

AN EVALUATION OF THE PALLIATIVE CARE UNIT AT GROOTE SCHUUR HOSPITAL

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Abbreviations/ Acronyms

ED	Emergency Department
WHO	World Health Organisation
LCP	The Liverpool Care Pathway for the dying patient
NHS	The National Health Service (Public Health Service in the United Kingdom)
UK	United Kingdom
USA	The United States of America
SUPPORT	The Study to Understand Prognoses and Preferences for Outcome and Risks of Treatments Trial
DNR / DNAR	Do Not Resuscitate / Do Not Attempt Resuscitation
ICU	Intensive Care Unit
CPR	Cardio-pulmonary Resuscitation
ROSC	Return of Spontaneous Circulation
PCU	Palliative Care Unit
ACPU	Acute Palliative Care Unit

Dedication

To Gogo M.S., who was kind enough to show me the person behind the patient.

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Abstract

Background Patients often present to the Emergency Department (ED) at the end of life. Caring for these patients present a unique set of challenges, and often the patients' and families' needs are at odds with the pervasive rescue-oriented ED culture. A potential solution to this problem is an Acute Palliative Care Unit. Groote Schuur Hospital opened such a unit in April 2011, managed by the ED staff. This kind of service was not available in this tertiary, academic state hospital prior to that.

Objectives This study aimed to evaluate aspects of care at the Groote Schuur Hospital Palliative Care unit by designing a questionnaire based on the Liverpool Care Pathway assessing elements of care, describing the population admitted demographically, recording outcomes and making recommendations based on the findings.

Methods A retrospective folder review was completed on all patients who were admitted to the unit between April 2011 and May 2013. Data was collected onto an Excel spread sheet, and was analysed using the SmallStata 13 software package. Demographic data collected included sex, age, area from which the referral came, diagnosis, length of stay and outcomes. Data on care were grouped into physical care, psychological care, spiritual care, communication skills and bereavement care.

Results 176 folders were identified. 167 were reviewed (nine were missing). Nine folders did not meet inclusion criteria. 158 folders were included in the study. The vast majority of patients were admitted from home via the ED. Mean age was 59.49 years (95% CI 56.76 – 61.53). Median length of stay was 25 hours (IQR 7-47). 97 patients had palliative care needs in the absence of malignancy, 60 had cancer. 111 (70.7%) patients died in the unit, 5 (3.18%) died en route to the unit, 16 (10.19%) went home, 8 (5.1%) were referred back to other specialities and 17 (10.83%) were referred to step down facilities. 96% of patients had their medication adjusted, and 128 (81.53%) were commenced on syringe drivers. Morphine, haloperidol and hyoscine butyl bromide were the commonest prescribed medicine in the syringe driver. None of the patients had an official "Do Not Resuscitate" (DNR) form completed, but more than 75% of patients had a note or clear proxy measures indicating that resuscitation is not indicated. Difficulty with communication was present in 8 (5.26%) patients and 10 (6.58%) families. Less than 15% of patients had documented psychological support and less than 30% had documented spiritual care. Bereavement care was also poorly documented.

Conclusion This study described the demographics of, and evaluated the care offered in the Groote Schuur End-of-Life unit. Much of the care is comparable to current recommendations, but there is concern that symptoms may be underestimated in the absence of formal tools. Recommendations include using different terminology w.r.t. the unit, establishing a consulting and outpatient service based at the hospital, implementing formal symptom assessment tools, implementing the formal policy w.r.t. DNR orders, and improved overall documentation. There is scope for further research on interventions such as this one, especially on its impact on staff and its cost-effectiveness. This model of care achieves care comparable to current global recommendations in end-of-life care and can be implemented in similarly resource-restricted contexts.

Chapter One: Introduction

“[A] decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards”

Institute of Medicine. Approaching death: improving care at the End of life. Washington, DC: National Academy Press, 1997 ⁽¹⁾

Background

Death is defined as the permanent disappearance of all evidence of life after a live birth has occurred. ⁽²⁾ It is a common occurrence. Each year, 58 million people die worldwide. In 2013, 458933 people died in South Africa. ⁽²⁾ This number is expected to increase; as we live in an increasingly ageing society, with many chronic illnesses. ⁽³⁾

An ever increasing number of people die in hospital every year worldwide. ⁽⁴⁾ Most of these patients are admitted via the Emergency Department (ED), and many of these deaths occur in the ED. ^(5,6) Nearly 50% of Americans who died in 2001, died in hospital. In 2000, nearly 379 000 Americans died in the ED. ⁽⁷⁾ 44.2% of deaths in South Africa in 2013 were in hospital and 1.7% of all deaths occurred in the emergency department (ED). ⁽²⁾

The question of where people want to die is extensively studied. In spite of a trend towards more hospital deaths and fewer home deaths, most adults in Europe would prefer to die at home. ⁽⁸⁾

Historically, people died quite suddenly, from infectious disease or trauma, and suffering was often short. With improvements in medical technology (antibiotics, cardio-pulmonary resuscitation and intensive care) many people now survive these insults. This results in many people now living with a life-threatening diagnosis for months to years before death, causing protracted suffering. ^(9,10) A significant number of these patients present to the ED in the months and days before their death. ^(11,12) In light of this, it is unsurprising that an increasing body of literature is emerging about care of dying patients and their families in the acute ED context.

In view of the changing demographic of the world's population, and prolonged disease trajectories, leading to suffering, the World Health Organisation (WHO) has identified palliative care as a public health priority.^(3,13)

What is palliative care?

The World Health Organisation (WHO) defined palliative care in 1990 as

"... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment of treatment of pain and other problems, physical, psychological and spiritual."⁽¹⁴⁾ It is applicable early in the illness, when curative therapy is still being given, and becomes increasingly important as the disease progresses.⁽¹⁵⁾

The National Health Service Cumbria and Lancashire End of Life Care Network defines End-of-life care as *"care that helps those with advanced, progressive, incurable illness to live as well as possible until they die."* This definition encompasses both palliative and supportive care.⁽¹⁶⁾ However, there is little consensus about what end-of-life care and terminal care actually means.⁽¹⁷⁾

The Oxford Textbook of Palliative Medicine describes the terminal phase as the period of inexorable and irreversible decline in functional status prior to death.⁽¹⁸⁾

When patients present to the ED towards the end of their life, especially in the context of end-stage chronic disease, it becomes important that the approach to their care changes from a purely curative approach to an approach that acknowledges their palliative care needs.^(19,20)

Another kind of patient who presents to the ED, who may need palliative care, is the patient who suffers from a massive, sudden insult with a very poor prognosis, often without a previous life-threatening diagnosis.

Terminal care aims to control all symptoms associated with death (pain, breathing difficulty, and emotional distress) and hopes to achieve a "good death", a process that involves the patient and the people important to them.⁽¹⁵⁾ A discussion on what may entail good death will follow below.

