A Study to Identify the Burden of Chronic Disease on a Private Emergency Medical Service in the Southern Sub-District of Cape Town, and if there is a Need for Palliative Care Provision in the Pre-Hospital Healthcare Sector

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This work is dedicated to all the EMS personnel that give so much, often with very little support, and are often the first line of support for patients and their families

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DECLARATION OF OWN WORK:

I, Linley Avant Holmes, hereby declare that the work on which this thesis is based is my original work, 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. Advice regarding appropriate bio-statistical tests and analysis was received from Dr. Deborah Constant, responsible for research development and implementation in the public health domain, at the UCT School of Public Health and Family Medicine.

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"Promote quality, equitable and professional people-centred Emergency Care for all."

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Ensuring compliance with standards.

Fostering on-going professional development, competence, and accountability.

Protecting the public in matters involving the rendering of emergency care.

Transparent public and stakeholder engagement; and

Upholding and maintaining ethical and professional standards within the Emergency Care and advocating for patient rights.

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ACRONYMS

ACD: Advanced Care Directives
ACP: Advanced Care Plan
AIDS: Acquired Immunodeficiency Syndrome
CCF: Congestive Cardiac Failure
CHF: Congestive Heart Failure
CCM: Chronic Care Model
CMR: Cape Medical Response
COPD: Chronic Obstructive Pulmonary Disease
DALYs: Adjusted Life Expectancy Years
DC: day centres
DM: Diabetes Mellitus
DNAR: Do Not Attempt Resuscitation
DoH: Department of Health
ECP: extended-care paramedic
ED: Emergency Department
EMS: Emergency Medical Service
EPIC: Expanding Paramedicine in the Community
GCS: Glasgow Coma Scale
GP: General Practitioner
HaH: Hospital at Home
HCP: Health Care Professional
HIV: Human Immunodeficiency Virus
HPCSA: Health Professionals Council of South Africa
ICD10: International Classification of Diseases 10th Revision
ICDM: Integrated Chronic Disease Management
LTC: Long-Term Care Program
MIH: Mobile Integrated Healthcare
NCD: Non-Communicable Disease
NHI: National Health Insurance
NIH: National Institutes of Health
N&V: Nausea and Vomiting
PRF: Patient Report Form
QDU: quick diagnosis units
SAMRC: South African Medical Research Council
SATS: South African Triage Scale
SOB: Shortness of Breath
SPICT: Supportive and Palliative Care Indicators Tool
TEWS: Triage Early Warning System
WHA: World Health Assembly
WHO: World Health Organisation
WPCA: World Palliative Care Alliance

ABSTRACT

Introduction

Paramedics are often the first healthcare personnel to provide contact and care to patients with exacerbation of their chronic, non-communicable disease. Many of these patients will call for assistance multiple times during the trajectory of disease, and may benefit from a palliative care program. Currently, paramedics are not trained to manage patients requiring palliative care, nor provided with specialist palliative care consultation resulting in many patients being transported to hospital unnecessarily.

Aim

This study aims to describe the burden of patients with non-communicable disease, experiencing acute symptoms, on Emergency Medical Services, and to assess whether palliative care in the pre-hospital sector should be considered. The objectives of the study include understanding whether patients with non-communicable disease symptoms were transported to a medical facility or remained at home, what clinical management they received, and whether there is a need for education, inter-disciplinary consultation, and provision of palliative care, in the pre-hospital environment.

Methods

This was a retrospective descriptive analysis of de-identified patient PRFs of adult patients, attended to by a private Emergency Medical Service (EMS) between January 1st, 2019, up until 30th April 2019.

Results

Of the 283 patients included in the study, many had more than one NCD, often experiencing more than one of the primary symptoms of pain, SOB, cognitive changes, and N&V simultaneously. The majority of these patients were likely to go to hospital with ambulance transport and frequently there was no appropriate clinical intervention by paramedics. Clinical advice was seldom sought by paramedics for patients with NCDs (cancer, chronic heart disease, chronic lung disease, dementia, and chronic kidney disease) experiencing symptoms of pain, SOB, cognitive changes and N&V, and it was evident that palliative care access, and availability, for patients was minimal.

Conclusion

Palliative care is a necessary approach to patient-centred care, with specifically trained EMS and paramedics being an available resource to assist with this approach. Access to available palliative/ home care networks, in conjunction with education and EMS support, will facilitate care for patients that have a need for palliative care support in the out of hospital context, and will limit the inappropriate transport of patients to already over-burdened Emergency Departments.

1 CHAPTER 1 – INTRODUCTION

"The focus of health care is on the patient centred approach and should utilise an interdisciplinary healthcare workforce to provide the best experience and outcome for the patient suffering with distressing symptoms of chronic disease"

(WHO Executive Board, 2013)

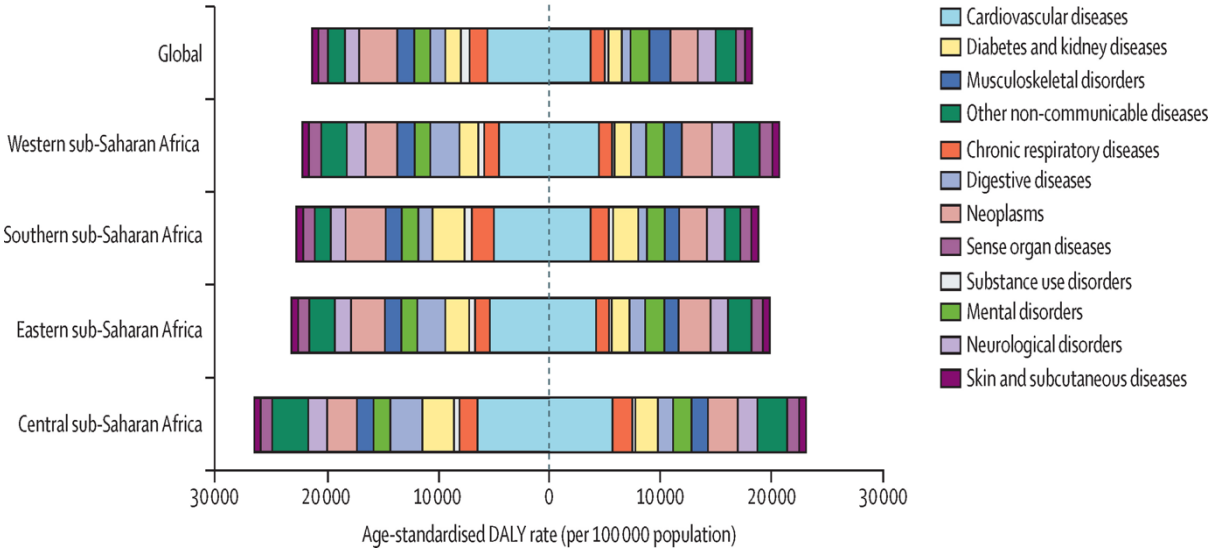
1.1 NON-COMMUNICABLE DISEASE AND HEALTHCARE SYSTEMS

Non-communicable disease (NCD) is on the rise globally with healthcare systems struggling to manage the increasing number of patients and acute exacerbations of these diseases. Clinical care in hospital or at primary healthcare facilities, is evidently insufficient, with patients (and their families) having inadequate care or lacking access to support programs throughout their disease trajectory (Bigna and Noubiap, 2019; Apps.who.int. 2014; Hirshon et al., 2013). Healthcare models, including those of Emergency Medical Services (EMS), have been based on providing curative care. In recognition of a globally changing disease profile, and the need to provide appropriate care to the general patient population, EMS in parts of the world are revising their historical culture of care (Al-Shaqsi, 2010).

Access to healthcare and the relief from suffering are considered human rights as published in "Strengthening of palliative care as a component of integrated treatment within the continuum of care" (WHA67.19). As populations expand, the effects of poverty, urbanisation and the globally expanding burden of disease, access to healthcare has become increasingly challenging. There are a growing number of patients presenting with chronic NCD, constituting 41 million deaths annually and includes 15 million deaths that occurred in people aged between 30 to 69 years old, who would be considered as able to work and provide for their families. This represents 71 percent of all global deaths per annum. Of these deaths, 85 percent occurred in middle- and low- income settings (WHO, 2018; Knaul et al., 2018; non-communicable diseases). This means that a large percentage of the income-generating population is incapacitated, which in effect exacerbates an already compromised socio-economic sector. Subsequently the morbidity and mortality rate of NCDs are higher globally than all other causes of disability and death combined (Global status report on non-communicable diseases 2014, 2021; Gouda et al., 2019). Refer to Figure 1.

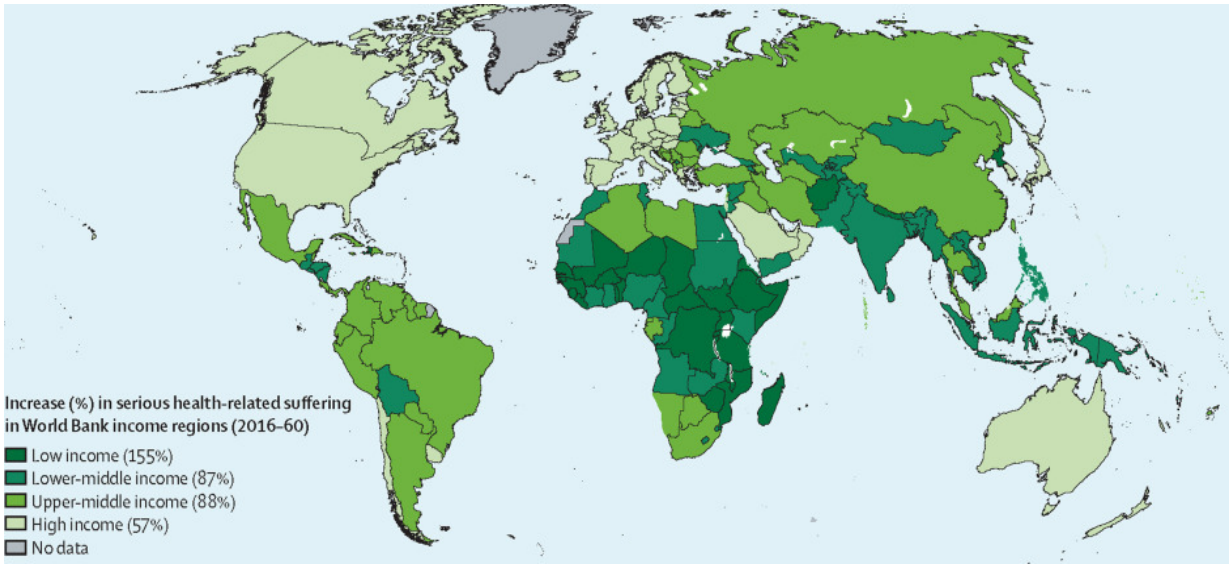
Developing countries, such as those in Central and Sub-Saharan Africa (see Figure. 2), are hit the hardest in terms of NCD burden, confounding the traditional disease burden of infectious disease, malnutrition and obstetric complications. Lifestyle choices, including food sources (often cheaper, but unhealthy), alternate and easier transport options (motorised with less need to exercise), and increased alcohol and cigarette use have increased the number of cases of cardiac disease, chronic respiratory disease, diabetes, and cancer in developing countries (Koopman et al., 2016). Socio-economic inequalities are also seen to exacerbate unequal access to healthcare distribution, including medication and supportive services such as palliative care (Knaul et al., 2018).

Figure 1: Burden of Non-Communicable Disease in Sub-Saharan Africa 1990-2017: Results from the Global Burden of Disease Study,2017 (Gouda, et al.,2019)



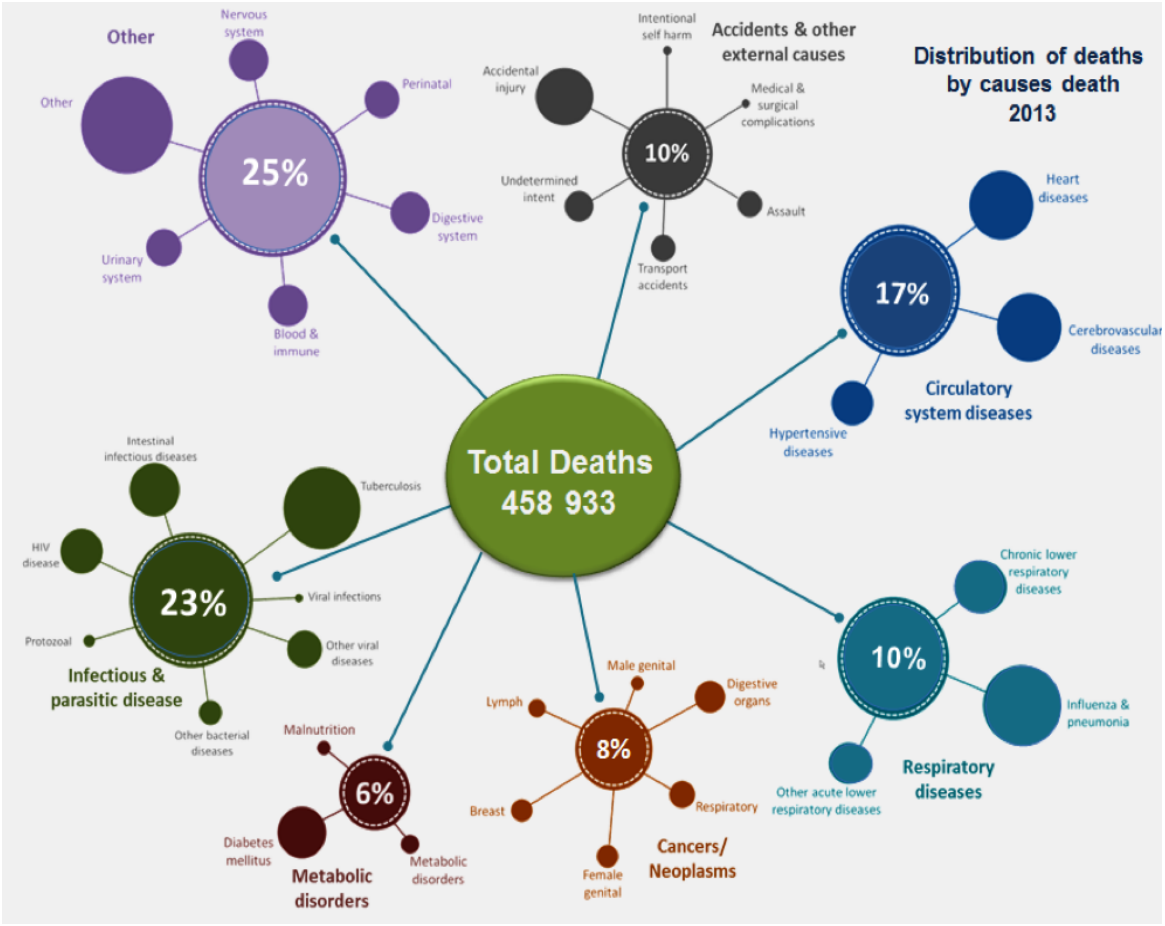
In 2018, the World Health Organisation (WHO) published the Non-Communicable Disease Country Profiles (WHO, 2018) which considered countries from high– to low-income states, profiling them on premature deaths, NCD deaths proportional to other deaths, risk factors and indication of national targets that were set (World Health Organisation, 2018). (See Appendix 1: World Health Organization – Non-communicable Disease (NCD) Country Profiles 2018.) Refer to Figure 2.

Figure 2: Increase in serious health related suffering in World Bank income regions



South Africa, a developing country, continues to strain under a collapsing health system and the impact of burgeoning communicable, and non-communicable, chronic disease (cardiovascular, respiratory and cancer) (Stats SA, 2017, Pillay-van Wyk et al., 2016) Refer to Figure 3.

Figure 3: Distribution of death by causes 2013 (Statistics South Africa 2017)



In an attempt to reduce the cost of NCDs and reduce the amount of associated health-related suffering, 186 countries have committed, as part of the United Nations Sustainable Development Goals and NCD Countdown 2030, to decrease the number of NCDs, and thereby improve physical, social and emotional wellbeing of communities (United Nations Development Programme, 2021, Knaul et al., 2018). South Africa is one of the countries that have made this commitment to decrease the incidence of cancers, cardiovascular disease, chronic respiratory disease and diabetes. Reducing the incidence, and thereby the cost of NCDs, will rely on reconfiguration of the current health system to take into account socio-economic challenges effectively and aim to "prevent, diagnose and manage" the symptoms and health requirements related to NCDs (SAMRC, 2018). As NCDs have increased globally, there will need to be a shift in the healthcare approach to chronic disease care in and out of hospital, in order to manage health-related suffering (Joshi et al., 2014).

1.2 The need for Healthcare System Adaptation

Therefore, proactive, preventative and planned care of chronic disease exacerbations has become a priority to cut the costs (monetary and non-monetary) associated with the effects of NCD. The access to an interdisciplinary team could potentially reduce healthcare costs, improve patient care, and ultimately quality of life, which is emphasised in the WHO report "Transitions of Care: Technical Series on Safer Primary Care", where concern over the evident rise of morbidity and mortality associated with chronic disease, and the increasing costs of healthcare has initiated attempts to change

practice to mitigate the failings of current global healthcare (Transitions of Care: Technical Series on Safer Primary Care. Geneva: World Health Organization; 2016).

Hirshon et al. support the integration of acute, primary and public healthcare (including curative, rehabilitative, palliative and preventative care) to provide a fundamentally well-functioning healthcare system. Patients with chronic disease should be managed with an inter-disciplinary approach as acute exacerbations of chronic disease do occur, which may be life-threatening and require emergency management. The management of these exacerbations may, however, need an understanding of the disease trajectory, and therefore an adjusted clinical approach and transition of care may be necessary to provide appropriate holistic patient care (Hirshon et al., 2013).

1.3 Chronic Disease and the Role of Palliative Care- a Global Perspective

Palliative care is not a recent concept, originating in the 1960's as an efficient, interdisciplinary approach that does not purely focus on the management of physical pain, but includes psychological and spiritual wellbeing in order to address patients' "total pain". The focus was originally to improve quality of life for people living with cancer, but palliative care has evolved to support patients with other types of life-threatening disease such as non-communicable, and communicable illnesses. Through early, effective patient and disease assessment, and the development of care plans, patient suffering due to disabling symptoms (such as pain, nausea, vomiting and shortness of breath) are easier to mitigate (WHO Definition of Palliative Care, not dated). The realisation that psychological and spiritual wellbeing is integral to the patient's care started to become evident in the clinical space and has been seen to improve patient and family wellbeing (Saunders, 2001).

Not only does palliative care support and encompass all aspects of patient care (spiritual, physical and psychological), it also empowers patients and families to communicate their wish for support from healthcare professionals during times of symptom exacerbation, to have an advanced care plan in place in order to manage the patient's disease journey and end-of-life care as necessary.

With the focus on improving health-related suffering, managing NCDs, and improving global healthcare, palliative care is strongly advocated for by the WHO, The Global Atlas of Palliative Care, and the Worldwide Hospice Palliative Care Alliance (WPCA, 2015; WHO, 2019; Global Atlas of Palliative Care, 2nd Ed 2020, 2021).

The Global Atlas of Palliative Care and the WPCA stated that worldwide 20 million people were suffering with end-stage NCD, and were in need of palliative care, however, it is estimated that only 12 percent of people needing palliative care actually receive it (Global Atlas of Palliative Care, 2nd Ed 2020). Thus, palliative care is imperative for many people suffering from NCDs but continues to be inaccessible to a vast majority.

1.4 Palliative Care- the South African Perspective

In South Africa, the first hospices were established in the 1980s as non-governmental organisations. In 1987, the need for a national palliative care organisation was recognised and the Hospice Palliative Care Association (HPCA) was formed. A focused mentorship program was developed by HPCA to advise best practice in the provision of palliative care (Drenth et al., 2018), yet the concept and provision of palliative care was unrecognised and not adopted by the formal healthcare sector. With the advent of HIV/AIDS in Africa and South Africa, the South African government's

recognition of the need for palliative care led to South Africa joining the World Health Assembly Resolution 67.19 (2014) urging all member states to integrate palliative care into country health systems (Drenth et al., 2018).

More recently, in 2017, the National Policy Framework and Strategy for Palliative Care (NPFSPC) was approved by the South African National Health Council. This policy recommends that resources from primary to tertiary level of care are needed to allow for a palliative care approach to effectively manage the patients with chronic disease (National Policy Framework and Strategy on Palliative Care 2017-2022). Acknowledging the efficacy of the Supportive and Palliative Care Indicators Tool (SPICT) tool (Boyd, 2010), a South African SPICT model has been developed and validated to support practitioners at all levels of care in identifying patients with NCDs requiring access to palliative care earlier in their disease trajectory (SPICT^{TM}-SA, 2020).

The challenges experienced in South Africa are not unique but have been experienced globally with acute care facilities focusing on the dying patient at the end of their disease trajectory, rather than early introduction of palliative care, with the use of interdisciplinary teams and advanced care planning (Rodriguez, Barnato and Arnold, 2007).

1.5 THE ROLE OF EMERGENCY MEDICAL SERVICES (EMS)

The concept of emergency medical care focuses on the premise that the patient has a curative illness, with paramedics providing resuscitation, early hospital access (via ambulance or aeromedical transport), and definitive care of the patient with a focus on "saving lives" (Lord et al., 2019). Triage scoring also plays a major role in how paramedics make decisions on patients' clinical management, on patient transport options, and to which definitive care facilities patients are transported to. In South Africa, the Triage Early Warning System (TEWS) that is used is called the South African Triage Scale (SATS). It is an adapted scoring system used by clinical facilities and EMS to assign triage status to patients for appropriately timed clinical interventions. The resources required for each Triage Score vary depending on patient need (See Appendix 4 SATS-Manual-A5-LR-spreads.pdf, 2012).

In South Africa, and globally, much of emergency medical care (provided by EMS) has been guided via an algorithmic, protocol-driven approach to patient care (MacFarlane et al., 2005). EMS Paramedics are trained to make decisions on how best to treat the patients' symptoms of shortness of breath (SOB), nausea and vomiting (N&V), and pain within their scope of practice (Vincent-Lambert and de Kock, 2015), and this treatment may vary as per each practitioner's perception, clinical assessment, and qualification (Clinical_Practice_Guidelines_Protocols_2018.pdf).

This algorithmic approach lays a foundation for an effective, evidence-based approach to patient care in austere environments but can equally disable sound clinical reasoning by paramedics to manage out-of-the-ordinary issues that require insight, flexibility and a more individualised approach to patients, especially those with acute exacerbations of chronic NCDs. With the development of new evidence-based guidelines released by the HPCSA in 2018, and legislated in 2020, there is potential for an effective, evidence-based approach to patient care in emergency environments and some flexibility in clinical reasoning for Emergency Care Practitioners (paramedics with a particular scope of independent practice) to manage patients with chronic disease effectively and compassionately, while considering patient's or family's wishes, and providing best care in the context of patient presentation (Hpcsa.co.za, 2020).

1.6 EMS AND PALLIATIVE CARE - ADAPTING APPROACH AND CARE

Healthcare is often inaccessible due to distance from facilities, transport costs, and legislation that limits healthcare application to silos rather than to development and use of pertinent skills (Nancarrow, 2015). It has become evident that the healthcare workforce, from tertiary to primary healthcare, and including emergency services, needs to adapt to changing needs of patients, with provision of accessible, appropriate care.

As the burden of chronic disease increases, so too has the need for early palliative care in the out-of-hospital environment. Patients with NCDs are more likely to be repeat users of ambulance and emergency services due to exacerbation of their diseases, with many of the symptoms associated with exacerbation of chronic disease able to be stabilised in the context of a palliative care consult, appropriate EMS care and advanced care planning, to allow the patient to remain at home (Søvsø et al., 2019). The last decade has seen an increase in the number of patients asking for assistance from emergency services. At-home patient care and carer support could ease the financial and time burden on the EMS sector, and on emergency centres (Arab, Carter and Harrison, 2016; Mason et al., 2007; Cameron and Carter, 2019; Wiese et al., 2013; Scottishambulance.com, 2019; Søvsø et al., 2019).

Paramedics are bound by standard operating procedures and scope of practice, so are often required to assess, and transport patients to an emergency centre, independent of their medical history. This results in few patients being managed at home (Lord et al., 2019).

