserved for hospice settings(9). There is, therefore, a lack of PC training for staff, together with an absence of standard operating procedures related to identifying and managing PC patients and their families in most hospitals(10). With the adoption by South Africa's National Health Council of the National Policy Framework and Strategy on Palliative Care in 2017, and a time frame of 5 years to achieve the goals set out therein, much growth in the PC field is anticipated in the near future(11, 12). A needs analysis at all levels is thus essential to ensure resources and training are allocated correctly.

This research was carried out in Groote Schuur Hospital, an academic tertiary hospital in the Western Cape province of South Africa. Groote Schuur Hospital is a 975-bed hospital and boasts two Emergency Centres – Trauma and Medical. This research was carried out in the Medical Emergency Centre. Only adults present to this Emergency Centre. Statistics from the Department from January 2017 to April 2018 reveal that the Medical Emergency Centre sees on average 2 742 patients a month(13). Of these patient visits, 13.4% result in hospital admissions(13). The public health system in South Africa, having to recover from apartheid's inefficiencies and racial segregation of services, is seriously under-resourced(14). This is especially true in Groote Schuur Hospital which was understaffed by 3 762 posts in September 2015(15). The Emergency Centre, therefore, also shares the burden of being understaffed and is significantly overloaded regarding its capacity. Groote Schuur Hospital also has a Cancer Centre, resulting in many of its patients presenting to the hospital Emergency Centre after hours when they fall ill or become distressed. This places an additional load on the Medical Emergency Centre. More broadly, South Africa suffers from a quadruple burden of disease with a high incidence of infectious diseases (such as HIV/AIDS), high levels of trauma from violence and injuries, a growing burden of non-communicable diseases, and maternal and child morbidity(16). This burden also manifests in the Emergency Centre and increases their workload. At the time that the data collection was done (August 2019), Covid had not yet made an appearance in our world and in our health systems. It is important to note, therefore, that the figures presented here are pre-Covid.

Groote Schuur Hospital has established a PC team comprising two registered nurses, two auxiliary social workers, a volunteer doctor, and an administration clerk. These staff work closely with the Medical Emergency Centre physicians to provide PC support to patients who present there. They assist with diverting on average 79-100 patients per month (garnered from across the whole hospital) to more appropriate levels of care, and address pain and symptom control(9). In the Emergency Centre, the Palliative Care team only sees the patients referred to them by the Emergency Centre physicians. Unfortunately, many of these physicians are not skilled in identifying patients in need of PC services nor on initiating PC. Thus, the PC needs of many patients are never attended to. The Palliative Care team is also only available during business hours on weekdays only, thus resulting in the Emergency Centre being unsupported after hours and on weekends.

This research sought to provide information on the numbers of PC patients accessing the Emergency Centre of a large tertiary institution and the reasons why they present to the Emergency Centre. These findings may be valuable because it will contribute to this area of knowledge and provide an understanding of the profile and symptom burden of South African patients with life-threatening diseases who present to an Emergency Centre. With limited information available in South Africa

currently on the profile of PC patients seeking assistance in an Emergency Centre, this new knowledge may potentially assist with improved planning to meet these patient needs within the Emergency Centre.

2. LITERATURE REVIEW

The following reference systems and databases were used to find the most relevant research done in this field: Google, Google Scholar, EbscoHost, Clinical Key, Elsevier, Ebook Central, Wiley Library, Science Direct.
The search terms used to identify articles related to the area of research are listed below:

Palliative care	Palliative care prevalence	Acute palliative care
Emergency Centre / unit	Trauma department / unit	Palliative care in an Emergency Centre / unit
Palliative care needs of carers/caregivers	Death in the emergency / trauma department / unit	End of life care in the emergency/trauma department/unit
Death in the Emergency Centre	Barriers to palliative care	The burden of palliative care
Palliative care in Africa	Palliative care in developing countries	

The following journals formed part of the search for related articles: Journal of Palliative Medicine, Palliative Medicine, Journal of Pain and Symptom Management, Journal of Clinical Oncology, Journal of Emergency Medicine, American Journal of Hospice and Palliative Medicine, The Lancet, Journal of Palliative Care, Journal of Palliative Medicine.

Articles published earlier than the year 2000 were not included in the research. Articles published in the English language only were considered. A search of English language articles since 2000 on Google Scholar with the key words “palliative care Emergency Centre” revealed 61 300 articles.
The researcher instituted alerts on Google Scholar that alerted her to all new articles related to this area of research. These new articles were assessed for relevancy and included in the write-up where appropriate.

2.1 THE GLOBAL STATE OF PALLIATIVE CARE

The WHO estimates that 40 million people per annum require palliative care and that 78% of these are to be found in developing countries. Further, that only 14% of patients who need palliative care, actually receive palliative care services(17). The WHO reports that the large majority of patients requiring PC services present with chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Other conditions also requiring PC include kidney failure, chronic liver disease, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis(17). These chronic and life-threatening diseases fall firmly within the WHO definition of palliative care. Further research has been done at a country level to rank progress made in PC delivery.

As part of an effort to map the global levels of PC services available per country over time, 3 studies have been published - in 2008, 2013, 2020 - describing categories of PC development per country and their changes over time(18-20). These studies measured PC services over the period 2006 to

2017. Clark et al, carried out the most recent study of the status of 198 countries as at 2017(20). They followed an online survey methodology of palliative care experts per country. The researchers used similar groups created years earlier in the 2008 study, and used again in the 2013 study. Encouragingly, the most recent findings show that since the 2008 study, 17 more countries form part of Group 4, the highest level of PC development, and 16 more countries form part of Group 3. There are 4 fewer countries in Group 1 – countries with no known PC activity. This research included 47 African countries. Of these, 10 (21%) showed no PC activity - a decrease from the 2008 study that showed 19 African countries in this group. This change and improvement in PC services in Africa has been due to support by the African Palliative Care Association and funders. Six African countries form part of Group 4. Through the various studies, South Africa has been listed in Group 4a – countries with PC services at a preliminary level of integration. Malawi and Swaziland are the only African countries listed in Group 4b – countries with PC at an advanced stage of integration(20). While it is encouraging to see this expansion in a growing number of African countries, there is much work to be done in Africa in the field of palliative care.

The worldwide palliative care access gap was the focus of the 2017 Lancet Commission Report. It stated that 56.2 million people died in 2015. Of these, 25.5 million (45%) suffered from serious illnesses and required PC services. Eighty percent (80%) of these PC patients were from developing countries(21). Further, another 35.5 million people suffered from serious illnesses in 2015 and did not die. Access to basic PC and pain relief is limited in developing countries. This lack of access to pain relief is clarified through the opioid distribution statistics - 298.5 metric tons of morphine are manufactured in the world each year, with only 0.03% of this volume distributed to developing countries. With developed countries accounting for only 20% of the world-wide PC patient burden, they receive nearly all of the manufactured opioids. As an example, the United States of America obtains an annual equivalent of 55 000mg of morphine-equivalent opioids per patient in need of palliative care. Canada obtains 68 000mg per PC patient. Both these countries are receiving opioids way above the requirements of their PC patients and other medical needs for opioids. Haiti, on the other hand, receives only 5mg per PC patient – resulting in 99% of patients not being adequately treated for pain. Magnifying the inequity, 80% of PC patients in developing countries receive 0.03% of globally distributed opioids. Pain is poorly managed in developing countries largely due to the lack of availability of opioids in those countries(21). Limited access to inexpensive morphine to alleviate suffering caused by pain is a global public health failure. Pain is a major factor driving PC patients to the Emergency Centre.

Barbera et al, found that pain was the number one reason for cancer patients visiting the Emergency Centre within the last six months of life(5). Their study was carried out in first world Canada, yet still, uncontrolled pain was the top reason for accessing the Emergency Centre. With developing countries bearing the bulk of the burden of seriously ill patients yet having only a tiny proportion of global opioids distributed to them, pain management of their PC patients must surely be a challenge for healthcare professionals, likely to result in poor pain management of patients. More research is needed that describes the health-seeking behaviour of patients and their families in developing countries when their loved ones show distressing symptoms. With large variations in health care systems, access and capabilities across countries, it is important to understand where palliative care research is being done.

While there is a growing field of literature covering the provision of palliative care in the emergency setting, the majority of these cover first world countries such as Canada, the United Kingdom and the United States of America(22-25). Whilst this research is set near the southernmost tip of the African continent, there is limited other research and information that pertains to Africa, South Africa or other developing countries. Ninety-nine percent (99%) of published literature relevant to palliative care is generated by first world countries, with only a 1% contribution from developing countries(26).

Further entrenchment of the need for research in developing counties was made by Potts M et al, (27). They performed a systematic literature review, researching PC outcomes and outcomes measures in developing countries (India, Vietnam, and Africa). Their study showed that while all the PC interventions showed positive outcomes across the physical, psychological, and psychosocial spheres, not all were statistically or clinically significant. They associated this gap not with the lack of models used, but rather with the lack of rigorous design of the studies. They also found that outcomes were measured largely where PC was delivered by formal healthcare professionals, with only a few evaluating outcomes of care delivered by community health workers and volunteers. The obvious need in poorly resourced countries is to expand the reach of palliative care, thereby advocating for the training and assessment of the more abundant resources of community health workers, volunteers, and other informal carers.

In a resource-constrained environment that is typical of developing countries, it is important to ensure that care of seriously ill patients is planned for and provided in appropriate settings, to reduce patient and family stress, and to avoid the inconvenience and resource pressures associated with the provision of unplanned care. Also, this kind of analysis in a South African context is needed to gain an understanding of the size of this population, and to ensure that healthcare workers are best equipped to manage the specific needs of PC patients.

A literature search revealed quite varying figures regarding the percentage of PC patients presenting to the Emergency Centre, but more correlating figures on the proportion that could have been dealt with in an alternative setting.

2.2 PALLIATIVE CARE IN THE EMERGENCY CENTRE

While the role of palliative care services is becoming further entrenched in health care of the seriously ill, there are still voices that question the value and effectiveness of providing PC services in an Emergency Centre.

Grudzen et al, carried out a first-of-its-kind prospective single-blind randomised clinical trial in the Emergency Centre of a quaternary care institution in New York City(28). They sought to evaluate the effect of Emergency Centre initiated PC services versus usual care on quality of life, health care utilisation, depression and survival in patients with advanced cancer. Their participants were 136 patients who presented to the Emergency Centre who had not previously received PC services, and who were admitted into the hospital thereafter. The measures for quality of life showed a

significant increase in the intervention group versus usual care group. While an increase in QoL became apparent at week 6, it did not show statistical significance. At week 12, however, the results were stronger and statistically significant. They found that there were no statistical differences in mood symptoms (depression), hospice use, hospital days or ICU admissions between the two groups – measured at baseline, week 6 and week 12. Encouragingly, the intervention group lived longer than the usual care group by 4.9 months. Although this measure did not show statistical significance (P = 0.20) due to the wide variation in survival periods of the participants, it should still serve to reassure healthcare professionals working in an Emergency Centre that PC initiated in the Emergency Centre improves quality of life without a negative effect on survival of patients. Fortunately, more research in this area was also supported by other teams.

da Silva Soares et al, in a systematic review looking at the effectiveness of PC in the Emergency Centre on various measures, found that there was no evidence that PC provision in the Emergency Centre affected patient outcomes(29). With many more articles in this area published since this time (number of articles doubled in the past 5 years), Wilson JG, et al. repeated the review in 2020 and reached a different conclusion(30). They found that the provision of PC in an Emergency Centre, and referral of patients from the Emergency Centre to hospice or palliative care, is achievable and may improve quality of life. They also found that the provision of PC services in an Emergency Centre does not affect patient survival time. All of this work around the value of PC services provided in an Emergency Centre would take on new meaning once we understand how many PC patients to expect in an Emergency Centre.

There is limited data available currently that sheds light on what proportion of Emergency Centre patients are PC patients. In 2014, Wong et al, published the results of their systematic search to determine the incidence of PC patients visiting an Emergency Centre (31). They were unable to make this determination due to lack of available data. The split in Emergency Centre admissions between those with PC needs, and those without, has therefore not yet been established. There is much published data about PC patients presenting to Emergency Centres, but their proportions relative to other patients in the Emergency Centre are not noted.

A 2012 study by Grudzen et al, looked into the proportion of PC consultations provided to patients referred from the Emergency Centre of an urban, academic, tertiary care hospital(32). Their study was a descriptive study with data gathered from patient records over the months of January 2005 and January 2009, with a total of 285 PC consultations provided. They found that of the 161 PC consultations provided in January 2005, 100 (62%) of these were for patients who arrived via the Emergency Centre. Of the 124 consultations done in January 2009, 63 (51%) were for patients who arrived via the Emergency Centre. The length of time between admission and consultation in January 2005 was 6 days, and 9 days in January 2009. Only 3(3%) of the consultations were initiated in the Emergency Centre in January 2005, while 4 (6%) were initiated in the Emergency Centre in January 2009. The most common chief complaint of Emergency Centre referred patients in January 2005 related to respiratory disorders e.g., shortness of breath, and related to neurological disorders e.g., weakness in January 2009. Interestingly, 15% of patients arrived at the Emergency Centre in moderate to severe pain in January 2005, with 44% in January 2009. Just over half of these patients were treated with analgesia.(32). In addition to these findings, the reasons why PC patients present to an Emergency Centre have been widely published.

Much research has been done in developed countries on PC patients that present to Emergency Centres, and the reasons why they present there(5, 22, 33-35). These studies found that the most frequently occurring symptoms that drive patients to the Emergency Centre are pain, dyspnoea, weakness, fatigue and malaise, and confusion. The research done thus far has sought to improve the quality of care as multiple Emergency Centre visits are deemed an indicator of poor quality of care, particularly for cancer patients nearing the end of their life(36). Other indicators of poor quality of care for end-stage cancer patients are multiple hospital admissions, intensive care unit admissions, death in an acute care facility, and chemotherapy dispensed in the last 14 days of life(37).