The concept of a good death

What constitutes a good death? Emanuel and Emanuel described a very useful framework to approach the care of the dying, with the aim of ensuring a good death. They described an approach to a good death as a dynamic process with three major grouping of factors affecting it. These are fixed characteristics of the patient (disease, prognosis, socio-economic background), modifiable

dimensions of patient experience (symptom control, relationships and support, management of appropriate hope, economic concerns and spiritual/ existential beliefs), care system interventions (communication, spiritual and social interventions, withdrawal of life-prolonging treatment , pain service and hospice, and taking care of socio-economic matters), all interacting for an overall outcome – a satisfactory death experience. Looking at death in this way is beneficial, as none of these factors operate in isolation – depression and anxiety about an economic matter that is unfinished may lead to inadequate pain control, for example.⁽²¹⁾

Tookman described a good death to have occurred when the patient was at peace and the realisation that they were dying, felt that they had lived life to the full, was dying in the place of their choice, was surrounded by the people they wanted close by and was comfortable (symptom-free) physically.⁽²²⁾

Henwood described the concept more elaborately. A good death is likely to occur if a patient is able to retain control of what happens to them. This includes the ability to have some control over pain and other symptom relief. They must be able to have a choice and control over the location of death and who is present to share their ending. The patient should have the right to know when death is approaching and what to expect. This should empower them to be able to issue an advanced directive and have access to palliative care in any location that they may choose (not just in the hospice or hospital). They must have the privacy that they need, and have their dignity acknowledged. Further needs that they may have, including access to information, expertise and spiritual and emotional support, need to be met. Further control, including enough time to say goodbye is crucial. Finally, when the time arrives, they need to be able to leave – not forced to prolong their life pointlessly.⁽¹⁵⁾

Sadly, the notion of achieving a good death is often an unachievable goal, rather than standard medical practice. Partly this because of a persistent social attitude that views death as unnecessary, as opposed to a non-negotiable part of life.⁽²¹⁾ Bringing it back to the ED context, these difficulties are more prevalent, as often the terminal phase may be reached because of an acute catastrophic insult, giving patients essentially no time, and their families very limited time to come to terms with the death.

How can a good death be achieved in an emergency environment? Recent literature explores the opportunities for palliative care to be incorporated into the emergency environment. However, the interaction between emergency medicine and palliative medicine is a complex matter.

Why do people die in the emergency department?

Two studies in France showed that in up to 80% of patients who had died in the ED, a decision was made to withdraw or withhold treatment after an initial resuscitation attempt.^(23,24) People are often so “hopelessly ill”, that death is near and they die in the ED.⁽²⁵⁾

However, as important as palliative care and terminal care may be in the treatment of dying patients in the ED, it does not fit in with the traditional ED culture, which focuses on rapid diagnosis of illness and institution of curative treatment. Emergency medicine requires clinicians to make rapid decisions about treatment with limited amounts of information (about previous health status, as well as investigations) available. The ED is a fast-paced environment, with limited time to forge relationships with patients and families.^(7,20)

This causes a strange paradox. Even though the ED is not the most appropriate place to die a good death, deaths often occur there. Death in the ED is also often viewed by staff and families as an unexpected event or a failure of medical skill.^(23,26)

In the context of a previously diagnosed terminal illness, patients, their families and their doctors should have had the discussion on what course of action should be taken in the case of acute deterioration, before it occurs.⁽²⁷⁾ However, even if this discussion had taken place (and often it has not), patients or their families may activate the emergency response system or present to the ED because of sudden uncontrolled symptoms, carer fatigue or inability to care for the patient. Inadequate communication and understanding of disease trajectory or a sudden, distressing change in condition may lead to arrival of these patients to the ED. For whatever reason they may present, they expect excellent care when they arrive – although they may also inappropriately expect life-saving measures- and they need their distress dealt with.^(7,11,28,29)

In the context of a new, catastrophic insult, for example significant hypoxic brain injury after successful CPR, the patient and family may have expectations of a cure, when the outcome is bound to be poor, which adds an additional level of complexity.⁽³⁰⁾

The study mentioned earlier in France and Belgium showed that just over half of patients who died in emergency units received some form of palliative care. The administration of palliative care was associated with several clinical conditions, namely metastatic cancer, liver disease, severe neurological or respiratory disease and the decision to withdraw or withhold life-supporting intervention. It was also associated with being in the observation unit of the ED, as opposed to examination cubicles.⁽²⁰⁾

This study also reiterated that end-of-life models do not fit in well with the emergency unit environment, which focuses on curing or stabilising acute injury and illness, and where the health care team may have limited access to the patient's history. The researchers agree that basic palliative care education is essential for emergency unit staff.^(7,31)

The situation is similar in the United Kingdom. More patients are presenting to emergency departments annually, and many of them are older people. A study conducted in South East London found that of all the patients aged 65 years and older who died in the emergency department, over half had presented in the preceding twelve months with a diagnosis that signalled a palliative care need, but very few were known to palliative care services.⁽¹⁹⁾ This indicates either an unawareness, or reluctance from emergency unit staff for timely referral of patients with complex needs. Early referral may prevent inappropriate presentation to the ED, giving patients a choice in location of death and reduce numbers and pressures on EDs.^(19,32) This responsibility does not lie with ED staff primarily, but rather with the doctors primarily responsible for their care – before crisis sends them to the ED.

Barriers to palliative care in the emergency department

There are multiple barriers to providing palliative care in the ED. These can be classed broadly as infrastructure-, hospital- and family-related.

Infrastructure-related barriers include the physical environment in the ED. Overcrowding, lack of privacy and a noisy environment are a few infrastructure-related barriers to quality palliative care in the ED.^(26,33)

Hospital-related barriers include both staff- and management-related barriers. Staff-related barriers involve the education of staff. Health care providers receive far more education about curing disease (as is to be expected) than about helping patients and families prepare for approaching death. The problem with this approach is that when cure is not a viable option, patients may be offered inappropriate care or – worst case scenario - no care at all. Nurses, especially, need to be versed in terminal care in the acute context. Beckstrand *et al* interviewed emergency nurses and identified several obstacles to providing adequate supportive care in the ED. These included high workloads not allowing adequate time to spend with dying patients and their families. ED staff feeling uncomfortable with death and dying, including their own mortality may add another barrier in providing care to dying patients and their families. Limited knowledge of primary care systems and

community palliative care systems add to the difficulty of getting patients to receive appropriate care. In a busy emergency environment, there are often severe time constraints, and this may negatively impact the doctor-patient relationship. Management-related barriers include poor referral pathways, poor financial incentives for providing palliative care, and assessment that does not prioritise care, but rather waiting times and cost.^(7,26,29,33) In South Africa, until recently, most public hospitals did not have a formal palliative care service and thus policies and protocols are sparse.⁽³²⁾

Family-related barriers involve patients and families having unrealistic expectations of medical care, and not realising what “life-saving” measures entail. Complicated family dynamics often tend to surface during times of extreme stress, making honest discussions and mutual decision-making extremely difficult. This, alongside with the fact that the ED is a high-paced environment (often overwhelming and terrifying to the patient and family) with limited time to establish rapport and a therapeutic relationship, can make doctors’ dealings with dying patients and distressed family members fraught with difficulty.⁽²⁶⁾

In spite of all these barriers, often it is crucial to commence palliative and/or end-of-life care in the ED. De Vader *et al.* showed that many of the above-mentioned barriers could be mitigated by a brief educational intervention. However, time constraints and the difficulties establishing the rapport and relationships perceived as necessary to have difficult discussions persisted.⁽³⁴⁾

Integrated care pathways

The concept of care pathways, or multidisciplinary action plans, has its roots in engineering, where it was used to assess quality in manufacturing. The “pathway” defined processes and audited variations and outcomes. In the 1980’s, the concept spread to the health care sector, in an attempt to deliver health care in a patient-focused, measurable way.⁽³⁵⁾

A care pathway has several aims. These include organising the process of the admission (administrative), identifying important outcomes and defining the tasks necessary to achieve these, avoiding duplication of procedure, fostering understanding of all team members’ roles, improving communication and continuity of care, aiding in decision making and problem solving. In addition, it aids by prompting discussion of the patient among team members, reducing paperwork, integrating research, policy and guidelines into one document, keeping track of whether outcomes were achieved and reducing inappropriate variation in practice.^(35–37)

All pathways have core elements. These include 1) *A measured timeline*. The length of the timeline will vary according to the setting of the pathway. 2) *Supportive evidence of practice*. Practice should be able to be adjusted as new information becomes available. 3) *Multidisciplinary involvement*. The aim is to be a unifying document across disciplines, to enhance communication. 4) *Elements of care are defined, usually within the context of the timeline*. This is meant to be a prompt for good care. 5) *Continuous review of practice*. Pathways create an easy way of auditing practice, both at point of care and retrospectively. 6) *It replaces the clinical record*. It is not meant to be additional paperwork, but rather aims to minimise paperwork to free up clinical time. 7) *It travels with the patient*. 8) *Risk and benefit*. It improves documentation and communication, increasing patient satisfaction and protecting health care providers by documentation.⁽³⁵⁾