In the South African pre-hospital context, mention of palliative care need and provision has been lacking in the literature with a dearth of South African research available. Recent research on "South African Paramedics perspectives on pre-hospital palliative care" was published, describing a topic that is becoming more relevant and challenging to paramedics in the out-of-hospital environment (Gage, Geduld and Stassen, 2020). International research into paramedics' perceptions of palliative care, and the development of out-of-hospital paramedic augmented palliative (and community) care provision indicates the potential of a similar approach in the South African context (Lord et al., 2019; Arab, Carter and Harrison, 2016; Mason et al., 2007; Cameron and Carter, 2019).

1.7 ASSESSING THE BURDEN OF NCDS ON EMS

With international emergency services experiencing a high workload, and challenges associated with managing increasing numbers of patients suffering with NCDs and exacerbations thereof (Kelly et al., 2016; Carron et al., 2015), it is important to ascertain whether a similar situation is experienced by South African EMSs.

In this study, Cape Medical Response (CMR) was chosen as it is an established service, and has been providing patient care in the southern peninsula of Cape Town, for over 20 years. It was important to understand the baseline of NCDs in the community, and how this EMS managed patients in this context. Choosing this EMS service allowed for a view of a particular community it serviced, with a consistent group of paramedics providing patient care, and allowing access to patients' records (histories, treatments, transport and receiving facilities).

CMR is a membership-based private emergency service and supports the public sector by providing emergency assistance in collaboration with public sector EMS ("Metro" EMS) when Metro has no vehicles or paramedics available. This small EMS service often has a high workload and due to the differences in the areas it serves, a very mixed patient

demographic. The callouts vary from trauma (such as motor vehicle collisions, assaults, shootings, falls, drownings) to medical reasons (cardiovascular, cerebrovascular, gastro-intestinal and other symptoms associated with exacerbations of NCDs), and may be acute or non-urgent. The crew numbers are small, with 3 to 4 ambulances, and 2 response vehicles covering the entire area. Callouts to non-emergency situations or where alternate patient support is required, affect the availability of these vehicles and crew to other patients needing urgent care (many of them members of CMR), and potentially increasing company costs of time, fuel, vehicle wear and tear, and human resource.

The burden of NCDs on CMR and other South African emergency services, small and large, requires investigation. The experiences and understanding of palliative care by South African paramedics, in conjunction with scope of practice, needs to be explored. Further review of the global approach to, and care of patients with NCDs, will be continued in the following chapter.

2 CHAPTER 2 – LITERATURE REVIEW

2.1 LITERATURE REVIEW OVERVIEW

Chapter 2 describes a literature search and review of literature that discussed aspects of pre-hospital, and paramedic care for patients with chronic NCDs experiencing distressing symptoms due to an exacerbation of disease. Furthermore, literature describing the experiences and approaches of primary caregivers and paramedics providing access to palliative care, either via consultation or referral, or actually providing palliative care, for these patients was searched for in order to inform the research question.

2.2 LITERATURE SEARCH METHODOLOGY

The review included literature and research up until, and including, 2020. Information was accessed via the EBSCOhost database platform and the researcher utilised MEDLINE, PUBMED and Google Scholar. Some documents were accessed via government and organisational websites, eBooks, National Policy and guidelines, and Journals. Keywords used in the literature search included “non-communicable disease” AND “paramedics” OR “EMS” AND /OR “palliative care”, “paramedics” AND “palliative care” AND “South Africa”, “paramedics” AND “palliative care”, “pre-hospital” AND “palliative care”, “emergency care” AND/OR “dyspnoea”, OR “pain”, OR “nausea and vomiting”, “palliative care” AND/OR “dyspnoea” , OR “pain”, OR “nausea and vomiting”, “palliative care”, “South Africa” AND “paramedic” AND “scope of practice” AND/ OR “dyspnoea” AND/OR “pain” AND/OR “nausea and vomiting” , “chronic disease ”AND “palliative care”, “non-communicable disease” AND “palliative transport” AND “chronic disease”, “home care” and “chronic disease”, “hospital admission” AND “chronic disease”, “out of hospital care” AND “palliative care” AND “South Africa”, “out of hospital care” AND “palliative care”, “quality of life”, “palliative care education”, “transitions of care”. These keywords assisted in identifying and providing context for the research. There was a paucity of literature when searching using keywords such as “non-communicable disease”, “paramedics”, "EMS", "palliative care" and "South Africa" in conjunction with one another.

Much of the research included was that of empiric research such as the publications by Lord et al., 2012 and 2019, among many others, including South African researcher Gage et al., 2020. The search included South African National Policy frameworks (Hospice Palliative Care Associate (HPCA) and South African council practice guidelines (Health Professional Council of South Africa (HPCSA) among others. Application of practice globally included research of community healthcare/ palliative care models such as The Chronic Care Model (CCM) and Early Palliative Intervention Care (EPIC). Educational platforms such as LEAP (Pallium, Canada) and service implementation of palliative care (Leeds Palliative Care Ambulance Service) were also included. The World Health Organisation was accessed multiple times for global policy recommendations and service implementation.

Following an extensive search through the literature, it became evident that information regarding the incidence of palliative care patients requesting assistance from EMS, or discussion around chronic disease as experienced and managed by EMS in South Africa, was scarce. There was limited literature discussing how healthcare systems in South Africa (including emergency services) manage patients with NCDs, the management of distressing symptoms such as dyspnoea, pain, nausea, and vomiting in the context of chronic disease, and whether patients with chronic illness are

provided access to palliative care. No data was found on community paramedicine and treating patients at home, versus admitting them to hospital in the South African context. In contrast, there was an ample amount of data available when the search parameters included the global approach of healthcare systems, including EMS, NCDs, and palliative care. The literature reviewed allowed the researcher to identify global, and South African, NCD trends. EMS practice was explored in the context of caring for patients with NCDs, highlighting novel and ongoing community, and palliative care programs provided by international EMS services, opening up discussion on the scalability of these programs to South African EMS services.

2.3 CHRONIC NON-COMMUNICABLE DISEASE: AN EXPANDING GLOBAL CRISIS

In 2014, the WHO released the Global Status Report that informed the Global Burden of Disease study (2015). This used systematic analysis to conduct a comparative risk assessment of 79 behavioural, environmental, occupational, and metabolic trends that attributed to death, and Adjusted Life Expectancy Years (DALYs) between 1990–2015 (Global status report on non-communicable diseases 2014, 2021). The findings of this analysis showed that risk factors such as obesity, substance use, sedentary lifestyles (influenced by rapid urbanisation), type of work, and ageing populations attributed to an increase of NCD. Cardiovascular disease (heart disease and stroke being the leading contributor of premature death at 17,9 million deaths annually), chronic respiratory disease (chronic obstructive pulmonary disease and asthma being responsible for 4,1 million deaths), cancer (9,3 million deaths) and diabetes (1,5 million deaths), accounted for 80 percent of these annual premature deaths. Of these deaths, 31,4 million occurred in middle- to-low-income countries.

Classification of income per capita as per the World Bank (calculated using the World Bank Atlas method) identifies lower-middle income countries as earning General National Income of $1,036 - $4,045 per capita and upper-middle income countries as earning $4,046 - $12,535 per capita (New World Bank country classifications by income level: 2020-2021). This analysis showed that the rapid increase in chronic disease impacts countries with mid- to low-level incomes where vulnerable populations are exposed to more risk (inadequate sanitation, nutrition, and access to care), have greater chance of getting sick and dying, and have increased household expenditure in response to healthcare needs. Due to their lower income- per -capita and the high burden of disease, middle-income countries are affected disproportionately.

The researcher recognises the importance and necessity of the Global Status Report recommendations of healthcare policy change especially in middle to lower income countries where the current approach to managing the burden of NCDs is insufficient. The Global Status Report strongly recommends strategies such as the necessary financial allocation, and access to appropriate healthcare systems including the workforce, healthcare facilities (skills), medicines and referral. Recognising NCDs via disease screening and improved access to palliative care, may mitigate the burden of chronic disease. However, implementation of these recommendations may be hindered by inadequate resources, with a lack of skills, tools, and people disabling the interdisciplinary team approach (Global status report on non-communicable diseases 2014, 2021).

These concerns were mentioned in the World Health Assembly (WHA) resolution 67.19 'Strengthening of Palliative Care as a Component of Integrated Treatment throughout the Life Course' where the WHO stated that effective provision of palliative care to a growing proportion of patients with chronic disease (communicable and non-communicable) is an ethical responsibility. The WHO urged that palliative care should be provided equitably by healthcare services across all aspects of healthcare and disease groups. Multi-sectoral interaction was encouraged through education and training. Improved access to appropriate medications, healthcare support (from primary patient contact to patient discharge), and to home care, was acknowledged as imperative (WHA67.19 Agenda item 15.5, 2014). The following literature gives an indication of the successes and inadequacies in response to this agenda.

2.4 CHRONIC DISEASE – A SOUTH AFRICAN PERSPECTIVE

The effect of burgeoning chronic disease is experienced in the South African context, with Nojilana et al. (2016) reporting on the impact of NCDs on age-related mortality trends in South Africa from 1997 to 2010. Consistent healthcare provision, disease prevention programs, and monitoring of trends in alignment with WHO world standards was the prevailing message in the Nojilana et al. study, with interdisciplinary role players being vital for effective management of NCDs. The authors outline the issues associated with increasing NCDs, especially in a middle-income country, and provide recommendations, but do not offer a concrete guideline on how to reach the goal as the publication is not solutions-based research but rather a gap analysis paper (Nojilana et al., 2016).

Nojilana et al. (2016) acknowledge how some policy changes (such as implementing tobacco controls) have been successful in decreasing cardiovascular and certain cancer-related mortality. Comment is also made on areas with very little policy change such as alcohol harm reduction, and the continued lack of data collection on quality-of-care, and the monitoring of mortality and cancer registers. The implications of these inadequacies are that without monitoring and records, there is little to guide policy change and interventions, or to identify reduction in disease-related harm due to the changes or interventions. Nojilani et al's research has a strong public health focus (with disease mitigation through lifestyle change being the focus) rather than a reactive approach to disease exacerbation. The public health approach coincides with that of palliative care, emphasizing the continuity of care between home-, primary, and inpatient healthcare. Provision of interdisciplinary healthcare support through transitions of care, and at the end of life is integral to both public health and palliative care (Nojilana et al., 2016).

Pillay-van Wyk et al (2016) used data from the National Burden of Disease Study and WHO (Global Status Report on Non-Communicable Diseases 2014), to calculate the percentages of prevalence globally (from 1997-2012) for malignant neoplasms, respiratory diseases, cardiovascular diseases and diabetes. Although there was a small decline in the prevalence of some NCDs, chronic disease was noted as having a greater burden on the social and economic aspects of already vulnerable populations especially during their productive years. This resulted in increased poverty and further socio-economic inequality, which concurred with the WHO findings mentioned previously (Global Status Report on Non-Communicable Diseases 2014). Similar research done by Wang and Wang (2020) focused on the NCD- related mortality, in the context of lower-income settings.

In 2020, Wang and Wang used a model to predict total global age-standardised mortality and global mortality for NCDs due to chronic disease (cardiovascular, respiratory, diabetes and cancer) per country by 2030 (Wang and Wang, 2020). The focus of this research was to identify mortality due to NCD in the context of socio-economic factors as indicated by neonatal infant mortality and urbanisation. The publication is complex, but clear, and uses a strong quantitative approach to describe the increase in mortality associated with chronic disease as income decreases (Wang and Wang, 2020).

Wang and Wang, (2020), also speak of the challenges faced by the WHO in initiating application of its NCD management and control recommendations during the World Health Assembly (WHA66.10) due to limited available resources on the ground to implement the recommendations effectively (WHA66.10). Adequate distribution of, and access to care remains only an administrative exercise, when there is an absence of strong local, and national government implementation of policy. It is clear that a change in the care approach is needed for more effective chronic disease management (Wang and Wang, 2020).

Considering global approaches to chronic disease management, the literature search revealed three different models of care identified in high, middle, and low-income countries. High income countries were included in this review as there is evidence that the burden of NCDs and need for a different approach to healthcare provision, may have similarities to those of low and middle-income countries.

2.5 Models of Care for Chronic Disease in High- Income Countries

Coleman et al's (2009) "Evidence on The Chronic Care Model in the New Millennium" explains that the Chronic Care Model (CCM) was created to support chronically ill patients with provision of planned, holistic healthcare delivery. The intervention had to provide fully integrated care delivered by clinical teams, creating a multifocal approach to patient care, improvement in health outcomes, and stronger patient-provider relationships. After an intense evidence review of accumulated data and experience, there was consensus that an improvement in outcomes and quality of care provided for patients with NCDs had been achieved. Cost of care, implementation of practice, and sustainability remained valid concerns where the cost of training staff, provision of reliable and safe patient access, creation and funding of programs, and willingness to change practice, requires extensive risk-benefit consideration. Provision of accessible, decentralised interdisciplinary healthcare may mitigate certain costs associated with unmanaged chronic disease. Costs in the form of transport linked to accessing centralised healthcare facility care, with associated loss of work hours for patients, and patient (and family) health education could be positively influenced (Coleman et al., 2009).

In 2017, in recognition of the changing global disease trends, and the subsequent need for review of healthcare provision, Clarke et al. explored the complexities of the United States healthcare system, exposing concepts of care clearly in need of improvement. Clarke et al. conducted a systematic review of 35 US studies reviewing the current challenges experienced in managing patients with multiple chronic conditions (MCCs), healthcare outcomes, and the cost of care with the increased need for healthcare (Clarke et al., 2017).

Mobile Integrated Healthcare (MIH) as described by Clarke et al., and initiated by an inter-professional clinical team, was developed using an intervention cohort compared with a propensity score-matched comparison cohort. The research was mandated by a Medicare Advantage Preferred Provider Organisation, to assess high-risk members, and understand

the impact of mobile integrated healthcare. The concepts of co-ordinated care transitions, longitudinal high-risk care, and unplanned episodic care were used to identify under-resourced areas of care for patients with chronic disease conditions. To improve transitions of care, emphasis was placed on collaboration and communication between stakeholders (multi-disciplinary healthcare providers, patient and family) (Clarke et al., 2017).

The model focuses on the interaction and collaboration of existing healthcare resources initiated from initial EMS patient contact. Community EMS was identified by Clarke et al., as a resource capable of assessing and managing patient care, making care at home or via transport to hospital decisions in collaboration with an EMS physician (guided by robust clinical guidelines). Tracking health trends in the community also allows for measurement of the benefits and risks of MIH to improve the system. Discharge plans and effective use of available human resources were noted as necessary to avoid unnecessary hospitalisations and manage costs (Clarke et al., 2017).

Costs are minimised when using available and accessible resources. Delegation of governance, resource costs and responsibility to each community, creates personal investment and effective program administration. Limitations to implementation of MIH are recognised, with multiple role players, communication systems and growing incidence and prevalence of chronic disease being an ongoing challenge. Considering NCD and the generally reactive nature of EMS, these primary patient-professional interactions could introduce patients into a care system that immediately creates a pathway allowing for consistent and planned healthcare support (Clarke et al., 2017).

2.6 Models of Care for Chronic Disease in Middle- Income Countries

Pericás et al. describe in a narrative review an approach to patients with chronic disease in a middle-income country such as Spain. Pericás et al. report Spain as having problematic access to primary care, as well as incurring high healthcare costs associated with hospital admissions of patients with exacerbation of NCD, such as Chronic Obstructive Pulmonary Disease (COPD) (Pericás et al., 2013).The authors explore the idea of mitigating the cost of standardised hospital care by providing alternate care in economically constrained situations, the concepts of Hospital at Home (HaH), day centres (DC), quick diagnosis units (QDU) and telemedicine being considered as options. Pericás et al. re-enforce the conversation around managing the high incidence of life limiting disease effectively when resources are limited and the cost of accessing healthcare is high. Although the concepts of HaH and telemedicine can be associated with palliative care, it was largely excluded in the data research and analysis by Pericás et al., with the research focusing mainly on identifying alternatives to conventional hospitalisation for medical disorders in an attempt to mitigate healthcare costs for chronic disease. Pericás et al. identify the global costs incurred in various developed countries as being due to increased length of hospital stays, with patients (especially those with NCDs) accessing the Emergency Department rather than being managed in a primary care setting, with middle- and low- income countries experiencing a similar trend. The authors conclude that there is a need for early identification of chronic disease and initiation of cost-effective care through alternatives to in-hospital care. In the context of chronic disease, Pericás et al. acknowledge that further studies are required to assess cost and clinical effectiveness of these approaches and recommend that palliative care and primary care programs work jointly so that the necessary skills, patient access and care planning coincide (Pericás et al., 2013).

This recommendation is in line with that of the WHO (2013) and is also highlighted in the South African National Policy Framework and Strategy on Palliative Care 2017-2022 (WHO, 2013; Health.gov.za. 2021).

2.7 MODELS OF CARE FOR CHRONIC DISEASE IN SOUTH AFRICA

In South Africa, a middle-low-income country, Mahomed, Asmall and Freeman developed and published the Integrated Chronic Disease Management (ICDM) Manual (2014), a public health initiative by the Department of Health (South Africa) in response to the expanding healthcare demand generated by communicable and NCD. The authors remark that historically healthcare in South Africa has had a curative approach, managed within a hospital setting, rather than focusing on healthcare prevention and promotion. The management of NCDs is recognised as requiring interaction between communities and healthcare disciplines, so that patient support can be provided over an extended period of time. The manual was developed in line with the stepwise progression as described in the WHO document "Innovative Care for Chronic Conditions: Building Blocks for Action (2002)" and initiated at the primary care level. Emphasis is placed on the need for accountability by the patient for their own disease control, with community support and upskilling of personnel to improve task competency and effective patient support (WHO, 2002; Mahomed et al., 2014).

The ICDM was founded on the HIV/ AIDS model, which found success and efficiency through integration of interdisciplinary teams, development of community healthcare workers, the use of standardised technology platforms to provide appointment and medication notifications, and patient support. However, Mahomed et al. noted that the HIV/AIDS model had inefficiencies related to the vertical nature of the program, which limited research and activity to being solely related to HIV/AIDS thus compromising use of resources and data collection for NCDs. The authors recognised that sustainable transitions of care and effective support of patients with chronic NCDs needed an integrated system which included clinical, community and consistent interdisciplinary care. In managing the need for appropriate healthcare provision, access to care is a vital part of the approach, with palliative care also identified as a necessary component of care at all levels (Mahomed, Asmall and Freeman, 2014).

The consistent theme emerging from research into Integrated Chronic Disease Management models, is that there is a need for alternative approaches to provide effective patient-specific care outside of the traditional acute, curative healthcare model. There is consensus in the recognition of a changing patient and disease profile that is globally defying the historical management of patients, traditional healthcare provider skills, and where and how patients are cared for (Mahomed et al., 2014; Clarke et al., 2017; Coleman et al., 2009; World Health Organisation, 2002).

2.8 USING THE CONCEPTS OF PALLIATIVE CARE TO MANAGE CHRONIC CONDITIONS

The Global Atlas of Palliative Care (2nd edition) published in 2020 refers to two Delphi studies to estimate the need for palliative care for adults, using International Classification of Diseases 10th Revision (ICD10) codes to identify the associated diseases. Pain prevalence and symptoms experienced within a year of mortality were identified as being indicators of the palliative care need for adults at the end of life, with 78% of patients being from low-and middle-income countries (Global Atlas of Palliative Care at the End of Life, 2014). The total percentage of adult patients requiring palliative care for NCDs was 83%. Predominant NCDs requiring palliative care (for adults) were identified as cancer (35-96%), cardiovascular disease (41-77%), chronic obstructive pulmonary disease (34-77%), diabetes (64%), kidney failure (47-50%), and dementia (47%). The findings made it clear that many people were dying from NCDs

without any provision of palliative care (as correlated with ICD 10 codes), and that the need for palliative care was not only indicated for countries where the socio-economic status and access to healthcare was inadequate. The study was recognised as being limited as ICD10 codes only allow for the identification of disease not the functional status of the patient, progression of disease, or the management thereof, indicating that the number of patients requiring palliative care might be higher.

Tziraki et al. published a development paper "Rethinking palliative care in a public health context: addressing the needs of persons with non-communicable chronic diseases in 2020" that aimed to identify key approaches from a global perspective to create a primary healthcare model able to provide palliative care in the context of chronic NCD. Tziraki et al. considered that this was necessitated by the fact that palliative care is still underprovided by healthcare systems and remains inaccessible to patients, especially in low-middle- income countries.

Tziraki et al. considered factors that would influence the integration of palliative care into the chronic disease management context. An interdisciplinary approach to care that allows for alternate access to palliative care as described by the WHO public health model, focusing on community level interaction was considered. In alignment with concepts of palliative care, focusing on the patient centred approach, critical aspects of care such as advanced care planning early in the course of the illness, psychosocial resilience and support for patient, family and caregiver/s are described. The role of the community as part of quality of life, day to day activities and the process of dying is understood to be critical in the development of the public health/ palliative care model.

Technology, professional and individual education, community policy change and leadership are recognised as major enablers for the development and sustainability of the public health/ palliative care model. The objectives of improved healthcare systems and access to integrated healthcare at the level of the community and home are noted as being imperative to the success of rethinking palliative care as a public health model (Tziraki et al., 2020).

Tzariki et al. do not provide any suggestions that differ extensively from the WHO recommendations around palliative care provision in the public health setting. WHO does, however, provide a number of support documents for implementation of palliative care, use of which is improved either via technology (resource that can improve access to information even in remote settings), or simple administrative processes. This implies a need for further research. However, the authors recommend initiating palliative care education and training at undergraduate level (across interdisciplinary spectra). This practical suggestion could be implemented and developed economically via current social media healthcare support platforms (Tziraki et al., 2020).

2.9 Palliative Care Approach to Managing Chronic Disease in South Africa

In the 2018 publication "The development of hospital-based palliative care services in public hospitals in the Western Cape, South Africa", Gwyther et al. emphasise the importance of collaboration of healthcare professionals and allied healthcare to provide effective care and support systems for patients requiring care for chronic, life-threatening disease from primary contact, through transitions of care, and into the in-hospital context. Palliative care in the context of emergency medicine and acute care is highlighted as being relevant in effectively dealing with end-of-life situations and complications arising from chronic disease. This emphasises the need for community and interdisciplinary involvement in creating a more efficient and patient-centred system. The development of palliative care in the public sector of South

Africa, as per the publication, has been due to collaboration between Emergency Medicine, Family Medicine, primary healthcare and hospice (Gwyther et al., 2018).

In Gwyther et al's publication, as in many of the Chronic Conditions Management models, the patient's primary healthcare contact is only considered as being at the level of a primary healthcare facility. There is no consideration of the primary contact being in the pre-hospital or pre-clinic environment, other than in the context of nursing home care. Although not discussed by the authors, the omission of EMS in the research may be due to the misperception of EMS being responsible for only acute care situations and hospital transfer, and thus not having a contributory role in the multidisciplinary management of chronic disease. Furthermore, EMS may be reluctant or unable to offer appropriate healthcare support outside of current call-out protocols, policy or scope of practice.

2.10 CHRONIC DISEASE IMPACT ON EMERGENCY SERVICE RESOURCES- THE GLOBAL PICTURE

Cooper and Grant, in their 2009 publication "New and Emerging Role in Out-of-Hospital Emergency Care: A Review of The International Literature", cite influences such as demographics (increasing aged population), and increasing healthcare demands (due to higher incidence of chronic disease) as resulting in longer EMS response times, overcrowding of hospital emergency departments, and funding issues creating a need for change in healthcare systems.

Inter-professional collaboration and enhanced training of EMS is suggested by Cooper and Grant (2009) as a route to manage the challenges experienced in the healthcare sector, especially with an increasing population with chronic NCD disease. Cooper and Grant noted that with cost factors being an integral part of the study, financial implications and the availability of personnel needed assessment. The authors also noted that Emergency Care and Paramedic Practitioner roles were seen as being cost effective, that inter-professional collaboration improved patient referral decision-making and was associated with fewer ambulance requirements, and that lower rates of emergency department admissions could improve costs (Cooper and Grant, 2009). The authors comment on challenges that arose during the data review, such as restricted paramedic scope of practice, lack of training and implementation of new practitioner practice and governance which are similar challenges to those experienced in South Africa.