Barbera et al, contributed significantly to the understanding of why cancer patients visit an Emergency Centre(5). Their research, a descriptive retrospective cohort study, involved the largest number of patients in this arena of research – n= 91 561. In this study, the records of all cancer patients who had died in Ontario over a 4-year period between 2002 and 2005 were analysed. They focused on Emergency Centre presentations in the last six months of life, and the last two weeks of life, as such presentations to the Emergency Centre are considered an indicator of poor care(38). Eighty-four percent (84%) of patients presented to the Emergency Centre in the last six months of life (average 2.2 visits each), while 34% presented during the last two weeks of life (average 1.2 visits each). Although this study did not mention the proportion of these patients that may have received PC services out of the hospital, it is likely that some proportion of these patients did indeed receive these services, as Canada provides PC services in each province(39). They found that the top 5 reasons for presenting to an Emergency Centre in both measured time periods were similar and within the scope of PC skills, although the frequency of the reasons differed in each measured period. The top 5 reasons were abdominal pain, lung cancer, pneumonia, dyspnoea, and malaise and fatigue. These reasons suggest that while patient needs did indeed escalate, they could have also been better served through additional support to allow patients to remain at home, or else, they could have been accommodated in a hospice or palliative care unit. In other words, many of the visits to the Emergency Centre were avoidable. The study also noted that 72% of the visits made during the last two weeks of life resulted in hospital admission, while 21% were discharged to their place of residence from the Emergency Centre. Five percent (5%) died in the Emergency Centre. The researchers noted that the high admission rate did not imply that the patients required acute facility care only. Rather, they proposed that the quantity and quality of care rendered to the patients, and perhaps to their caregivers, was lacking. They proposed that when patients are nearing the end of life at home, additional support from a palliative care team is required to either keep them there or to arrange for a transfer to a hospice. While this study was limited to the examination of the Emergency Centre requirements of cancer patients only, it confirmed that uncontrolled pain and failure to cope are the primary reasons that drive cancer patients to the Emergency Centre.

Lawson et al, carried out a retrospective data review of 4 444 patients in a tertiary hospital in Nova Scotia, Canada(40). Their study was one of the formative studies looking into the association between PC patients and Emergency Centre use. They looked at the Emergency Centre presentations made by all patients admitted to the PC services in the hospital over a 7-year time

frame (1999 – 2005), who also died in that measured period. Of these, 1 182 (27%) visited the Emergency Centre 2 103 times. 545 (54%) resulted in hospital admissions. Forty percent (40%) were discharged home, and 0.7% died in the Emergency Centre. The most frequent mode of transport used was by ambulance (57%). Visits per day of the week were stable with a slight increase on Sundays. Lawson BJ et al, made a noteworthy distinction in their study. They pointed out that 1 223 patients (28%) were hospitalised for the entire duration of the study, and therefore not capable of making an Emergency Centre visit. Finally, only 3 221 patients had the potential to make an Emergency Centre visit, and 34% of them did. They noted that the top 5 reasons for presenting were pain (24%), dyspnoea (21.5%), weakness malaise fatigue (8%), confusion, dizziness (5%), nausea and vomiting (4%). These results were similar to the findings of Barbera et al. Forty-nine percent (49%) of the Emergency Centre visits were made after hours (5 pm to 8 am). Their study further provided valuable information on the demographics of patients and their caregivers. They found that when carers were parents or a relative of the patient, then emergency admissions were higher, as opposed to when carers were spouses or partners of the patient. While this study was highly pertinent in that it covered patients with varied life-threatening diagnoses, it did not examine those patients with life threatening illnesses who were not registered with PC services. This excluded population might have significantly impacted these findings, given that patients with life threatening illnesses who are not receiving PC services present to an Emergency Centre more frequently than those registered with the service(41).

Covering research on cancer patients again, but this time in a cancer centre in Texas, Delgado-Guay et al, researched the frequency of potentially avoidable visits to the Emergency Centre(34). Over a 2-year period, 2 713 patients were evaluated at the centre's palliative care clinic. Of these, 1 841 (68%) visited the Emergency Centre, closely correlating with the figures presented by Barbera et al. From these, 200 patients with advanced cancer were randomly selected, and their first Emergency Centre visit records were reviewed. Their results showed that 23% of the Emergency Centre visits were avoidable, with 77% unavoidable. They found that the symptom burden was similar in the two groups, although dyspnoea was more prevalent in the patients in the unavoidable visits group. Their top 5 reasons for presentation to the Emergency Centre were uncontrolled cancer pain, treatment-related complications, infection, neurological events and cancer-related dyspnoea. They went further and looked at the timing of the visits to the Emergency Centre. Sixty-seven percent (67%) of visits in the avoidable group were after hours, with 49% of the unavoidable visits after hours. Sixty-four percent (64%) of the unavoidable visits resulted in an admission, with all of the avoidable visits being discharged from the Emergency Centre. Delgado-Guay et al, concluded that both avoidable and unavoidable visits to the Emergency Centre need to decrease and that this can be done through increased collaboration to improve care amongst the various care teams(34). This study was carried out in a highly specialised cancer centre and may therefore not be pertinent to other circumstances. This study also measured visits to its own Emergency Centre only, not accounting for those patients who may have presented to other Emergency Centres. A further research effort was also carried out with a view to describe avoidable visits to the Emergency Centre.

This was done by Wallace et al, who analysed 348 patients in Ireland who were identified as PC patients and referred to PC services, and their visits to the Emergency Centre over a 6-month period(33). This study again covered cancer patients only. Of these, 30 patients made 35 visits to

the Emergency Centre. They found that a much higher proportion (52%) of these visits were potentially avoidable. Their top 5 reasons for presentation were dyspnoea, gastrointestinal problems, pain, bleeding and acute deterioration. Also, although not commented on in their study, the figures nevertheless show that 8% of the studied PC patients presented to the Emergency Centre in the measured period. This figure is significantly lower than the 84% and 34% prevalence figures found in Barbera et al's study. This may be due to the short study period (6 months) of this study compared to the 4-year study period of the Barbera et al, study. Interestingly here, a much higher proportion of Irish patients were admitted to hospital (94%), with only 6% being discharged from the Emergency Centre. Twenty percent (20%) of the studied patients died in hospital indicating that they were near the end of their lives when they presented to the Emergency Centre. The researchers also looked at the time of presentation. They found that 63% of visits were after hours (5pm-9am weekdays, weekends, and public holidays), 37% within business hours. 57% of the visits were from Monday – Thursday, with 43% from Friday to Sunday(33). With these findings, this study highlighted the huge after hour burden on Emergency Centres. Again, a limitation of this study is that it focused on patients registered with PC services only, and only on patients with a cancer diagnosis. The experience of those not registered with the PC service and those with other life-threatening diagnoses were not investigated - this gap is therefore not well understood.

In contrast to the findings of the research mentioned earlier, Green et al, in another small study undertaken in 2015, conducted a single-centre observational study in a city hospital in London, and looked at why patients already receiving PC services still required the services of an Emergency Centre(4). Their patient base was broader, covering all PC-related diagnoses, and not restricted to those with a diagnosis of cancer alone. This hospital's Emergency Centre serviced 110 000 visits per year. They gathered data over a 10-week period, identified the reasons for presentation and focused on whether these reasons were avoidable or unavoidable. Their data showed that in this study period, 105 patients visited the Emergency Centre 112 times, 70% of whom had an underlying diagnosis of cancer. The top 5 reasons for presenting were dyspnoea, pain, fall, neurological symptoms and nausea and vomiting. In contrast to the findings of Barbera et al, they found that 83% of the patients met their criteria for urgent care and that this could not have been provided in an alternative facility. Only 4.5% of visits required no immediate care and would have been better managed in a primary care facility. Sixty-two percent (62%) of these visits resulted in admission, while 32% were discharged from the Emergency Centre. Their findings showed that seriously ill patients often have a legitimate need to present to the Emergency Centre and that episodes of sudden acute deterioration are to be expected with this vulnerable group. They concluded that the needs of patients receiving PC services cannot be fully met in an outpatient or primary care setting alone and that higher levels of care are still required by this vulnerable patient group(4). Despite the need for emergency medical care when symptoms become acutely distressing, patients needing PC services still face challenges when they present to an Emergency Centre.
All of the studies mentioned above involved a review of patient records. What about a personal perspective of patients and their caregivers on why they present to an Emergency Centre?

This angle was covered by Smith et al, who carried out a qualitative study at 2 academic medical hospitals, in which 14 terminally ill patients who had been admitted through the Emergency Centre and 7 family caregivers were interviewed with a view to understand their experiences in an

Emergency Centre (42). They found that nearly all the patients presented to the Emergency Centre because they were unable to manage their symptoms at home, clearly highlighting the need for education around end-of-life symptoms and more rapid responses to the changing need of patients in a home setting. Most of the patients had called their treating doctors first and were advised by their doctors to present to the Emergency Centre. The need for improved communication between the regular treating doctor and the Emergency Centre doctor, as well as between the Emergency Centre staff and patients was highlighted. The diagnostic procedures required were often made clear to the Emergency Centre doctor, but not the symptom control measures, which left patients with unattended acute symptoms over long waiting times. Patients and their caregivers experienced enhanced anxiety related to the noise and activity of the Emergency Centre, as well as the long waiting times. This could be better managed through explaining to patients the reasons for the waiting times, and their care plan path. Pain was the primary symptom that brought patients to the Emergency Centre. There were mixed experiences noted on pain management with only one third of patients reporting that their pain was effectively managed. It is noteworthy that those patients who experienced PC services for the first time through this admission, showed mixed responses. Those patients who viewed the role of PC services to be symptom management services, experienced the involvement of the PC team in a positive light. Those patients who viewed the PC team as part of end-of-life care, expressed reservations, as they felt unprepared for the change in focus from cure to palliation, being unprepared to conceptualise that they were dying(42). This feedback highlights the need for the introduction of PC services early on in an illness trajectory.

2.3 BARRIERS TO PROVIDING PALLIATIVE CARE SERVICES IN THE EMERGENCY CENTRE

Doctors working in Emergency Centres face several challenges with regards to the management of patients with PC needs. The findings of Smith et al, opened the dialogue related to the extent to which palliative care could or should be incorporated in an Emergency Centre(43). Their research covered the experiences, perceptions and beliefs of Emergency Centre providers on the role of palliative care in the Emergency Centre. In their qualitative study carried out with various Emergency Centre staff members (physicians, nurses, social workers and technical staff) of 2 academic institutions in Boston, USA – they revealed differing healthcare professional views on the role of palliative care in the Emergency Centre. Physicians cite the chaotic environment of the Emergency Centre, the long waiting times, the competing demands, and the little information they have on these patients, as the barriers they see to incorporating palliative care in the Emergency Centre. The plight of these patients is worsened by the fact that physicians trained in Emergency Medicine are not trained to deal with the needs of these patients. The majority of nursing staff, on the other hand, reported that caring for PC patients in the Emergency Centre was a rewarding experience, and that “palliative care was consistent with the goals of emergency medicine”(43).

Grudzen et al, provided further important insights into these challenges. In a qualitative descriptive study published in 2012, they obtained and analysed the views of 20 emergency medicine doctors regarding the provision of PC services in their respective Emergency Centres(44). They identified five themes that emerged from this study. Firstly, that doctors had limited knowledge and understanding of palliative care, with little training – expressing uncertainty as to how to integrate

palliative care into their procedures. Secondly, that there existed a fixed view of the doctor's role in the Emergency Centre. This translated into the belief that goals of care were best discussed early in diagnosis by the primary doctor, especially as emergency doctors often meet their patients and families for the first time in the Emergency Centre. Thirdly, there was acknowledgement of the complexity in decision-making associated with palliative care. Goals of care discussions are complex and time-consuming in an Emergency Centre within which there is high urgency, a lack of privacy in which to hold difficult discussions, and healthcare professionals who are unable to provide undivided attention to a patient for lengthy periods of time. Fourthly, they found a pervasive practice of defensive medicine in response to a fear of potential lawsuits when opting for less aggressive care. The fifth and last theme involved logistical challenges. Emergency doctors are frequently interrupted as other competing patients require urgent care. They reported a lack of PC team support after hours and on weekends(44).

Together with highlighting the problems, the doctors also overwhelmingly acknowledged the potential benefits of having a specialised PC team with whom to consult, and of enhancing their PC skills to improve their management of these patients.

There are barriers as well as opportunities for improving care to seriously ill patients in the Emergency Centre. For best care, Emergency Centre providers, outpatient providers and PC teams need to work together. One of the foundations required in such teams is an agreed means to identify which patients are PC patients.

2.4 TOOLS TO IDENTIFY A PATIENT WITH PALLIATIVE CARE NEEDS

Clinicians require a reliable means by which to identify patients who are at risk of deteriorating and dying. This is a crucial first step that allows the clinician to start the end-of-life care planning and discussion with the patient and family, and initiate a physical, psychosocial and spiritual needs assessment. The Supportive and Palliative Care Indicators Tool (SPICT) is a clinical tool that was developed in 2010 through a collaborative effort between the University of Edinburgh Primary Palliative Care Research Group and the NHS Lothian (also based in Edinburgh, Scotland). It is a simple tool that serves to identify patients at risk of dying in a wide range of care settings, using commonly recognised clinical indicators of advanced illness(45). This is important for patients with complex needs, who are likely to require care in various settings. In developing this identification tool, the clinicians aimed to ensure that the tool was in a simple, easy-to-use format (1-page format), containing language that was accessible and concepts that could be used to initiate discussions with patients and their families. The tool also incorporates commonly recognisable general indicators of deteriorating health, that are associated with advanced illnesses. In 2013, Highet et al, refined the SPICT tool and validated it by testing it to identify patients with advanced illness following an unplanned hospital admission(45). They found that the SPICT tool provides clear indicators which can readily be used by clinicians regardless of their palliative care experience or expertise. Furthermore, they found that the tool allowed clinicians to identify seriously ill patients and to initiate discussions with patients and their families on their preferences regarding their future care.