A well-known integrated pathway at the end-of-life (the last few days before dying) is the Liverpool Care Pathway (LCP). Initially, the pathway was lauded as an excellent tool to improve care of the dying. However, in 2009, media frenzy ensued, claiming that patients were put onto the pathway inappropriately and without their families' consent.⁽³⁸⁾

In response to this, the National Health Service of the United Kingdom (NHS) commissioned an independent enquiry, led by the Baroness Julia Neuberger. The review found that, in spite of good principles underpinning the approach, the pathway was often initiated and managed inappropriately, leading to distress of patients and family members. Poor communication was mentioned as especially problematic.⁽³⁹⁾

In the aftermath of this report, a Cochrane review was published assessing the impact that the Liverpool Care Pathway (and other related end-of-life pathways) had on the quality of care of dying. Surprisingly, they found no studies that qualified for review. This means that of 2042 potential studies that were reviewed, none satisfied the criteria of being randomised, cluster-randomised, quasi-randomised, or controlled before-and-after studies.⁽¹³⁾ The authors concluded that the evidence-base for using integrated care pathways at the end of life is lacking, and thus did not recommend their routine use, especially considering the multiple concerns (including safety concerns) brought to light by the Neuberger report. However, they agreed that the pathways are based on sound principles of palliative care and recommended further research, especially adequately controlled trials.^(13,39)

Since the Cochrane review and Neuberger report, one cluster randomised control trial has been published, dealing with end-of-life pathways. The findings were that there was no significant

improvement in care when an end-of-life pathway was employed. This will be discussed in greater detail in the next chapter.

A new document, “One Chance to get it Right” was published by the Leadership Alliance for the Care of Dying People in the UK in June 2014. The principles of sound palliative care are outlined, and this will serve as a new policy document going forward, replacing the LCP.⁽⁴⁰⁾

Acute palliative care

When faced with the difficult clinical situation of caring for the dying in an emergency situation, it would seem that clinicians now have an even bigger dilemma. They may or may not feel adequately equipped to deal with dying patients, and the main resource they could have drawn on previously, has been withdrawn. Where to from here? It seems that the literature has exploded with recommendations. Commitment to quality palliative care seems as high as it has ever been. A new gold standard document has been published, outlining a new approach to the care of the dying. However, it serves to state, that the approach is *not* new. It includes the principles that the LCP was founded on, but it emphasises patient-centredness and moves away from “ticking-the-boxes” for its own sake. The five so-called “Priorities of Care” outlined in the new document, “One Chance to get it Right”, describe priorities to implement.

“When it is thought that a person may die within the next few days or hours”: “1) This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly; 2) Sensitive communication takes place between staff and the dying person, and those identified as important to them; 3) The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants; 4) The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible; 5) An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.”⁽⁴⁰⁾

In terms of the place of terminal care for patients identified in the ED as actively dying, several options exist. Some units prefer to keep the patients in the ED, especially if a more private side ward is available. Referral to palliative care services or hospice is possible, as is sending the patient home, if adequate support is available in the community.^(10,32,41)

Another option described in the literature is an acute palliative care unit. This is relevant to all dying patients, not just patients from the ED. Mount described the experience at a hospital in Canada in 1976. A palliative care service was integrated into the hospital, comprising of three branches – a palliative care facility in the hospital, allowing primary care physicians to continue managing their patients concurrently with the palliative care team, a domiciliary service, allowing patients to be cared for at home and a consultation service on the general wards. This allowed patients to receive quality palliative care in the setting of their choice, and eased the stress of caring for dying patients in other acute wards.⁽⁴²⁾

The situation at Groote Schuur Hospital

Groote Schuur Hospital is a large tertiary teaching hospital in Cape Town. The hospital has 964 inpatient beds. In recent years, more of the government's health budget has been invested in primary care facilities. This has led to Groote Schuur Hospital experiencing budget constraints, leading to bed numbers being cut. This has been coupled with an increase in numbers of patients presenting to the hospital for care. The medical emergency unit is extremely busy, treating up to 2700 patients per month. Stretcher occupancy pushes the hospital past capacity and the waiting time for admission into a ward bed ranges from 24 hours to 72 hours. As a casualty unit treating acutely ill patients, there is a mortality rate of 60-80 patients per month in casualty.⁽⁴³⁾

Before the acute palliative care unit existed, dying patients would be kept in the ED, dying on a stretcher, not a bed, and their families, if present, adding to the significant overcrowding experienced in the unit.

In an attempt to improve the care of the dying and their families at this hospital, a palliative care unit was proposed. This unit offered a service to patients assessed as dying with no reversible factors. The aims of the unit were to provide quality terminal care to patients and their families in an environment that was more suitable than the ED, give families 24-hour access to their dying loved ones and provide supportive care for families.

The unit opened in April 2011. There is no staff member exclusively dedicated to the unit. When patients are admitted, an enrolled nurse or nursing assistant from an adjacent ward attends to the patients. If the unit is empty, s/he returns to duties in the adjacent ward. S/he is assisted by the professional nurse in the adjacent ward. The head clinician from the Emergency Department does a daily ward round to assess patients and adjust their treatment. The local hospice, St. Luke's Hospice, has assisted the process by offering on-going training, mentorship and a weekly ward round to involved staff. To date, there has not been a formal audit on the intervention.

The Unit is situated within Groote Schuur hospital, a large tertiary referral hospital in Cape Town. The unit is attached to a medical ward and has 4 beds. The unit is one large ward that can accommodate 6 beds if need be. Admission rates during the study period ranged from 1-15 patients per month.

The current research aimed to evaluate the unit, in terms of demographics, length of stay and care offered in the unit. Only by describing the patients admitted and care offered this unit, can one have a baseline to compare it to current recommendation. The aim is to assess the impact this unit has had in this context, and how the intervention can be improved.

Chapter Two: Literature review

“The timing of death, like the ending of a story, gives a changed meaning to what preceded it.”

Mary Catherine Bateson⁽⁴⁴⁾

Dying is an event that will ultimately happen to everyone. Society’s perceptions and beliefs about death have changed over the years. Previously, death was considered part of life – inescapable. With recent advances in medical research, many previously life-threatening illnesses became curable, leading to death being perceived as a failure in medicine, and anxieties related to death escalating.

However, death is still present with us. It is still inescapable. What has changed, significantly, is the causes, perceived timing, location and medicalization of death.