In Sovso et al.'s (2019) study, over 52000 patients (over the period 2011-2014) were included in a population-based historic cohort study that examined repeated ambulance use in Denmark, especially by patients with chronic NCD (rather than acute curable or traumatic incidents) experiencing exacerbation of distressing symptoms. The purpose of the study was to identify whether there were better care alternatives, such as caring for the patient at home or transferring the patient to a care facility, as opposed to EMS transport and hospital admission. Repeat users constituted 16% of the calls, with breathing difficulty being the most frequent symptom experienced (15%). Finding alternatives in care for these patients was mentioned as a suggested solution to these repeat call outs (not identified in Sovso et al.). Other reasons for increased EMS use were neurological disease (seizures), psychiatric disorders and alcohol-related symptoms. Although these are often relevant in the context of NCDs, Sovso et al. found that numerous ambulance call-outs were associated with psychiatric issues, which added further complexity to the decision to transport and admit to hospital.

The data as reported by Sovso et al. emphasises the costs of time, resources and patient discomfort in a system that fails to address the needs of patients with chronic illness. Consideration was given to whether patients with exacerbation of their disease symptoms could be better managed in a non-curative context. Alternative approaches to care such as preventative rather than reactive interventions, were suggested as a means to mitigate the burden by repeated use of EMS resources. Missing data in the patient PRFs such as patient symptoms, or omission of a diagnosis could have been construed as selection bias, potentially limiting the research (Søvsø, Kløjgaard, Hansen and Christensen, 2019).

2.11 Adapting EMS Models of Care to Manage Current Health Challenges

After implementation of an extended-care paramedic (ECPs) program in Canada, the Novel Paramedic Long-Term Care Program (LTC), Jensen et al. published the results of focused, semi-structured interviews that were analysed thematically (2013). The perceptions and experiences of paramedics providing acute care for patients suffering from exacerbations of their chronic NCD was explored in the context of long-term care patients. The program had been implemented in collaboration with physicians, long-term care staff and the patient's family. Twenty-one participants including ECPs, consultants and decision-makers were interviewed, with themes of program implementation, communication, ECP process of care and end-of-life care emerging.

Novel outcomes included the sense of purpose felt by paramedics when providing patients with positive care experiences and quality end-of-life care. Collaboration with physicians, staff and families was viewed as being beneficial to effective patient care. The extended education of paramedics (including wound care, understanding antibiotics and clinical insight), were recognised as fundamental to improving patient outcomes.

There was a positive response by paramedics and ECPs to the implementation of the LTC program, with increased scope of practice and skill sets, improved patient and physician interaction and adoption of proactive care rather than reactive care. Limitations of the research were recognised as being the potential for incomplete sharing of sensitive views by the paramedics, and possible limitations in understanding systems between paramedics and physicians, and some bias of views by representative parties (Jensen et al., 2013).

In 2014, Drennan, et al. conducted a randomised control trial that compared a Canadian community paramedic care intervention, "Expanding Paramedicine in the Community" program (EPIC) with standard paramedic care of patients with chronic diseases including chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF) and diabetes (DM). The key objective was to determine whether use of community paramedics (versus conventional paramedical care) in conjunction with primary care physician consultation, would result in a decrease in the number of hospitalisations and emergency centre use by patients (with chronic disease and acute exacerbations) over one year. The objectives of the researcher's study relate strongly to the principles of the work by Jensen et al. (2013), with the results of the researcher's study intended to translate into similar paramedical care intervention programs, and outcomes such as decreased hospital admissions as mentioned in Jensen et al. (2013). This will be discussed further in Chapter 4.

Other objectives in Drennan's study included assessment of cost effectiveness, appropriate health system utilisation and the general psychological, physical and social wellbeing of the patient. The results were used to inform feasibility and practice of using paramedics to provide community health. The discussion points focused on what resources paramedics were able to offer beyond the scope of home nursing, including physician consultation and timeous emergency care as

needed, in the context of expanding paramedics scope of practice and training. Although Drennan et al. acknowledged that it may be difficult to identify the true impact of this project, the study suggests that a different approach to chronic disease management is necessary. Another spin-off is the potential use of EMS crews on "light duty" who are unable to work due to physical challenges, being able to manage patient bookings and assistance with their managed chronic care (Drennan et al., 2014).

The interdisciplinary approach and support for specially trained paramedics, by primary care physicians, utilised in the Expanding Paramedicine in the Community: EPIC program, was reported by Dainty et al., (2018) as showing positive results in dealing with primary care challenges. Qualitative data trends were identified using a grounded theory approach to analyse specific data and its true impact. Thirty patients and 10 family members, as well as the 8 paramedics trained as EPIC community paramedics, were interviewed together and separately, with covert and overt trends being identified. Dainty et al. identified trends positively influencing patient outcomes such as improved patient autonomy, patient health education and accountability, and the EPIC Safety Net (hospital readmission prediction models used to improve, and co-ordinate care for vulnerable patients) (Dainty, Seaton, Drennan and Morrison, 2018).

Patients (and family members) in the EPIC program reported feeling more engaged in their own wellbeing due to an improved understanding of their illness and how to manage their health appropriately and described their evolving relationship with their community paramedic as giving them security and comfort. They reported trusting their EPIC paramedic with their fears, symptoms and care plans. Patients felt they would get the appropriate professional and personalised care from their EPIC paramedic whether it was via physician appointment planning, emergency care, or communication around health concerns.

Dainty et al., acknowledge that improving patient outcomes requires a more holistic approach, rather than a purely biomedical, with focus being on adopting a bio-psychosocial approach when developing and implementing new patient care programs. Such a bio-psychosocial approach is reminiscent of a palliative care approach mentioned earlier. Dainty et al recognised that the EPIC program may not be scalable to all contexts but may offer useful insight for program development and changing approaches to chronic disease management. Again, further research and context specific models of care for patients with chronic disease, is needed (Dainty, Seaton, Drennan and Morrison, 2018).

2.12 The Global Approach to Palliative Care Integration into EMS Practice

Themes of palliative care need and access by patients, with provision of care by emergency physicians and paramedics are not new, with Wiese et al., describing in 2009 how the expertise of pre-hospital practitioners (in this case pre-hospital emergency care physicians) in the field of palliative care significantly affected the care and experience of the patient being treated. Wiese et al identified gaps in care and the need for improving practitioner practice in line with the current global approach to palliative care. In research done in 2013, Wiese questioned international palliative care provision and availability, performing an extensive literature analysis, collecting data from a survey disseminated to 50 international experts in palliative care. Wiese collected international feedback from 35 different countries where current approaches to outpatient palliative care emergencies in relation to prevention and care of emergencies were described. Early integration of palliative care teams, accessible outpatient palliative care, documentation and appropriate medication, end-of-life discussions, and palliative care training for emergency physicians and paramedics were themes

that emerged from the data. Results from the research indicated a widely differing approach internationally to palliative care emergencies in the outpatient context and gave insight to patients' access to palliative care. Wiese et al. concluded that access to a specialised palliative care team, in the outpatient setting, could be successful in providing actual or supportive care in palliative care emergencies (Wiese et al., 2009; Wiese et al., 2013).

Rogers et al. explored paramedics perceptions of palliative care in Australia in 2015 using a mixed methods approach that had been validated in a previous research study by Lord et al., (2012). Rogers et al found that paramedics perceived palliative care as being associated only with end-of-life care, and that cancer was the predominant pathology requiring palliative care. Rogers emphasised a need for education of paramedics in palliative care and ethics, especially in end-of-life situations. There was little understanding of a palliative care approach outside of end-of-life care, or of diseases that may require a palliative care approach, exposing an area of educational need (Rogers et al., 2015). The Australian pre-hospital context has educational similarities with that of South African emergency services, as identified by Gage, Geduld and Stassen in 2020 (Gage et al., 2020).

Interest in out-of-hospital palliative care is not new, with much attention being given to paramedics' perceptions of palliative care, rethinking the approach to chronic disease and its exacerbations by EMS, and the development of community EMS programs to improve care for patients with chronic disease.

Lamba et al. (2013) published "Integrating Palliative Care in the Out-of-Hospital Setting: Four Things to Jump Start an EMS-Palliative Care Initiative". Four cases were reviewed, each having a palliative care and out-of-hospital context. Clinical cases presenting a need for EMS and palliative care collaboration and aspects of palliative care relevant to EMS with guidance for EMS, were discussed. Administrators and faculty were included in the development, and integration of, palliative care protocols in the pre-hospital environment.

Dominant themes emerging from frequently experienced presentations were: firstly, out-of-hospital management of patients in a hospice program; secondly, advance directives with consideration of "do not attempt resuscitation" (DNAR) orders, living wills, instructional directives and proxy decision makers; thirdly, out-of-hospital pain management including use of valid pain assessment tools, pharmacological-and non-pharmacological pain management approaches, and risk: benefit assessments; and finally, mass casualty events and palliation including allocation of comfort resources for patients not likely to survive. A stepwise approach to managing these possible palliative care situations out-of-hospital was considered.

Identifying EMS personnel that were willing to drive the process, reviewing current protocols and policy for adjustment, doing a service and patient needs assessment, and action plan development were considered imperative to the success of an EMS-Palliative care initiative. Practical measures suggested in this literature include identifying the needs of patients, families, and EMS providers, to highlight the gaps in current approach and management so that the training of invested EMS systems, and care of patients and their families can be improved. This requires an understanding of the problem, the resources available, and identifying possible barriers to program investment and implementation. A successful program is seen as one where a robust plan is in place to meet patient and service needs, with continuous reflection and measurement of outcomes to meet the objectives of the program (Lamba et al., 2013).

Lamba et al. concluded that the need for palliative care provision is identified frequently, and it is recognised that initiation of care by paramedics in collaboration and activation of the interdisciplinary team, is necessary for sustainability of the program and better patient outcomes. The process suggested in this publication affirms themes in literature reviewed earlier and should be considered reproducible in other countries facing similar challenges in adequate care provision.

Exploring palliative care in paramedic practice, Lord et al. published a retrospective cohort study in 2019. The data considered all patients over the age of 17 attended to by paramedics in Victoria, Australia between 1st July 2015 and 30th June 2016 that were associated with palliative care or end-of-life situations. A sample of 4348 out of a total of 650,208 patients transported to hospital met the criteria, with respiratory distress (15.24%), pain (13.3%) and nausea and vomiting (15%) being the most frequent complaints. Lord et al. acknowledge that referral to a palliative care team or doctor was not recorded. This missing data may have provided important information on how many patients are on palliative care programs, or the accessibility of advice for paramedics. This data highlights the need for a shift in the focus of care by paramedics from that of curative intent with escalation of care, to managing chronic disease exacerbations and end-of-life situations in the community understanding the principles of palliative care. The introduction of palliative care education into paramedic curriculum, adapting scope of EMS practice to manage patients at home, and challenging legislation is highlighted in Lord et al's discussion. The authors recommend the integration of interdisciplinary care (including EMS), and delivery of palliative care through a community-based program.

The inclusion criteria specifically looked at palliative care associations, which may have resulted in missing cases, and also may have limited numbers. The authors recognise there may have been cases recorded or missed due to inaccuracies of call records. This has been a common finding in previously detailed literature (Lord et al., 2019).

2.13 Outcomes of Palliative Care Provision by Paramedics

In 2012, Burnod et al. conducted a retrospective study in France, considering whether patients' wishes for care were being respected in emergency situations, in the home context with access to palliative care and an advanced care plan or directive in place. As part of this care structure, collaboration was facilitated between the emergency services (pre-hospital) and the palliative care network enabling joint decision-making for patients' optimal comfort. The indicators used were the percentage of times the emergency service doctor and palliative care doctor collaborated and how often the patients' life plans were respected. The findings were that patients' wishes, and "life plans" were respected in 83% of cases when emergency practitioners collaborated with the community palliative care network to decide on patient care. Without this collaboration, patients' wishes were only respected 40% of the time. This reinforces the concept that interdisciplinary partnership (formed through inter-facility and practitioner collaboration) is more likely to provide care consistent with patients' wishes, and to consider ethical concepts such as futility and patients' best interests.

In order to understand patient and carer experiences in the context of EMS assistance, Carter et al. (2019) used a mixed methods study to examine the "Paramedics Providing Palliative Care at Home" program in Canada. This program had been launched to provide palliative care guidelines and training to paramedics. The study aimed firstly to determine patient and family satisfaction with paramedics providing palliative care at home; and secondly, paramedic confidence and comfort in providing palliative care at home before and after specific palliative care training and subsequent to

palliative care experience on call-outs. Patients reported that their care wishes tended to be respected, they had peace of mind and felt supported with accessible emergency care, and experienced professionalism, compassion and symptom relief. Comfort and confidence in managing patients at home and not being obligated to transport patients to a facility were themes that emerged from the paramedics' feedback. The outcomes were positive, and the results indicate that similar program initiatives could be successful in providing patients access to palliative care (improving quality of life) and supporting end-of-life care in the comfort of their homes. Use of an interdisciplinary healthcare community is shown to have a positive impact on patients, carers and healthcare providers, and therefore healthcare provision should be re-conceptualised, with supportive policy change, to improve out-of-hospital palliative care.

2.14 PALLIATIVE CARE CONCEPTS IN SOUTH AFRICAN EMS

Gage et al. (2020) published "The Thoughts and Opinions of Advanced Life Support Providers in the South African Private Emergency Medical Services Sector Concerning Pre-Hospital Palliative Care". This paper was a small qualitative study, utilising semi-structured interviews with 6 South African Emergency Care Practitioners (paramedics). Gage et al. used similar methodology as used by Lord et al. (2012) and Rogers et al. (2015) to inform their research as there was a paucity of local data available in the context of South African paramedics and palliative care. Reference was made to HIV/AIDS and cancer in the context of palliative care, but disease type was not the focus of this research, rather, the understanding and perceptions of palliative care by EMS.

Common themes to those of Lord et al. (2012) and Rogers et al. (2015), emerged from Gage et al's. study. These included understanding the need for pre-hospital palliative care, accessing and training of pre-hospital healthcare providers in palliative care, and challenges and ideas for implementing pre-hospital palliative care. Challenges included educational and system barriers to change, as well as practitioner mind set, echoing similar trends identified in the studies by Lord et al., and Roger et al (Lord et al. 2012; Rogers et al. 2015; Gage et al., 2020).

2.15 CHANGE THE SYSTEM, IMPROVE THE CARE

In response to the need for care in the context of chronic disease, and access to care, Cockrell, Reed and Wilson (2019) have recently published a systematic literature review that considered the concept of salutogenic theory (influencing health and well-being) in the context of pre-hospital care. Fifty-four articles were identified that highlighted factors impacting paramedics' ability to practise holistic, patient- centred care in rural communities. The following were considered: 1. the impact of socio-economics on health and how paramedics respond to these challenges 2. how this impacts resilience and capability of communities 3. engaging paramedics in evolving paramedicine practice and introducing the concepts of expanded scope and roles. The research indicates that paramedics are able to invest in community health and provide access to patient care that is not always an emergency but that deals with social issues of health and management thereof. However, it is recognised that the concept of paramedics providing community care and care-at-home is relatively recent and requires further pilot programs (Cockrell, Reed and Wilson, 2019).

In conclusion, the literature published by Lamba et al., Lord et al., Rogers et al., and Carter et al., all identify that the historical curative approach of EMS is often misaligned with the palliative care approach to chronic disease, often allowing for inappropriate management of disease exacerbations, and not accounting for the patients' wishes. The reviewed literature acknowledges the need for change in EMS practice in terms of scope and policy, improved palliative

care education, improved measurement of palliative care training and intervention outcomes, and implementation of palliative care guidelines (applicable to EMS) in the pre-hospital environment (Lamba et al., 2013; Lord et al., 2019; Rogers et al., 2015; Carter et al., 2019). Ongoing research in the South African context may unearth unique challenges in the process of developing paramedics able to navigate new scopes of practice, such as providing pre-hospital palliative care. Global research, however, indicates that there is a need to find solutions to many commonly identified concerns in order to adapt practice to meet emerging healthcare needs. The researcher considers that lack of advocacy for, and understanding of, palliative care by paramedics and other stakeholders, remains one the biggest stumbling blocks in initiating collaboration between disciplines, and effective communication during transitions of care. Without insight into the nature of palliative care, human resource, financial, and time costs may be a concern to stakeholders. Advocacy requires education and a true understanding of what palliative care can mean to patients and their families, as well as the potential benefits to healthcare systems.

2.16 RATIONALE FOR THE STUDY

As paramedics provide medical assistance to increasing numbers of patients, with many of them experiencing distressing symptoms associated with their NCD (Roeper et al., 2018), the burden and management of acute exacerbations of chronic NCD on emergency services needs to be re-assessed. There is no accessible data available, in the South African context that refers to paramedics providing palliative care to chronic NCD patients who require acute symptom management (specifically for pain, nausea and dyspnoea).

This study provides a view on the number of patients with NCDs who called CMR with acute symptoms, such as dyspnoea, nausea and vomiting, and/or pain associated with chronic disease. The intent was to highlight the need for pre-hospital palliative care provision, and to provide insight into the potential impact of patients with NCDs on the healthcare system. The analysed data will be used to assist policy makers to identify the number of palliative care patients requesting pre-hospital assistance so that effective and appropriate care for these NCD patients in the pre-hospital arena is well planned for and provided.

2.17 RESEARCH QUESTION

The research asks what is the burden of acute exacerbations of chronic disease on a private emergency medical service in the southern sub-districts of Cape Town, how are these symptoms managed, and what is the need for pre-hospital palliative care provision in order to manage the symptom burden created by NCDs.

2.17.1 AIM

This study aims to describe the burden placed on EMS (represented by CMR) due to the number of patients with chronic NCDs experiencing acute symptoms of SOB, pain, N&V, and cognitive changes (seen as a necessary inclusion) requesting EMS assistance, and the existing approach to symptomatic care of these patients by EMS.

2.17.2 OBJECTIVES

1. To quantify the number of patients with specific symptoms that CMR assisted out of the total number of call-outs over 4 months.

2. To identify the prevalence of four specific symptoms associated with chronic NCD (dyspnoea, nausea and vomiting, cognitive changes and/or pain), in patients assisted by CMR.
3. To assess the assigned patient triage, interventions undertaken and whether the patients were transported to a medical facility or remained at home.
4. To identify whether there is a need for education and provision of palliative care by paramedics in the pre-hospital environment.

3 CHAPTER 3 – METHODOLOGY

Chapter 3 discusses how the research was planned and conducted as well as describing the methodology used to analyse the statistical data.

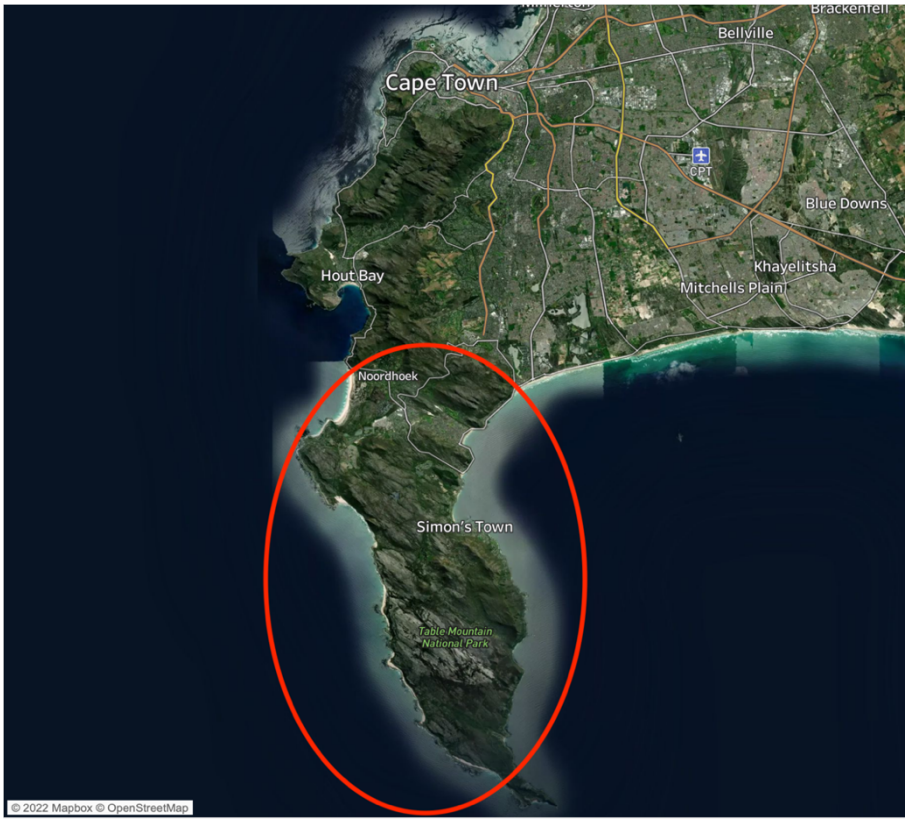
3.1 STUDY DESIGN

This was a retrospective descriptive analysis of adult patients attended to by CMR between January 1st, 2019, up until 30th April 2019. The PRFs that presented with the inclusion criteria (3.2.1) in the methodology section were then included in the study.

Study setting

The study took place in the southern peninsula of Cape Town, which includes the councils of Fish Hoek, Kommetjie, Muizenberg, Noordhoek, Scarborough and Simon's Town and consists of urban, suburban and rural communities, as well as an expanding informal housing community. The study was limited to callouts within the following areas: Tokai/Lakeside (northern point), Scarborough/Cape Point (southern point), Kommetjie/ Noordhoek (western point), and Muizenberg/ Strandfontein (eastern point). See Figure 4.

Figure 4: Cape Medical Response Service Area



3.2 STUDY POPULATION

The population included in this research were anonymous patient report forms (PRFs) of those patients 18 years of age or older and used CMR for medical assistance during January 1st, 2019, and April 30th, 2019.

The demographics include all patients that fit the age criteria (adult, 18years and older), from the formal and informal sectors (CMR members and non-members) and residing in the area covered by CMR Emergency Service.

3.2.1 INCLUSION CRITERIA

- The patient report forms (PRFs) of adult patients over 18 years of age with the following criteria:
    - The PRFs of patients with chronic NCD, noted as "for palliative care", terminal illness, cancer, organ failure, end-of-life or end stage disease mentioned or recorded on the patient's PRF
    - Distressing acute/ acute-on-chronic symptoms of shortness of breath (SOB), Nausea and Vomiting (N&V), pain and cognitive changes associated with chronic NCD

3.2.2 EXCLUSION CRITERIA

- The PRFs of minors (any person under the age of 18)
- PRFs not including any of the previous key points were excluded from the research.
- The PRFs of patients that had reported having a communicable disease, in the absence of NCD.

3.3 SAMPLE SIZE AND SAMPLING METHOD

A sample size of (n) 246 (PRFs) was calculated to provide sufficient data for reliability. A simple sampling method was used to extract relevant patient records (as per inclusion criteria) between the dates of 1st January 2019 and 30th April 2019.

The following sample size calculation was used to predict how many PRFs would be needed to prove reliability:

Sample size for a single proportion	
Enter expected proportion *(p)* %	20
Enter precision *(d)* %	5
Required sample size *(n)*	246

3.4 DATA COLLECTION

3.4.1 DATA SOURCES

PRFs were extracted, with permission from CMR management, and were assessed for inclusion criteria.

3.4.2 DATA EXTRACTION SHEET

A Google Forms data extraction sheet was designed by the researcher having been informed by the literature after discussion with paramedic colleagues and palliative care practitioners. The researcher's supervisors reviewed and assisted with revision of the data extraction sheet. Many of the parameters were included as part of the researcher's experience.

The following variables were included in the extraction tool: patient's age, suburb, reason for call out, date of call, scene findings including cardiac arrest, severity of symptoms and triage, interventions provided by paramedics, consultation with other healthcare professionals, private transport, refusal of care, hospital transport or other (funeral service). Refer to Appendix 3: Data extraction sheet for description of relevant variables used in the study.

Each of these variables were recorded including descriptions of each variable.

The data extraction sheet allowed for trends within the service to be recorded via the use of tool-related statistics to provide quantitative research results.

3.4.3 RECRUITMENT AND TRAINING OF DATA CAPTURE ASSISTANTS

Two data capture assistants were given permission by CMR management to assist the researcher. Both assistants were CMR paramedics, who understood medical terminology, and were identified, recruited and trained by the researcher on the proposal methodology and research ethics and were able to extract data as per the research ethics protocol. They were given access to the Google Forms data collection tool on their phones and computers for data collection. The researcher was available to assist with any queries the data capture assistants had in connection with data capture, ethics or the research protocol. As soon as the forms were submitted the information was no longer stored on their phones or any other device, but went to a central, confidential site only accessible to the researcher and the form developer, who conformed with the research criteria. The researcher ensured that the data capture assistants and form developer were aware and adhered to research ethics practices (DoH 2015 Ethics in Health Research Guidelines, 2015).