In 2015, Walsh et al, conducted a systematic review of diagnostic tools used for the early identification of seriously ill patients and assessed these tools for their effectiveness. Their study selection revealed four tools in use(46). They found that the SPICT tool best supported the international shift towards expanding the provision of end-of-life care to include non-malignant diagnoses, such as dementia and frailty. The researchers also found this tool, which offered a web-based evaluation platform, the most suitable for their environment (Australia)(46).

The SPICT tool was adjusted (SPICT-LIS) to accommodate the unique health challenges of developing countries. An assessment for deteriorating TB and HIV patients was added that made this tool more suitable to a developing country setting and disease burden(47).

Groote Schuur Hospital's PC team have developed a Palliative Care Indicator and Referral Form, which is currently being used by the PC team and other medical professionals in the hospital to identify patients requiring palliative care (see Appendix 3). As this form is currently in use at the hospital, this form will be used to identify PC patients presenting to the Emergency Centre. This form, although not validated, compares favourably to the SPICT-LIS tool, including most of the categories contained therein. It is noted that at the time of data collection, the Groote Schuur Palliative Care Indicator and Referral Form included HIV/AIDS as a palliative care diagnosis yet made no mention of Tuberculosis (TB). Considering that South Africa is amongst the Top 6 countries with the highest TB burden in the world(48), this exclusion of TB was particularly noteworthy. The researcher intentionally made a note of critically ill TB patients as PC patients to ensure that this vulnerable population was included in the count of PC patients in the Emergency Centre.

3. AIM AND OBJECTIVES

Aim

To determine the prevalence and presenting complaint of palliative care patients admitted to the Groote Schuur Hospital Medical Emergency Centre.

Objectives

1. To determine the prevalence of palliative care patients admitted to an Emergency Centre
2. To establish the reasons why (presenting symptoms and diseases) palliative care patients present to the Emergency Centre
3. To determine the palliative care related diagnoses of admitted patients
4. To determine the length of stay of palliative care patients in the Emergency Centre
5. To explore differences in reasons for admission of palliative care patients during office hours and after hours

4. METHODOLOGY

4.1 STUDY DESIGN

The study was an exploratory and descriptive quantitative study based on a review of folders of admitted patients.

4.2 STUDY SITE

This study was conducted in the Medical Emergency Centre of Groote Schuur Hospital, a premier tertiary academic hospital in the Western Cape province in South Africa. The hospital was established in 1938. Groote Schuur Hospital has 2 Emergency Centres – a Medical Emergency Centre and a Trauma Department. The Medical Emergency Centre is the unit to which patients with non-trauma related needs are sent to upon presentation to the Emergency Centre. The Medical Emergency Centre comprises of a resuscitation ward as well as several short-term stay facilities, with formal wards and allocated beds for patients.

4.3 STUDY POPULATION

Three hundred and eighty-three (383) patients admitted to the Medical Emergency Centre of Groote Schuur Hospital from 01 – 11 August 2019.

4.3.1 SELECTION CRITERIA

Inclusion

- The records of patients who were admitted to the Emergency Centre's four wards (Anteroom, Medical Admissions Area, Holding Area, Ward C13) in the data collection period
- The records of patients who died in the Emergency Centre
- Records of patients older than 18 years

Exclusion

- Patients without records – where the patient record was being used by a healthcare professional or misplaced during the time the researcher was on site
- Patients who were successfully treated and discharged i.e., not admitted to the Medical Emergency Centre wards

4.3.2 SELECTION PROCESS

All admitted patient records were screened using the Groote Schuur Palliative Care Indicator and Referral tool (see Appendix 3) to identify those who were seriously ill or had life-threatening illnesses. Their hospital admission records were assessed to determine their presenting complaint/ reasons why they presented to the Emergency Centre.

4.3.3 SAMPLING

Non-random sampling with a convenience sampling method was used.

Sample Size

The sample size for determining the proportion of PC patients presenting to the Emergency Centre was determined by the following formula suited to quantitative variables(49):

$$\text{Sample Size} = X \quad \frac{z_{1-\alpha/2}^2 p(1-p)}{d^2}$$

Where :

$z_{1-\alpha/2}^2$ = the level of confidence – we used 95%

p = expected proportion

d = level of precision – we used 5%

As the proportion of expected PC patients in an Emergency Centre is unclear in the literature, sample size estimations were calculated assuming both a low prevalence and a high prevalence. The highest sample size number from these estimations was used, as demonstrated in the table below:

Expected proportion %	2	70
Precision (d) %	5	5
Level of confidence (%)	95	95
Required sample size (n)	30	323

The most suited sample size choice for determining prevalence was therefore 323 patient records.

4.4 DATA COLLECTION

4.4.1 DATA COLLECTION TOOLS

Data collection was done via a **Patient Demographics and Information Tool (Appendix 4)** developed with input from the supervisors, which allowed an estimation of the prevalence of patients with PC needs in the Emergency Centre of Groote Schuur Hospital, and a determination of the reasons why patients present to the Emergency Centre. This tool was formatted in an Excel spreadsheet which contained the fields of information that were recorded in the research. Patient information was garnered from patient files in the ward and was noted on this tool. The following areas of information were collected:

- Patient demographics including gender, age, and home district
- Patient diagnosis and the reason for attendance to the Emergency Centre
- List of patient symptoms
- Time and date of presentation to the Emergency Centre
- Mode of transport to the Emergency Centre
- Receipt of previous assistance from palliative care services

Patient charts were assessed using the Groote Schuur Palliative Care Indicator and Referral tool to

identify patients requiring palliative care i.e., those patients with various conditions who may be at risk of dying or deteriorating. The Groote Schuur Palliative Care Indicator and Referral tool has been developed by doctors in Groote Schuur Hospital, drawing from validated tools such SPICT and the Gold Standards Framework. This tool was discussed and piloted with experienced staff in the Emergency Centre. Discussions with supervisors were undertaken and this tool was determined to be applicable in this setting.

4.4.2 DATA COLLECTION PROCESS

Before the data collection month, ethics approval was obtained from the University of Cape Town's Ethics Committee (HREC Ref 210/2019) (See Appendix 1), and site permission from Groote Schuur Hospital (See Appendix 2). Once such permission was granted, the research was introduced to the staff of the Emergency Centre on the morning of the planned pilot study. The staff showed interest in the research and no concerns were raised. The researcher was cognisant that these professionals were already very busy and took great care to not interfere with their daily duties.

The review and analysis of patient files for information did not require patient consent.

Pilot

Following approval from the University of Cape Town's Human Research Ethics Committee, the Groote Schuur Palliative Care Indicator and Referral tool was piloted before conducting the study. The Groote Schuur Palliative Care Indicator and Referral tool was tested on five files of patients who attended the Emergency Centre. For the pilot, the researcher was supported by the co-supervisor, who assisted with clinical support and logistics of moving through the Emergency Centre. These 5 pilot cases were included in the final study.

After ethics approval and site permission were received, the primary researcher began the data collection process and remained accountable for the process. The researcher had attended the M.Phil. Palliative Care training course, had been trained in ethics related to Palliative Care, and had been sensitised to the needs of vulnerable patients.

Data Collection

Data collection started on 01 August 2019, with the intention to continue daily until sample size was reached. Sample size was achieved after 11 days on 11 August 2019. Data was gathered through the review of patient files each morning at the Emergency Centre, of patients who were present and had been admitted to the Emergency Centre. The primary researcher proceeded methodically through the Emergency Centre via the four main wards, following the same process each day. The researcher started in the Ante-Room, then proceeded to the Medical Admissions Area, then the Holding Area and finally Ward C13, the short stay ward. The researcher moved from bed to bed, reviewing the patient files found at each patient bed-side table. This provided the full picture of the number of patients that presented to the Emergency Centre. Patient files were not removed from the patient bed-side tables.

Each patient file was assessed against the Groote Schuur Palliative Care Indicator and Referral tool to help identify which patients had PC needs. All patient files were checked each day – as there was

often more information on patient charts on consecutive days, resulting in (as an example) some patients being considered non-PC on day 1 then being considered PC patients on Day 2 or 3. For the first 2 days of data collection, the co-supervisor accompanied the researcher and was on hand to provide guidance and assistance. Thereafter, in situations where the PC need was unclear, the co-supervisor was called on his cell phone for guidance and advice. The demographic details of each patient, as well as clinical details such as the reason for admission, list of symptoms, and diagnoses were captured on a portable iPad, and later saved in the researcher's secure iCloud facility. All data was anonymised. After data collection, this information was accessed from a secure desktop computer for further analysis. The researcher liaised with the doctors and nurses in the Emergency Centre to verify the information collected from patient folders where necessary, especially when the handwriting on the folders was illegible. The relevant data fields were copied onto an Excel database for later analysis.

While all admitted patients presenting at the Emergency Centre during the data collection period were counted, relevant data was only collected for PC patients. No additional data was gathered for patients who were not identified as having PC needs.

4.4.3 DATA STORAGE AND CONFIDENTIALITY

All data will be stored electronically for five years. Data was stored on the researcher's password protected laptop only during the data collection period and was backed up electronically to the researcher's password protected iCloud facility every day. Patient names were not collected. Patient folder numbers were collected. Each patient was allocated a patient identifier number, and this workbook was saved separately by the researcher. A new patient workbook with deleted folder numbers, including new patient identifier numbers was then worked on for all analyses. The patients' folder numbers were anonymised. Access to the data was password protected on the researcher's iCloud facility. After the data storage period (5 years), all information on the researcher's laptop and the secure iCloud facility holding the data will be deleted.

The anonymised data was shared with Ms Shelan Hutton, experienced in Excel database reporting, who assisted with creating analysis and results tables.

4.5 DATA ANALYSIS

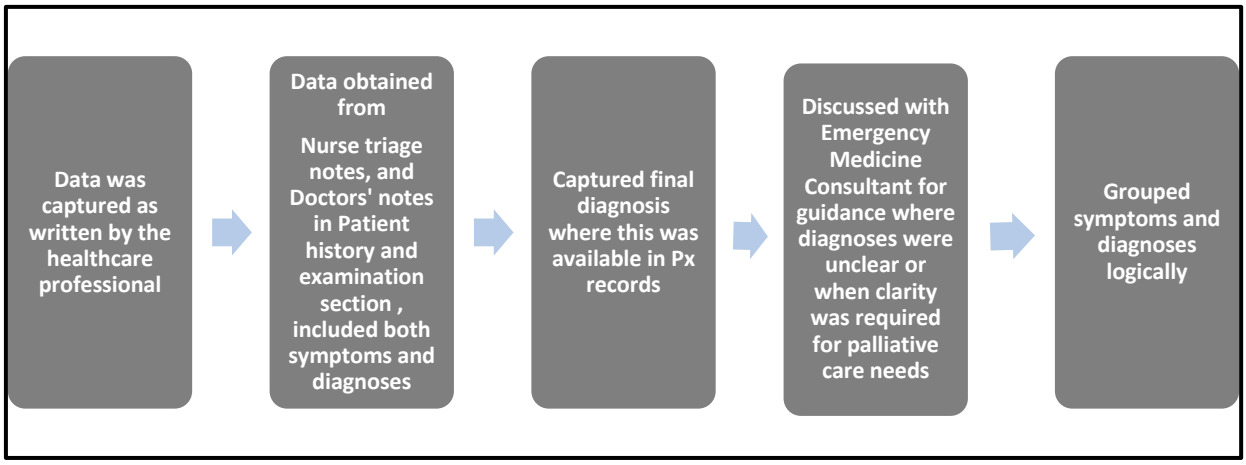
Prevalence was calculated using a simple calculation of identified PC patients (numerator) divided by the final sample size (denominator). Patients were identified as having PC needs via a process that involved a review of files, the collection of clinical data, and a comparison of this data to the Groote Schuur Hospital Palliative Care Referral Sheet. It was this final comparison stage that grouped patients into those with PC needs, and those without. The final sample size (denominator) comprised the total number of all patient files reviewed - those found to be meeting the PC requirements and those not i.e., all patients that occupied a bed irrespective of their PC status.

To understand the reasons why patients present to the Emergency Centre, an analysis of the collected data from patient records was carried out. In order to determine the profile of the type of PC patient that presents to the Emergency Centre, descriptive data was generated for demographic and medical variables. Numerical variables were reported as averages (e.g., age) and

categorical variables were reported as percentages (e.g., males, females). To determine the reasons why patients present to the Emergency Centre, symptoms were categorized according to common themes and ranked according to frequency, to create a picture of symptom burden. Descriptive analyses of variables were used to determine their frequency, mean, mode, standard deviation, range and median. The symptoms of patients presenting to the Emergency Centre was also compared to the international literature to determine similarities and differences.

While all data per patient was gathered in a single process, the demographic data did not require any further manipulation. The clinical data captured, however, did require logical grouping in order to facilitate analyses and comparison to other studies. The following process was followed for the clinical data :

Flow Diagram of Clinical Data Capture and Analyses



4.5.1 CALCULATION OF PREVALENCE

Prevalence was calculated in 2 ways to provide different pictures of prevalence: one figure provided a daily prevalence rate, so that hospital staff would understand what proportion of admitted patients were likely palliative patients on any given day.
The second figure calculated was a prevalence over the study period, taking into account that some patients stayed in hospital for several days.
The daily prevalence rate was calculated using the following formula:
(Total number of palliative patients per day / total number of admitted patients per day) x 100.