Epidemiology and place of death

Gomes and Higginson, in 2008, looked at mortality trends from 1974 – 2003 in England and Wales. Their method was based on official statistics, with forecasts modelled on trends of the last five years of their data collection period. They found that the number of deaths fell by 8% between 1974 and 2003, but that it is expected to rise by 17% during the period between 2012 and 2030. More deaths are likely to be at an older age, with 44% of deaths being in people age 85 years and older, as opposed to 32% in 2003. The proportion of home deaths are likely to decline to under one in ten deaths by 2030 – meaning more people will die in institutions. Their conclusion underlined the need for future planning in providing end of life care.⁽⁴⁵⁾

In response to this, Hospice UK launched a campaign aimed at the public to put pressure on politicians. In a brief, called *“The crisis facing terminally ill people and their families”*, they advocate for around-the-clock access to palliative care consultation, expedited, free social assistance for terminally ill people and their carers, increased coordination between various health services (by means of electronic record keeping), increased funding for research pertaining to the end-of-life and increased feedback from affected family members about their experiences. The aim of this campaign is to increase the number of home deaths by supplying the support currently lacking in the community.⁽⁴⁶⁾

The World Health Organisation (WHO) published a policy statement, called *“Better Palliative Care for Older People”* in 2004. Changes in disease profile and ageing populations mean that serious chronic

illnesses are far more prevalent. In the developed world, public health advances, including prevention and treatment of infectious diseases and decreased childhood mortality mean that far more people are living into their sixties and beyond. In France, the United Kingdom, Germany, Italy and Japan 4% of the population are over the age of 80. In the face of this, and considering the complex needs of people approaching the end of their life, the WHO stated that palliative care should be integral to all health services offering care to older people.⁽³⁾

Further recommendations include that health care professionals should ensure their own adequate training in palliative care, respect older individuals' rights to decision-making and help to build an integrated system of referral between different services. Policy and decision makers should acknowledge the public health implications, especially the palliative care needs of ageing populations, institute quality improvement activities to implement and improve quality of care to these populations, have local governance of care facilities and care planning, ensure sufficient training in palliative care, encourage patient-centred care and active decision-making and provide information on services offered to people facing life-threatening illness.⁽³⁾

Ten years later, at a World Health Assembly meeting (23 January 2014) the importance of palliative care across the board in health systems and the role of end-of-life care were re-iterated.

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

"...palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care;"⁽⁴⁷⁾

The outcome was the integration of palliative care across the continuum of health care systems. Palliative care actions and indicators have been included in the WHO comprehensive global monitoring framework for prevention and control of non-communicable diseases and the global action plan for prevention and control of non-communicable diseases 2013-2020. This was the first time palliative care was debated in this context, and the adoption was by unanimous vote.⁽⁴⁸⁾ The interdisciplinary nature of palliative care is mentioned as both a strength and a drawback. This is because effective palliative care relies on robust networks between professional palliative care providers, support care providers, volunteers, affected families, the community, acute care

providers and aged care providers. These relationships are crucial but often suboptimal. As De Vader and Jeanmonod noted in 2012, even when ED physicians recognize the need for referral to palliative care, their knowledge on how to refer to palliative care services was often lacking.^(33,47)

Providing care at the end-of-life presents many challenges to health care providers, patients and families. Many people would prefer to die at home. Gomes *et al.* conducted a study in 2012 in which a telephonic survey of people older than sixteen years in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain found that between 51% and 84% of people would prefer to die at home if they were known to have an incurable disease.⁽⁸⁾ This trend is similar in the United States of America, according to Morrison *et al.*⁽⁴⁹⁾

In 2000, Higginson and Sen-Gupta performed a systematic review of the literature regarding patient wishes concerning end-of-life care setting. All studies included in the review had methodological issues – low or unreported response rates, measurement and sampling bias and loss to follow-up. Most studies dealt with patients suffering from cancer. More than 50% of respondents preferred home care, and slightly less than that preferred actual home death.⁽⁵⁰⁾

A similar trend was found by Meñaca *et al.* in their study, based in the south of Europe, where in spite of differences in culture and lower rates of disclosure of prognoses than other studies, fewer people died at home than what their wishes suggested.⁽⁵¹⁾

Leadbeater and Garber set out in 2010 to audit the place and manner of people dying in Britain and project how this may change in the future. Next, they investigated experiences of, and attitudes to death and dying from several stakeholders; as well as identify national and international examples of innovations that have improved people's experience at the end-of-life. They also investigated costs of end-of-life care in Britain and how these may change under several possible scenarios. They collected data using archives, online polls and field research. Archival data collection was an in-depth literature search of grey literature, peer-reviewed literature and government publications. The online polling was administered by YouGov PLC. The poll had a sample size of 2127; the response rate was not reported accurately. This may be related to the fact that they did not do their own data collection. The sample is reported to be representative of all UK adults, but they do not specify how that was calculated. Field research included interviews, focus groups and ethnographic type research. People interviewed included dying people, their families, bereaved family members, academics, policy experts, government officials and medical and ancillary staff members. Ethnographic visits were made to three hospices and four care homes. Their methodology clearly described how they recruited vulnerable participants in a way that was less likely to harm them.

This varied based on the context. They were also clear about their data protection policy. Data analysis was similar to grounded theory, but they had started with concepts that they wanted to test from their literature search.⁽⁵²⁾

This is an important study, as it looks at the multiple facets that influence death outcomes. However, it is difficult to comment on the rigor of the methods used in the polling, as the administration of the polls was not conducted by the authors, but by YouGov PLC. The findings reflect current literature well, and the report is important in its comprehensive nature.

Their findings were that two thirds of people would prefer to die at home, one per cent would prefer to die in a care home and seven per cent of people would prefer to die in hospital. They did not report where the remaining 16 per cent of people would like to die. They compared this with Gomes and Higginson's⁽⁴⁵⁾ 2030 predictions of fewer than one in ten people dying at home, twenty per cent dying in care homes and 58 per cent of deaths likely to occur in hospital. Their work looked at ways to reconcile people's wishes regarding dying to the reality, so that people can "*...die with family and friends nearby, cared for, free from pain, with medical support available when it is needed.*"⁽⁵²⁾

The recommendations in this report echo many others in the literature. They include creating a safe environment for people to communicate their wishes with regards to dying, more widespread training in palliative care for doctors, nurses and home based carers, to learn from hospice models to provide holistic care and finally to work at actively integrating public, private and voluntary services to provide congruent care.

The report also advocated for creation of places to die that are closer to communities, with back-up medical services accessible, supporting family carers a model demonstrated by hospice care. More appropriate support of family members – including extra leave and/or financial support was recommended as well as coordination of volunteer efforts on a bigger scale, creation of an on-call nursing support service at all hours, creation of a telephonic help-line for carers of people at the end-of-life, nationalising hospices and educating society with regards to end-of-life planning.⁽⁵²⁾ Some of these recommendations will be described further later in this chapter. Many of these services are provided by community hospices both in the UK & in South Africa

As mentioned earlier, most people wish to die at home. However, these same people do not wish to be a burden to their family, and this is cited as one of the reasons why so many people present to hospital at the end of life.^(52,53)

The concept of a good death

When considering how to approach end-of-life care, especially in a context of people presenting to hospital and not necessarily wanting to be there, one needs to consider what the goals of treatment are, i.e. how does one achieve a so-called “good death”? Emanuel and Emanuel wrote a review/expert opinion article discussing this complex topic. Their starting point is that a ... “*decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.*”^(1,21) They argue that, in spite of this being a worthy ideal, the vagueness of the terminology makes it difficult to achieve that ideal. This is a valid point, and one that will be discussed again later. In spite of the fact that a good death will have to be individualised for each patient, it is important to look for generalizable factors that can be improved upon. The authors then offer a comprehensive chart showing how several factors interact in the death experience. These factors are described in the introduction chapter. Looking at dying in this comprehensive way is extremely useful in individual patients, but it may very difficult to translate into measurable outcomes on a policy level.⁽²¹⁾

Leadbeater and Garber summarises this difficulty in translating these outcomes in to measurable goals. “*All this means that a good death cannot be delivered to someone in the way we deliver parcels, pizzas or even babies.*”⁽⁵²⁾

It would seem that a good death is achievable in many cases, especially if patient autonomy can be preserved and physical transitions (between places) can be avoided.^(22,54)

Walczak *et al.* conducted a qualitative study in patients in Australia and the USA who had a diagnosis of incurable cancer with a prognosis of less than twelve months. The research explored communication relating to prognosis and end-of-life care, and ways to optimise these discussions.