3.4.4 DATA COLLECTION PROCESS

The researcher approached CMR for permission to analyse PRFs, after HREC approval was granted to conduct the research, on the basis that it could inform CMR of the population it served that had chronic NCDs. It was agreed that the information extracted from the research would be made available for use by CMR for planning resource purposes.

Ethics approval was granted by the University of Cape Town Health Research Ethics Committee (HREC) on the 6th of August 2020, for de-identified PRFs to be accessed and reviewed (HREC REF:176/2020; see Appendix 5). No names, or other identifying factors, could be traced back to the PRFs included in the research.

Access to data and data extraction was limited during 2020 due to the national mandatory COVID-19 lockdown and so only commenced in June of 2020, adhering to necessary COVID-19 protocols.

PRFs from 1st January 2019 up until the 30th of April 2019 were manually read and assessed for possible inclusion criteria, and data was captured manually using Google Forms. All PRFs were paper-based and temporarily removed (for data extraction) and replaced in the company filing cabinets once the data had been recorded on the Google Forms. All data was collected onsite at the CMR offices, and the researcher was responsible for the security of the PRFs and data during the collection process, with no breaches of confidentiality or mishandling of PRFs noted.

Although CMR uses standardised PRFs, patient information was recorded by different on-duty paramedics with varying scopes of practice and experience, creating a potential for incomplete record-keeping. In portions of the PRFs there are areas of reporting that are open to subjectivity, with records of patient symptoms, diagnosis and clinical reasoning sometimes being inconsistent. This was discussed with the data capture assistants to standardise data capture and improve reliability.

Cases were extracted for data if they included the terms “chronic disease”, “non-communicable disease”, “palliative care”, “palliation”, “terminal illness”, “end-of-life”, “end-stage disease”, “COPD”, “organ failure”, “cancer” and/or “heart disease”. PRFs were considered if chronic NCD was indicated via medication and/ or patient history and was discussed if the data collection assistants had any queries. Non-communicable diseases as recorded in PRFs as comorbidities such as diabetes, dementia, COPD, and renal failure were included to describe the patient’s chronic disease state. Inter-facility transfers, and repeat call outs were included, as was any facility the patient had been transported to.

3.4.5 Data Storage and Confidentiality

Collected data was backed up on a secure cloud-based server (Google Drive) and password-secured and stored in a password-protected file on a computer only accessible to the researcher and form developer. The records of patients were anonymised by assigning numbers to PRFs. As there were no hypotheses or comparisons being tested, the data capturers were not blinded.

Access to CMR PRFs was regulated, and patient confidentiality secured, by only having access to patient data on site, and all data collected was not available for viewing by the data collection assistants once the forms had been populated and submitted. All data previously recorded on cell phones used by data collectors was deleted as soon as it was submitted.

3.4.6 Data Analysis

PRFs were analysed and data variables were extracted with Google Docs /Sheets according to the data collection tool and inclusion/exclusion criteria stated earlier. Data variables were extracted, and placed in an Excel format, definitions are described in Appendix 3: Data extraction sheet.

Python, Jupyter Notebook and Pandas were used to prepare and clean the data as well as to perform all statistical calculations and data visualisation.

The steps in creating the target data set used for analysis are summarised below:

- Data preparation
- Data cleaning
- Statistical and data visualisation

Data collected via the data extraction sheet described in the Data Collection Process above, was exported to a comma separated (.csv) file using Microsoft Excel.

A separate .csv file was created only including data that met the eligibility criteria of the study. This was called the "valid calls" data set. Each variable in the "valid calls" data set was analysed and unique entries for each variable were tabulated and counted. This provided a data frame to use for statistical analysis and visualisation. The data was summarised in tables (refer to List of Tables), and graphs (refer to List of Graphs) were created to visualise the data as seen in the Results section in Chapter 4. The data extracted was analysed and is presented in the following chapter, using tables and graphs as descriptive tools.

4 CHAPTER 4 – RESULTS

The following results are documented to show progression from the primary patient contact, paramedics' approach to patients with NCDs, clinical decision-making for patients with NCDs, and ultimately the support provided for patients/ carers who could benefit from a palliative care program.

Graphs and tables have been used to visually illustrate the results.

4.1 CALLS, AREA OF CALL-OUT AND LOCATION OF THE PATIENT

During the study period of 1st January 2019 to 30th April 2019, CMR-responded to 1572 callouts, of which 283 met the research criteria, contributing to 18% of the workload experienced by CMR over that time. Call-outs occurred predominantly in council areas of Fish Hoek (including suburbs of Clovelly and Sun Valley), followed by Noordhoek (including suburbs of Masiphumelele and Capri), Kommetjie (including Ocean View), Simonstown (including suburbs of Red Hill and Glencairn) and Muizenberg (including suburbs of Kalk Bay, St. James and Lakeside). See Figure 5.

Figure 5: Number of patient call-outs per council area

Table 1: Number of call-outs per council area and broken down by suburb

Council Area	Suburb	Number of patient Call-outs
Fish Hoek	Fishhoek	69
	Sun Valley	10
	Clovelly	2
	Total	**81**
Kommetjie	Ocean View	46
	Kommetjie	9
	Scarborough	5
	Total	**60**
Noordhoek	Noordhoek	38
	Capri	20
	Masiphumelele	2
	Total	**60**
Other	Other	31
	West Lake	1
	Total	**32**
Simonstown	Glencairn	15
	Simonstown	11
	Total	26
Muizenberg	Muizenberg	13
	Lakeside	6
	Kalk Bay	3
	St James	2
	Total	**24**
Grand Total		**283**

CMR call-outs were predominantly made to patients' homes (67% of cases), with call-outs to hospital wards (for transport home or to another unit) at 14%, call-outs to frail care facilities were noted in 6% of cases and in cases to hospice facilities at 5% (either transport home or to hospital). The remaining call-outs were to EDs (transfer to other facilities or home), public spaces, pharmacies, and doctors' rooms.

Table 2: Number of patient call-outs and percentage thereof per patient location

Patient Location	Number of patient call-outs per location	%
Home	191	67%
Hospital - Ward	39	14%
Frail care	18	6%
Hospice / palliative care unit	13	5%
Public space	7	2%
Hospital - Emergency Department	7	2%
Clinic	4	1%
Other	2	1%
Pharmacy	1	0%
GP Practice	1	0%
Grand Total	**283**	**100%**

4.2 PRIMARY SYMPTOMS AS RECORDED BY CMR CONTROL CENTRE (REASON FOR CALL-OUT) AND PATIENT SYMPTOMS AS RECORDED BY PARAMEDICS

The 4 most common "primary" patient symptoms reported by callers to the CMR Control Centre, and recorded by the call takers, were SOB (43%), pain (35%), N&V (10%), cardiac arrest (6%) and cognitive changes (5%). These initial symptoms assisted in identifying inclusion criteria for the study, but were not necessarily the symptoms found, or recorded, by paramedics on patient assessment. Any non-primary symptoms were not noted here and so resulted in fewer symptoms recorded that patient numbers. Refer to Table 3.

Table 3: Primary reasons (matching study criteria) for call-outs recorded and percentage broken down by primary reason

Reason	Number of primary reasons for call-outs recorded	%
Shortness of Breath	81	43%
Pain	66	35%
Nausea	19	10%
Cardiac Arrest	11	6%
Cognitive Changes	10	5%
Grand Total	**187**	**100%**

The most common (primary) symptoms recorded by paramedics on patient assessment were pain (34%), SOB (30%), cognitive changes (23%), and N&V (7%) of total cases. The biggest discrepancy was between the number of reported cases of SOB at the time of requesting a call-out, versus the number assessed as being SOB at patient contact (43% vs 30%). Cardiac arrest was recorded by paramedics in 7% of the included cases. These patients may have had other

symptoms reported to the call taker prior to paramedics' arrival, and were subsequently found by the paramedics to be in cardiac arrest or triaged as P4 (deceased).

The total number of symptoms recorded (297) exceeded the number of patients included in the study as some of the patients experienced more than one of the primary symptoms of pain, SOB, cognitive changes, N&V and/ or cardiac arrest. Refer to Table 4

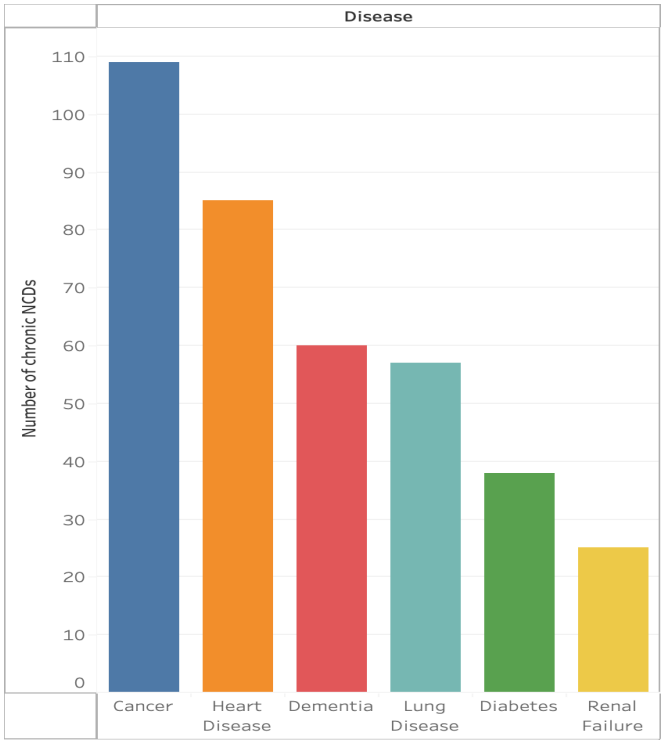
Table 4: Primary symptoms recorded by paramedics and percentage broken down by primary symptoms

Symptoms	Number of primary symptoms recorded	%
Pain	100	34%
Shortness of breath	88	30%
Cognitive Changes	67	23%
Nausea	22	7%
Cardiac Arrest	20	7%
Grand Total	**297**	**100%**

4.3 CHRONIC NON-COMMUNICABLE DISEASE (NCDS) RECORDED BY PARAMEDICS

Cancer was the most prevalent disease recorded at 29%, followed by chronic heart disease (23%), dementia (16%), chronic lung disease (15%), diabetes (10%), and renal failure (7%). The total number of NCDs (374) recorded exceeded the patient numbers (283) included in the study as some of the patients had more than one NCD. Refer to Graph 1.

Graph 1: Chronic non-communicable disease recorded



4.4 SYMPTOMS RECORDED PER NON-COMMUNICABLE DISEASE

Pain was reported predominantly in patients with cancer (34%), with cognitive changes (20%), SOB (19%), cardiac arrest (14%) and N&V (13%) being the other symptoms recorded for that disease category.

Chronic heart disease had SOB (45%) as a predominant symptom and was associated with pain (32%) and cognitive changes (16%). N&V (5%) and cardiac arrest (2%) occurred seldom in this group.

Patients with chronic lung disease had SOB (53%) and pain (32%) as their main symptoms, while cardiac arrest occurred in 8% of these patients, with the balance suffering from cognitive changes and N&V.

Patients with dementia had a high percentage of cognitive changes (56%), with pain being reported in 31% of patients, and SOB in 10% of cases. N&V and cardiac arrest made up the balance of symptoms.

Diabetic patients experienced pain in 39% of cases, SOB in 37% of cases, cognitive changes occurred in 15% of cases with 10% of patients experiencing N&V.

Patients with renal failure reported pain in 42% of cases and SOB in 38% of cases. Cognitive changes were reported in 12% of cases, with N&V and cardiac arrest occurring in 4% of renal failure patients.

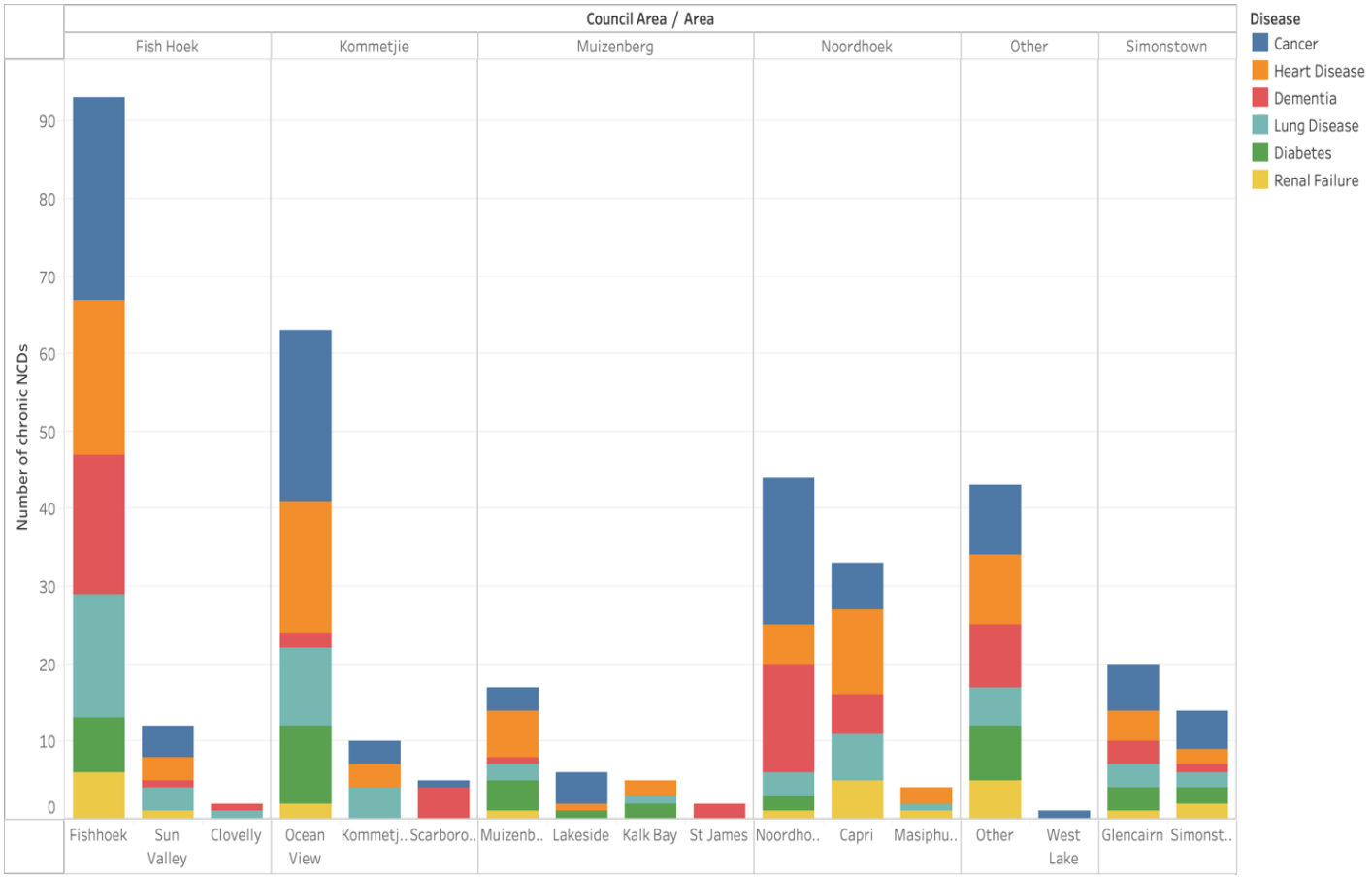
The significance of the symptom/disease relationship was not explored as many NCDs had multiple associated symptoms which would have impacted validity.

4.5 NON-COMMUNICABLE DISEASE PREVALENCE RECORDED PER AREA

The research indicates that cancer is the predominant NCD in all the council areas, other than in Muizenberg, where heart disease is seen as being slightly higher. Heart disease and dementia have a high prevalence in council areas such as Fish Hoek and Noordhoek (with the high percentage of dementia very likely attributed to its ageing population and retirement villages). Lung disease was documented more frequently in Fish Hoek, Kommetjie, and Noordhoek. The total diseases reported differ from the total number of patients researched as some of the patients had more than one NCD.

Refer to Graph 2.

Graph 2: Number of chronic NCDs for each suburb broken down by council area



4.6 SYMPTOMS NOTED PER COUNCIL AREA

Pain was the predominant symptom recorded in Fish Hoek, Noordhoek and Muizenberg while the most common symptom noted for Kommetjie, Simonstown and "Other" suburbs was SOB, with high numbers of SOB noted for Fish Hoek as well.

Cognitive changes were also noted to be high in Fish Hoek, Kommetjie, Noordhoek and "other" suburbs relative to the findings of pain and SOB. N&V is noted in all council areas, but the numbers are small.

Cardiac arrest was recorded in 8 patients in Kommetjie/Ocean View, 6 in Fish Hoek area, 4 in Noordhoek, and 1 in Simonstown and "Other" suburbs.

Refer to Table 5.

Table 5: Number of symptoms observed per council area

		Symptoms					
Council Area	**Suburb**	**Pain**	**Shortness of breath**	**Cognitive Changes**	**Cardiac Arrest**	**Nausea**	**Grand Total**
Fish Hoek	Fishhoek	23	19	16	6	4	**68**
	Sun Valley	4	3	1	0	0	**8**
	Clovelly	0	1	1	0	1	**3**
	Total	27	23	18	6	5	**79**
Kommetjie	Ocean View	12	17	11	7	2	**49**
	Kommetjie	3	2	3	1	0	**9**
	Scarborough	2	0	2	0	0	**4**
	Total	17	19	16	8	2	**62**
Muizenberg	Muizenberg	7	3	3	0	2	**15**
	Lakeside	4	1	0	0	0	**5**
	Kalk Bay	1	1	0	0	1	**3**
	St James	0	0	1	0	0	**1**
	Total	12	5	4	0	3	**24**
Noordhoek	Noordhoek	16	8	11	3	3	**41**
	Capri	8	6	2	1	2	**19**
	Masiphumelele	0	2	1	0	0	**3**
	Total	24	16	14	4	5	**63**
Other	Other	10	12	10	1	5	**38**
	West Lake	0	0	1	0	0	**1**
	Total	10	12	11	1	5	**39**
Simonstown	Simonstown	7	6	2	0	1	**16**
	Glencairn	3	7	2	1	1	**14**
	Total	10	13	4	1	2	**30**
Grand Total		**100**	**88**	**67**	**20**	**22**	**297**

4.7 INTERVENTIONS PERFORMED BY PARAMEDICS IN CONTEXT OF PATIENT SYMPTOMS

Data analysis indicate that for all the primary patient symptoms recorded, there were often no interventions performed by paramedics to manage those symptoms.

When noting the interventions by paramedics for patients with SOB- oxygen, nebulisation, and intravenous fluids/ access (no differentiation noted for fluid or pharmacological administration) were the most common. No intervention by paramedics was recorded in 22% of cases with SOB, which may have been attributed to the fact that the patients' oxygen saturations may not have indicated a need for oxygen administration. American Heart Association (AHA) guidelines (the gold standard followed by SA guidelines), encourage oxygen administration to maintain saturations between 92% and 98%) (Lorraine Anne Liu, 2020).

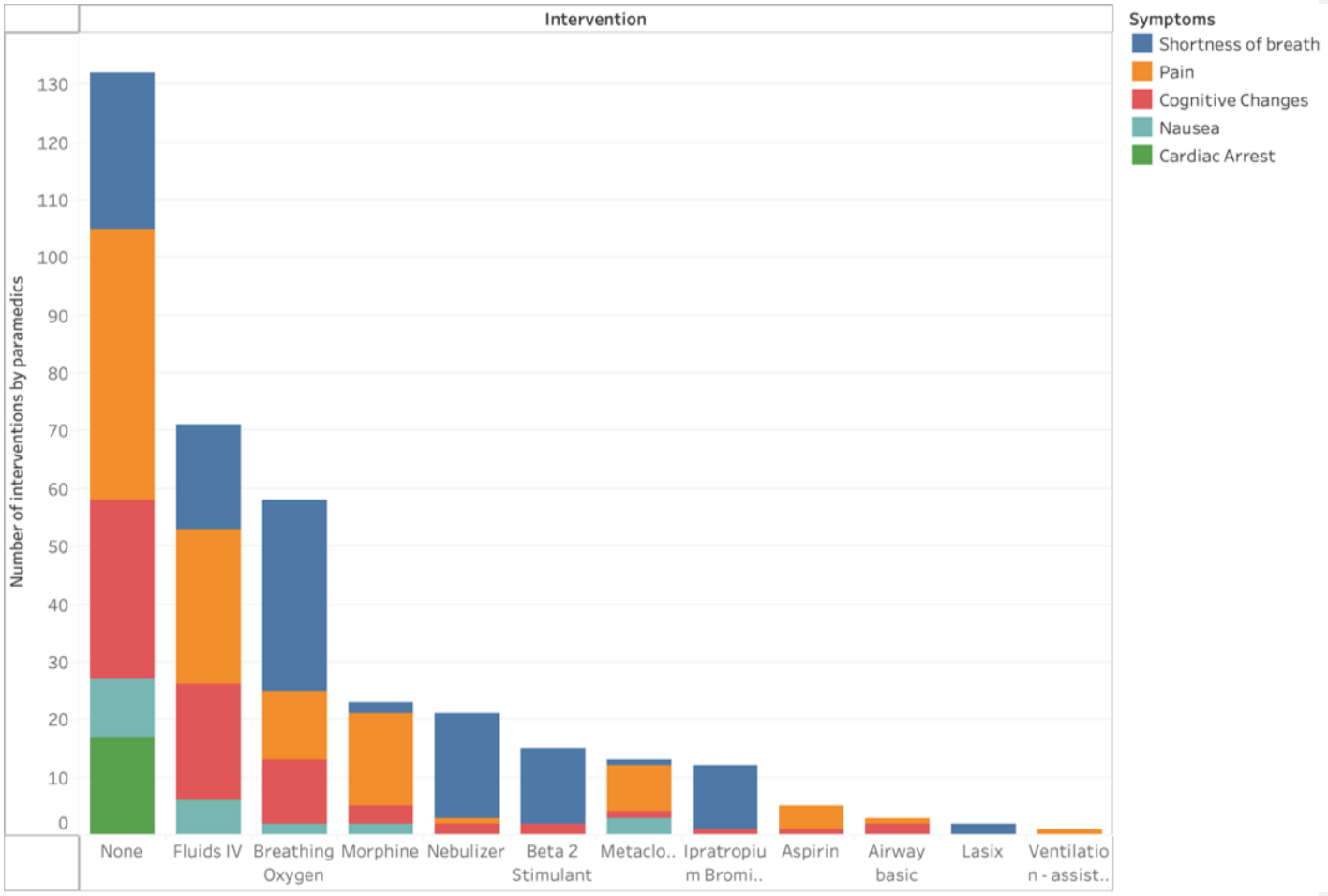
There were a high percentage (40%) of patients experiencing pain that had no intervention by paramedics. This may be due to the scope of practice of the attending paramedic, mitigating analgesic administration. In cases where intervention was commenced, intravenous fluids/ access, morphine administration and oxygen were noted as the most common interventions by paramedics to manage patients' symptoms. Morphine dosages administrated would have been consistent with SA guidelines but were not recorded for this study.

Patients with cognitive changes frequently (42%) had no intervention recorded by paramedics, although intravenous fluids/access and oxygen were recorded as most common interventions. Patients experiencing N&V mostly received no intervention (43%) but those who did, received mainly intravenous fluids/ access, and fewer than 1% received an anti-emetic.

None of the 17 patients recorded as being in cardiac arrest were resuscitated or had any intervention performed. These patients would have been recorded as P4 or deceased (as per TEWS). Note that cardiac arrest as a symptom is only recorded in 17 patients, however, as per section 4.8 and Table10, 20 patients were recorded as being P4 (deceased) with 3 patients not having the symptom of cardiac arrest included in the PRF. The reasons for not initiating CPR are to be mentioned in the discussion chapter.

See Graph 3 for interventions administered for symptom management by paramedics.

Graph 3: Number of interventions by paramedics for each symptom



4.8 PATIENT TRIAGE SCORING

The South African Triage Emergency Warning Score (SA TEWS) was used as a guideline to analyse the data collected. See Appendix 4.

As per the data, 66% of patients were triaged as P2, followed by 26% triaged as P3 patients, and 7% of patients were recorded as being P4 (in cardiac arrest or deceased). There were 3 patients (1%) recorded as critical, or P1. Considering interventions by paramedics, none of these patients received advanced airway management (intubation) or Cardio-Pulmonary Resuscitation (CPR). Refer to Table 6.