The study period prevalence was calculated using the following formula:
(Total number of unique palliative patients over study period/ total number of unique admitted patients over study period) x 100

4.5.2 DETERMINATION OF REASONS FOR ADMISSION

In determining the Reason for Admission, the researcher used the information noted in “Presenting Complaint” on the Groote Schuur Emergency Unit Adult Triage form. The information noted was only a single item, sometimes a symptom, and sometimes a diagnosis, and these were captured just as they were written, and not interpreted. The triage nurse filled in the “Presenting Complaint” on

the form. Symptoms captured imply an unknown diagnosis. A diagnosis captured often implies that the patient has presented with a referral letter noting the diagnosis. Many patients arrived at the Emergency Centre with a diagnosis. This is the reason why symptoms and diagnosis are both captured under Presenting Complaint. Many of the "Presenting Complaints" were grouped for ease of analysis. This was done in the following areas

Shortness of Breath was a grouping of "shortness of breath" and "severe shortness of breath".
Weakness was a grouping of "weakness", "weakness in lower limbs" and "progressive deterioration/suspected sepsis".
Pain was a grouping of "pain", "chest pain", "pain large cervical mass felt", "severe radiating chest pain suspected upper aortic involvement", "pain in legs and back", and "abdominal pain".

4.5.3 DETERMINATION OF DIAGNOSES

Patients' diagnoses were garnered from either the "Presenting Complaint" section of the Groote Schuur Emergency Unit Adult Triage form or from the doctor's notes in the "History" section of the form. The diagnoses captured were the actual words written in each folder by the attending doctor. The data was captured in a manner that allowed for multiple unique diagnoses per patient.
For purposes of analyses, the diagnoses captured were also grouped into categories. This was done in the following areas:

1. Cancer was a grouping of all types of cancer e.g., "Ca metastatic prostate", "Ca cervix Stage IVB", "Ca metastatic bladder", "Ca metastatic rectal", "Ca colon", Ca oesophageal", etc.
2. Heart Disease was a grouping of "congestive cardiac failure", ischaemic heart disease", "biventricular heart disease secondary to uncontrolled hypertension", "rheumatic heart disease", etc.
3. Diabetes was a grouping of "Diabetes" and "DM".
4. Tuberculosis was a grouping of "disseminated TB", "Pulmonary TB" and "PTB".

4.5.4 DETERMINATION OF SYMPTOMS

Patient symptoms appeared in 2 places on the Groote Schuur Emergency Unit Adult Triage form. Often, a symptom was captured in the area designated as "Presenting Complaint". The symptoms noted here were used to determine the Reason for Admission or presentation to the Emergency Centre.
Symptoms were also noted from the attending doctor's notes in the "History" and "Examination" sections of the Groote Schuur Emergency Unit Adult Triage form. Similarly, as was done for diagnoses, the symptoms captured from these sections were the actual words written by the doctor. This data was captured in a manner that allowed for multiple unique symptoms per patient. This was done in the following areas:

1. Pain was a grouping of "chest pain", "abdominal pain", "pain", "headaches", "pain in left hip", "acute abdominal pain", etc.
2. Loss of or Reduced Level of Consciousness was a grouping of "LOC", "confusion", "delirium", "collapsed LOC", "confused", etc.

3. Weakness/ fatigue was a grouping of “dizziness”, “weakness”, “left sided weakness”, “fatigue”, etc.

5. RESULTS

The study involved a review of patient files of patients who were admitted (occupied a bed) at the time of the study into the Medical Emergency Centre of Groote Schuur Hospital. The Groote Schuur Hospital Palliative Care Referral Sheet (see Appendix 3) was used as a guideline to identify PC patients in the wards.

5.1 PREVALENCE OF PALLIATIVE CARE PATIENTS

On average, there were 51 patients admitted to the Medical Emergency wards per day, with a range of 19 – 60 patients (Table 1). There was also an average of 16 PC patients in the wards per day, with a range of 9-21 PC patients. Two types of prevalence were calculated - A daily prevalence and a study period prevalence.

Daily, accounting for every patient occupying a bed each day, nearly one third of these patients were PC patients. In other words, the daily prevalence of PC patients admitted to the Medical Emergency Centre of Groote Schuur Hospital was 32.1%.

Over the 11-day measured period, accounting for the fact that some patients stayed for many days, there were 383 distinct patients in total, with 124 of these being distinct PC patients. This distinct patient prevalence over the measured 11-day period was 32.4% - quite similar to the daily prevalence of 32.1% (Table 2).

Table 1: Daily Prevalence of Palliative Care Patients

	Total Patients per Day	Palliative Care Patients per Day	Prevalence of PC Patients per Day
Day 1	19	9	47,4%
Day 2	51	21	41,2%
Day 3	47	15	31,9%
Day 4	43	12	27,9%
Day 5	50	14	28,0%
Day 6	53	17	32,1%
Day 7	56	16	28,6%
Day 8	48	13	27,1%
Day 9	60	18	30,0%
Day 10	53	13	24,5%
Day 11	41	14	34,1%
Average Daily Prevalence			**32,1%**

Table 2: Study Period Prevalence

Total No. of Unique Patients Admitted over Study Period	Total No. of Unique Palliative Care Patients Admitted over Study Period	Study Period Prevalence
383	124	32.4%

5.2 GENDER AND AGE

The gender and age of presenting PC patients were documented. The dates of birth of 3 patients were not recorded – 2 males and 1 female (Table 3). Only 10% of patients were under the age of 40. The bulk of palliative patients (76%) fell between the age band of 40-80 years. Twelve percent (12%) of patients were over the age of 80 years.

Overall, there was a reasonable balance between the genders showing 65 (52.4%) females and 59 (47.6%) males. Seventeen percent (17%) of females were over the age of 80, with only 7% of males in the same age band. The 50–60 year age band formed the largest group with 31 patients. Interestingly, males accounted for 2/3 of this age band. There was also a relatively even distribution of female patients in the age bands covering 50 - 70 years of age. Females, however, dominated the 70-100 year age band.

Table 3: Gender and Age of Palliative Care Patients

Age Band	Males	Females	Total	Proportion of Total Patients
20 - 30	2	2	4	3,2%
30 - 40	1	7	8	6,5%
40 - 50	10	7	17	13,7%
50 - 60	20	11	31	25,0%
60 - 70	11	12	23	18,5%
70 - 80	9	14	23	18,5%
80 - 90	4	8	12	9,7%
90 - 100	0	3	3	2,4%
Unknown age	2	1	3	2,4%
Total	**59**	**65**	**124**	**100,0%**

5.3 PREASONS FOR ADMISSION

The Groote Schuur Emergency Unit Adult Triage Form (Triage Form) recorded a "Presenting Complaint" usually noting only one issue in this field. This information was used as the Reason for Admission. The researcher recorded the reason for admission as indicated in the folder. Clinicians entered both symptoms and diagnoses as Reasons for Admission. Reasons for admission and symptoms on presentation often overlap but were recorded separately. Symptoms were often recorded under "History" in the Triage Form. The "Presenting Complaint" or reason for admission was sometimes a symptom e.g., shortness of breath or abdominal pain, and sometimes a diagnosis e.g., pneumonia or myocardial infarction.

Of the 124 PC patients, 73 files (59%) noted the reason for admission. The reasons for admission were captured as written on the patient file and were thereafter grouped into obvious categories e.g., the category "Pain" was created and included "Chest pain"," Abdominal pain", "Pain in legs and back", "Severe radiating chest pain".

The most frequent reasons for admission on 9 patient files each was shortness of breath, followed by 8 patients with pain, and a further 8 with loss of/or reduced levels of consciousness. Fourth most frequent was heart disease, with stroke following in fifth place (Table 4).

Table 4: Top 10 Reasons for Admission

	Top 10 Reasons for Admission	Number of Patients (n=124)	Percentage of PC Patients
1	Shortness of Breath	9	7%
2	Pain	8	6%
3	Loss of/Reduced Level of Consciousness	8	6%
4	Heart Disease	6	5%
5	Stroke	4	3%
6	Weakness	4	3%
7	Hypoglycaemia	3	2%
8	Seizures	3	2%
9	Pneumonia	2	2%
10	Kidney Failure	2	2%

Staying true to the data raised the risk of reflecting a reduced number of patients who very likely presented with pain, thereby obscuring the actual clinical picture for pain. If the word "pain" was not used in the "Presenting Complaint" section, then that record was not counted as "Pain" in Table 4 above. There were reasons for admission noted which indicated conditions that were highly likely associated with pain, but because the word "pain" was not written as part of these patients' reasons for admission, these reasons were not counted as pain. There were 8 such cases reflected in Table 5 below. Adding these 8 to the 9 cases of Pain already noted would elevate Pain to 17 cases linked to 14% of patients. This adjustment elevates Pain to the most frequent reason for admission.

There were 73 noted Reasons for Admission. Some of these were logically grouped together e.g., pericardial infusion and MI were grouped together under Heart Disease. The Top 10 Reasons accounted for 73% of all noted Reasons for Admission. The balance of the Reasons for Admission (20) were 1 patient each and included the following examples:
Cough and running nose, diarrhoea, vomiting blood, fever, haematuria, anaemia, neutropenia. etc.

Table 5: Reasons for Admission with Implied Pain

Reasons for Admission implying Patient in Pain	Number of patients
Clinical synovitis	1
Swollen legs and testes	1
Fall	1
Possible faecal impaction	1
Large bowel obstruction	1
Swollen testes	1
Abdominal bloating	1
Obstructive jaundice	1
Total	8

5.4 TIME OF PRESENTATION TO EMERGENCY CENTRE

The time at which patients presented to the Emergency Centre was documented to understand the load over business hours when other facilities were usually open for healthcare services, versus after hours, when other facilities were typically closed for service. Business hours were counted from 08:00am to 04:00pm, as many health professional and services in the hospital were typically readily available only during these hours. Out of the 124 PC patient records, 120 records noted the Time of Presentation. The Time of Presentation of 4 patients was not noted and was recorded as "Unknown".
During business hours, 35% of patients presented to the Emergency Centre. Sixty-two percent (62%) of patients presented after hours between 04:00pm and 08:00am.

Table 6: Time of Presentation to the Emergency Centre

Time Range	No. of Patients Presenting to the Emergency Centre	Proportion of Patients in Time Periods
0 - 2am	13	22%
2 - 4am	6	
4 - 6am	5	
6 - 8am	3	
8 - 10am	9	35%
10 - 12am	16	
12 - 14pm	12	
14 - 16pm	6	
16 - 18pm	12	40%
18 - 20pm	10	
20 - 22pm	17	
22 - 24pm	11	
Unknown	4	3%
Total	**124**	100%

5.5 REASONS FOR ADMISSION DURING BUSINESS HOURS VERSUS AFTER HOURS

The reasons for admission are significantly different during business hours versus after hours. Forty-four patients presented during business hours. Of these, the reason for admission was recorded for 43% of patients (19 patients). The leading reason for admission were shortness of breath and heart disease, followed by loss of or reduced levels of consciousness. Very notably, none of the reasons for admission during business hours indicated pain or a diagnosis that related to pain.

Eighty patients presented to the Emergency Centre after hours. The reasons for admission were recorded more often after hours with 61% of patient files (49 patients) noting this information. Pain was the top reason for admission after hours with 10% of patient files listing pain. There were 6 other reasons highly indicative of pain, but which did not specifically note the word “pain” on the reason for admission e.g., clinical synovitis, large bowel obstruction, etc. These reasons for admission related to pain were not included as “Pain” in the count in the interests of recording only what was written in the patient record. However, including these pain related reasons expands the number of patients with pain to 14, equal to 18% of patients presenting to the Emergency Centre after hours. Loss of or reduced levels of consciousness and shortness of breath were the second and third most frequent reasons for admission after hours.

Fisher’s Exact Test was carried out to investigate the association between the most frequent Reasons for Admission during business hours and after hours. There was no significant association found between reasons for admission during business hours and after hours ($p = 0.180$). This is likely due to the low frequency numbers, which reduces the power to detect any differences.
It is important to note that when grouping together all Pain i.e., phrases/words with Pain as well as

diagnoses strongly linked to Pain, then Pain presents with a p value of 0.002, and there is therefore a significant association between patients presenting with pain after hours versus pain during business hours. A significantly higher proportion of patients presented with pain after hours (No patients presented with Pain or pain related diagnoses during business hours).

Table 7: Reasons for Admission - Business Hours vs After Hours

	Business Hours (n=44 patients)		After Hours (n= 80 patients)		Fisher's Exact Test
Reasons for Admission	Frequency	Percentage of Business Hours Patients	Frequency	Percentage of After Hours Patients	*p*
Shortness of Breath	3	6,8%	6	7,5%	1.00
Reduced/Loss of Consciousness	2	4,5%	6	7,5%	0.711
Heart Disease	3	6,8%	4	5,0%	0.698
Weakness	2	4,5%	1	1,3%	0.287
Stroke	1	2,3%	3	3,8%	1.00
Pain	0	0,0%	7	8,8%	0.050
Others	8	18,2%	22	27,5%	0.280
Total	19	43,2%	49	61,3%	0.180

5.6 SYMPTOMS

Symptoms experienced by patients were drawn from 2 places: the "History" section of the admission form, as well as from the "Presenting Complaint" or Reason for Admission. Some patient records did not note any symptoms (5 records = 4%). Forty-six percent (46%) of patients had 1 symptom noted, 25.8% presented with 2 symptoms, 17.7% with three, 4.8% with 4 symptoms, and 2 patients with 5 symptoms.

Table 8: Number of Symptoms per Patient

	Number of Symptoms (n = 124 patients)					
	0	1	2	3	4	5
Number of Patients	5	57	32	22	6	2
Percentage of Patients	4,0%	46,0%	25,8%	17,7%	4,8%	1,6%

The most frequently noted symptom was Loss of/Reduced levels of Consciousness - with 38 patients (30.6% of PC patients) presenting with this symptom. Following closely behind, the second most frequent symptom was Pain with 33 patients (26.6%) presenting with this. Shortness of breath and weakness/fatigue followed in third and fourth place.