Two main themes emerged in their research. The first theme related to the patients’ readiness for end-of-life. Subthemes included adjustment and acceptance of the condition (influenced by coping style, exposure to disease symptoms and/or imaging, mental space, religion or spirituality, family, age and time) and doctor/patient relationship and communication skills. The second theme related to prognostic discussions, needed to achieve readiness for end-of-life discussed in the first theme. Both doctor and patient needed to be ready for the conversation in order to have a successful outcome. The outcome of the discussion had two subthemes – achievement of a sense of control and moving on.⁽⁵⁵⁾

This study exhibited good rigor in thematic analysis, using iterative consensus. The response rate is reported and acceptable. The limitations include that both groups were in a first world context, and only included English-speaking participants, leaving concerns about the usefulness of this information in the South African context. However, in spite of some differences between the groups and major differences between the US and Australian health care systems, the two groups' responses were so similar that it very well may be applied in our context.⁽⁵⁵⁾

Steinhauser *et al.* tried to quantify people's needs at the end-of-life. They recruited a group of 1462 people, including seriously ill patients, bereaved family members, doctors and other care providers. Their measurements consisted of Likert scale rating of 44 attributes of experience at the end-of-life, previously encountered in focus groups and in-depth interviews. Then, participants had to rank the nine most common items identified in the focus groups and rank them from most to least important.⁽⁵⁶⁾

The response rate to the mailed surveys was very good, at 77.5%. 26 items were ranked as very important by more than 70% of all participants. These can be grouped into symptom control, or care-related (freedom from pain, anxiety, dyspnoea, being clean and having physical touch), adequate preparation for the end-of-life(financial preparation, knowing what to expect, feeling prepared to die and knowing that your family is prepared for your death), achieving closure or completion (saying all important goodbyes, resolving unfinished business and remembering your accomplishments), and treatment preferences (having them in writing or having appointed a trusted proxy). The nine ranks from previous research were rated, from most important to least as freedom from pain, being at peace with God, having family present, being mentally aware, having your treatment choices followed, having your finances in order, the feeling that your life was meaningful, having conflicts resolved and to die at home.⁽⁵⁴⁾

To connect these wishes back to the fact that people would like to die at home, it becomes evident that, approached correctly, a good death can be achieved in places other than the home environment – even a place like the Emergency Department.⁽⁵⁶⁾

Death in the Emergency Department (ED)

There are many reasons why, in spite of the fact that most people report preferring home death, many present to the ED at the end-of-life. Firstly, one must consider the group of people, without known terminal disease who present to the ED after catastrophic insult – cardiac arrest, major trauma and other insults with very poor prognosis. These patients present a special challenge, as their families are often completely unprepared for such a crisis, and the patients are usually not conscious.⁽⁶⁾ In addition, there is the group of patients that are known with terminal illness, but presents to the ED because of patient or family distress, severe symptoms, inability to care for them at home, poor communication and/or insight, as well as carer burnout.^(7,29)

Another important concept in understanding why deaths may occur in the ED in the context of chronic life-threatening illness is the concept of different disease trajectories and the difficulty of accurate prognostication.^(52,57)

Murray *et al.* wrote a clinical review on this concept in the British Medical Journal in 2005. They divided chronic illness as having three major trajectories. The first trajectory described is one with a short period (usually a few months) of evident decline, a common example being cancer. Function is typically high until the last few months. With early diagnosis and improved treatment options, oncological intervention may have short term positive and negative effects on function, but function is generally preserved until a fairly predictable course of decline in the final weeks or months of life. Patients may present to the ED in this time because of symptoms burden, carer fatigue, or poor communication and understanding leading to anxiety about what is happening. This echoes the reasons cited by Chan in 2004 as to why people may present to the ED in a known terminal illness. Leadbeater reproduced Murray's trajectories and superimposed the physical, social, psychological and spiritual well-being of the patient.^(7,52,57)

The second trajectory Murray describes is of organ failure. This typically has long-term functional limitation and slow decline, punctuated by severe illness exacerbations. This is where providing end-of-life care becomes more complicated, as each of the exacerbations are potentially fatal, but most are treatable and the patients improve. These patients tend to present in an acute deterioration and curative treatment is usually indicated, unless refused by the patient in an advanced care plan. The impression is often that these patients died suddenly and/or unexpectedly, even though the trajectory suggests otherwise.⁽⁵⁷⁾ This is why work is now being done to offer early palliative care to these patients (often concurrently with life-prolonging treatment), to improve their quality of life

and eventual death experiences The work done by the Gold Standards Framework is an example of efforts to offer early palliative care to people without malignant disease.^(58,59)

The last illness trajectory described by Murray is the one of prolonged dwindling. This usually happens in old age, with increasing frailty, as well as in dementia. These people lose weight and become increasingly frail until an otherwise less serious event, like a fracture or pneumonia, causes their eventual death. The case studies presented in Leadbeater and Garber's introduction describes this trajectory well.^(52,57)

Death is a common occurrence in the ED. However, death in the ED is often different from death in other settings and often far from the "good death" ideal discussed previously. Van der Heide *et al.* and van Tricht *et al.* summarises these differences to include the unexpected nature of many of these deaths, lack of time to build a doctor-patient relationship (and families often feeling isolated from the doctor), the rapid rate of decision-making, the lack of background information and the high incidence of resuscitation.^(6,20,60)

Van Tricht *et al.* performed a post-hoc subgroup analysis on a cohort of 2420 dying patients in 174 emergency departments across France and Belgium to explore the provision of palliative care in this setting. The motivation for their study included other studies that showed that increasing numbers of people who present to medical emergency units each year come in with life-threatening and often life-ending illness. In 80% of these patients, according to a large multi-centre study in France (Le Conte *et al.*), a decision is made in the ED to withhold or withdraw life-support therapies.^(20,23)

Their methodology was a retrospective folder review by a senior clinician, using a standardised data collection sheet in all the participating centres. The study protocol included a definition of palliative care and the data collection sheet had a tick box answering whether or not palliative care was provided. The following actions were also recorded separately: administration of analgesics, sedation, mouth care, repositioning for comfort and emotional support to the patients and their families.⁽²⁰⁾

Van Tricht *et al.* found that about half of dying patients in the emergency department received palliative care. They identified several factors that were associated with receiving palliative care. These included specific diagnoses such as severe neurological disease, metastatic cancer, liver disease, severe respiratory disease; and decisions to withhold or withdraw life supporting therapies. Being in the observational unit of the ED was found to be a factor associated with a longer time to death.⁽²⁰⁾ These findings echoed earlier findings in a single centre survey in France where the decision to withhold or withdraw life-sustaining treatment was made.⁽²⁴⁾

This study had several limitations. . The retrospective nature of the cohort made it difficult, if not impossible, to determine the need for therapies like sedation and analgesia. The data captured also only looked at six defined therapies and not at the holistic nature of palliative care. This is of some concern. However, some attempt at comfort care is better than none, and as previously mentioned, it is difficult to translate holistic care into quantitative outcomes^(20,21,61)

De Vader *et al.*, in a prospective cohort study at a level one community trauma centre in California, showed that although there is an increased need for palliative care, there are many perceived barriers to initiating palliative care in an emergency setting. Their unit had showed a 20% increase in emergency department visits for cancer related problems in 2005. The results showed that 27% of cancer patients visited their unit in the last two weeks of life. In spite of this, few residents received formal training in palliative care.⁽³³⁾ In South Africa, where large areas are not served by the non-governmental organisations and community-based palliative care is less common than the first world, emergency presentations at the end-of-life are even more common.^(32,62)

Reyniers *et al.* looked at reasons why hospital admission may be required at the end-of-life. Their methodology was qualitative with focus group discussions as their data collection method. All their participants were health care providers. They found that although, for the most part, death in a familiar setting remained the first priority; it is often not feasible. The patient's preferences should always be considered but knowing what those would be often posed a problem in the context of lack of capacity and limited advanced care planning. The care capacity of the care environment often impacts on the need for hospitalisation with patients in care homes often being better supported than patients dying at home. A major influence on hospital admission at the end of life is acute medical emergency situations, e.g. acute major bleeds or intractable symptoms.⁽⁶³⁾