Table 6: Number of patients per triage score

Patient Triage	Number of patients per triage score	%
P2	187	66%
P3	73	26%
P4	20	7%
P1	3	1%
Grand Total	**283**	**100%**

4.9 TRIAGE AND SYMPTOMS RECORDED

Patients noted as being in cardiac arrest did not correlate with patients with P4 triage (n=20) as 2 were noted as having symptoms of pain and SOB by paramedics, and subsequently going into cardiac arrest and declared as deceased. One of the patients recorded as P4 did not have cardiac arrest, or one of the common symptoms noted in the PRF and therefore created some discrepancies in the numbers i.e. cardiac arrest n=17 and P4 n=20. None of these patients had any resuscitation intervention as per table and graph, with these patients possibly having been recorded as palliative care patients or meeting the HPCSA criteria for non-resuscitation/ no CPR.

The term “primary symptoms” will be mentioned here as pain, SOB, cognitive changes, N&V and cardiac arrest that have been included in this study. Some of these patients would have reported other symptoms which were not included in this research.

Of the total patients, 66% of these were triaged as P2 with a total of 223 primary symptoms, meaning that these patients often reported having more than one primary symptom at a time. Of the total symptoms for P2 patients, pain was recorded as 34% of the total, SOB as 34%, cognitive changes as 24%, and N&V as 1% of the total symptoms.

Of the patients triaged as P3, with a total of 49 primary symptoms recorded. Pain accounted for 47% of total symptoms, 24% of the total symptoms were cognitive changes, 22% were SOB, and N&V accounted for less than 1% of the total primary symptoms.

Patients triaged as P1 were 0,01% of patients, with SOB accounting for 33% of the total symptoms and cognitive changes accounting for 67% of the total primary symptoms.

Refer to Table 7.

Table 7: Number of symptoms recorded per triage score and described by percentages

	Symptoms					
Patient Triage	**Pain**	**Shortness of breath**	**Cognitive Changes**	**Nausea**	**Cardiac Arrest**	**Total**
P2	76	75	53	19	0	**223**
P3	23	11	12	3	0	**49**
P4	1	1	0	0	20	**22**
P1	0	1	2	0	0	**3**
Total	**100**	**88**	**67**	**22**	**20**	**297**

4.10 TRIAGE AND INTERVENTIONS ADMINISTERED BY PARAMEDICS

P4: No interventions were recorded for patients triaged as P4 (deceased).

P3: Of patients triaged as P3, 93% received no treatment or medical intervention, with a small number receiving oxygen and nebulisation for SOB.

P2: Of the P2 patients 30% received no intervention/treatment.

A third of these patients received no interventions by paramedics, and those who did, receiving mainly intravenous access/fluids and oxygen. Patients receiving nebulisation (which would include B2 stimulants and Ipratropium Bromide) accounted for 6,8% of P2s, and patients receiving metoclopramide for N&V accounted for 4% of P2 patients. Metoclopramide is not given to every patient receiving morphine as protocol.

P1: Patients who received intravenous access/ fluids accounted for 43% of patients and those receiving oxygen/nebulisation/ medication accounted for 57% of patients. Refer to Table 8.

Table 8: Number of interventions and percentage of total intervention broken down by patient triage vs intervention

Patient Triage	**Intervention**	**Number of Interventions**	**% of Total Interventions**
P2	Airway basic	2	1%
	Aspirin	4	2%
	Beta 2 Stimulant	11	5%
	Breathing Oxygen	44	19%
	Fluids IV	50	21%
	Ipratropium Bromide	10	4%
	Lasix	2	1%
	Metoclopramide	10	4%
	Morphine	17	7%
	Nebulizer	16	7%
	None	71	30%
	Total	**237**	**100%**
P3	Beta 2 Stimulant	1	2%
	Breathing Oxygen	1	2%
	Nebulizer	1	2%
	None	53	93%
	Ventilation - assisted	1	2%
	Total	**57**	**100%**

P4	None	17	100%
	Total	**17**	**100%**
P1	Beta 2 Stimulant	1	14%
	Breathing Oxygen	1	14%
	Fluids IV	3	43%
	Ipratropium Bromide	1	14%
	Nebulizer	1	14%
	Total	**7**	**100%**

4.11 TRIAGE AND PATIENT TRANSPORT

Of the 20 patients triaged as P4, none were transported by ambulance however 3 were recorded as being transported by undertakers.

P3 patients that did not go to hospital (51%), were almost triple the number of P2 patients who did not go to hospital (16%). For the P3 patients this is a high percentage of call-outs where patients utilised EMS but did not require transport to hospital (these reasons were not recorded). P2 patients were less likely to stay at home, and given their triage status had most likely received some care in the form of oxygen, IV/fluid administration, or other medication.

Of the P3 patients, 48% were transported by ambulance to hospital, and 82% of P2 patients were transported by ambulance to hospital, with P2 patients more likely to have had more worrisome symptoms (such as SOB with low oxygen saturations) requiring intervention, or hospital support (these reasons will be discussed in Chapter 5).

In the P3 group 1% of these patients went to hospital with private transport and 2% of P2 patients went to hospital with private transport.

All 3 of the P1 patients were transported by ambulance to hospital.

As patients were categorised from P3 to P2 there was an escalation in the use of ambulance transport of patients, which is consistent with patient assessment and interventions as per their triage. Similarly, there is an association with the increased number of P3 patients staying at home with no ambulance transport, versus the lower percentage of P2 patients staying at home.

In total, 192 patients were transported by ambulance, 84 patients were not transported at all, 4 patients went to a facility with private transport and 3 patients were transported by mortuary vehicle.

Refer to Table 9 and Graph 4, for number of patients transported, transport type and patient triage score.

Table 9: Number of patients transported, transport type and patient triage score

	Transport									
Patient Triage	**Ambulance**		**None**		**Private**		**Mortuary Van**		**Total**	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
P2	154	82%	30	16%	3	2%	0	0%	**187**	**100%**
P3	35	48%	37	51%	1	1%	0	0%	**73**	**100%**
P4	0	0%	17	85%	0	0%	3	15%	**20**	**100%**
P1	3	100%	0	0%	0	0%	0	0%	**3**	**100%**
	192		84		4		3	**Total**	**283**	

4.12 TRIAGE P4 AND REASON FOR THE CALL-OUT

For patients triaged as P4 or declared as “deceased” by paramedics, the control centre had documented the reason for the call as being cardiac arrest in 11 patients, SOB in 3 patients, and pain in 1 patient, the balance of patients (4) did not have symptoms that were part of the “primary symptoms” inclusion criteria.

4.13 RECEIVING FACILITY FOR PATIENTS TRANSPORTED BY AMBULANCE

Patients transported by ambulance to a hospital Emergency Department (ED) accounted for 67% of all patients transported by ambulance. Patients transported to palliative care units comprised 12% of the patients transported by ambulance with the balance transported home from a facility (8%) the original call-out location unknown, to frail care (6%), received at hospital ward (6%) and clinic (1%).

4.14 PATIENT TRIAGE AND RECEIVING FACILITY

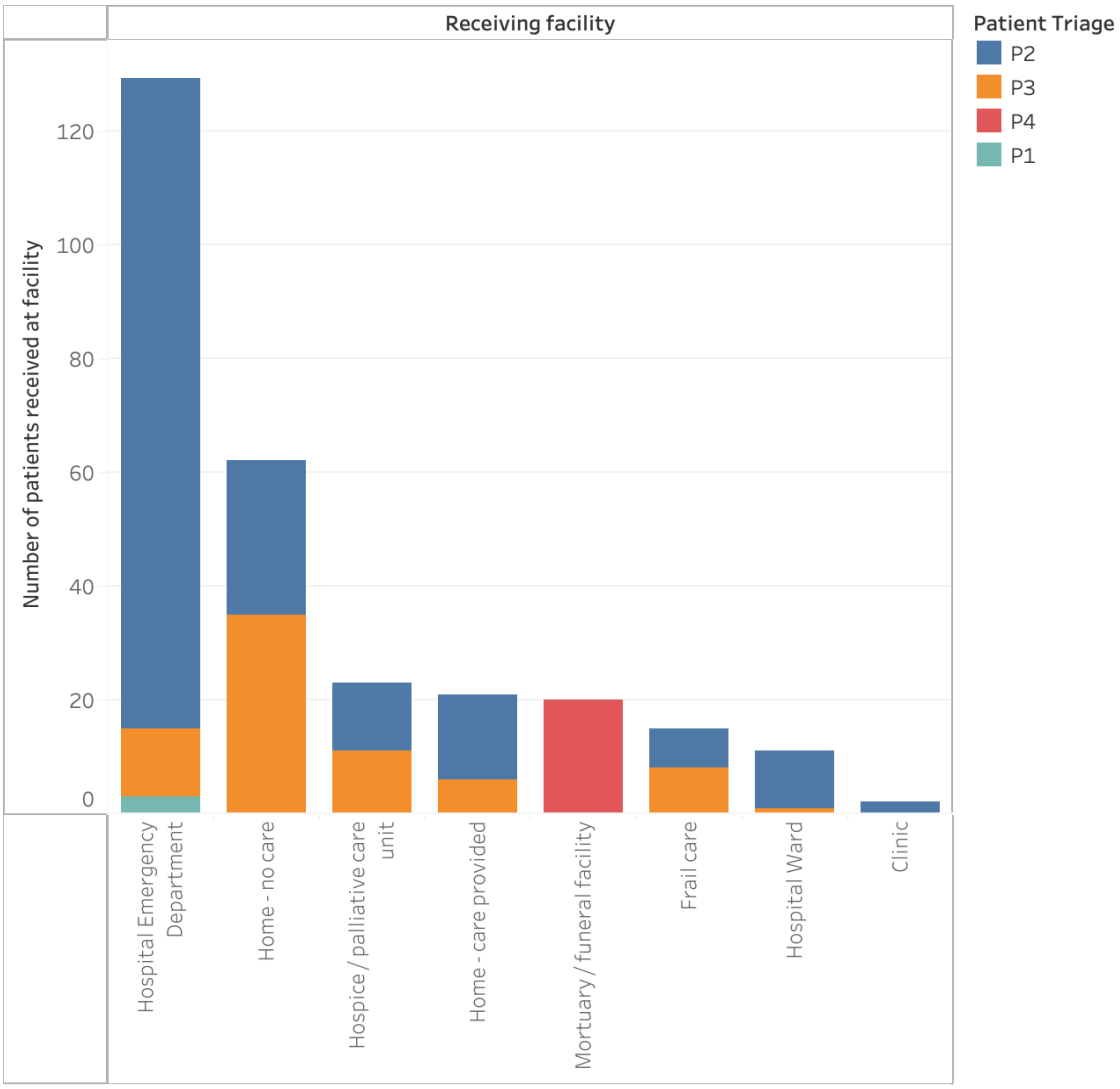
All 3 P1 patients, 88% of P2 patients, and 9% of P3 patients, went to an ED.

Of the 23 patients going to a palliative care facility, P2 patients accounted for 52% of these, and the rest of the patients were P3 patients (48%).

Patients received in a hospital ward were mostly P2 patients (4% of total patients).

Refer to Graph 4.

Graph 4: Patient triage and associated receiving facility



Of the 126 patients transported to a hospital emergency department, 114 (90%) were P2 patients compared to 12 (10%) P3 patients. There were also more P2 patients admitted directly to hospital ward -10 (90%) compared to the 1 (1%) P3 admission. Whereas 52% of the 23 patients transported to a palliative care unit were P2s and 48% were P3 patients. Fewer P2 patients were received at a frail care (47%) than P3 patients at 53% but there was not a large discrepancy between the numbers (7 P2 patients and 8 P3 Patients). The numbers of P2 patients (44%) that stayed at home were fewer than the P3 patients at 56%. P2 patients that stayed at home were more likely to have access to home care provided by a nurse or care giver at 71% versus a far lower number of P3 patients (29%) receiving care at home. Only 2 P2 patients were transported to a clinic.

Refer to Table 10.

Table 10: Patients with P2 and P3 triage scores and the associated receiving facility

	Patient Triage					
Receiving facility	**P2**		**P3**		**Grand Total**	
	N	**%**	**N**	**%**	**N**	**%**
Clinic	2	1%	0	0%	**2**	**1%**
Frail care	7	4%	8	11%	**15**	**6%**
Home - care provided	15	8%	6	8%	**21**	**8%**
Home - no care	27	14%	35	48%	**62**	**24%**
Hospice / palliative care unit	12	6%	11	15%	**23**	**9%**
Hospital Emergency Department	114	61%	12	16%	**126**	**48%**
Hospital Ward	10	5%	1	1%	**11**	**4%**
Mortuary / funeral facility	0	0%	0	0%	**0**	**0%**
Grand Total	**187**	**100%**	**73**	**100%**	**260**	**100%**

4.15 SYMPTOMS OF PATIENTS TRANSPORTED TO THE EMERGENCY DEPARTMENT

Of the 129 patients transported to a Hospital Emergency Department, there were 157 "primary" symptoms recorded of which 36% were pain, 33% were SOB, 21% were cognitive changes and 9% were recorded as N&V. These patients often reported having more than 1 of the primary symptoms.

Refer to Table 11.

Table 11: Number and percentage of primary symptoms observed in patients transported to the emergency department

Receiving facility	**Symptoms**	**Number of symptoms recorded**	**%**
Hospital Emergency Department	Pain	57	36%
	Shortness of breath	52	33%
	Cognitive Changes	33	21%
	Nausea	15	10%
Grand Total		**157**	**100%**

4.16 SYMPTOMS OF PATIENTS TRANSPORTED TO HOSPICE OR PALLIATIVE CARE FACILITY

Of the 23 patients transported to a palliative care facility, 22 "primary" symptoms were recorded, with pain as 46%, SOB as 27%, and cognitive changes as 27% of the total recorded primary symptoms. These were the primary symptoms recorded, with one or more patients not having any of the primary symptoms reported but being referred to a palliative care facility (with other symptoms not recorded for this research purpose). All of these transfers would have been pre-arranged, through CMR management and the admitting facility, with CMR providing transportation. Refer to Table 12.

Table 12: Number and percentage of primary symptoms observed in patients transported to a hospice or palliative care facility

Receiving facility	Symptoms	Number of symptoms recorded	%
Hospice / palliative care unit	Pain	10	46%
	Shortness of breath	6	27%
	Cognitive Changes	6	27%
Grand Total		**22**	**100%**

4.17 SYMPTOMS OF PATIENTS WHO DECLINED HOSPITAL TRANSPORT

Of the 84 patients that were not transported to a facility for further care, 71 "primary" symptoms were recorded with pain as 28%, SOB as 28%, cognitive changes as 14%, and N&V as 6%, of the total primary symptoms reported. Cardiac arrest (17%) was included as these patients were not transported by ambulance or private transport to a facility.

Refer to Table 13.

Table 13: Number and percentage of symptoms recorded for patients who refused hospital transport

Transport	Symptoms	Number of symptoms recorded	%
None	Shortness of breath	20	28%
	Pain	20	28%
	Cardiac Arrest	17	24%
	Cognitive Changes	10	14%
	Nausea	4	6%
Grand Total		**71**	**100%**

4.18 SYMPTOMS OF PATIENTS RECEIVING NO TREATMENT

Of the patients that received no treatment or intervention by paramedics, pain was recorded as 36% of total primary symptoms, cognitive changes as 23% of primary symptoms, SOB as 20% of primary symptoms, and N&V a s4% of the total primary symptoms recorded. Of the 17 patients recorded as in cardiac arrest (deceased) none received intervention by paramedics. Refer to Table 14.

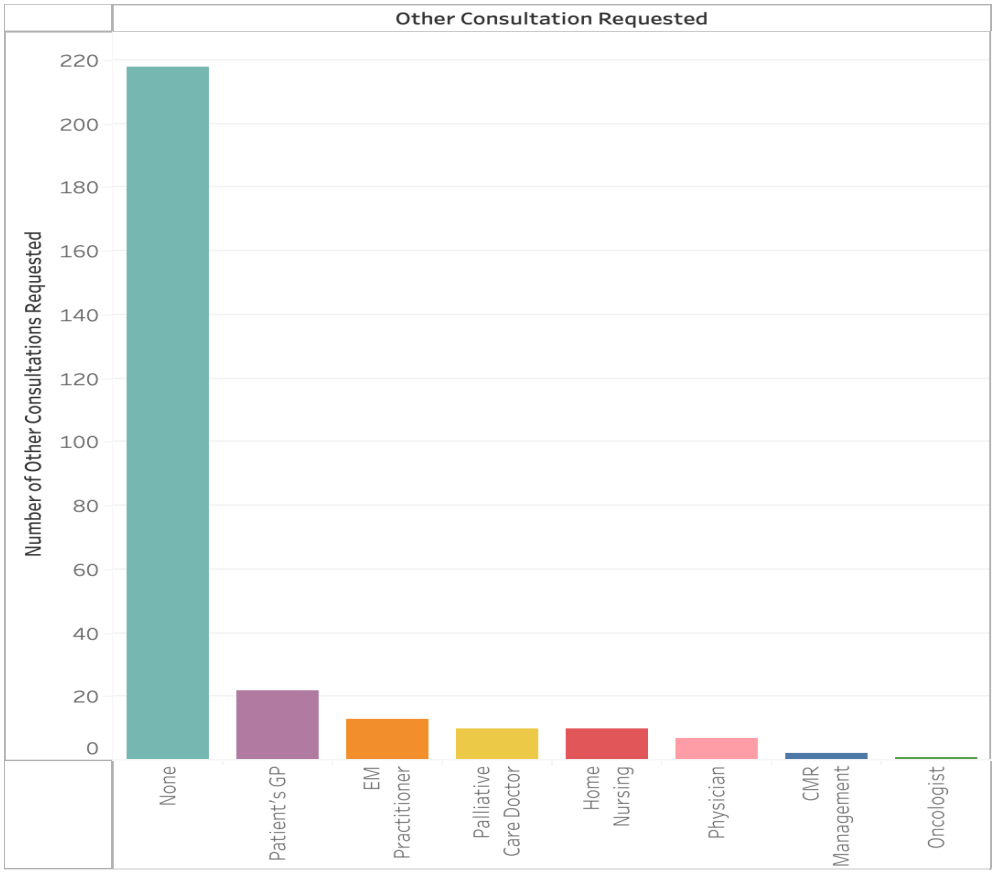
Table 14: Number and percentage of primary symptoms recorded in patients not receiving treatment

Intervention	Symptoms	Number of symptoms recorded	%
None	Pain	47	36%
	Cognitive Changes	31	23%
	Shortness of breath	27	20%
	Cardiac Arrest	17	13%
	Nausea	10	8%
Grand Total		**132**	**100%**

4.19 OTHER CONSULTATION REQUESTED BY PARAMEDICS

Out of the total call-outs, "no consultation" was recorded most frequently (77%), while non-palliative doctor consult (GP, EM doctor, and physician) was requested in a small number of cases (15%), as were palliative care practitioners and oncologists (4%). Consultation between paramedics and other healthcare professionals was in total 19%. No data was recorded by the researcher as to whether there was documentation of paramedics giving patients, or caregivers, instructions or advice for further care. Refer to Graph 5.

Graph 5: Other consultation requested by paramedics



4.20 CONSULTATION REQUESTED BY PARAMEDICS FOR P4 TRIAGE

Of the 20 patients triaged as P4, "no consultation" occurred in 90% of cases, with a palliative care doctor, and the patient's GP only contacted once each. "Consultation requested" refers to a telephonic or radio discussion, that would have occurred between paramedic and the consultant as stipulated in Health Professionals Council of South Africa, (2016). Refer to Table 15.

Table 15: Other consultation requested for patients with a P4 triage score

Patient Triage	Other Consultation Requested	Number of consultations requested	%
P4	None	18	90%
	Palliative Care Doctor	1	5%
	Patient's GP	1	5%
Grand Total		**20**	**100%**

4.21 ALTERNATE CARE IN SITU (HOME CARE/ PRIVATE NURSING/ PALLIATIVE CARE PROGRAM)

"Alternate care" was considered home care/ private nursing/ or a palliative care program. Alternate care for patients (not receiving any intervention by paramedics) was recorded mainly for patients receiving palliative care (17%) and patients with private home nursing (5%). Of the total patients receiving no intervention by paramedics, 73% had no "alternate care" or continuity of care mentioned. Refer to Table 16.

Table 16: Number of care plans recorded

Alternate Care Recorded	Number of Patients	%
None	207	73%
Palliative care program	48	17%
Home nursing	13	5%
Professional Care giver	8	3%
GP Home Call	7	2%
Grand Total	**283**	**100%**

4.22 CARE PLANS MENTIONED

Patients with care plans and associated triage:

Care plans such as Advanced Care Directives, Living Wills, clinician communication (Doctor's referral letter) and DNRs were recorded in patient PRFs. A total of 3 Living Wills (1%), and 23 for doctor referral letters (6,4%) were mentioned. Of the 20 patients triaged as P4, only 1 of the patients had an advanced care plan. Refer to Table 17.

Table 17: Number of patients with care plans and associated triage score

Care Plan	Patient Triage	Number of patients	%
None	P2	172	92%
	P3	63	86%
	P4	19	95%
	P1	3	100%
	Total	**257**	**91%**
Doctor's referral letter	P2	9	5%
	P3	9	12%
	Total	**18**	**6%**
Advanced care plan	P2	1	1%
	P3	1	1%
	P4	1	5%
	Total	**3**	**1%**
Living Will	P2	3	2%
	Total	**3**	**1%**
Hospital appointment card	P2	2	1%
	Total	**2**	**1%**
Grand Total		**283**	**100%**

Method of transport for triaged patients with a care plan:

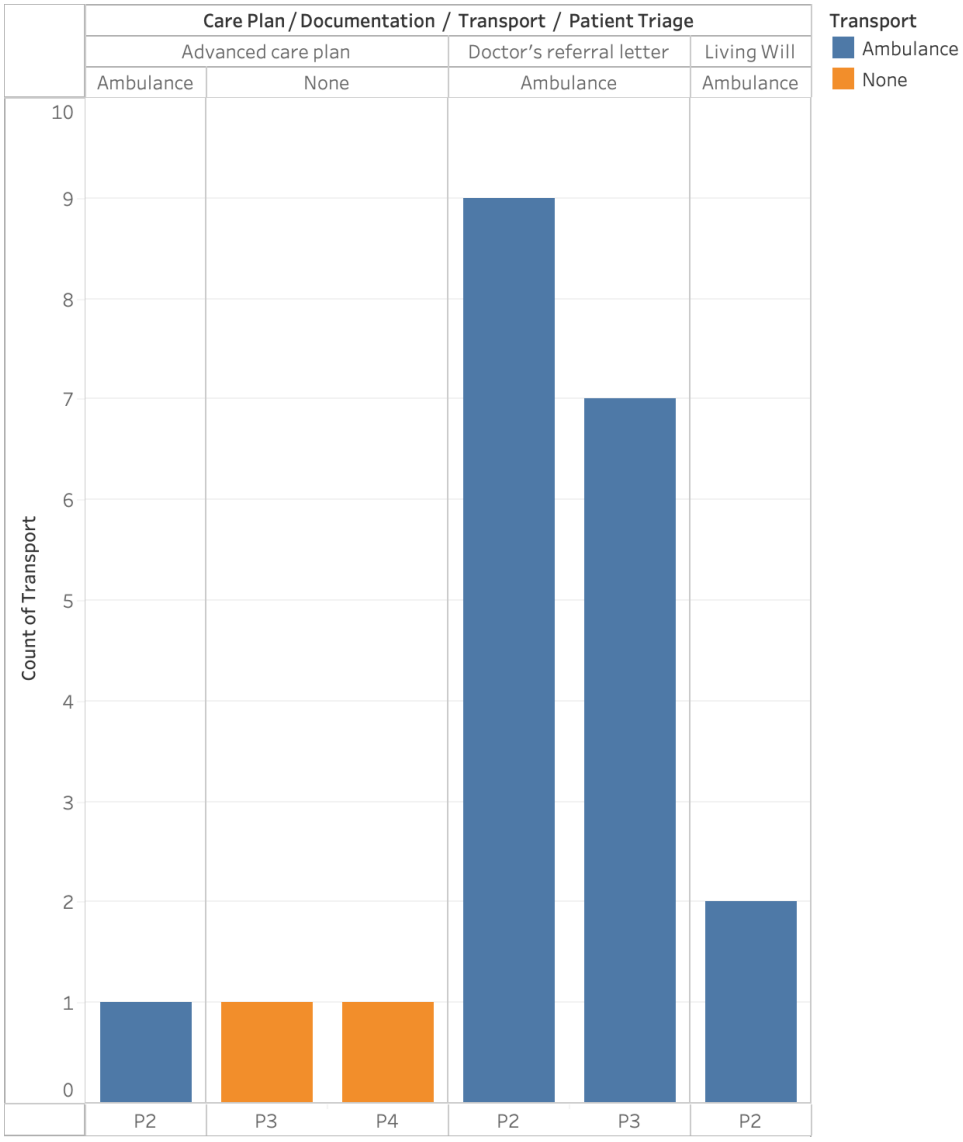
Of the 18 patients with a doctor's referral letter, 9 of the P2 patients and 7 of the P3 patients, went to hospital via ambulance transport. The 2 P3 patients that were not transported to a facility by ambulance would have gone with private transport.