There were 6 additional symptoms which implied that the patient had pain, which were not included in the table below. Examples of these are foot ulcer, fall, swollen testes, clinical synovitis. Adding these 6 to the 33 reported number of patients with Pain, brings Pain to the number one position with 39 patients or 32% of patients with Pain. With this adjustment, Pain is the most frequent

symptom presented by PC patients.

Table 9: Top Symptoms by Frequency

	Top 10 Symptoms	Number of Patients (n=124)	Percentage of Patients
1	Loss of/Reduced Level of Consciousness	38	30,6%
2	Pain	33	26,6%
3	Shortness of Breath	30	24,2%
4	Weakness / Fatigue	20	16,1%
5	Vomiting and/or Diarrhoea	19	15,3%
6	Cough	7	5,6%
7	Hemiplegia	7	5,6%
8	Seizures	6	4,8%
9	Constipation	5	4,0%
10	Fever	4	3,2%

5.7 DIAGNOSES

5.7.1 PALLIATIVE CARE RELATED DIAGNOSES

The palliative care patients presented with a wide array of life-threatening illnesses. Diagnoses were captured from the "History" section of the Triage Form as well from the "Presenting Complaint" section. While all the diagnoses presented by the PC patients were recorded, it was important to specify which criteria each patient met on the Groote Schuur Referral to Palliative Care Form. Hypertension, as an example, was not one of the disease conditions on this form. Not every patient with a PC diagnosis such as cancer or HIV, were counted as PC patients for this research. Only those with advanced disease and/or deteriorating health were considered to have met the PC guidelines as per the Groote Schuur Referral to Palliative Care Form. Some patients met the criteria in more than one category e.g., metastatic cancer and stroke, HIV and disseminated TB. Cancer, heart disease, stroke and HIV/AIDS were the predominant diagnoses of PC identified patients.

Heart disease was the most common diagnosis with 36 patients (29%) presenting with this. Heart Disease was a grouping of several heart disorders such as congestive cardiac failure, myocardial infarction, ischaemic heart disease, etc. There were 33 unique cancer patients forming just over a quarter of all PC patients, 13 of whom had metastatic disease. For analysis purposes, only the primary cancer diagnoses were reported. The diagnosis "Stroke" was also a category created including several diagnoses e.g., left internal carotid artery aneurysm with sub-arachnoid haemorrhage and mass effect, basal ganglia billed with mass effect, subdural haemorrhage. Tuberculosis was the one diagnosis that was not included in the Groote Schuur Palliative Care Indicator and Referral Tool at the time of data capture, yet 11 of the PC identified patients presented with tuberculosis. However, subsequent to collating this data, Tuberculosis has been added to the

Groote Schuur Palliative Care Indicator and Referral Tool.

The table below specifies each category as noted on the form, and the number of patients that met these criteria.

Table 10: Palliative Care Related Diagnoses

	Category	Top 10 Palliative Care Diagnoses	Number of Patients	Category Total	Percentage of Patients
1	Cancer Progressive and/or Metastatic	Cancer - Progressive	20	33	26,6%
		Cancer - Metastatic	13		
2	Heart/Vascular Disease	Heart Disease	33	36	29,0%
		Vascular Disease	3		
3	HIV/AIDS	HIV/AIDS	20	20	16,1%
4	Neurological Disease/Stroke	Stroke	16	24	19,4%
		Neurological Disease	8		
5	Respiratory Disease	Respiratory Disease	14	14	11,3%
6	Renal Failure	Renal Failure	10	10	8,1%
7	TB/Disseminated TB	TB/Disseminated TB	11	11	8,9%
8	Frailty/Dementia	Dementia	7	11	8,9%
		Frailty/Reduced Consciousness	4		
9	Liver Disease	Liver Disease	3	3	2,4%
10	Other - general indicators of deteriorating health		7	7	5,6%
		Sepsis	3	3	
		Inflammatory bowel disease	1	1	
		Kearns-Sayre Syndrome	1	1	
		Haemophilia	1	1	
		Emaciation	1	1	

5.7.2 ALL DIAGNOSES – PC AND NON-PC RELATED

Heart disease is a typical example of where the count of patients across PC related diagnoses and all diagnoses differs. There are 41 patients with heart disease in total. Of these, 33 have severe heart disease that qualifies them as a PC patient. One patient, for example, had ischaemic heart disease and COPD – but it was the disabling COPD with breathlessness at rest that made him a PC patient. His heart disease alone was not severe enough to meet the criteria for a PC patient. It was his respiratory disease that met the criteria of a PC patient. As such, he was counted as a PC patient under respiratory disease and not under heart disease. One patient with advanced rectal cancer also had HIV. His HIV was well controlled, so HIV was not counted as a PC diagnosis. His advanced rectal cancer qualified him as a PC patient and he was counted as a cancer patient in the table above.

Table 11 below lists the top diagnoses (PC and non-PC related) found in all PC patients. Heart

disease featured most frequently with 33% of patients presenting with this, followed by hypertension.

Table 11: Top 10 Diagnoses - PC and non-PC related

	Top 10 Diagnoses	Frequency	Percentage of Patients
1	Heart Disease	41	33,1%
2	Hypertension	36	29,0%
3	Cancer	33	26,6%
4	Diabetes	21	16,9%
5	HIV	21	16,9%
6	COPD	14	11,3%
7	Stroke	16	12,9%
8	TB	15	12,1%
9	Renal Failure	11	8,9%
10	Dementia	7	5,6%

Hypertension and cancer were the top 2 diagnoses for female patients with 29.2% and 27.7% presenting with these diagnoses respectively. For men, heart disease was the most frequent diagnosis by a large margin with 42% of males presenting with this, followed by hypertension and cancer. The prevalence of stroke was higher in females (15.4%) than in males (10.2%). Diabetes, Hypertension, COPD and Tuberculosis showed similar proportions in both males and females. Heart Disease and Renal Failure were much higher in males (42.4% and 15.3% respectively) compared to females (21.5% and 3.1% respectively). Cancer presented in equal proportions across the genders – approximately one quarter of males and females presented with cancer. Only females presented with asthma and rheumatoid arthritis, albeit in low numbers (2 patients each), and only males presented with liver disease (4 patients).

Table 12: Top Diagnoses by Frequency for Females

Females (n = 65)			
	Top Diagnoses	**Frequency**	**Percentage of All Female Patients**
1	Hypertension	19	29,2%
2	Cancer	18	27,7%
3	Heart Disease	16	24,6%
4	HIV	12	18,5%
5	Diabetes	11	16,9%
6	Stroke	10	15,4%
7	TB	8	12,3%
8	COPD	7	10,8%
9	Dementia	3	4,6%
10	Rheumatoid Arthritis	2	4,5%

Table 13: Top Diagnoses by Frequency for Males

Males (n = 59)			
	Top Diagnoses	**Frequency**	**Percentage of All Male Patients**
1	Heart Disease	25	42,4%
2	Hypertension	17	28,8%
3	Cancer	15	25,4%
4	Diabetes	10	16,9%
5	HIV	9	15,3%
6	Renal Failure	9	15,3%
7	COPD	8	13,6%
8	TB	7	11,9%
9	Stroke	6	10,2%
10	Liver Disease	4	6,8%
	Dementia	4	6,8%

It was only possible to run the chi-square test on Diagnoses 1-5 in Table 14, as the numbers were of a reasonable size. Diagnoses 6-10 were analysed using the Fisher's Exact Test, due to small sample sizes.

There was a significant association between heart disease and gender in particular, with males being significantly more likely to have a heart disease diagnosis ($p = 0.024$). Although a significantly higher proportion of males presented with liver disease, this must be interpreted with caution given the small numbers (4 male patients, 0 female patients).

Table 14: Comparison of Top Diagnoses - Males and Females

	Females (n = 66)			Males (n = 59)			
	Top Diagnoses	**Frequency**	**Percentage of Patients**	**Frequency**	**Percentage of Patients**	X^2	***p***
1	Cancer	19	28,8%	17	28,8%	< 0.01	0.998
2	Hypertension	19	29,2%	17	28,8%	< 0.01	0.998
3	HIV	12	18,5%	9	15,3%	0.039	0.844
4	Diabetes	11	16,9%	10	16,9%	0.002	0.966
5	Heart Disease	10	15,2%	25	42,4%	5.084	0.024
6	Stroke	10	15,4%	6	10,2%	-	0.436
7	COPD	7	10,8%	8	13,6%	-	0.784
8	TB	8	12,3%	7	11,9%	-	1.00
9	Dementia	3	4,6%	4	6,8%	-	0.706
	Asthma	2	6,1%	0	0,0%	-	0.498
	Rheumatoid Arthritis	2	3,1%	0	0,0%		0.498
10	Liver Disease	0	0,0%	4	6,8%	-	0.047

Interestingly, males formed 2/3 of the PC patients in the 50-60 year age band. While the proportion of hypertension in this age group was similar to the proportion in all males, this group has larger proportions of Diabetes and COPD. The percentage of patients with Diabetes in the 50-60 year group was higher at 23.8% compared to 16.9% in all males. Heart disease prevalence is much lower

in this group (23.8%) than in all males (42.4%). The proportion of COPD in this group is high at 19,0% compared to 13.6% in all males.

Table 15: Top Diagnoses by Frequency for Males (50-60 year age band)

	Males (50 - 60 Age Band) (n=21)			All Males (n=59)
	Top Diagnoses	**Frequency**	**Percentage of Male Patients in 50–60 year age band**	**Percentage of All Male Patients**
1	Hypertension	6	28,6%	28,8%
2	Heart Disease	5	23,8%	42,4%
3	Diabetes	5	23,8%	16,9%
4	COPD	4	19,0%	13,6%
5	Cancer	4	19,0%	25,4%

While the number of females in the 50-60 year age band are small (n=11), the proportions of cancer, COPD and Stroke are nearly double in this age band compared to all women.

Table 16: Top Diagnoses by Frequency for Females (50-60 year age band)

	Females (50 - 60 Age Band) (n=11)			All Females (n=66)
	Top Diagnoses	**Frequency**	**Percentage of Female Patients in 50–60 year age band**	**Percentage of All Female Patients**
1	Cancer	5	45,5%	26,2%
2	Stroke	3	27,3%	15,4%
3	COPD	2	18,2%	10,8%
4	Heart Disease	1	9,1%	21,5%
	Hypertension	1	9,1%	29,2%

Despite the proportions of Cancer, COPD and Stroke being twice as high for males than females in the 50-60 year age band, there was no significant association between gender and diagnoses in the 50-60 year age band (See Table 17).

Table 17: Top Diagnoses By Frequency Males & Females (50-60 year age band)

	Males (50 - 60 Age Band) (n=21)			Females (50-60 Age Band) (n=11)		Fisher's Exact test
	Top Diagnoses	Frequency	Percentage of Patients	Frequency	Percentage of Patients	*p*
1	Hypertension	6	28,6%	1	9,1%	0.374
2	Heart Disease	5	23,8%	1	9,1%	0.637
3	Diabetes	5	23,8%	0	0,0%	0.138
4	COPD	4	19,0%	2	18,2%	1.00
5	Cancer	4	19,0%	5	45,5%	0.213
6	Stroke	1	4,8%	3	27,3%	0.106
7	Asthma	0	0	1	9,1%	0.344

With women forming 65% of the 70-100 year age band, it became pertinent to look into what women were presenting with in this band. Analysis showed that hypertension and diabetes in this group were nearly double the proportion found in all females, while heart disease was three times higher in this age band than in all females. Cancer prevalence was lower by a large margin in this age band.

Table 18: Gender Split in 70 – 100 year age band

70 - 100 year age band (n=37)	
Male	**Female**
13	24
32,4%	67,6%

Table 19: Top Diagnoses by Frequency for Females (70-100 year age band)

Females 70 - 100 year age band (n=25)				
Top Diagnoses		**Frequency**	**Percentage of 70-100 year age band Female Patients**	**Percentage in All Females**
1	Hypertension	12	48,0%	28,8%
2	Heart Disease	11	44,0%	15,2%
3	Diabetes	7	28,0%	16,7%
4	Stroke	4	16,0%	13,6%
5	Cancer	4	16,0%	28,8%

For men in the 70–100 year age band, the prevalence of the top 5 diseases was noticeably higher than for all males. Hypertension and heart disease showed higher prevalences by large margins in this age group than in all males. Cancer prevalence was 38.5% in this age band compared to 25% in all males. Dementia was significantly higher at 30.8% in this older age group compared to all males (5%).

Table 20: Top Diagnoses by Frequency for Males (70-100 year age band)

Males 70 - 100 year age band (n=13)				
	Top Diagnoses	**Frequency**	**Percentage of 70-90 year age band Male Patients**	**Percentage in All Males**
1	Heart Disease	8	61,5%	37,3%
2	Hypertension	6	46,2%	32,2%
3	Cancer	5	38,5%	25,4%
4	Dementia	4	30,8%	5,1%
5	Stroke	2	15,4%	10,2%

Despite the large variances found in the prevalence of certain diseases between males and females in this age group, there was no significant association between gender and diagnoses in the 70-100 year age band (See Table 21).