Merryn Gott, in the same issue of Palliative Medicine's editorial discusses the research of Reyniers *et al.* and De-Korte Verhoef *et al.* , who reported that 24% of general practitioners in their study felt that their patients' terminal admissions could have been avoided by clear communication prior to the crisis, additional care and support at home and supporting families.^(64,65)

She addresses the concept that *"...for people who are nearing the end of their life and their families, going into hospital may be a logical step, even when it is not seen as 'appropriate' or 'justified' from a clinical perspective; even if the hospital isn't the preferred place of care..."* She points out that this may be related to our socialisation of reacting to illness by seeking medical help and the medicalization of death. The conclusion is that avoiding unnecessary hospitalisations may start in a far wider social context than dealing with dying people and their families.^(63,64)

This ties in well with the Hospice UK 2014 campaign that aims to move care for terminally ill people back into the community by increasing medical support in the community after-hours, increasing access to social benefits for terminally ill patients and their care-givers, improving coordination between different levels of service, increasing funding for end-of-life –related research and improving data collection on dying people and their care.⁽⁴⁶⁾

Smith *et al.* agrees that there are common reasons for admissions towards the end of their life and that many admissions can be avoided by earlier palliative care, either outpatient-based or instituted in the ED. In a qualitative study of fourteen patients and seven caregivers on a palliative care service who had recently visited the ED, the five most common themes that emerged were: 1) that people were unprepared to manage difficult symptoms at home (especially pain); 2) that patients and caregivers had experienced significant uncertainty and related anxiety; 3) that patients and/or caregivers had difficulties communicating with ED staff 4) that pain was often underdiagnosed and undertreated; and 5) that some people were reluctant to accept palliative care because of equating it with end-of-life care.⁽⁶⁶⁾

Other patients who may die in the ED may have been referred to specialities like neurosurgery or surgery and been found to have sudden advanced illness with poor prognosis. These patients tend to be referred for palliative care in the first world context.^(6,30) However, in our resource-constrained setting, with lack of palliative care units in hospitals and lack of palliative care specialists, these patients tend to stay in the care of the ED team, and die in the ED.

Diagnosing dying

Predicting when exactly death is approaching can be exceedingly difficult. Ellershaw and Ward described the process of diagnosing dying in the context of on-going care. They emphasise the importance of communicating the possibility of death to the patient and family earlier rather than later. If more information comes to light, or clinical improvement occurs, reassessment is important. In cancer they describe several signs that death might be approaching. These include the patient becoming confined to their bed, a deteriorating level of consciousness, stopping eating and only taking oral sips and the patient being unable to take oral medications. In non-malignant disease, it may be far more difficult to distinguish whether the patient's underlying disease has progressed or whether a reversible factor may lead to clinical improvement.⁽⁶⁷⁾ The Neuberger report (see under the discussion on the Liverpool Care Pathway) echoes this finding.⁽³⁹⁾

The role of palliative care in the Acute Care Setting

It is often cited that palliative care should be instituted early in the disease process. The thinking is that, given more time to address the patients' need holistically, outcomes should improve considerably. The Study to Understand Prognoses and Preferences for Outcome and Risks of Treatments trial (SUPPORT)⁽⁶⁸⁾ aimed to assess this wisdom and quantify the benefit. The setting was five teaching hospitals in the United States.

The objective of the study was "to improve end-of-life decision-making and reduce the frequency of mechanically supported, painful and prolonged process of dying." The study had two phases. Phase one was a two-year prospective observational study of 4301 patients, describing the process of decision-making and outcomes. Phase one confirmed the many barriers to optimal management and shortfalls in doctor-patient communication. It also showed significant variation in care practice between the different establishments and between different specialities. Phase two was a cluster randomized controlled trial with 4804 patients. The intervention group was 2652 and the control group 2152 patients in the same setting. The intervention consisted of a trained nurse providing doctors with accurate predictive information on functional ability, survival probability for each day up to six months and patient preferences for their care at the end-of-life. A skilled nurse was also involved in the team to ascertain patient preferences, counsel patients of prognoses, enhance patient and family understanding, enable palliative care and facilitate advanced care planning. They reported on five outcomes: 1) physician understanding of patient preferences; 2) incidence and timing of Do Not Resuscitate (DNR) documentation; 3) prevalence and severity of pain; 4) time spent in ICU, whether patients were comatose or mechanically ventilated before death; and 5) hospital resource use.⁽⁶⁸⁾

The results showed no significant effect from the intervention.. There was a small association that intervention improved patient -doctor agreement on DNR orders (not significant) (adjusted ratio 1.22, 95% CI 0.9-1.49). DNR orders had the same timing between groups (adjusted ration of median time 1.02, 95%CI .9-1.15). The reported frequency and level of pain was higher in the intervention group; the number of days spent in ICU, comatose or ventilated remained the same (adjusted ratio 0.97, CI 0.87-1.07) and there was no change in hospital resource use.⁽⁶⁸⁾ The discussion is not optimistic regarding the possibility of an intervention such as this to making a difference in care. However, there are interesting take away points form the study, several which are frequently cited.

The SUPPORT study is widely cited. The most common cause for citation is that it provided objective proof of deficiencies of care at the end-of-life. These include poor communication between doctor and patient, DNR preferences not being resolved and poor symptom control.^(11,69–74) Norton *et al.* used it to underline the importance for the need for further research, as well as increasingly implementing palliative care and end-of-life care standards and guidelines.⁽⁷⁵⁾ Santa-Emma *et al.* adds good insight to the SUPPORT investigators' recommendations. They agree that the intervention most likely failed because of "systemic impediments" in the provision of care at the end of life. They stress the importance of physician mentorship programmes, increased participation in decision-making by patients and families and system adjustments to provide appropriate care.^(68,76)

Patients dying in the ED and in general hospital wards have palliative care needs.^(20,77) The question on how such needs are to be addressed is one that is receiving considerable attention in the literature currently. Becker *et al.* performed a descriptive study in Germany, looking at consecutively dying patients in a University Hospital in 2004. The study was a retrospective folder review of all patients who had died. They used a mixed methodology to assess the treatment of dying patients in the institution. Their concern was that healthcare in Germany is very curative focused with Palliative Care being a young, emerging field. This is similar to the South African situation which makes this study of particular relevance. Their aim was to accurately describe the patterns of medical and nursing practice in patients dying in an acute care setting. They set out to replicate two studies, an American study by Fins *et al.*, and an Australian study by Middlewood *et al.*^(29,78,79)

Sample size and methodology was based on these two studies, with a few alterations specific to the German context. In addition to the data collection tool, they triangulated data and included qualitative data to correlate with the file reviews. They took great effort to ensure data reliability.