Of the 3 patients with ACPs, only 1 P2 patient was transported by ambulance to a facility, with the P3 and P4 patient receiving no transport.

There were 3 P2 patients with living wills, of which 2 of those patients went to a facility via ambulance**.**

Refer to Graph 6.

Graph 6: Patient Triage Score and method of transport for patients with a care plan



Intervention by paramedics for patients with a care plan:

Of the 3 P2 patients with an ACP, none received an intervention by paramedics, although as seen in Graph 8, 1 patient had been transported to a facility by ambulance.

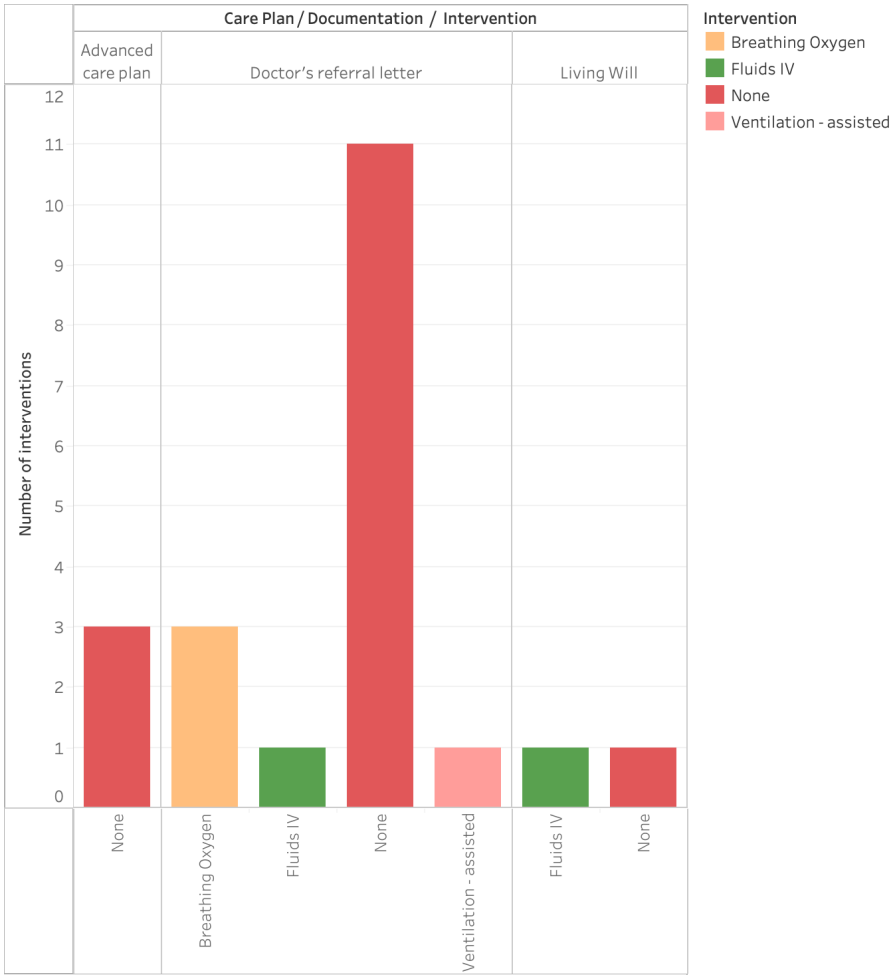
There was a total of 18 patients with doctor referral letters, 16 had been transported by ambulance and 11 of those patients had received no intervention by paramedics. Of the 5 patients receiving an intervention, 1 had been assist-ventilated, 3 had been given oxygen, and one had an IV line sited.

Of the 2 patients with living wills who were transported by ambulance, 1 patient received no intervention by paramedics, and 1 patient had an IV line sited.

In total, of the 19 patients with care plans who were transported by ambulance, 14 received no intervention by paramedics.

Refer to Graph 7.

Graph 7: Intervention by paramedics for patients with a care plan



4.23 RESULTS CONCLUSION

Among the 283 patients that met the research criteria, many had more than one NCD, often experiencing more than one of the primary symptoms of pain, SOB, cognitive changes and N&V simultaneously. The majority of these patients were triaged as P2 or P3 patients, and were likely to go to hospital with ambulance transport. Frequently there was no clinical intervention or treatment by paramedics even when patients were transported by ambulance to hospital, and when interventions were noted, there was seldom explanation of why interventions were administered. It is also clear that consultation for clinical advice was seldom sought, and that there was a paucity of associated care plans. These results lead into the discussion of why patients with NCDs (cancer, chronic heart disease, chronic lung disease, dementia and chronic kidney disease) and primary symptoms (pain, SOB, cognitive changes and N&V) call for EMS assistance, what the patient and paramedic/ EMS reasoning is behind mode of transport to hospital, and the inevitable journey to the ED, where the chance of patients receiving appropriate palliative care is debatable.

5 CHAPTER 5 – DISCUSSION

This study aimed to identify whether there was a burden placed on EMS when managing acute exacerbations of chronic NCD, and whether there is a need for pre-hospital palliative care need – recognition, education, and provision via consultation - by paramedics.

The researcher's objectives were to identify whether there were a significant number of patients with symptoms associated with their NCDs, transported by ambulance to EDs inappropriately. Of these patients, it was important to establish who could benefit from care at home that fell within paramedical scope of practice, and whether any of these patients could be possible candidates for advanced care planning, with early access to palliative care consultation and support.

5.1 THE PROBLEM

Healthcare models, including those of EMS, have been based on providing curative care. In recognition of a globally changing disease profile with NCDs on the rise globally, and the need to provide appropriate care to the general patient population, EMS in parts of the world are revising their historical culture of care (Al-Shaqsi, 2010). In line with this, EMS systems and tertiary facilities across the globe are including palliative care training in their core curricula and service infrastructure (Lord et al, 2019; Pallium Canada, 2019).

5.2 KEY FINDINGS

The data found that CMR respond to a significant proportion of patients with NCDs experiencing an acute exacerbation of their disease, with symptoms of SOB, pain, N&V, and cognitive changes.

Patients are frequently transported to emergency departments by paramedics, but receive inconsistent, or no, symptom management prior or during transport. The consideration here is that if interventions were instituted at home, transportation to an ED could be avoided in many cases. As patients seldom have any form of advanced care planning, or specialised consultant contacts, there is often little support for these patients and their care givers and EMS becomes the first port of call for assistance. Similarly, paramedics are often disempowered when making patient care and transport decisions with no guidance or consultant support, and are forced to inappropriately transport patients to hospital. The reasons for this are linked to scope of clinical practice, EMS protocols and procedures, lack of support structures such as palliative care networks and home care services, and ineffective discharge plans. Ultimately there is also a lack of palliative care and NCD symptom management education in undergraduate syllabi for paramedics, and a lack of clinical support structures within the community or available around the clock accessible care.

5.2.1 THE PREVALENCE OF NCDS

During the study period of 1st January 2019 to 30th April 2019, the workload experienced by CMR over that time indicated that 18% of callouts were to patients with symptom exacerbation of NCDs, with patients, and carers, often requiring paramedics' support during symptom exacerbation. Fear, discomfort and exhaustion is often the stimulus for patients and their care-givers to reach out for support. This support is often required out of normal office hours. The need for clinical, and emotional assistance, results in patients regularly being transported to hospital, even if transport by ambulance, and ED admission was not necessarily appropriate. This potentially creates a resource burden not only

on EMS, but the healthcare system. In this study, it was important to identify the most prevalent NCDs and their associated symptoms (as reported by CMR paramedics), and compare the global picture, in order to start arguing the case for a similar approach to managing NCD exacerbations by South African EMS.

The data from this study indicated that cancer was the most prevalent NCD, followed by chronic heart disease, dementia, chronic lung disease, diabetes and renal failure. The research data therefore did not align with all of the African, or global data (as per Fig.6 and 7), as chronic heart disease was shown as being the most prevalent NCD in both studies, with cancer, respiratory disease and diabetes following (Gouda et al., 2019; Bennett et al., 2018).

The data recorded cancer as any record of patient having, or having had, cancer (this was difficult as some of the records did not always define or elaborate on remission, chemo/radiation therapy or disease staging, or whether symptoms were associated with the cancer). Heart disease included Congestive Cardiac Failure (CCF), pulmonary oedema (with use of diuretics and other medication included) and chronic heart problems. Lung disease included Chronic Obstructive Pulmonary Disease (COPD), lung problems with wheeze, or signs of bronchospasm. Asthma was not included as an NCD due to the definition being that of a reversible disease. However, there were instances where the patient's condition, and paramedic record, indicated a possible chronic, rather than acute, bronchospasm. Dementia and diabetes were not originally included in the data collection, but it became evident that both were prevalent and were relevant to the research.

It is interesting to consider symptoms in the context of NCDs, and why and when patients call for assistance. Considering that symptoms associated with NCDs do not usually have sudden onset as found in acute disease or injury, but may be insidious and by the time the situation becomes uncomfortable the patient and their care giver have little resilience, and are panicked. This means that private patient transport, or managing the patient comfortably at home becomes less likely, resulting in EMS activation and resulting ambulance transport to hospital.

5.2.2 LOCATION OF CALL-OUT AND SYMPTOMS REPORTED

Paramedic call-outs were predominantly to patients' homes, followed by the need for ambulance transport after hospital discharge, or inter-facility transfer of patients by ambulance from a hospital ward to another facility. Call-outs to frail- or palliative care units/ hospices constituted just over 10% of the ambulance responses. Unfortunately, the time of the calls, or repeat call-outs to patients previously treated, were not recorded. This would have been important as it may have supplied information on patients with NCDs and repeat call-outs, and indicated a burden on EMS resources having to make those repeat call-outs. Repeat call-outs can also identify gaps in the healthcare systems such as inadequate patient advanced care planning and education, inadequate patient education on discharge, inadequate patient/ caregiver support infrastructures especially out of normal clinic or business hours, and inappropriate patient care by EMS and healthcare facilities. Additionally, repeat call-outs can result in repeat ambulance transport to hospital and increased ED admissions. When considering adapting paramedical function, and service provision as described in Paramedics Providing Palliative Care at Home Program, this information may have provided valuable insight (Carter et al., 2019; Sovso, 2019). Repeat call outs were also linked to the symptoms, and exacerbation thereof, experienced by the patient, and the resulting discomfort for patient and care-giver, leading to a repeat call out of EMS.

The most common symptoms recorded on patient assessment by CMR paramedics were pain, SOB, cognitive changes, and N&V, with a small number of patients recorded as being in cardiac arrest. Pain was associated with NCDs in order of cancer, heart disease, dementia and lung disease. Surprisingly, although pain is associated with cancer, patients with heart disease, dementia and lung disease reported experiencing pain. Unfortunately, pain assessment methods by paramedics were not investigated in this research but further research could bring interesting insight into pain assessment in NCDs, and appropriate management thereof. Pain assessment is included in paramedic practice and training, and is found in CMRs PRFs using a pain scale of 1-10 with 1 being the least pain experienced, and 10 the most pain experienced. The score is often biased due to how patients' pain is assessed, and is prone to subjectivity. Shortness of breath was associated with the following NCDs in order of heart disease, lung disease, cancer, which was not unanticipated. Cognitive changes were predominantly noted with dementia followed by cancer, heart disease and lung disease. The cognitive changes reported were seldom described further as to whether there were associations with analgo-sedation, cerebral metastases or hypoxia especially in patients with cancer, heart disease or lung disease.

Nausea and vomiting were predominantly reported in cancer, and a small number of patients with heart disease. It's not clear whether there were factors that caused the N&V such as morphine administration, or whether the N&V were primary symptoms. These findings are consistent with similar international research outcomes as shown in Kelly et al (2016) and Carron et al (2015). Lastly, patients in cardiac arrest predominantly had a history of cancer and heart disease, which is consistent with South African and global statistics (Gouda et al., 2019; Bennett et al., 2018).

5.2.3 INTERVENTIONS BY PARAMEDICS TO MANAGE PATIENTS' SYMPTOMS

In the majority of cases, no intervention was performed by paramedics with possible reasons including not knowing what to do in a situation that doesn't fall within the normal parameters of the paramedic's training, and not having access to appropriate consultation.

Intravenous fluid (IV) fluid administration was the predominant intervention by paramedics for patients complaining of pain, cognitive changes, SOB and nausea. IV access is seen as a relevant intervention in many cases as intermediate life support, and advanced life support (ALS) paramedics as siting IV lines falls within their scope of practice, and there is an expectation from the ED's that patients are received with IV lines accessed. Often when there is confusion around how to best manage a patient, IV access is an easy intervention, with the thought that maybe fluids or pharmacological interventions will be administered in hospital. Often, without any evidence that IV access is needed, hospital staff will demand that patients have IVs in situ when brought in to the ED by paramedics. This is often an algorithm –led weakness, and may relate to inadequate science-based education, historical and outdated approaches, private sector EMS billing (can charge more for particular interventions) and EMS paramedics going to a default practice. As soon as an IV is sited, the patient is triaged as P2, and will be transported to an ED, whether the IV access was appropriate or not. From a palliative care perspective siting an IV line is often inappropriate, unnecessarily painful, can lead to false expectations and may actually be harmful to patients as fluid overload and infection can result.

Oxygen (delivered via facemask or nasal prongs) was administered to patients with SOB, sometimes with the use of a nebulizer and bronchodilator drugs. Oxygen was also given to patients with pain and cognitive changes. Oxygen in the presence of SOB is appropriate even in the setting of normal oxygen saturation, as it may aid patient comfort via air

flow over the patient's face, decreasing patient anxiety, and indirectly, pain. It also becomes necessary to use in patients with cognitive deficit as a means of ruling out hypoxia (and may be useful in the presence of analgo-sedation with associated bradypnoea). Again, oxygen is often unnecessarily administered to patients when paramedics have no guidance with, or understanding of, symptom management in NCDs.

There was little evidence to indicate whether Morphine was administered predominantly to patients experiencing pain (this would be most likely as morphine is indicated as an analgesic in the advanced life support paramedics scope of practice, not as an anxiolytic adjunct in SOB). Morphine use was not clearly indicated as having been administered to patients with SOB, or whether it caused SOB. There is no absolute contra-indication in the Clinical Practice Guidelines or to the use of morphine in SOB and therefore Emergency Care Practitioners (ECPs) should have scope of practice to use morphine in cases of SOB where clinically relevant, and with clinician consultation (Clinical_Practice_Guidelines_Protocols_2018.pdf). The concept of using opioids to manage SOB is reinforced in the Journal of Paramedic Practice, where consensus was reached that opioids are effective in managing refractory breathlessness in adults experiencing dyspnoea (Parkinson., M. 2014).

In some cases, cognitive changes as per the Glasgow Coma Scale (GCS), had been recorded with no indication as to whether cognitive changes had been present prior to, or as a result of, the morphine administration.

Metoclopramide was mostly administered to patients with pain, more than likely in the context of analgesic administration (morphine) to mitigate associated nausea. This has been a routine practice for many South African paramedics trained in the 1990's and early 2000's. This, similarly, could have been the reason for administration of metoclopramide in the cases of SOB and cognitive changes, post morphine administration and resulting nausea. This practice is slowly changing with evidence-based practice and slow, titrated IV morphine doses, however, palliative care teaching still advises that pre-emptive metoclopramide administration is best practice in palliative care.

The fact that interventions were often not performed may indicate that although paramedics may have the scope of practice to intervene, they lack palliative care knowledge and clinical support (Gage et al, 2020). There seems to be a feeling of disempowerment, or even a lack of awareness that they are able to provide effective interventions and appropriate patient care.

No advanced airway management, or CPR, was initiated by paramedics for patients recorded as P4 (cardiac arrest/ deceased). Reasons for non-initiation of resuscitation could have included the patient's healthcare proxy expressing the patient's wishes or the patient's condition falling with the HPCSA guidelines of when to withhold resuscitation (McQuoid-Mason, 2013; Health Professions Council of South Africa, 2016). The researcher recognises that CMR may also respond to repeat call-outs to the same patients as many patients are CMR clients, especially for exacerbations of their chronic disease. It is therefore possible that the paramedics may have been aware of the patients' history of disease, but this awareness does not translate into the healthcare system supporting alternative care approaches for patients other than transport to hospital by EMS, as discussed in Søvsø et al., 2019. In the context of cost to the service for repeat call-outs this could have been relevant information.

The fact that patients were not automatically resuscitated is an interesting finding in that it indicates that the CMR paramedics do not automatically resuscitate all patients, although the paramedics are trained and equipped to manage

patients in cardiac arrest. This could indicate that there is a consideration of the concept of futility in the case of non-curative disease, and the wishes of patients and their families, although there was no noted discussion or consultation discussed, or recorded, in the PRFs. The potential medico-legal ramifications of incomplete documentation would form part of the research feedback for CMR.

The smaller, private service that CMR offers may allow for more personal patient-family-paramedic interaction, especially in the context that CMR has paying patients that may frequently request service from CMR for symptom – exacerbation during the trajectory of their disease. This has similarities to the content discussed in Arab et al (2016), Mason et al. (2007), and Cameron and Carter (2019). The findings in this study were not consistent with the findings in the publication by Lord et al. (2019), which indicated that 40% of patients in cardiac arrest associated with palliative care and "end-of-life' situations were resuscitated. Keeping in mind that Lord et al (2019) was a very large study, which included multiple EMS services and paramedical scopes of practice, the increased resuscitations may be consistent with the experience of large South African EMS services. It is unlikely that there is as consistent, or as personalised, service as found in a small private EMS such as CMR (Health Professions Council of South Africa, 2016; Health Professionals Council of South Africa, 2018; Clinical Practice Guidelines - Protocols- July 2018.pdf).

5.2.4 PATIENT TRIAGE SCORING, SYMPTOM MANAGEMENT AND AMBULANCE TRANSPORT

The data collected and analysed in this study indicates that most patients were triaged as P2, with about a quarter of patients being scored as P3, and a small number of patients recorded as P1. As per the SATS, P2 Yellow patients need urgent care within an hour, need to be transported on a stretcher, and includes patients with abdominal pain (surgical), moderate pain and persistent vomiting. It is considered that as soon as a patient is transported on a stretcher, they automatically meet a P2 triage status, which is not necessarily in line with a true SATS system. P3 (green patients) will often wait to be seen for an extended amount of time (SATS-Manual-A5-LR-spreads.pdf, 2012; Appendix 4).

This is consistent with the transport of patients to hospital by ambulance, an historical EMS approach to acute symptomatic care, a very different approach to that of palliative care, which attempts to support patients' wishes for care, and where they wish to be cared for. Although the majority of P2 patients received no intervention or treatment they were transported to hospital in accordance with the EMS algorithmic triage approach to care, which may have been contrary to many patients' wishes. Only a small sample of P2 patients refused ambulance transport to hospital.

Almost half of the P3 patients were transported by ambulance, and all of the P1 patients were transported by ambulance, in accordance with SATS scoring. The data correlates with the findings of Lord et al. (2019) indicating that paramedics transport most patients to hospital following assessment, with patients exhibiting similar symptoms, and receiving marginal symptom management. Globally, EMS's have a need for standardised approaches to guide patient care in order to mitigate issues of litigation and support governance, but a completely static algorithm does not allow for clinical reasoning, and results in non-beneficence for patients. The concept of palliative care, on the other hand, encourages interdisciplinary communication and integrated patient management in order to provide the best experience for the patient, and their caregivers. Concepts of autonomy and beneficence extend all the way through aspects of patients care, from pre-hospital into the ED.

Diaz et al's (2015) research indicates that patients with chronic disease are often brought to the ED as there are no other perceived options for their symptom management, even though they may not fit into an acute care or triage profile. Acute injury or illness is often managed through an algorithmic approach in the EMS or ED space. This can differ when managing chronic disease exacerbations. Algorithms, with emergency interventions may not be appropriate for the patient with an NCD. These patients rely on care that is based on disease trajectory, considers medications, prior symptom exacerbations and hospital visits, and considers multifactorial influences such as psychosocial, and spiritual wellbeing. The relevance here is that emergency services often fulfil a "transport" service rather than a service providing clinical or supportive care, evident by the fact that many of the patients transported by CMR received no care, or clinically unnecessary care, with most patient handovers occurring at the ED. With the advent of SPICT and SPICT^{SA}, there is a higher likelihood that with education and training, paramedics and ED staff may more easily identify patients with NCDs requiring a different care approach, and possibly palliative care assistance.

The challenges for paramedics managing patients with chronic disease, potentially those who could benefit from a palliative care program, are complex. This is due to the various EMS scopes of practice, from basic life support (BLS) through strata of practice, eventually culminating in three different levels of advanced life support (ALS). These scopes of practice, under the clinical practice guideline (2018) and HPCSA (2018) dictate the decision –making abilities of each practitioner, and what interventions that practitioner can use (Health Professionals Council of South Africa, 2018; Clinical Practice Guidelines - Protocols- July 2018.pdf). South African EMS remains under-resourced, with many post-graduate paramedics, with extensive clinical experience and scope being employed overseas. This limits the chance of creating specialities within paramedicine, limits the use of clinical reasoning and allows for perpetuation of an ineffective healthcare system. This is also exacerbated by ineffective patient handover between EMS and within healthcare systems, with important patient health information being lost. The emphasis is that EMS is a transport system. Rather than caring for patients effectively at home, the efficacy of an EMS is measured on call times and delivery of patients to a receiving facility. This is in alignment with an historical approach to EMS and acute patient care where definitive patient management often relies on hospital-based resources such as operating theatres. When considering palliative care, the opposite may routinely apply, with excellent patient assessment occurring at home, by the paramedics, with consultation and guidance from PC doctors, and other specialised healthcare practitioners. A joint decision in these cases would be far more effective, and supportive of the patient's wishes, and the space in which they convalesce or die (National Policy Framework and Strategy on Palliative Care 20172022.pdf, 2017; Clinical Practice Guidelines - Protocols- July 2018.pdf, 2018; Health Professionals Council of South Africa, 2019).

5.2.5 SCOPE OF PRACTICE

The term "paramedic" can be broadly used to refer to all ambulance, emergency medical service staff. However, the levels of education and scope of practice of South African EMS personnel are varied, from Basic Life Support, through to highly educated, and often specialised, paramedics able to provide advanced life support, and who may be experts in intensive care, paediatric care, aviation medicine, or rescue. The need for palliative care in the pre-hospital environment is creating discussion amongst paramedics, as more patients present with symptoms of chronic disease, but the approach, diagnosis, and care of these patients, and the resulting record keeping, remains influenced by the scope of practice, and training, of these practitioners. The positive angle here is that paramedics can be specially trained in different areas of

care to improve the quality of patient care. The challenge is to get buy-in from educational facilities, create adjunctive specialities to the present curriculum, and facilitate legislature change in increasing the scope of paramedic practice, allowing for broader use of available medications (South African Medical Research Council (SAMRC). If emergency medicine, EMS policy and the national policy framework for palliative care could meet on common ground, this would allow for more robust "care-at-home" practice for Advanced Life Support paramedics in the context of doctor/EMS/ interdisciplinary team context. Encouraging less qualified paramedics to work within a consultant-based practice would possibly enhance patient care, and support decision-making as discussed in Clarke et al. (2017) who identified EMS as an effective link between transitions of care, a potential way of monitoring, managing, and assisting with chronic disease prevention (Clarke et al., 2017).