Table 21: Top Diagnoses – Males and Females (70-100 year age band)

		Females 70 - 100 year age band (n=25)		Males 70-100 year age band (n=12)		
Top Diagnoses		Frequency	Percentage of 70-100 year Female Patients	Frequency	Percentage of 70-100 year Male Patients	*p*
1	Hypertension	12	48,0%	6	46,2%	1.00
2	Heart Disease	11	44,0%	8	61,5%	0.295
3	Diabetes	7	28,0%	1	7,7%	0.232
4	Stroke	4	16,0%	2	15,4%	1.00
5	Cancer	4	16,0%	5	38,5%	0.116
6	Dementia	4	16,0%	4	30,8%	0.395

5.7.3 CANCER

There were 33 unique cancer patients – 55% female and 45% male. The bulk of the patients (67%) fell within the 50-80 year age band. These patients presented most frequently with symptoms of abdominal pain and vomiting.

Females presented with 11 types of cancer. The most commonly occurring cancers in women were cervical cancer (5 patients) and breast cancer (3 patients). The other cancers presented with one patient each. Males presented with 14 types of cancer. The most commonly occurring cancer in males was prostate cancer (3 patients). The other cancers in males also presented with one patient each.

Table 22: Demographics of Cancer Patients

Cancer Patients - Demographics					
Age Band	**Females**	**Percentage of All Female Cancer Patients**	**Males**	**Percentage of All Male Cancer Patients**	**Total**
20 - 30	0	0,0%	1	6,7%	1
30 - 40	2	11,1%	0	0,0%	2
40 - 50	2	11,1%	1	6,7%	3
50 - 60	5	27,8%	4	26,7%	9
60 - 70	4	22,2%	3	20,0%	7
70 - 80	2	11,1%	4	26,7%	6
80 - 90	1	5,6%	1	6,7%	2
90 - 100	1	5,6%	0	0,0%	1
Unknown age	1	5,6%	1	6,7%	2
Total	**18**	100,0%	**15**	100,0%	**33**

The most frequent symptom in cancer patients was pain with 16 patients - just under half of all cancer patients presenting with this. A further 5 symptoms were found to have a high association with pain. These include swollen testes, large bowel obstruction, constipation for over a week, fall

and swollen legs. Including the 4 additional cancer patients with these symptoms brings the total number of patients with Pain to 20 - showing that 60% of all cancer patients presented with Pain.

Table 23: Most Frequent Symptoms of Cancer Patients

Most Frequent Symptoms of Cancer Patients	Number of Patients
Pain	16
Implied Pain	4
Weakness	9
Vomiting	6
Loss of/Reduced Levels of Consciousness	5

5.7.4 HIV

There were 21 patients with a diagnosis of HIV and who were critically ill. They formed 17% of all PC patients. Females accounted for 57% of this group of HIV patients, while males formed 43% of this group. The bulk of the patients (76%) with this diagnosis fell into the 30-60 year age gap. HIV patients presented with the following most frequent symptoms: vomiting, cough, and shortness of breath.

Table 24: Demographics of HIV Patients

HIV Patients - Demographics			
Age	**Female**	**Male**	**Total**
20 - 30	1	1	2
30 - 40	6	1	7
40 - 50	3	3	6
50 - 60	0	3	3
60 - 70	2	1	3
Total	**12**	**9**	**21**

5.8 MODE OF TRANSPORT TO THE EMERGENCY CENTRE

The Groote Schuur Emergency Unit Adult Triage Form notes the mode of transport under “Arrival Type”. One hundred and sixteen patient records noted the mode of transport. In eight patient records, the mode of transport was not noted. Over half of these patients (55,6%) arranged their own transport to the Emergency Centre. Twenty-six percent (26%) of these patients were referred from other health facilities via ambulance. Twelve percent (12%) of patients were delivered via an ambulance they called for. Altogether, 38% of patients arrived by ambulance.

Table 25: Mode of Transport to the Emergency Centre

Mode of Transport to Emergency Centre	No. of Patients	Percentage of Patients
Own / Walk-in	69	55,6%
Ambulance	15	12,1%
Referral from CHC or other hospital - Ambulance	32	25,8%
Unknown	8	6,5%
Total	**124**	**100,0%**

5.9 LENGTH OF STAY

Length of stay was calculated from the date of admission to the last date the patient was still present in the department, or the last day of data gathering. As there will have been some patients that extended their stay past the last day of data gathering, their noted length of stay is therefore a minimum figure.

There were 14 PC patients in the Emergency Ward on the last day of data gathering. Their accurate length of stay is therefore unknown. The first day of admission was counted as Day 1. Most patients (79%) stayed for 1-2 days in the Emergency Centre. Only 2 patients stayed for 6 days.

One patient stayed for 7 days. She was a 67-year-old female who was house-bound on home oxygen, who presented with shortness of breath. Her history noted that she was diagnosed with COPD, diabetes and hypertension.

An 81-year-old gentleman was admitted for 9 days. He presented with shortness of breath and was diagnosed with pneumonia on presentation. His records also noted that he had been totally bed-bound and fully dependent on others, had dementia, benign prostatic hypertension and GORD.

Table 26: Length of Stay of Palliative Patients

Length of Stay in Medical Emergency Ward (Days)	No. of Patients	Percentage of Patients
1	39	31%
2	59	48%
3	18	15%
4	4	3%
6	2	2%
7	1	1%
9	1	1%
Total	124	100%

5.10 WEEKENDS VS WEEKDAYS AND A PUBLIC HOLIDAY

Six of the 11 days of data gathering were weekdays, there were 2 weekends (4 days), and one day which was a national public holiday. For the purposes of comparing weekends and weekdays, the public holiday has been grouped together with the weekends. There was no statistically significant difference in the proportion of PC patient prevalence over the weekdays vs weekends ($z = 0.74$, $p = 0.459$).

Table 27: Weekdays vs Weekends and a Public Holiday

Weekdays	**Total No. of Patients**	**No. of Palliative Patients**	**Prevalence of Palliative Patients**
Day 1	19	9	47,4%
Day 2	51	21	41,2%
Day 5	50	14	28,0%
Day 6	53	17	32,1%
Day 7	56	16	28,6%
Day 8	48	13	27,1%
Averages	46	15	32,5%
Weekends & Public Holiday	**Total No. of Patients**	**No. of Palliative Patients**	**Prevalence of Palliative Patients**
Day 3	47	15	31,9%
Day 4	43	12	27,9%
Day 9	60	18	30,0%
Day 10	53	13	24,5%
Day 11	41	14	34,1%
Averages	49	14	29,5%
Differences	7% more admitted patients over the weekends and public holiday	7% fewer palliative care patients over the weekends and public holiday	3 percentage points lower palliative care prevalence over the weekends and public holiday

5.11 ACCESS TO PALLIATIVE CARE SERVICES

Seven of the identified PC needs patients had been referred to PC services. Three of these patients had already been served by PC teams prior to their admission, while four of the patients were referred to PC services from the Emergency Centre. These 7 patients comprise a small percentage of 5,6% of the 124 identified PC patients who were referred for PC services. Five of the patients had a cancer diagnosis, while the other three presented with a right intracerebral haemorrhage with mass effect, inoperable mesenteric ischaemia and Parkinson's Disease respectively.

Table 28: Diagnoses of Patients Referred for Palliative Care Services

Patients (n=7)	Diagnoses per Patient	Assistance from Palliative Care Services
1	Metastatic bladder cancer	Prior to Emergency Admission
2	Prostate cancer, ischaemic heart disease	Prior to Emergency Admission
3	Metastatic rectal cancer, HIV, Tuberculosis, COPD	Referred from Emergency Centre
4	Spinal cancer	Referred from Emergency Centre
5	Stroke	Referred from Emergency Centre
6	Mesenteric Ischaemia, diabetes, cholecystitis	Referred from Emergency Centre
7	Parkinson's Disease, hypertension, BPH	Prior to Emergency Admission

There are 2 main hospice services covering the Cape Town metropolitan areas viz. St Luke's Hospice and Tygerberg Hospice. A comparison of the suburbs covered by these hospices with the areas from which the PC patients resided was done. The PC patients resided in 67 unique suburbs and towns. Encouragingly, it showed that hospice services were available in 96% of these suburbs. This is important information for the referring doctors, as they can be confident that most of their patients will have access to PC post referral.

Table 29: Coverage by Hospice Services

	Count	Percentage
No. of Unique Patient Addresses	124	
No. of Unique Suburbs	67	
Suburbs Served by Hospice	62	96%
Suburbs Not Served by Hospice	5	4%
Patients in Suburbs Served by Hospice	115	92,70%
Patients in Suburbs Not Served by Hospice	9	7,30%

6. DISCUSSION

6.1 PREVALENCE

On any given day in the Emergency Centre, the prevalence of palliative care patients in the wards averaged 32.1% - with a range from 25% to 47%. There is limited information available in the published literature for comparison purposes, so it is unclear what the experience of other Emergency Centres are. There being no comparison available, a statistical significance of this result was not possible. This new information can now form part of other studies for comparison purposes. The guesstimate prevalence used when determining the required sample size low (2%). With the actual prevalence being significantly higher, it highlights the very special needs of a large proportion of Emergency Centre patients.

6.2 GENDER AND AGE

Overall, there was a reasonable balance between male and female palliative care patients – 52% female and 48% male. The findings of Green et al, supported this result as they also noted that 53% of the PC patients that visited an Emergency Centre were female. Lawson et al, also found a balance between males and females presenting to the Emergency Centre - 49.7% males and 50.3% females (40). They also noted that 37.5% of patients were under the age of 65, compared to this study in which 48% of patients were under the age of 60 years. Our study showed a larger proportion of younger patients. There were, however, some age bands which showed large differences in gender proportion.

In the 50-60 year age band, males formed 65% of this age band. Relatively young males are therefore presenting in large proportions with life-threatening illnesses. An analysis of their diagnoses reveals that their top 5 diagnoses are hypertension, heart disease, diabetes, COPD and cancer. Hypertension presented in this age band in similar proportions in all males, but COPD and diabetes were found in much higher proportions in the 50-60 year age band for males. The prevalence of cancer is also lower in this age band.

Another age band which showed large gender discrepancies was the 70-100 year age band. This group showed very high rates of hypertension and heart disease compared to the prevalence of these diseases in all age bands. Dementia is also three times higher in this group compared to all age bands.

Grudzen et al, provided some insight into diseases occurring in the palliative care elderly when they described the PC needs of this elderly group(50). They looked at patients over the age of 65 years, presenting with a set list of disease conditions/criteria that included cancer, end stage liver disease, end stage kidney disease, congestive heart failure, stroke, oxygen dependent pulmonary disease, dementia and a severe functional deficit. Although their study used a convenient sampling method, it is possible to gain some insight of disease prevalences in this elderly group. They found a cancer prevalence of 42% versus this study finding of 24.3%. They found a congestive heart failure prevalence of 24%, compared to this finding of heart disease of 48.6%. It is the dementia prevalences which were significantly different, with their study reporting a 4% prevalence, and this study finding a 19% prevalence in this age group. Females dominate this age group, forming 68% of the 70-100 year age band.

Table 30: Top Diagnoses in 70-100 Year Age Band

70-100 Year Age Band (n=37)				All Patients (n=125)
Top Diagnoses		**Frequency**	**Percentage of Patients in 70-100 Year Age band**	**Percentage in all Age Bands**
1	Hypertension	18	48,6%	29,6%
2	Heart Disease	18	48,6%	29,6%
3	Cancer	9	24,3%	24,8%
4	Diabetes	8	21,6%	18,4%
5	Dementia	7	18,9%	5,6%

Closer analysis of females in the 70-100 year age band reveals that this group also presents with nearly double the rates of hypertension and diabetes compared to all females. Heart disease was three times higher in this age band compared to all females. Interestingly, this group had lower rates of cancer compared to all females.

6.3 REASONS FOR ADMISSION

The reason for admission is also the presenting complaint – this being the actual written notes in the patient triage form that indicated why the patient came to the Emergency Centre. The reasons for admission, in reflecting the healthcare professional's notes, are therefore a combination of diagnoses and symptoms. It must be noted that not all reasons for admission are necessarily revealed nor captured in a patient folder e.g., exhaustion of caregivers, lack of home care support. It is important to understand the reasons why PC patients present to the Emergency Centre, in order to meet their PC needs and reduce the distress associated with acute symptoms more timeously.

Pain and shortness of breath were the top 2 reasons for admission to the Emergency Centre, followed closely by loss of/reduced levels of consciousness and heart disease. The actual proportion of patients presenting with pain might be as high as 14%, through logical extension of the healthcare professionals' noted reasons for admission.
This is nevertheless a low proportion when compared to the findings of Grudzen et al. They found that 15% and 44% of PC patients arrived at an Emergency Centre in moderate to severe pain over the months January 2005 and January 2009 respectively(32).
Barbera et al, who studied the reasons why cancer patients visit an Emergency Centre, also reported a combination of symptoms and diagnoses(5). Their top 5 reasons were abdominal pain, lung cancer, pneumonia, dyspnoea, and malaise and fatigue.

These results have some areas in common with the findings of Lawson et al, who also noted pain (24% of patients) and dyspnoea (21.5% of patients) as their top 2 reasons for PC patients presenting to the Emergency Centre (40). The Lawson et al, study also included patients who were receiving PC services at the time of the study. It does lead to conjecture of how the findings may have been influenced by the behaviour of patients who had not yet experienced the benefits of PC services.

Given that the receipt of PC services leads to better management of symptoms, and reduced Emergency Centre visits, the proportions of patients presenting with these symptoms would likely be higher in the group not receiving PC services (51, 52).

Lawson et al, noted symptoms only as their reasons for presentation, and their top 5 reasons for presentation to an Emergency Centre also included weakness malaise and fatigue, confusion dizziness, and nausea and vomiting(40). Weakness malaise fatigue, and confusion dizziness also form part of the top 5 reasons for admission in this study. With so many studies focusing on cancer patients, this comparison is pertinent as the Lawson et al, study included patients who had varied life-threatening diagnoses.