Results showed that the majority of patients who died in hospital (60%) had been suffering from cancer and/or cardiovascular disease. In addition, 20% suffered from severe neurological disorders and the remaining 20% was a variety of disorders. Most of the patients (56.2%) who had died in hospital had been admitted via the Emergency Department (ED). The results showed that 74% of patients who had died had been admitted to the Intensive Care Unit (ICU).⁽²⁹⁾ Most of the patients died in the ICU. In South Africa, ICU beds are a very scarce resource. In 2007, a national audit by Bhagwanjee and Scribante found that in public hospitals, the ICU bed to total hospital bed ratio is 1.7% nationally, and 3.9 % if one only includes hospitals that have ICUs.⁽⁸⁰⁾ This means that the entrance criteria for being admitted into ICU are higher than the first world where ICU beds make up about 10% of total beds. Fewer patients admitted to ICU translates to fewer patients dying in ICU.⁽⁸¹⁾

It was noted that 65% of patients had decision-making capacity when admitted to hospital but, of these, 58% lost this capacity during the admission (terminal restlessness in the last 48 hours was excluded from this statistic). During the last 48 hours, 79.2% of all patients had lost consciousness. An Advance directive was only available for 6.6% of patients and only 22.1% had a health care proxy with 76% of these proxies being completed during this final admission. “Indirect advance directive” was obtained in 70.3% of cases. This meant that the partner or family was consulted about the patient’s preferences.⁽²⁹⁾

“Do not resuscitate” (DNR) orders were documented in 64.6% of cases, on average 5.9 days prior to death (median 3 days). There was no statistically significant difference between patients with short or long hospital stays in whether a DNR order was documented. In 41.3% of cases, DNR order was discussed with the family but not the patient and in 30.8% there was no evidence of any discussion when DNR status was decided.⁽²⁹⁾

They extracted data out of the charts by a chart abstraction tool that they had developed and piloted. This revealed that in 16.8% there was a preference for death, and in this group, a documented DNR order was available significantly more than in other patients. (78.9% vs. 61.7%, $p = 0.043$)⁽²⁹⁾

End-of-life decision making was assessed and in 98.7% no ethical dilemma was documented. In the five patients that this problem was documented, conflicts were resolved by hierarchical decision making (three patients), informal conversation (one patient) and Ethics Committee for one patient.⁽²⁹⁾

In 36.7% of the study population, notes in the records suggested that the responsible clinicians considered them to be dying, on average 3.8 days prior to the actual death occurring. They distinguished between “partial palliative care plans” and “full palliative care plans”, if clear goals of care were outlined. In 59.3% of dying patients, no palliative care or comfort care plan was in place.⁽²⁹⁾

In most of the patients who had comfort care plans, blood tests and life-sustaining treatments were still on-going. However, 70.8% of all dying patients were put on an opioid infusion prior to death. The mean length of time on the infusion was 5.4 days (median 46.5 hours, range 1 hour-52.9 days).

Clinicians were statistically more likely to identify dying in patients dying of cancer than of cardiovascular disease ($p=0.029$). This also translated into significantly more patients dying of cancer having comfort care plans in place than patients dying of cardiovascular disease, head injury

or stroke. The reasons why it can be very difficult to initiate palliative care for non-malignant conditions have been discussed earlier in the text.⁽²⁹⁾

A study in France by Morize *et al.* found that 13% of all patients hospitalised on a certain day had palliative care needs. 64% of these patients were in acute care beds.⁽⁸²⁾

Dignity in healthcare

A need that patients have, that palliative care can address, but often seems to be overlooked in the emergency setting is patient dignity.⁽⁷⁾ Dignity is truly a complicated, poorly understood topic; relating to feeling in control, self-presentation, privacy and relationships. All patients are vulnerable to losing their dignity when they come to the hospital, but dying patients are at greater risk.⁽⁸³⁾ In dying with dignity, there are several surrogate markers that can signal a dignified death. These include maintaining autonomy and independence, having relief from symptoms and associated distress, being treated with respect, maintaining “human-ness” and a sense of self (even in the face of very advanced illness), maintaining meaningful relationships, experiencing existential satisfaction and having privacy upheld.⁽⁸⁴⁾

One of the main authors writing on dignity is Harvey Chochinov. He described a model for achieving dignity and “dignity-conserving interventions” in 2002. His model consists of three main areas that constitute patient dignity 1) concerns related to the physical illness, 2) concerns relating to the preservation of dignity and 3) an inventory for social dignity. The first area includes symptom management, but also includes conversations about what to expect with disease progression, the uncertainty in prognosticating, level of independence and functional capacity and anxiety relating to death and the unknown. The second area he describes relates to preserving a sense of self, hope, control, autonomy and acceptance of what is happening. This area also focuses on things that have not changed in their life and spirituality. The third area he describes relates to the way in which the patient wants to be cared for. This includes privacy, social support and the feeling of burden that terminally ill people can struggle with. It also includes planning for after death. This comprehensive model gives a good understanding of how dignity can be achieved.⁽⁸⁵⁾ In 2007, he published another article simplifying these complex issues to make it easier to apply. His “ABC and D” of dignity-conserving care was intended to make it more easy to apply in clinical practice. The acronym stand for “attitudes” (empathy and ensuring the preservation of patient autonomy), “behaviours” (professionalism and continued care, even in the face of curative options being inappropriate, also, clear, honest communication) “compassion” (allowing oneself to feel with the patient and communicating this verbally or non-verbally) and “dialogue” (acknowledging the patient’s personhood, knowing what is important to the patient and psychotherapeutic approaches).

Although it does make it easier to remember the prompts, his model in 2002 is more comprehensive.⁽⁸⁶⁾

Dignified death is not always easy to achieve. Van Gennip *et al.* in a Dutch study in the elderly population in 2013 found that families felt their loved ones had a dignified death in 69% of cases. Factors associated with a higher chance of a dignified death were feeling peaceful and ready to die, absence of anxiety, depression and fatigue, and a clear discussion about treatment options in the last months of life.⁽⁸⁷⁾

Excellent palliative care also implies that the patient's family is adequately cared for. Fridriksdottir *et al.* performed cross-sectional, descriptive and comparative study in Iceland that rated the families' needs in order of importance. They used the twenty needs according to the Family Inventory of Needs (FIN) tool. The most important needs that family members reported was to feel that the health care professionals really cared about the patient, assurance that the best possible care was being offered to the patient, have questions answered directly and honestly, have information about how to care for the patient at home and explanations in clear, understandable terms.⁽⁸⁸⁾

Other than adequate symptom control, which is cited as the most important need in most of the literature, other needs at the end-of-life include not prolonging the dying phase, achieving a sense of control and strengthening relationships with loved ones. Relieving the burden associated with having to receive care, as well as the thought of family members witnessing their death and having to make difficult decisions on their behalf is also crucial.^(89,90)

Related to appropriate care at the end-of-life is stopping unnecessary interventions. In the study by Becker *et al.* mentioned earlier, most patients who were on comfort care plans at the end-of-life still had routine bloods taken.⁽²⁹⁾ Le Conte found that life-sustaining treatments are withheld or withdrawn in up to 80% of patients who die in the ED.^(7,20,23,24) This is quite at odds with the prevailing ED culture, as described by Chan in 2004, which is rescue-oriented, always in a perpetual state of readiness to diagnose, treat, "save lives" and "never give up" (see footnote). Also, the ED is traditionally a fast-paced, high patient turn-over environment, where time is of the essence. Taking time with patients dying from chronic illnesses and their families does not come naturally for many ED clinicians.⁽⁷⁾ Yet, in the face of the worldwide trend of more institutional deaths, and the ED being the doorway into the acute care system, this is becoming a daily reality.^(7,43)

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Furthermore, worldwide changes causing hospital downsizing, leads to more overcrowded EDs, and waiting times for hospital beds may put dying patients at a lower priority for a bed than someone with a curable disease.⁽⁷⁾

Cardio-pulmonary resuscitation and Do not attempt resuscitation orders

Related to the “rescue” approach of the ED physicians, is the role of Cardio-pulmonary resuscitation (CPR). Closed-chest cardiac massage and cardio-pulmonary resuscitation is a technique to resuscitate patients with a reversible cause of cardiac arrest. It was developed in the 1960’s.⁽⁹¹⁾ According to Blackhall, the technique was initially only used to treat patients suffering from acute insults such as drowning, electrical shock, adverse drug reactions, anaesthetic accident, heart block, acute myocardial infarct and surgery.^(92,93) Soon enough though, CPR became standard practice for any patient suffering a cardiac arrest from any cause in the first world. Resuscitation efforts are used in an attempt to reverse or arrest the acute dying process. In an article about resuscitation ethics in the journal *Resuscitation*, it is stated that the intention of CPR should be to preserve life, restore health, limit suffering and limit disability.⁽⁹⁴⁾