5.2.6 PATIENT TRIAGING AND RECEIVING FACILITY - TRADITIONAL CARE STRUCTURE FOR CHANGING PATIENTS

Almost half of the patients transported by ambulance were taken to a hospital ED as a default to clinical and triage guidelines (Health Professionals Council of South Africa, 2018; Clinical Practice Guidelines - Protocols- July 2018.pdf Appendix 4), with only 11,6% of patients being received at a palliative care unit (majority of these patients were triaged as P2), and a small number of patients were taken to a hospital ward (SATS-Manual-A5-LR-spreads.pdf, 2012). The palliative care units and hospital wards would have been pre-arranged by the patient's physician or GP. This was consistent with consultation noted by the recording paramedic. Non-palliative doctor consult (GP, EM doctor, and physician) was requested in about 15% of cases, palliative care practitioners and oncologists were consulted in about 5% of cases, with no consultation requested in the majority of calls, which was consistent with the findings of Lord et al. (2019). Of the patients triaged as P4, a palliative care doctor, and patient's GP were contacted once each for two of the deceased patients, with no description as to whether it was for consult with the doctor, or to inform them of their patient's demise.

The results of the study indicate that the majority of patients attended to by CMR paramedics were transported to hospital, many of them receiving no specific care although they were triaged as priority 2 patients. The data may indicate that although these patients went to hospital there was not a clear idea on how to manage their symptoms appropriately, or paramedics' skills and ability to provide interventions were limited by clinical guidelines, or even EMS protocols (as per HPCSA). This indicates a clear gap in accessibility for patients, and paramedics, to home-based, consultant-based or palliative care support, re-enforcing the concept of EMS as a transport system, rather than an innovative, and skilful, patient care profession.

The patients that were identified as having pain, shortness of breath, and nausea and vomiting that received interventions such as oxygen, intravenous access for fluids, and pharmaceutical therapy to manage their symptoms were transported to hospital. This would have been influenced by national EMS guidelines (which also apply to private EMS such as CMR), and ultimately not having alternate access to ongoing care at home, or a palliative care facility for patients, via paramedic/specialist consultation.

The data showed that of the patients transported to an ED, over a third reported having pain, over a third had SOB, a fifth had cognitive changes and a small number had N&V. Similar symptoms and percentages were reported by the

patients transported to a palliative care facility, indicating that many patients that were transported to an ED may have benefited from a palliative care admission. The paramedics treating these patients would have been directed to these palliative care facilities after arrangement with the patient, and/ or family's, GP or physician. Unfortunately, in this setting, palliative care facilities do not usually accept acute admissions, further hindering EMS ability to manage PC patients. There are also limited HCPs available to do home visits for PC patients, or patients meeting PC requirements, especially out of office hours, or patients not in a palliative care program. The findings indicate that most of these patient transfers were arranged prior to CMRs arrival, with only a limited number of consults recorded between paramedic and doctor. This highlights the fact that if patients with NCDs had effective advanced care planning done early on in their disease trajectory that their symptoms during exacerbations could have been better managed either with home care, via their GP or at a primary care facility, avoiding transport to over-burdened EDs.

Alternate care for patients was minimal, with home nursing and home visits by a GP recorded a few times. No palliative care was mentioned for patients, with the majority of patients reporting as having no supportive care. Care plans such as Advanced Care Directives, Living Wills, clinician communication (Doctor's referral letter) and DNRs were recorded in patient PRFs with a total of 3 Living Wills (1%), and 23 doctor referral letters (7,5%). Of the 20 patients triaged as P4, only 1 had an advanced care plan. In South Africa, advanced directives and Living Wills are still not considered legal documents, with presentation of these documents by family often creating confusion for EMS personnel, and therefore not being enforced by EMS. This highlights the gap, and need for, palliative care training in the community, not only with EMS personnel, but also for other healthcare practitioners such as local GPs and nurses. With the concept of interdisciplinary teamwork being integral to palliative care it is vital for healthcare practitioners to work together, and consult within the team in order to provide best patient care. It is vital for paramedics to have current patient information, especially when considering advanced care plans and living wills. Unfortunately, in an emergency situation, living wills (advanced care plans) are often not taken into consideration, but in the context of a patient who made the request when cognitively intact, advanced care plans are considered valid in common law (McQuoid-Mason, 2013; HPCSA, 2018). An advanced care plan/ request offered by the patient's healthcare proxy is also considered valuable in the context of futility (intervention that would not result in benefit to the patient's quality of life). In an EMS setting, advanced care plans may often be discredited due to lack of documented evidence at the time of patient crisis, leading to inappropriate patient management. Due to this ethical challenge, it would seem appropriate for patients with chronic disease to have an advanced care book, and centralised patient records for easy interdisciplinary healthcare access. Updates through patients' transitions of care, recorded by their healthcare practitioners (with contact details) after each contact session would allow for quick and accessible information for paramedics, and other practitioners, allowing for consultation, as well as more effective clinical, and transport decision-making.

In 2014, Caron et al., described four cases where Emergency Care Physicians were called out to assist with cases involving palliative care emergencies including mainly dyspnoea, and end-of-life situations. The ethical and practical implications of considering patients' wishes with the inclusion of caregiver capabilities, and family wishes was discussed, and the conclusion was that when managing palliative care situations, especially acute symptoms, requires time, expert communication, specialised training, and co-ordination with palliative care networks (Caron et al., 2014).

In Paramedics Providing Palliative Care at Home (Carter et al., 2019), it was emphasised that patients' wishes, provision of care at home, and support from interdisciplinary healthcare professionals was integral to a positive patient and carer experience. This re-enforces the concept of creating access to palliative care through an effective healthcare system that communicates with, and educates its practitioners, and patients, in palliative care and available support structures. Both of these studies, done in different parts of the world, re-enforce the message that palliative care is needed, is not clearly understood or taught, and remains under provided for patients (and their care givers) who could benefit from the support, and care, of an interdisciplinary approach to palliative care. This study strongly indicates the need for integration of palliative care through the patient's transitions of care, from EMS to supporting facilities or alternative care services, and through to discharge. This approach would mean fewer hospital visits for patients with NCD exacerbations, better advanced care planning with improved systems and support for patients and carers especially during out-of-office hours, less burden on the EDs and better quality of life for patients. Effective communication and accessible, transferrable patient records for all transitions of care are imperative for a truly effective interdisciplinary approach for patients requiring support during the trajectory of their NCDs, and ultimately benefitting from palliative care.

As the burden of chronic disease increases, so too does the need for palliative care in home –based, and out-of-hospital environment. EMS providing palliative care could work in the South African healthcare context and is in no way exclusive to only developed countries. Data from this study indicates that many patients that are transported to hospital receive very little definitive care during their transport and care transitions (further research is needed to identify if the care from EMS is different to that within the ED). Potentially this indicates that with appropriate consultation with specialised consultants, that paramedics may be able to manage many more patients at home, and identify home –based care for their patients, rather than offering just a transport system to routinely over crowded EDs. However, having said this, public sector EMS is often under-resourced from a paramedic, equipment and vehicle perspective, which potentially indicates the need for private sector EMS to fill the gaps, often providing support for priority calls only. This means that patients with NCDs and symptoms thereof may only have belated access to care, and potentially care that is under-qualified to make any decisions other than transport the patient to hospital. This potentially means that private EMS will need to initiate (and test) community and palliative care pilot projects before public sector EMS will commit to providing a palliative care service. Public sector EMS is also less likely to have access to consultation or clinical histories for these patients, making on-scene decision-making challenging.

There is evidence from the literature, and from this study's data, that very few patients with chronic disease have any advanced care planning which highlights a paucity of transitional communication between facilities and healthcare providers, and their patients. Simply put, access to patient history via a simple updated patient/ hospital/ GP book, with relevant medications and contact numbers for consultation, would immediately allow for appropriate patient care, and improve clinical decision-making around home care versus hospital transport. Tools such as SPICT and SPICT^{SA} are available for use by all healthcare practitioners, and facilities, and should be implemented in order to identify those patients that require, or will require, palliative care support. These tools are easy to use as part of patient triaging, or screening, and are able to inform healthcare practitioners of where in the trajectory of disease the patient is, allowing for appropriate care, PC intervention or otherwise. Again, private sector EMS is more likely to have the necessary resources to support on-scene decision-making, and have the necessary infrastructure to support patient care from an interdisciplinary perspective. Just as a point of interest, this approach would require a restructuring of patient billing,

moving costs from ambulance transport through to a palliative/ community care service. With the implementation of the National Health Insurance (NHI) equitable access to healthcare, including that of palliative care, may initiate private/ public sector service collaboration.

As per the previous paragraphs' discussion, the present healthcare system has challenges that would include integration and collaboration of public and private resources, and equity of care for all patients across socio-economic structures. Non-standardised healthcare information systems between facilities (public, private and interdisciplinary) could lead to gaps in patients' transitions of care and improvement of these systems would be an additional cost initially. Inter-professional capacity is noted to mitigate uncoordinated patient care associated with fragmented healthcare systems, limiting cost and improving care for vulnerable populations hindered by chronic disease as noted in the data review published by Clarke et al., 2017.

Clarke et al. (Mobile Integrated Healthcare, 2017), and Lebina et al. referring to the publication by Mahomed, Asmall and Freeman (Integrated Chronic Disease Management (ICDM) Manual, 2014), consider that a successful healthcare model, rests completely on the policies that support it, including the buy-in of stakeholders, sustainable funding, and effective leadership. The actual provision of care relies on sufficiently skilled, and trained human resources on the ground, in a realistic healthcare worker to patient ratio to effectively assist the patients they interact with to manage patients appropriately within the requirements of the Integrated Chronic Disease Model (Lebina et al., 2020). It is worth mentioning again that this model, or any other health systems model is reliant on collaboration between private and public healthcare sectors, especially under the auspices of the National Institutes of Health (NIH).

The role of acute/emergency care could be included under the umbrella of primary care as a vital component of the patient's path of care. Failing to identify a palliative care need at initial patient contact may result in an exclusion of a large percentage of patients that could benefit from palliative care, thereby increasing the patients' suffering. A pilot program, using EMS paramedics that are palliative –care trained, with physician support, will identify if there is a population that can benefit from palliative "out-of-hospital" care for certain conditions and symptoms. Furthermore, understanding perceptions of palliative care by South African paramedics' and the role EMS could play in assisting these patients will be necessary for palliative care to be implemented in the pre-hospital environment, and during transitions of care (Gage, Geduld and Stassen (2020)). A vital component of identifying patients that could benefit from palliative care, and providing consult support for paramedics, hinges on system change but also includes access to training in the use of screening tools such as SPICT (and now a recent SA SPICT tool see Appendix 2: SPICT^{TM} –SA, October 2020) which gives practitioners guidance, specifically giving a breakdown of what constitutes a need for palliative care for different diseases (Krause, Gwyther and Barnard, n.d.).

This process is critical when embarking on change within any system, including within South African EMS integrating into the healthcare system as part of a palliative care team and transition of care. A gap analysis, training of EMS champions and a pilot program could be practical steps towards identifying the need for palliative care and provision thereof for all patients, whether they are state patients or have medical aid. Record of patients transported to the local government hospital versus public/ private hospitals outside of the area would have indicated a time and resource cost to CMR. The time of call -out, as well as repeat call-outs to the same patient, would have been interesting to record in order to identify if there were similar trends to that of the US, Canada, Australia, Europe and the UK, who have revisited,

and adapted, how healthcare provision is being delivered. Paramedics in the out-of-hospital situation respond to, and assist, patients with chronic disease who may not require hospitalisation but who are experiencing exacerbation of their symptoms out-of-hours, or when their caregivers are fatigued or feeling overwhelmed (Clarke et al., 2017). The options for home-based, versus hospital, care still need to be patient and family centred, especially in middle-to-low-income countries where resources, and social context may not always be appropriate or comfortable for the sick (or dying) patient and the household.

With an increasing need for collaboration between emergency services, public health and primary healthcare, paramedics should have access to interdisciplinary care teams to assist with patient-referral decision-making. Paramedics, in consultation with a medical officer are able to provide symptom management and palliative care at home as described in the Novel Paramedic Long-Term Care Program (Jensen et al.), allowing for modification of algorithms, broadening the scope of paramedic practice (physician-supported) and administration of drugs appropriate for PC patients. This also offers a practical method of mitigating the costs accrued through repeat ambulance call-outs, and emergency centre use, as well as placing patient comfort first.

Access to interdisciplinary healthcare is steadily becoming highlighted as a human right to assist patients with NCDs, and their families, to manage the trajectory of disease. Education around what to expect symptom-wise, and disease progression, as well as spiritual, and emotional, support through transitions of care and end-of-life care are seen as a whole rather than in silos. Coleman et al. (2009) discuss models of care aimed at assisting patients, and systems, with healthcare education, advanced care planning, and how to access appropriate care. Goals of the CCM follows a team-based model, with patient-care team interventions, and joint planning and decision-making. Considering the cost of healthcare, and often the lack of resources, the inter-collaboration of healthcare systems and professionals is becoming imperative to prevent the collapse of such systems under the burden of chronic, non-communicable disease. One of the more mobile, and flexible components of healthcare is that of the Emergency Medical Services (Coleman et al., 2009).

It is often only when assistance is required in an emergency situation or exacerbation of disease, that patients will access healthcare out of desperation, with primary healthcare facilities and/or emergency services more than likely being the default initial contact. With EMS being recognised as routinely used to provide support, care, and advice, for these patients, this should indicate a need for appropriate education for paramedics required to manage these situations, access to specialist consult for advice, and the provision of specialised paramedics to assist with disease exacerbations and emergencies in the context of chronic disease (Al-Shaqsi, 2010; Lamba et al., 2013).

Successful transitions of care rely on effective communication such as referral notes and advanced care planning. This poses the question as to whether the omission of pre-hospital patient care by EMS is due to oversight, having insufficient data identifying the initial contact point of the patient care pathway, or the reluctance of the pre-hospital/ emergency service sector to be involved with palliative care. Evidently, a need for an integrated national health information platform has been highlighted with the proposed NHI development by the South African Department of Health. This platform will aim to improve communication between health entities and improve patient access to care (National Department of Health Republic of South Africa, 2019).

In response to this situation, research has been done that highlights the needs and gaps within systems that could benefit from access to palliative and home care (Arab, Carter and Harrison, 2016; Lord et al., 2019; Søvsø et al., 2019). The predominant message is that access to healthcare still remains a barrier to many patients due to issues such as transport constraints, unavailable nursing or home care, time challenges (especially for people working for a daily wage), transport (public transport is not always available and is expensive), and health education (people are not always aware of disease and the need for screening). These are consistent themes between high and low income countries, despite high income countries being better resourced (Clarke et al., 2017). As a result, palliative care policy has been initiated in these countries, to manage and enhance current healthcare approaches (Lord et al., 2019; Mason et al., 2007; Wiese et al., 2013). The fact that CMR is a subscription-based service means that palliative care could be offered as an add-on to the service, and patient/ care-giver education, and appropriate care for patients through transitions of care, could be more easily monitored, and secured by CMR. This does mean that patients with medical insurance, or those that have a CMR membership are more likely to have access to a palliative care service.

Paramedics from Canada, the UK, Australia and the USA have access to specialised education via adjunctive tertiary education to enable them to provide palliative care for patients at home, negating hospital transfer. In Europe, training in palliative care is now provided to doctors providing pre-hospital emergency care (Wiese et al., 2013). This specialised practice allows for effective clinical decision-making as to whether the patient can be safely cared for at home, including the provision of appropriate medication, or whether their condition may be better managed in hospital. This avoids patient crowding in emergency centres, and encourages appropriate paramedical care at home, with patients and their carers reporting a benefit in having access to palliative care at home (Mason et al., 2007; Lamba et al., 2013; Wiese et al., 2013; Arab, Carter and Harrison, 2016; Cameron and Carter, 2019; Scottishambulance.com, 2019).

The literature reviewed was generated from outside of the African and South African context, which potentially highlighted different challenges to those of South Africa. It is, however, likely that many of these challenges would be consistent with global findings when considering expanded roles of paramedical care in the South African context. As with any new professional role development, pilot programs need implementation, with cost implications tested and regulatory bodies updated.

The integration of palliative care remains a slow process. Limited experience, lack of trained professionals, limited understanding of the palliative care concept and practice, and patient education are barriers to implementing palliative care in healthcare systems (Asmall and Mahomed, n.d.).

5.3 LIMITATIONS TO THE RESEARCH

The use of symptoms and key words indicating chronic disease serve to highlight the number of patients potentially requiring palliative care for their NCDs over time, but the data does not truly identify the number of patients currently needing access to palliative care (as identified using the SA SPICT score). The data purely serves to indicate the number of patients that are not acute emergencies but are still needing medical, or transport support in a situation that they are not comfortable in managing themselves. Data captured over 1 year may also have been beneficial as seasonal trends would have been interesting to analyse, in the interests of EMS planning, identifying resource demand and supply.

The data analysis also indicates that areas such as Masiphumelele (a densely-populated township, with poor socio-economic demographics), Westlake, and Red Hill (lower socio-economic communities) have a very low number of call-outs to CMR in comparison with their area populations. This indicates that there may be missing data as many patients may have accessed alternate transport to hospital, rather than calling CMR. Patients with exacerbation of their NCDs are either not going to hospital, potentially dying without adequate end-of-life care, or are forced to access public-sector EMS or private transport to hospital. From a global, and South African perspective, data indicates that these populations have an increased risk of mortality and morbidity associated with NCDs. This highlights a consideration around distributive justice, in that Metro EMS may be transporting a number of patients that could benefit from a palliative care program, or care at home, to hospital. Alternatively, EMS may leave patients at home who have refused hospital transport, and therefore receive no access to appropriate care.

The NCDs included in the data focused on lung disease which included mention of COPD, but not asthma, as risk factors were seldom recorded in the patient PRF that could have indicated chronic disease. During data collection, structure of the patient PRF was noted by the researcher as omitting patient risk factors such as smoking, potentially exposing a gap in clinical reasoning and influencing differential diagnosis, especially in the context of "asthma" a term often used in the place of emphysema or COPD. This could indicate that the numbers for chronic lung disease may have been higher than recorded in the data extraction. In these cases, repeat call out information to the same patients would have been informative.

Heart disease included mention of CCF and cardiovascular disease, but the researcher could not always include those patient PRFs even though there was a high likelihood of cardiovascular disease as per medications recorded. This was done to maintain the validity and objectivity of the study. Again, record of repeat call-outs to the same patients would have been informative in highlighting the lack of advanced care planning, and the symptom exacerbation experienced by patients during the trajectory of their disease. It would also have made evident if patient care was administered differently by different paramedics, and what influenced the decision for ambulance transport, and ED admission.

Bias was noted as a possibility due to the subjective nature of record keeping. Paramedics working for CMR complete paper-based PRF after attending a call out. Each of these forms is backed by two transfer forms, one of which goes to the hospital, with the main form being filed by CMR, and the third form being kept as a copy. Each patient PRF should ideally be completed and audited. The efficacy and reliability of record keeping is potentially influenced by the subjective nature of paramedical scope of practice, clinical understanding and experience of each individual completing the patient PRF.

Limitations of this study include qualitative feedback from paramedics, and EMS providers. The absence of subjective (and objective) data leaves a gap in the understanding of how "burden" really is perceived, and experienced, by the individuals providing the patient –faced care, the patients receiving the care, and the organisations that need to budget, access and provide the service resources.

5.4 CONCLUSION TO DISCUSSION

In conclusion, there are multiple factors that disable the process of healthcare provision, and continue to increase the cost of healthcare, globally, and in South Africa. From this study's findings, it is evident that many of the healthcare

experienced by wealthy, developed countries, are similar to those experienced by South Africa, even in a small, contained community. Access to care, cost of care, limited communication during transitions of care and subsequent patient safety and quality of care (including ethical) issues continue. It is evident from the study that healthcare platforms continue to focus on the need for EMS as an acute care and transport system, evident from the fact that most patients, even if stable, are transported to hospital, and that consultation between paramedics and other healthcare professionals is uncommon. Isolation between healthcare disciplines potentially increases risk to patient safety through miscommunication and delays. It also results in overloaded healthcare systems, and limits patient autonomy and satisfaction with care, especially when PC provision may have been more appropriate.

Limitations to providing palliative care by South African EMS include disparities in patient socio-economic status, and lack of reliable care due to politics, crime, and EMS resources. The success of a pilot program that would provide palliative care via EMS relies largely on policy development, commitment to develop skilled interdisciplinary teams, and improve safe access to care at a regional level, before it is scalable to a provincial, and national level.

6 CHAPTER 6 – CONCLUSION AND RECOMMENDATIONS

6.1 INTRODUCTION

Palliative care is gaining ground as a necessary approach to patient-centred care, particularly for patients with NCDs. In order to meet the changing demands of healthcare, and adapting how patient care can be effectively supplied for NCDs, and achieve the health policy goals of the WHO, current health systems, and use of resources, need to be reviewed and adjusted to best meet the needs of a changing disease prevalence. EMS and paramedics are an available resource to assist with primary, and palliative care, if they are trained appropriately during their undergraduate, and post-graduate, education. Access to an available 24hour palliative/ home care network, in conjunction with education and EMS support, will be a good start towards identifying, and facilitating care for patients that currently, or in the future, will have need for palliative care.

6.2 THE RESEARCH QUESTION

The researcher aimed to evaluate the burden and management of acute exacerbations of chronic disease on a private emergency medical service in the southern sub-districts of Cape Town, and the need for pre-hospital palliative care provision.

The research achieved the stated objectives of quantifying the number of patients with NCDs and primary associated symptoms that CMR responded to. The primary symptoms of pain, SOB, cognitive changes and N&V were identified and reflected association with NCD, paramedic interventions and transport to hospital. The quantitative research approach was possibly not descriptive enough of the burden of NCDs on CMR, and therefore understanding the true need for pre-hospital palliative care education and provision needs further qualitative and exploratory research around educational approaches, and development of dedicated palliative care consultation and clinical support for South African EMS.

6.3 THE FINDINGS

In terms of NCD burden the results from this research indicate that close to a fifth of patients seen by CMR paramedics have NCDs. In terms of management these patients receive minimal, inappropriate, or no care by paramedics, for their symptoms associated with NCDs. They are frequently transported to hospital by ambulance, with no clear treatment path, or options for alternative care out of hospital.

The associated factors for the approach of EMS paramedics to patients with NCDs, and symptoms thereof, seem to be partly lack of insight into the pathology of the diseases, lack of educational guidance on management of these symptoms, but frequently not having consultation or home-care support, resulting in patients receiving minimal interventional care and inappropriate transport by ambulance to hospital. The present HPCSA scopes of practice, and the potential threat of malpractice (especially for private EMS services) can influence paramedics decision-making around clinical care, and transport options for the patient.

Other influences on present management of patients' symptoms, and unwillingness to treat patients at home without hospital transport, are identified as inadequate consultant support (and referral assistance), inadequate access to home nursing and palliative care programs, or other professional care for patients at home. These factors may be driven by socio-economics, patient/family dynamics, and/or misconceptions around palliative care by patients, paramedics, and doctors, leave few options for patient care outside of hospital, for patient, carers, or paramedics.

The data extracted from this study has similarities to much of the data, and experiences, published in international research. Themes consistently noted in literature are the need for paramedic education (palliative care), consultant and palliative care support networks, evolving paramedic scope of practice, patient/ carer experience, advanced care planning, and the need for appropriate and effective EMS care of patients with NCDs.

In terms of the need for pre-hospital palliative care provision, there are multiple factors that need to be addressed. A clear decision by the DoH, and collaboration with educational facilities and national EMSs to integrate primary and palliative care training into educational and service infrastructure is imperative for successful out- of- hospital palliative care provision. Furthermore, palliative care education for nurses, home care services and GPs is needed to create a robust, integrative system that encourages interdisciplinary communication and support. Ongoing research, with a pilot program similar to that of EPIC (Drennan et al, 2014; Dainty et al, 2018), are needed in order to evaluate the benefit: cost ratio of providing palliative care education and provision in the pre-hospital environment. Having focused on system gaps, and necessary changes, ultimately patient and caregiver education, and access to care, is integral to the success of such a program working.

This small-scale study highlights a gap in transitional care, advanced care planning and EMS approach to patients with symptoms of NCDs, indicating a need for provision of palliative care support in the out- of- hospital context.

6.4 RECOMMENDATIONS

Publications, and palliative care initiatives in the EMS context, have predominantly arisen from more developed countries. The researcher acknowledges that EMS in South Africa has challenges that may differ from many of these countries, with challenges often related to socio-economic factors, and large rural spaces with minimal, or no, EMS support. Many areas may not be accessible to EMS due to gang, criminal activities, and inappropriate home –care

situations. However, South African EMS experiences similar frustrations as in developed countries, and concerns around caring for the high number of patients living with NCDs, and the associated complexities of symptom exacerbation, inappropriate hospital admission, ineffective care and lack of systemic support.