Delgado-Guay et al, reported on the reasons why cancer patients in receipt of PC services, still visited an Emergency Centre(34). They noted symptoms only and also found that pain is the primary symptom for patients presenting to an Emergency Centre. Their study showed a 36% prevalence of pain, followed by 9% with nausea and vomiting, and 8% with dyspnoea. Their most frequent symptoms match our findings well, but the proportions differ vastly.

This study reports higher proportions of cancer patients with these symptoms – 54% present with pain and 18% present with vomiting. This is not surprising taking into consideration the very low proportion of patients (3 patients = 2.4% of all PC patients) who were already receiving PC services and support.

6.4 TIME OF PRESENTATION TO THE EMERGENCY CENTRE

This study found that 64% of patients presented to the Emergency Centre after hours, after hours being from 4pm to 8am, when many other health care facilities would have been closed. The findings of Wallace et al, in their analysis of the visits made by cancer patients to an Emergency Centre, most closely matched our results. They found that 63% of visits were made after hours (5pm – 9am), and 37% within business hours. Many other studies reported lower after hour visits to the Emergency Centre.

Lawson et al, also looked into the time at which patients presented to the Emergency Centre of a New York based quaternary care institution(40). They found that 48% of visits were made after hours from 5pm to 8am. Other researchers showed similar findings to them. Green et al, found that 50% of patients already receiving palliative care presented to the Emergency Centre of a British inner-city hospital after hours(4).
Delgado-Guay et al, when looking at avoidable and unavoidable visits by cancer patients to an Emergency Centre found that 54% of the visits took place after hours (5pm – 9am)(34).

The higher figure found in this/our study appears logical given the low number of patients already receiving PC services at the time of admission, as the receipt of PC services results in improved symptom control of patients, and therefore a reduced need for ED visits (41).
It is pertinent that the top reason for presentation to the Emergency Centre after hours was Pain. Pain did not present as a reason for admission during business hours. With the closure of the other health care facilities after hours, patients have only one option for assistance with unmanageable

symptoms, and this is the 24-hour Emergency Centre. The development of acute symptoms has no regard for time of day and availability of health resources. These findings highlight the very urgent need for PC services to be provided after hours.

6.5 SYMPTOMS

Only 5 patient records noted no symptoms in the Groote Schuur Emergency Unit Adult Triage Form. It is important to remember that these patients are sometimes too ill to provide a symptom history, and this may account for the lack of information.

This data is supported by previous studies in terms of the common symptoms found in PC patients. The most frequently presenting symptoms were pain, loss of/reduced levels of consciousness, shortness of breath and weakness/fatigue. The study of Green et al, supported this finding when they found that the top symptoms noted by PC patients visiting an Emergency Centre included dyspnoea, pain, nausea and vomiting(4).
Lawson et al, also reported similar results - that pain was the most frequently reported symptom with 23.8% of patients reporting pain, followed by shortness of breath in 21.5% of patients(40). These patients were already managed by PC services but still presented in high numbers with acute uncontrolled symptoms. They found a low proportion of patients (5.2%) that reported reduced levels of consciousness, compared to this study proportion of 21.6% of patients. Our levels of weakness and fatigue were also considerably higher at 17.6% compared to their finding of 7.7%.

The cancer patients in this study presented with pain (54%), weakness (27%) and vomiting (18%) as their most frequent symptoms. The results of Delgado-Guay et al, supported our study finding as they also found that the most frequent symptoms reported by cancer patients visiting an Emergency Centre were pain (36%) and nausea and vomiting(9%) (34). This study proportions were much higher, likely due to the low level of PC support experienced by these patients.

The key issue that arises out of the finding that pain and shortness of breath are driving PC patients to the Emergency Centre, is the need to train caregivers to manage these symptoms at home as they arise.

6.6 DIAGNOSES

Thirty percent (30%) each of our PC patients presented with hypertension and heart disease. The WHO reports that 38.5% of PC patients present with cardiovascular diseases, 34% with cancer, 10.3% with chronic respiratory diseases, 5.7% with AIDS, and 4.6% with diabetes. In our study, patients presented with lower proportions of heart disease and cancer, and higher proportions of diabetes, HIV and COPD. In fact, our HIV prevalence figures were three times higher than the WHO figures, and our diabetes prevalence also over three times higher.

Table 31: Comparison with WHO Palliative Care Diagnoses Figures

	Top Diagnoses	Percentage of Patients	WHO Figures
1	Hypertension	29,0%	-
2	Heart Disease	33,1%	38,5%
3	Cancer	26,6%	34%
4	Diabetes	16,9%	4,6%
5	HIV/AIDS	16,9%	5,7%
6	COPD	12,1%	10,3%

Grudzen et al, carried out a study that looked at the characteristics of Emergency Centre patients who received a PC consultation over 2 periods – January 2005 and January 2009(32). They found that a cancer prevalence of 22% and 24% respectively over the 2 measured periods, and a very low prevalence of HIV of 4% and 5%. Our study found a 12% prevalence of stroke while they reported a 9% stroke prevalence. They also reported very low levels of COPD – 0% in January 2005 and 3% in January 2009.

Green et al, in their study looking at why patients receiving PC services still require the services of an Emergency Centre, noted a prevalence of 70% cancer in their patient cohort (4). Our cancer prevalence was much lower at 24.8%.

6.7 MODE OF TRANSPORT TO THE EMERGENCY CENTRE

It is worrying to note that 55% of patients are making their own way to the Emergency Centre because these patients are typically in acute distress with significant symptoms and a high burden of disease. This emphasises the heavy burden of care carried by the patients and their families.

Only twelve percent (12%) of patients called for an ambulance privately and were brought by ambulance. Twenty-six percent (26%) of patients were transferred to the Emergency Centre via ambulance from other community health centres or hospitals. Altogether, 37.6% of patients arrived at the Emergency Centre via ambulance, thereby placing significant pressure on the ambulance services. Lawson et al, looked at the mode of transport to the Emergency Centre used by PC patients in Canada (40). They found that transport by ambulance was the most frequently used mode of transport (57%). Green et al, found that 79% of visits to an Emergency Centre were via ambulance. This was for patients already receiving PC services (4). Cape Town has a shortage of ambulances, which might explain the lower use of ambulances as a mode of transport(53).

6.8 LENGTH OF STAY AND WEEKENDS/PUBLIC HOLIDAYS VERSUS WEEKDAYS

This Emergency Centre includes a short-term stay facility. 80% of patients stayed for 1-2 days, 13% for 3 days. Some of these patients were discharged home, while others were transferred to appropriate wards in the hospital.

There were slightly higher admissions of patients over the weekends and public holidays (7%). Notably, the PC patient admissions over this period dropped by 7% as well. This contrasts with the study done by Lawson et al, who found no significant difference between presentation to the Emergency Centre over weekdays versus weekends. In fact, they noted a fairly constant level of

patients over weekdays and weekends (40).

6.9 ACCESS TO PALLIATIVE CARE SERVICES

It is encouraging that PC services are available in nearly all suburbs (96% of suburbs) within which the patients reside. Given this access, the poor levels of referral are puzzling. Clearly, training is required to better identify patients with PC needs at an earlier stage, together with a clear process for referral, and assurance that these patients will be taken care of by the PC team.
Another issue that affects access is safety. Only 9 patients (7%) lived in areas not covered by hospice services. Five of these patients lived in a suburb that was considered too dangerous for health professionals to enter. In this single suburb, the likelihood of criminal activity against health professionals was a high risk. Four of the patients lived in outlying areas several hours away from the city. The expansion of PC services to the rural areas will serve this vulnerable group well.

6.10 STUDY LIMITATIONS

This study was carried out prior to the Covid pandemic. The pressure on health resources has increased drastically since its arrival. The study was also carried out in one of the better resourced hospitals, in a better resourced province (Western Cape), in South Africa. The demographics of patients and their ability to access care at an Emergency Centre may differ significantly in other provinces. It is also important to note that the Emergency Centre at Groote Schuur has 2 arms – Trauma and Medical Emergency. This research was carried out in the Medical Emergency Centre. Palliative care patient prevalence in Emergency Centres including both trauma and medical emergency may differ. There was a missed opportunity at the time of data gathering. Several patients died in the Emergency Centre. No record of these deaths was recorded by the researcher. This would have been an important piece of information to add to that already gathered. Finally, there may have been some reasons for admission that were not revealed by the patient and family, or were simply not captured e.g., lack of home care support, exhaustion of caregivers, unstable home environments.

7. ETHICAL CONSIDERATIONS

This research complied with the World Medical Association Declaration of Helsinki, safeguarding the rights, well-being and health of patients(54).

This research made use of a quantitative research methodology and was carried out through review of records of admitted patients in a medical emergency unit setting. This was a non-therapeutic research methodology and posed minimal risk to the patients. No engagement with patients was required. However, confidentiality of patient records was ensured through anonymising patient records, and through securing their information stored on computers and Cloud facilities via password protection.

8. BUDGET

All costs were carried by the researcher.

9. CONCLUSION

The role, if any, of palliative care in the Emergency Centre of tertiary care institutions has been a subject of much debate and research, given the growth and maturation of PC services globally(4, 20, 22, 23, 29, 44). Research has shown that patients with PC needs will present to the Emergency Centre when symptoms become too severe or there has been a sudden change in health status. The Emergency Centre is therefore an important catchment zone for the identification and management of palliative patients.

Understanding that a presenting patient has PC needs, should influence the care provided, as well as the discussion held with the patient and family. There is limited data available on what this means for physicians in the Emergency Centre in terms of the volume of PC patients that present there(31). This study sought to determine this prevalence to allow an indication of the volume of PC patients in an Emergency Centre setting. The prevalence of PC patients presenting to the Groote Schuur Emergency Centre is 32.1%. This finding will allow Emergency Centre staff to calculate an approximate prevalence in their setting based on current all-patient volumes, and to plan for the special needs of PC patients and their families.

The second objective of this study was to understand why patients with PC needs present to an Emergency Centre. Pain was the most common reason for presentation to the Emergency Centre, with providers noting this on the Triage Form for 14% of patients. An interesting finding and an important one to note was that no patients presented because of pain during business hours. All the patients presenting with pain did so after hours only when other facilities were closed. Shortness of breath (7%) and loss of/reduced levels of consciousness (6%) were also driving patients to the Emergency Centre.

While it is encouraging that South Africa has been found to have a preliminary level of integration of PC services with health services (20), PC services are not available to patients and their families on weekends and after hours. Until this has been remedied and other sources of care are in place, Emergency Centres remain an important site of access to care for distressed patients. Nearly one third of all patients in an Emergency Centre have PC needs, which therefore requires that a palliative care approach be followed to meet the patient needs, and that palliative care training is prioritised for healthcare professionals working in an Emergency Centre.

This study highlighted the need for earlier identification and referral of PC patients in an Emergency Centre to community PC services. Training of Emergency Centre staff to identify when a patient has PC needs will enable this referral. Training will also allow staff to meet some of these needs in the Emergency Centre. Lastly, further studies on the experiences of PC patients and their families in the Emergency Centre will be valuable to best support this vulnerable sector of our society.

10. REFERENCES

1. World Health Organisation. Palliative Care. 2018 [cited 2019 Feb 04] Available from: http://www.who.int/news-room/fact-sheets/detail/palliative-care.
2. University of Edinburgh. SPICT 2019. 2019 [cited 2019 Apr 20] Available from: https://www.spict.org.uk/the-spict/.
3. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the Aggressiveness of Cancer Care Near the End of Life. Journal of Clinical Oncology. 2004;22(2):315-21.
4. Green E, Ward S, Brierley W, Riley B, Sattar H, Harris T. "They Shouldn't Be Coming to the ED, Should They?": A Descriptive Service Evaluation of Why Patients With Palliative Care Needs Present to the Emergency Department. American Journal of Hospice and Palliative Medicine®. 2017;34(10):984-90.
5. Barbera L, Taylor C, Dudgeon D. Why do patients with cancer visit the emergency department near the end of life? Canadian Medical Association Journal. 2010;182(6):563-8.
6. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non–small-cell lung cancer. New England Journal of Medicine. 2010;363(8):733-42.
7. Cherny N, Fallon M, Kaasa S, Portenoy RK, Currow DC. Oxford Textbook of Palliative Medicine. Oxford, UNITED KINGDOM: Oxford University Press, Incorporated; 2015.
8. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. Journal of pain and symptom management. 2002;24(2):91-6.
9. Gwyther L, Krause R, Cupido C, Stanford J, Grey H, Credé T, et al. The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa. South African Medical Journal. 2018;108(2):86-9.
10. Fourie AE. A Needs Assessment for palliative care training in undergraduate students at the University of Stellenbosch: University of Cape Town; 2015.
11. South Africa DoH. National Policy Framework and Strategy on Palliative Care 2017–2022. 2017.
12. Western Cape Government DoH. Proposed Model for the Implementation of the Palliative Care Policy in the Western Cape. 2018.
13. Szymanski P. C15 Stats. In: Govender R, editor. Personal email, 01 June 2018.
14. Mayosi BM, Benatar SR. Health and health care in South Africa—20 years after Mandela. New England Journal of Medicine. 2014;371(14):1344-53.
15. Medical Brief. Innovation needed to stem shortages – Groote Schuur CEO. 2018, June 16.
16. South African Government. National Development Plan 2030 : Chapter 10 - Promoting Health. 2015.
17. World Health Organisation. WHO Fact Sheets - Palliative Care. 2019 [cited 2019 Apr 20] Available from: http://www.who.int/en/news-room/fact-sheets/detail/palliative-care.
18. Wright M, Wood J, Lynch T, Clark D. Mapping levels of palliative care development: a global view. Journal of pain and symptom management. 2008;35(5):469-85.
19. Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. Journal of pain and symptom management. 2013;45(6):1094-106.
20. Clark D, Baur N, Clelland D, Garralda E, López-Fidalgo J, Connor S, et al. Mapping levels of palliative care development in 198 countries: the situation in 2017. Journal of pain and symptom management. 2020;59(4):794-807. e4.
21. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete XJ, et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. The Lancet. 2017.
22. Cassel JB, Lyckholm LJ. Identifying palliative care needs in the emergency department: better care, lower cost. Academic Emergency Medicine. 2006;13(5 Supplement 1):S96.
23. DeVader TE, Albrecht R, Reiter M. Initiating palliative care in the emergency department. Journal of Emergency Medicine. 2012;43(5):803-10.
24. George N, Phillips E, Zaurova M, Song C, Lamba S, Grudzen C. Palliative care screening and assessment in the emergency department: A systematic review. Journal of pain and symptom management. 2016;51(1):108-19. e2.
25. Grudzen CR, Stone SC, Morrison RS. The palliative care model for emergency department patients with advanced illness. Journal of palliative medicine. 2011;14(8):945-50.
26. Hannon B, Zimmermann C, Knaul FM, Powell RA, Mwangi-Powell FN, Rodin G. Provision of palliative care in low-and middle-income countries: Overcoming obstacles for effective treatment delivery. Journal of Clinical Oncology. 2015;34(1):62-8.
27. Potts M, Cartmell KB, Nemeth L, Bhattacharjee G, Qanungo S. A Systematic Review of Palliative Care Intervention Outcomes and Outcome Measures in Low Resource Countries. Journal of pain and symptom management. 2018.
28. Grudzen CR, Richardson LD, Johnson PN, Hu M, Wang B, Ortiz JM, et al. Emergency department–initiated