The researcher recommends that a robust palliative care/ community care module be included in the Bachelor of Emergency Care (BMC) and MPhil Emergency Medicine programs, that supportive palliative care networks are made available to paramedics working in public and private sector EMS, and that paramedics, GPs and allied healthcare services can access specialised palliative care/ community care posts (especially in the rural sector). Interaction and communication between these multi-disciplinary role-players will improve continuity of care for patients, and provide support from EMS as a professional patient care facility, rather than just a transport service, ultimately expanding the scope of paramedic practice, and improving professional longevity.

It is recognised that change cannot occur in one healthcare sector only, or only in private healthcare, but that systemic change is necessary for a smooth pathway of care for patients from primary contact, through the trajectory of their disease, and ultimately appropriate palliative care support for patients and families at each stage of their disease journey. This approach would benefit the overburdened ED, healthcare system and ultimately patient care. Encouraging ongoing specialised education, interdisciplinary work and inter-facility patient/ practitioner support would improve paramedic retention in EMS, allowing for career progression, job satisfaction and improved patient care, especially for those many patients whose quality of life would be improved.

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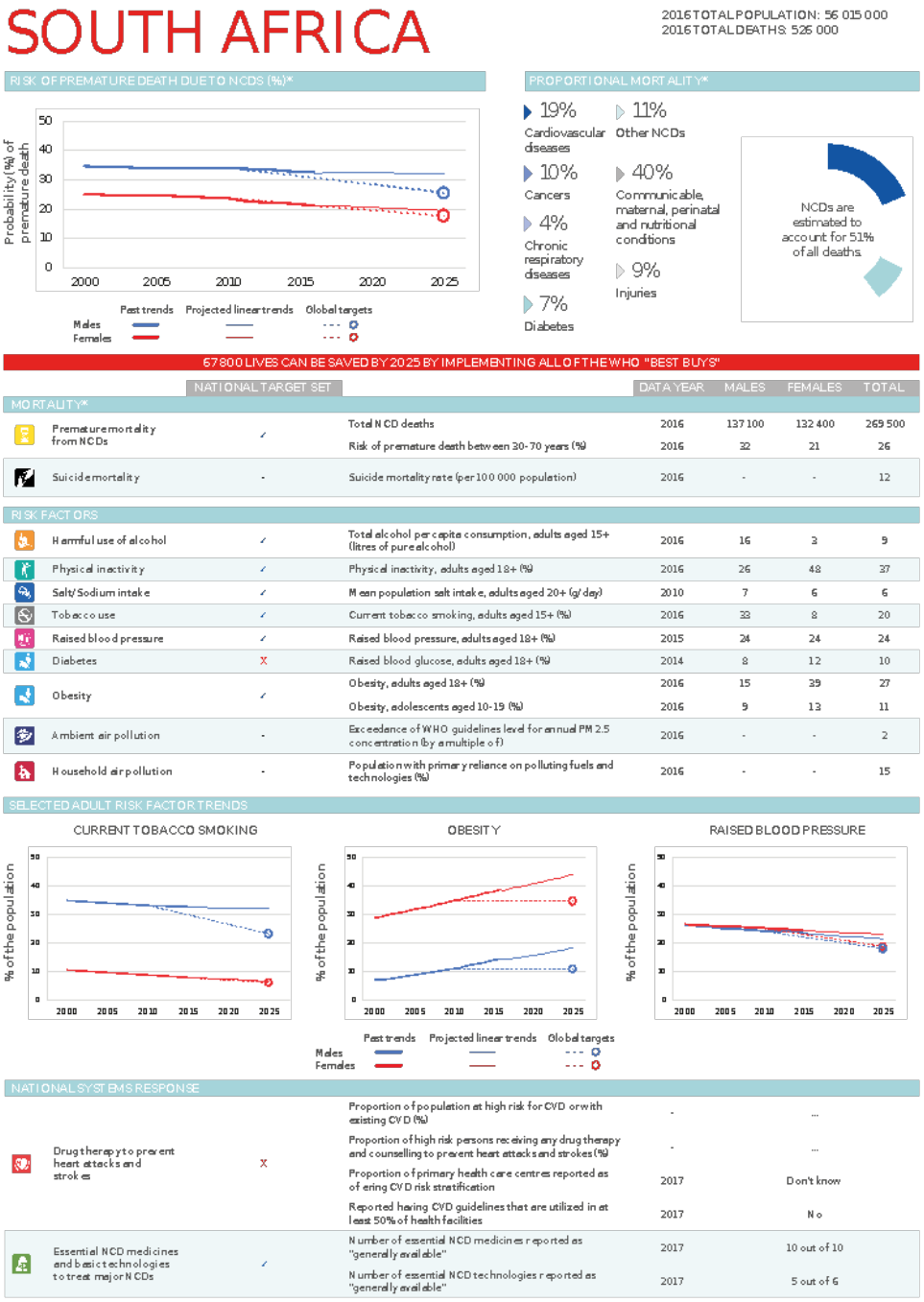
8 APPENDICES

8.1 APPENDIX 1: WHO NON-COMMUNICABLE DISEASE (NCD) COUNTRY PROFILES



SOUTH AFRICA

2016 TOTAL POPULATION: 56 015 000
2016 TOTAL DEATHS: 526 000

RISK OF PREMATURE DEATH DUE TO NCDS (%)*

Probability (%) of premature death

Past trends Projected linear trends Global targets
Males
Females

PROPORTIONAL MORTALITY*

19% Cardiovascular diseases
11% Other NCDs
10% Cancers
40% Communicable, maternal, perinatal and nutritional conditions
4% Chronic respiratory diseases
9% Injuries
7% Diabetes

NCDs are estimated to account for 51% of all deaths

67800 LIVES CAN BE SAVED BY 2025 BY IMPLEMENTING ALL OF THE WHO "BEST BUYS"

	NATIONAL TARGET SET		DATA YEAR	MALES	FEMALES	TOTAL
MORTALITY*						
Premature mortality from NCDs	✓	Total NCD deaths	2016	137 100	132 400	269 500
		Risk of premature death between 30-70 years (%)	2016	32	21	26
Suicide mortality	-	Suicide mortality rate (per 100 000 population)	2016	-	-	12
RISK FACTORS						
Harmful use of alcohol	✓	Total alcohol per capita consumption, adults aged 15+ (litres of pure alcohol)	2016	16	3	9
Physical inactivity	✓	Physical inactivity, adults aged 18+ (%)	2016	26	48	37
Salt/Sodium intake	✓	Mean population salt intake, adults aged 20+ (g/day)	2010	7	6	6
Tobacco use	✓	Current tobacco smoking, adults aged 15+ (%)	2016	33	8	20
Raised blood pressure	✓	Raised blood pressure, adults aged 18+ (%)	2015	24	24	24
Diabetes	X	Raised blood glucose, adults aged 18+ (%)	2014	8	12	10
Obesity	✓	Obesity, adults aged 18+ (%)	2016	15	39	27
		Obesity, adolescents aged 10-19 (%)	2016	9	13	11
Ambient air pollution	-	Exceedance of WHO guidelines level for annual PM 2.5 concentration (by a multiple of)	2016	-	-	2
Household air pollution	-	Population with primary reliance on polluting fuels and technologies (%)	2016	-	-	15

SELECTED ADULT RISK FACTOR TRENDS

CURRENT TOBACCO SMOKING

OBESITY

RAISED BLOOD PRESSURE

% of the population

Past trends Projected linear trends Global targets
Males
Females

NATIONAL SYSTEMS RESPONSE

Drug therapy to prevent heart attacks and strokes	X	Proportion of population at high risk for CVD or with existing CVD (%)	-	...
		Proportion of high risk persons receiving any drug therapy and counselling to prevent heart attacks and strokes (%)	-	...
		Proportion of primary health care centres reported as offering CVD risk stratification	2017	Don't know
		Reported having CVD guidelines that are utilized in at least 50% of health facilities	2017	No
Essential NCD medicines and basic technologies to treat major NCDs	✓	Number of essential NCD medicines reported as "generally available"	2017	10 out of 10
		Number of essential NCD technologies reported as "generally available"	2017	5 out of 6

... = no data available
*The mortality estimates for this country have a high degree of uncertainty because they are not based on any national NCD mortality data (see Explanatory Notes)

World Health Organization - Noncommunicable Diseases (NCD) Country Profiles, 2018.

8.2 APPENDIX 2: SPICT – SA SUPPORTIVE AND PALLIATIVE CARE INDICATOR TOOLS

SPICT™ - SA Supportive and Palliative Care Indicators Tool

SPICT™-SA is a generic tool to help identify adults with advanced life-limiting illnesses when the best available and appropriate treatment has been given and their condition continuis to deteriorate. These people benefit from a palliative care approach as well as ongoing care by their current clinician or team. SPICT™ is designed for South Africa and similar middle income countries and settings.

Disease Specific Indicators

Cancer

- Cancer not amenable to curative treatment.
- Progressive or metastatic cancer with symptoms.
- Too frail for oncological interventions.

Haematological Disease

- Haematological cancer with recurrent bleeding or infection or needing recurrent transfusions.
- Any haematological condition or cancer with deteriorating clinical condition and not responding to best available treatment.

Infectious Disease

HIV

HIV with deteriorating clinical condition and not responding to best available treatment.

TB

TB with deteriorating clinical condition and not responding to best available treatment.

Other

Other infections with deteriorating clinical condition and not responding to best available treatment.

Kidney Disease

- Stage 4 or 5 chronic kidney disease with deteriorating health.
- Stopping or not starting dialysis.
- Kidney disease complicating other life-limiting conditions or treatments.

Lung Disease

- Patients on long term oxygen.
- Breathlessness at rest or on minimal effort between exacerbations.

Heart / Vasoular Disease

- Heart failure or extensive, untreatable coronary artery disease with breathlessness or chest pain at rest or on minimal exertion.
- Severe, inoperable peripheral vascular disease.

Liver Disease

Cirrhosis with one or more complication in the past year:

- Diuretic resistant ascites
- Hepatic encephalopathy
- Hepatorenal syndrome
- Bacterial peritonitis

Neurological Disease

- Progressive deterioration decline in physical and/ or cognitive function.
- Increasing difficulty communicating and/or progressive difficulty with swallowing.
- Stroke with significant loss of function, and ongoing disability and dependency.
- Recurrent pneumonia, breathlessness or respiratory failure.

Dementia / Frailty

- Unable to dress, walk or eat without help
- No longer able to communicate using verbal language; little social interaction
- Recurrent febrile episodes or infections.
- Fractured femur/hip.
- Swallowing difficulties and/ or significant reduction in oral intake.

Trauma

- Severe burns (ABSI score >10)
- Brain injury with clinical deterioration and no benefit from surgical intervention.

Other Diseases

Any deteriorating clinical condition not responding to best available or appropriate treatment.

Look for one or more general Indicators of deteriorating health:

- Two or more unplanned health care facility visits within a period of 3 months with deteriorating life-limiting illness despite best available or appropriate treatment.
- Performance status is poor or deteriorating, with limited reversibility e.g. the person stays in bed or in a chair for more than half the day.
- Dependent on others for care due to increasing physical and/or emotional and/or mental health problems.
- The person's carer needs more help and support in caring for the patient.
- Progressive weight loss over the last few months or remains underweight or low muscle mass.
- Persistent symptoms despite best available or appropriate treatment of the underlying condition(s).
- The person (or family) ask for palliative care; chooses to reduce, stop or not have treatment; wishes to focus on quality of life.

Review supportive, palliative care and care planning

- Review current treatment and medication so the patient receives best available or appropriate care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT™ website (www. spict.org.uk) for information and updates

SPICT™, - SA, October 2020

8.3 APPENDIX 3: DATA EXTRACTION TOOL

Variable	Definition	Valid data included in analysis
Timestamp	Time and date the data was captured	YYYYMMDD hh:mm:ss
Call Date	Date of actual call attended by paramedics	YYYYMMDD
PRF Number	CMR patient report form number	10-digit PRF Number
Eligibility	Binary value indicating if call meets the eligibility criteria of the study	Binary – Yes or No
Reason for call	Reason given for calling out emergency services	Shortness of Breath (including asthma, coughing, gasping) Pain (including chest pain, abdominal pain) Nausea (including vomiting and diarrhoea)
Non-communicable Disease	Non -communicable disease recorded	Heart Disease, Lung Disease, Cancer, Renal Failure, Rheumatoid arthritis, Motor Neuron disease, Dementia
Patient Triage	Triage level of patient	P1, P2, P3, P4
Patient Location	Location of patient	Home, Clinic, Frail care, Hospital (including ward or emergency department, Palliative care unit (including Hospice), Pharmacy, GP Practice
Symptoms	Symptoms recorded by paramedics	Pain (including neural, muscular, somatic, chest, visceral)

		Shortness of breath (including bronchospasm, wheeze, pulmonary oedema, crackles) Nausea (including vomiting and diarrhoea)
Gender	Gender of patient	Male, Female, Other
Age	Age of patient	Numeric value
Demographic	Area that paramedics were called to	Fish Hoek, Muizenberg, Kalka Bay, St James, Simonstown, Glencairn, Red Hill, Scarborough, Ocean View, Kommetjie, Masiphumelele, Capri, Sun Valley, Clovelly, Lakeside, Noordhoek, Westlake
Intervention by paramedics	Interventions initiated by paramedic	Airway basic, Airway advanced, Breathing oxygen, Nebulizer, Ventilation – assisted, Fluids IV, Morphine route and dose, Lasix route, Ketamine route and dose, Midazolam route and dose , Diazepam route and dose , Lorazepam route and dose , Beta 2 stimulant, Ipratropium Bromide ,'Aspirin', Metoclopramide route and dose , Dextrose 50% , CPR - basic life support , CPR - advanced life support , None
Other consultation	Any other consultation paramedic requested	Patient's GP, CMR Doctor, Palliative Care Doctor, Hospice Doctor, Cardiologist, Physician, Gastroenterologist, Emergency Medicine Doctor, Oncologist, Home Nursing, CMR Management, None

Transport	Type of transport used for the call	Private, Ambulance, Helicopter, Funeral service (including mortuary van)
Receiving facility	Facility where the patient was transferred	Hospital Ward (including clinic), Hospital Emergency Department, Palliative care unit (including hospice), Frail care, home care, No care
Care plan / Documentation	Any care plan that the patient had in place or documented	Living Will, Advanced Care Plan, DNR, Doctor referral letter, Hospital appointment card
Special care mentioned	Any other special care that was mentioned to paramedic	Palliative care program, Home Nursing, Professional care giver, Occupational therapy, GP home call

8.4 APPENDIX 4: SOUTH AFRICAN TRIAGE SCALE

ADULT TRIAGE SCORE © South African Triage Group 2008

	3	2	1	0	1	2	3	
Mobility				Walking	With Help	Stretcher/ Immobile		Mobility
RR		less than 9		9-14	15-20	21-29	more than 29	RR
HR		less than 41	41-50	51-100	101-110	111-129	more than 129	HR
SBP	less than 71	71–80	81-100	101-199		more than 199		SBP
Temp		Cold OR Under 35		35-38.4		Hot OR Over 38.4		Temp
AVPU		Confused		Alert	Reacts to Voice	Reacts to Pain	Unresponsive	AVPU
Trauma				No	Yes			Trauma
over 12 years / taller than 150cm								

Colour	RED	ORANGE	YELLOW	GREEN	BLUE
TEWS	7 or more	5-6	3-4	0-2	DEAD
Target time to treat	Immediate	less than 10 mins	less than 60 mins	less than 240 mins	DEAD
Mechanism of injury		High energy transfer			
Presentation		Shortness of breath - acute		ALL OTHER PATIENTS	
		Coughing blood			
		Chest pain			
		Haemorrhage - uncontrolled	Haemorrhage - controlled		
	Seizure - current	Seizure - post ictal			
		Focal neurology - acute			
		Level of consciousness reduced			
		Psychosis / Aggression			
		Threatened limb			
		Dislocation - other joint	Dislocation - finger or toe		
		Fracture - compound	Fracture - closed		
	Burn – face / inhalation	Burn over 20%	Burn - other		
		Burn - electrical			
		Burn - circumferential			
		Burn - chemical			
		Poisoning / Overdose	Abdominal pain		
	Hypoglycaemia - glucose less than 3	Diabetic - glucose over 11 & ketonuria	Diabetic - glucose over 17 (no ketonuria)		
		Vomiting - fresh blood	Vomiting - persistent		
		Pregnancy & abdominal trauma or pain	Pregnancy & trauma		
			Pregnancy & PV bleed		
Pain		Severe	Moderate	Mild	
	Senior Healthcare Professional's Discretion				

8.5 APPENDIX 5: UCT FACULTY OF HEALTH SCIENCE RESEARCH ETHICS COMMITTEE (HREC) APPROVAL LETTER

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

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

06 August 2020

HREC REF: 176/2020

A/Prof L Gwyther
Department of Family Medicine
Falmouth Building-Entrance 5
Email: liz.gwyther@uct.ac.za
Student: linley.holmes@uct.ac.za

Dear A/Prof Gwyther

PROJECT TITLE: TO EVALUATE THE BURDEN AND MANAGEMENT OF ACUTE EXACERBATIONS OF CHRONIC DISEASE ON A PRIVATE EMERGENCY MEDICAL SERVICE IN THE SOUTHERN SUB-DISTRICTS OF CAPE TOWN, AND THE NEED FOR PRE-HOSPITAL PALLIATIVE CARE PROVISION - (Masters' candidate- Mrs Linley Holmes)

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

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

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 August 2021.

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

The HREC acknowledge that the student: Mrs Linley Holmes will also be involved in this study.

Please quote the HREC REF in all your correspondence.

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

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

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

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

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC 176/2020sa

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	30-03-2023
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	1/3/2022

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 the deviation document AR

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	28/02/2022		
HREC REF Number	176/2020	Current Ethics Approval was granted until	30/08/2021
Protocol title	To evaluate the burden of and management of acute exacerbations of chronic disease on a private emergency medical service in the southern sub-districts of cape Town, and the need for pre-hospital palliative care provision.		
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			

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

Principal Investigator	Linley Holmes
Department / Office Internal Mail Address	

1.1 Does this protocol receive US Federal funding?	☐ Yes	☑ No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval? **Note:** Any annual approvals for **Full Committee** review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-submission@uct.ac.za)	☐ Yes	☐ No

If yes in 1.2 please complete section 1.3 below for invoicing purposes

1.3 Ethics Renewal Fee

Please **(tick ✓)** appropriate box for billing purposes:

Submission Type	***Description***	***New fee (Vat Incl.)***	***tick ✓***
Research funded solely from UCT departmental/ divisional/group budget	Annual evaluation of research progress report for re-certification	**R0,00**	☐
Non-sponsored student research for degree purposes at UCT/Other Universities & Colleges	Annual evaluation of research progress report for re-certification	**R0,00**	☑
Annual re-certification / Progress report (FHS016 Form)	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Full Committee Approval	**R7000,00**	☐
Annual re-certification / Progress report (FHS016 Form)	Clinical Trial & International Grant Funded Research - Annual evaluation of research progress report for re-certification for Expedited review	**R3 710.00**	☐
Annual re-certification / Progress report (FHS016 Form)	National grant funded research - Annual evaluation of research progress report for re-certification for Full Committee Approval	**R6000.00**	☐
Annual re-certification / Progress report (FHS016 Form)	National Grant funded research for Annual evaluation of research progress report for re-certification for Expedited review	**R1 500,00**	☐

NB: Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from these charges.

Please provide details for invoicing, either complete section 1 or 2 :

1. Invoice billing – Directly to Sponsor

Sponsor's name	

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

Billing Address of Sponsor:	
Vat Number:	
Contact person	
Telephone number	
Email Address	
2. Internal Journal Billing:	
Fund Number:	
Cost Centre Number:	
Account Holder Name:	
Division of Account Holder:	

2. List of documentation for approval

3. Protocol status (tick ✓)

☐	Open Enrolment
☐	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☑	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	
Number of participants enrolled, since last HREC Progress report (continuing review)	
Additional number of participants still required	

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

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	

6. Cumulative summary of participants

Total number of participants who provided consent	
Number of participants determined to be ineligible (i.e. after screening)	
Number of participants currently active on the study	
Number of participants completed study (without events leading to withdrawal)	
Number of participants withdrawn at participants' request (i.e. changed their mind)	
Number of participants withdrawn by PI due to toxicity or adverse events	
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	
N/A	
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	
N/A	

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:
Research is complete, with the thesis in editing stages and final data analysis – submission of dissertation by April 2022

8. Protocol violations and exceptions (tick ✓ all that apply)

☑	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved

☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

☐	No Prior amendments have been made since the original approval
☐	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.
N/A

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	☐ Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?		
☐ Yes	☑ No	☐ Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	☑ No	☐ Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	☐ Not applicable

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

	DSMB report attached	☐ Yes	☐ No	☐ Not applicable

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	☑ No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
☑	Shown no change
If there has been a change, please explain:	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.

13. Insurance

Please confirm that valid no fault insurance is still in place? (tick ✓)			
☐ Yes		☐ No	
If yes, please complete the following:			
Insurer's name:			
Policy no.		*Coverage Period:	
For UCT sponsored studies please liaise the insurance office via fhs.sponsorship@uct.ac.za regarding the required documentation and information required obtain a renewed UCT No-fault Insurance Certificate.			

14. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	☑ No
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

15. Signature

My signature certifies that the above is complete and correct.			
Signature of PI		Date	28/02/2022

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

Form FHS011: Study deviation

HREC office use only (FWA00001637; IRB00001938)			
This serves as acknowledgement of a protocol deviation as described below.			
Chairperson of the HREC signature/ Designee		Date	1/3/2022

Note: Please note that incomplete submissions will not be reviewed.
Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please clarify your plan for research-related activities during COVID-19 lockdown

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	28/02/2022
HREC REF Number	176/2020
Project Title	To evaluate the burden of and management of acute exacerbations of chronic disease on a private emergency medical service in the southern sub-districts of cape Town, and the need for pre-hospital palliative care provision.
Protocol number (if applicable)	
Principal Investigator	Linley Holmes
Department / Office Internal Mail Address	Dept. of Family Medicine

2. Protocol deviation description

Please describe the deviation below, including the reason why the deviation occurred.
Research nd data collection had been finalized well before ethics approval expired 30/08/2021, but the write-up, data analysis and editing has taken longer than expected and submission of the dissertation will occur by the end of April 2022.

3. Follow-up actions

3.1 Please describe any follow-up action(s) taken or planned as a result of this deviation e.g. DSMB reporting, report to sponsor, informing participants.

Supervisors are aware of the required extension due to change in submission time
3.2 Please describe what action(s) have or will be taken to prevent similar deviations in future.
Dissertation is to be completed and submitted by end of April 2022

4. Principal Investigator's acknowledgement of responsibility

This signature indicates the PI has reviewed the deviation, taken appropriate follow-up action and implemented or plans to implement preventative steps where possible.			
Signature of PI		Date	**28/02/2022**

8.6 APPENDIX 6: CMR PERMISSION REQUEST LETTER

Dear CMR Management

Cape Medical Response

106 Kommetjie Road

Fish Hoek

7976

Permission request to undertake research at your facility

I am writing to request permission to undertake a research study at your facility in the southern sub-district of Cape Town. In order to complete the Masters of Philosophy in Palliative Medicine (Department of Family Medicine, University of Cape Town) I would like to evaluate the burden of chronic disease on your emergency service, and assess the need for identification, and provision, of pre-hospital Palliative Care.

Please see the proposal for this research attached to this email. Any of the data accessed for the research will be password protected and kept secure. This research will not interfere with management or care of patients

The length of time foreseen for the collection of this data should be three to four months, during 2020, and extended into 2021 as necessary.

The findings of my research will be made available to your facility with a printed dissemination brief and/or presentation, on request.

This proposed research has been granted ethical approval by the University of Cape Town's Health Sciences Research Ethics Committee and conforms with the principles pertained within the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research involving Human Subjects.

I look forward to working with you and will inform you as to when the research might begin (with permission from Monday 17th August, 2020). Should you have any further queries or comments in the interim please don't hesitate to contact me. If your concerns are of an ethical nature, please raise these with the UCT Research Ethics Committee.

Kind regards

Linley Holmes

linleyholmes@gmail.com

073 7554019

HLMLIN003