palliative care in advanced cancer: a randomized clinical trial. JAMA oncology. 2016;2(5):591-8.
29. da Silva Soares D, Nunes CM, Gomes B. Effectiveness of emergency department based palliative Care for Adults with advanced disease: a systematic review. Journal of Palliative Medicine. 2016;19(6):601-9.
30. Wilson JG, English DP, Owyang CG, Chimelski EA, Grudzen CR, Wong H-n, et al. End-of-life care, palliative care consultation, and palliative care referral in the emergency department: a systematic review. Journal of Pain and Symptom Management. 2020;59(2):372-83. e1.
31. Wong J, Gott M, Frey R, Jull A. What is the incidence of patients with palliative care needs presenting to the Emergency Department? A critical review. Palliative medicine. 2014;28(10):1197-205.
32. Grudzen CR, Hwang U, Cohen JA, Fischman M, Morrison RS. Characteristics of emergency department patients who receive a palliative care consultation. Journal of palliative medicine. 2012;15(4):396-9.
33. Wallace EM, Cooney MC, Walsh J, Conroy M, Twomey F. Why do Palliative Care Patients Present to the Emergency Department? Avoidable or Unavoidable? American Journal of Hospice and Palliative Medicine®. 2013;30(3):253-6.
34. Delgado-Guay MO, Kim YJ, Shin SH, Chisholm G, Williams J, Allo J, et al. Avoidable and unavoidable visits to the emergency department among patients with advanced cancer receiving outpatient palliative care. Journal of pain and symptom management. 2015;49(3):497-504.
35. Hjermstad MJ, Kolflaath J, Løkken AO, Hanssen SB, Normann AP, Aass N. Are emergency admissions in palliative cancer care always necessary? Results from a descriptive study. BMJ open. 2013;3(5):e002515.
36. Jang RW, Krzyzanowska MK, Zimmermann C, Taback N, Alibhai SMH. Palliative Care and the Aggressiveness of End-of-Life Care in Patients With Advanced Pancreatic Cancer. JNCI: Journal of the National Cancer Institute. 2015;107(3):dju424-dju.
37. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. Journal of Clinical Oncology. 2003;21(6):1133-8.
38. Dy SM, Kiley KB, Ast K, Lupu D, Norton SA, McMillan SC, et al. Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. Journal of pain and symptom management. 2015;49(4):773-81.
39. Association CHPC. Fact Sheet: Hospice Palliative Care in Canada. Canadian Hospice Palliative Care Association 2012.
40. Lawson BJ, Burge FI, Mcintyre P, Field S, Maxwell D. Palliative care patients in the emergency department. Journal of palliative care. 2008;24(4):247.
41. Burge F, Lawson B, Johnston G. Family physician continuity of care and emergency department use in end-of-life cancer care. Medical care. 2003:992-1001.
42. Smith AK, Schonberg MA, Fisher J, Pallin DJ, Block SD, Forrow L, et al. Emergency department experiences of acutely symptomatic patients with terminal illness and their family caregivers. Journal of pain and symptom management. 2010;39(6):972-81.
43. Smith AK, Fisher J, Schonberg MA, Pallin DJ, Block SD, Forrow L, et al. Am I doing the right thing? Provider perspectives on improving palliative care in the emergency department. Annals of emergency medicine. 2009;54(1):86-93. e1.
44. Grudzen CR, Richardson LD, Hopper SS, Ortiz JM, Whang C, Morrison RS. Does palliative care have a future in the emergency department? Discussions with attending emergency physicians. Journal of pain and symptom management. 2012;43(1):1-9.
45. Highet G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ supportive & palliative care. 2014;4(3):285-90.
46. Walsh RI, Mitchell G, Francis L, van Driel ML. What diagnostic tools exist for the early identification of palliative care patients in general practice? A systematic review. Journal of Palliative care. 2015;31(2):118-23.
47. University of Edinburgh. SPICT-LIS. 2018, April 26.
48. WHO G. Global Tuberculosis Control 2018. 2018.
49. Charan J, Biswas T. How to calculate sample size for different study designs in medical research? Indian journal of psychological medicine. 2013;35(2):121.
50. Grudzen CR, Richardson LD, Morrison M, Cho E, Sean Morrison R. Palliative care needs of seriously ill, older adults presenting to the emergency department. Academic Emergency Medicine. 2010;17(11):1253-7.
51. Brumley R, Enguidanos S, Jamison P, Seitz R, Morgenstern N, Saito S, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. Journal of the American Geriatrics Society. 2007;55(7):993-1000.
52. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. Archives of internal medicine. 2004;164(1):83-91.
53. Western Cape Government DoH. Western Cape Department of Health Annual report 2019/2020. 2020.
54. Association GAotWM. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. The Journal of the American College of Dentists. 2014;81(3):14.

11. APPENDICES

11.1 APPENDIX 1 – UNIVERSITY OF CAPE TOWN ETHICS APPROVAL FORMS

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

Room E53-46 Old Main Buildin
Groote Schuur Hospit
Observatory 792
Telephone [021] 406 662
Email: shuretta.thomas@uct.ac.z
Website: www.health.uct.ac.za/fhs/research/humanethics/form

16 May 2019

HREC REF: 210/2019

Dr R Krause
Family Medicine
Room 2.28
Entrance 5
Falmouth Building

Dear Dr Krause

PROJECT TITLE: A DETERMINATION OF THE PREVALENCE AND REASONS WHY PALLIATIVE CARE PATIENTS PRESENT TO THE GROOTE SCHUUR HOSPITAL EMERGENCY DEPARTMENT. (MPHIL CANDIDATE: MS. R. GOVENDER)

Thank you for submitting your response to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

- Please add to the informed consent form, that patient clinical notes will also be assessed. This allows care-givers to agree or disagree to use these.

Approval is granted for one year until 30 May 2020.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Radha Govender will also be involved in this study.

UNIVERSITY OF CAPE TOWN

HUMAN RESEARCH ETHICS COMMITTEE
30 JUN 2020
UNIVERSITY OF CAPE TOWN

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.			
☐ Approved	Annual progress report	Approved until/next renewal date	30-05-2021
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	30/6/2020

Note: Please note that incomplete submissions will not be reviewed.
Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown

Comments to PI from the HREC
Digital interviews approved My best wishes

Principal Investigator to complete the following:

1. Protocol Information

Date (when submitting this form)	29 June 2020		
HREC REF Number	210/2019	Current Ethics Approval was granted until	30 May 2020
Protocol title	A Determination of the Prevalence and Reasons Why Palliative Care Patients Present to the Groote Schuur Hospital Emergency Department		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes ✓ No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Radha Govender		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

UNIVERSITY OF CAPE TOWN

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.			
☑ Approved	Annual progress report	Approved until/next renewal date	30/11/22
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	8/11/2021

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.
Please clarify your plan for research-related activities during COVID-19 lockdown.
Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

Comments to PI from the HREC
Thank you for your Study Deviation HREC Chair Signature Date: 8/11/2021

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	05 November 2021		
HREC REF Number	210/2019	Current Ethics Approval was granted until	30 May 2021
Protocol title	A determination of the prevalence and reasons why palliative care patients present to the Groote Schuur Hospital Emergency Department		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?		☐ Yes	☑ No
If yes, could you please provide the HREC Reference number for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Rene Krause		
Department / Office Internal Mail Address	Faculty of Family Medicine		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

HUMAN RESEARCH ETHICS COMMITTEE
08 NOV 2021
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

11.2 APPENDIX 2 – APPROVAL LETTER FROM THE INSTITUTION – GROOTE SCHUUR HOSPITAL

Western Cape Government
Health

GROOTE SCHUUR HOSPITAL
Enquiries: Dr Bernadette Eick
E-mail : Bernadette.Eick@westerncape.gov.za

Dr R. Krause
FAMILY MEDICINE

E-mail: rene.krause@uct.ac.za / radha@redchilli.co.za

Dear Dr Krause

RESEARCH PROJECT: A Determination Of The Prevalence And Reasons Why Palliative Care Patients Present To the Groote Schuur Hospital Emergency Department (MPhil Ms. Radha Govender)

Your recent letter to the hospital refers.

You are granted permission to proceed with your research, which is valid until **30 May 2020.**

Please note the following:

a) Your research may not interfere with normal patient care.
b) Hospital staff may not be asked to assist with the research.
c) No additional costs to the hospital should be incurred i.e. Lab, consumables or stationary.
d) **No patient folders may be removed from the premises or be inaccessible.**
e) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
f) Confidentiality must always be maintained .
g) Should you at any time require photographs of your subjects, please obtain the necessary indemnity forms from our Public Relations Office (E45 OMB or ext. 2187/2188).
h) Should you require additional research time beyond the stipulated expiry date, please apply for an extension.
i) Please discuss the study with the HOD before commencing.
j) Please introduce yourself to the person in charge of an area before commencing.
k) On completion of your research, please forward any recommendations/findings that can be beneficial to use to take further action that may inform redevelopment of future policy / review guidelines.
l) Kindly submit a copy of the publication or report to this office on completion of the research.

I would like to wish you every success with the project.

Yours sincerely

(on behalf of) DR BERNADETTE EICK
CHIEF OPERATIONAL OFFICER
Date: 18 July 2019

C.C. Mr. L. Naidoo
Dr L Booyens
Dr A. Kropman

G46 Management Suite, Old Main Building,
Observatory 7925
Tel: +27 21 404 6288 fax: +27 21 404 6125

Private Bag X,
Observatory, 7935
www.capegateway.go.v.za

11.3 APPENDIX 3 - GROOTE SCHUUR REFERRAL TO PALLIATIVE CARE FORM

Western Cape Government
Health

Referral to Palliative Care

Sister Jennie Arendse,
jennifer.arendse@westerncape.gov.za
Room G3-30
Speed dial: 76536

Purposeful, Planned, Positive
PALLIATIVE CARE

PATIENT DETAILS: (*Sticker or complete details below)*
Name: **Folder:**
Contact number:
Ward:
Bed:

REFERRING FROM:
Date:
Firm:
Dr:
Speed dial:

PATIENT DIAGNOSIS:

Has the patient/family been informed of diagnosis?

REASON FOR REFERRAL and D/C plans to date:

PALLIATIVE CARE REFERRAL CRITERIA		
1. Would you NOT be surprised if this patient dies within the next 6 months – 1 year? (tick) ☐		
2. **What is the patients current functional status? (circle)** **a.** Bedbound b. Requires assistance c. Fully mobile		
3. DOES THE PATIENT MEET THE CRITERIA BELOW?		
Condition	**Criteria**	**TICK**
Cancer	• Stage IV malignancy (Metastatic) • Not for (further) definitive treatment • Spends >50% of time in bed / bedridden	
Heart/vascular disease	• Symptoms despite maximal medical therapy • Disabling Shortness of breath at rest (NYHA Class IV) • ≥ 5 Admissions in past 6 months • Other associated organ involvement • Severe inoperable peripheral vascular disease	
Respiratory disease	• Disabling Shortness of breath at rest (NYHA Class IV) • ≥ 5 Admissions in past 6 months	
Renal Failure	• End stage renal disease (GFR <15ml/min) • Not suitable / Declined for dialysis	
Neurological Disease/Stroke	• Severely disabling • Progressive functional decline • Severe dysphagia • Recurrent fever and sepsis	
Liver disease	• Advanced cirrhosis with additional complications (resistant ascites, encephalopathy, recurrent variceal bleeds, heptorenal syndrome)	
Frailty / Dementia	• Significant functional impairment • Unable to do ADLs • Incontinence • Recurrent infections • Fractured femur, multiple falls	
HIV/AIDS	• Stage 3 or 4 disease with dementia • Severe cachexia • Neoplasm, Failure of HAART	
Other	Please specify:	

11.4 APPENDIX 4 - PATIENT DEMOGRAPHICS AND INFORMATION TOOL

Patient Demographics			Home Address		Time and Mode of Transport		
Folder Number	**DoB**	**Gender**	**District**	**Postal Code**	**Date of presentation**	**Time of presentation**	**Transport to the ED**

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Clinical Information									
Diagnosis 1	**Diagnosis 2**	**Diagnosis 3**	**Reason for Admission**	**Symptom 1**	**Symptom 2**	**Symptom 3**	**Symptom 4**	**Previous Assistance from PC Services**	**Will the Px be admitted**

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12. LIST OF TABLES