However, CPR is not a benign intervention. A full-blown resuscitation is a highly stressful procedure, with many painful, undignified interventions and side effects, including insertion of endo-tracheal tube, arterial line, central venous catheter, urinary catheter, exposure of the patient and even fracturing of ribs. Furthermore, CPR increases the risk of the patient who achieves return of spontaneous circulation (ROSC) being in a persistent vegetative state. CPR outcomes vary according to the underlying pathology causing the cardiac arrest, but few patients survive to hospital discharge. Blackhall reviewed 13 papers published from 1960 to 1987, most of which reported survival rates of lower than 15%. Three studies that reported higher survival rates had excluded patients with cancer, repeated arrests, chronic illness and poor baseline. Initial response rates tended to be higher - up to 44% - but survival to discharge remained poor. Diseases such as metastatic cancer, sepsis, acute stroke and cardiomyopathy almost invariably proved fatal – even with CPR.⁽⁹²⁾

It then becomes apparent that CPR is not always in the patient’s best interests. It may prolong suffering and lead to an undignified death. Without any hope for survival, CPR carries a big risk and no benefit.⁽⁹⁴⁾

Within twenty years of CPR becoming the standard practice, patients formalised their request to not be subjected to this therapy, in the form of a “Do not resuscitate” order (DNR, later changed to “Do Not Attempt Resuscitation or DNAR). Many concerns remain about CPR as an intervention, or its

omission at the end-of-life. The literature seems to agree that patients and their families should be involved in the decision of whether CPR should be commenced. However, it is important that consensus should be reached globally as to when CPR is indicated.⁽⁹²⁾

The literature also suggests that doctors are often reluctant to write out a DNAR form, as they believe it will lead to sub-optimal care. Fritz *et al.* conducted a survey on doctors and nurses in Cambridge. The research revealed that there was a large variation in interpretation of the order, including fewer nursing observations, a lower rate of contacting the medical team in case of deterioration after hours, a difference in administering intravenous fluids and analgesia.⁽⁹⁵⁾

Documentation seems to be universally poor, even if the intervention had been discussed with the family. A study in the Netherlands by Meilink, van de Wetering and Klip found only 9.3% of dying patients had a documented DNAR order. Factors increasing the likelihood of a DNAR order being present included older age, longer admission and the type of admission the patient was in the hospital for. There are several theories why this problem remains so prevalent. Difficulty in communication and a reluctance from doctors to discuss resuscitation decisions and their consequences, lack of knowledge about the benefits and risks of resuscitation and an unwillingness to make resuscitation open for mutual decision-making are but a few.⁽⁹⁶⁾

The primary doctor, patient, and family should be involved in the discussion on whether CPR should be commenced in the case of a cardiac arrest, but an often overlooked member of the team, who may have to make the emergency decision about whether to commence CPR, is the nurse looking after the patient. De Gendt *et al.* reported better outcomes have been reported when nurses are consulted in the decision as well.⁽⁴⁾ The ethical principles on which these decisions are based include

- 1) *patient autonomy*. The patient has a choice about what treatment they receive. However, several problems with decisions like CPR and the end-of-life exist. In the emergency setting, the patient cannot express their wishes, and there is no time to discuss it with family members. Advanced directives and the living will are ways in which competent patients can make their wishes for such a situation known, but they have not gained common acceptance in our context. Also, the documentation may once again not be available in the crisis situation. Furthermore, in terms of the concept of *informed consent*, which is closely related to patient autonomy, if there is no conceivable benefit from an intervention, there is no ethical imperative to offer it or administer it.^(92,97–100)
- 2) *Beneficence and non-maleficence*. As discussed above, there needs to be a potential benefit from treatment in order to justify the harms associated with starting a resuscitation.
- 3) *Justice*. If the patient is not a candidate for ICU care, dialysis or other similar life-prolonging interventions, the discussion becomes more complicated. If there is a small, but real chance of CPR resuscitating the

patient, but if there is no capacity to offer them higher levels of care post-resuscitation, it just prolongs suffering in the context of inevitable death. However, in patients known with these diagnoses, it is important to have these difficult conversations prior to crisis, if at all possible.⁽⁹⁹⁾

A discussion on resuscitation in South Africa would be incomplete if regional variances are not assessed. The literature on this matter is sparse.

Ragavan, Schneider and Kloeck assessed medical practitioners in the Northern Province of South Africa (now Limpopo Province) with regards to skill in resuscitation. They found poor performance of most practitioners studied in resuscitation. This was related poor training and unsupervised resuscitation. It may also be related to greater areas served, as patients may not arrive at hospital in time for meaningful CPR.^(101,102)

McQuoid-Mason published a review article in the South African Medical Journal discussing these difficulties. The South African Constitution and the National Health Act states that no one will be refused emergency medical treatment. A medical emergency is defined by the Constitutional Court as “a dramatic, sudden situation or event which is of passing nature in terms of time” and that can be cured with appropriate medical treatment. Anticipated deaths from chronic illness, thus doesn’t constitute medical emergencies in terms of the Constitution. However palliative care can still be offered to the patients. In South Africa, DNR orders may be lawfully employed when patients have an advanced directive, makes an informed decision to refuse CPR, when clinical judgement assesses that CPR is a futile intervention (the patient is dying from an irreversible condition) and if, after discussion with the patient and their family, agreement is reached that the potential benefit of CPR are outweighed by the harms.^(100,103–105)

Obstacles to palliative care in the ED

Some obstacles to initiating end-of-life care in the ED have been mentioned earlier. Beckstrand *et al.* performed a study in which they tried to assess the size, frequency and magnitude of selected obstacles to, and supportive behaviours for the provision of end-of-life care in the ED. The bulk of their data was Likert scale-type questionnaire data. The study had a 46% response rate (272 eligible respondents). The obstacle magnitude was calculated by multiplying the mean obstacle size score by the mean obstacle frequency score. There were 28 perceived obstacles that were rated. The perceived supportive behaviour magnitude score was calculated by multiplying the mean size of each supportive behaviour by its frequency.⁽²⁶⁾

According to this research, the biggest obstacle to providing end of life care related to ED nurses having too high a workload to allow them adequate time to care for dying patients. The next biggest obstacle related to poor infrastructure design. Emergency departments tend to have limited capacity for providing privacy for dying patients and their families. The third ranked obstacle was the fact that families often do not realise that “life-saving measures” are often painful and futile. Next came limited time again, because the nurse still had to give care trying to save the patient’s life (conflicting priorities of care) and then was the nurse needing to deal with upset family members while still having to care for the patient.⁽²⁶⁾ This was a well-conducted study attempting to quantify what modifiable factors contribute to quality end-of-life care-both positively and negatively. There was a random sample and the study was adequately powered. They used an instrument that was previously studied and adapted it according to previous studies’ recommendations. The response rate was documented. They used multiple similar questions on the Likert scale to quantify feelings and beliefs. This study can also guide future infrastructure as well as job descriptions. Spending less time doing paperwork, and more time rendering patient care is what these nurses were asking for in order to facilitate better deaths in the ED.⁽²⁶⁾

Smith *et al.*’s study that explored attitudes, experiences and beliefs about palliative care in emergency care gives some insight into why there may be reluctance in initiating palliative care in the emergency unit. Gaps in knowledge was a contributing factor, especially regarding the fact that referral to palliative care does not have to mean a black and white discontinuation of active treatment. Lack of communication between different levels of care was also mentioned as a difficulty in accessing palliative care services. Deep discomfort in talking about end-of-life decisions was also mentioned as a significant factor. They often felt that the ED is not the ideal environment to be having these conversations, with overcrowding and noise being mentioned as particularly detrimental. The researchers suggest basic palliative care training for emergency unit staff, early involvement of palliative care and communication as three areas that could improve care significantly.⁽¹¹⁾ Rodriguez *et al.* found similar obstacles. Lack of knowledge on what palliative care entails, and late referrals were particularly problematic. Their article is an excellent example showing how hospital staff barriers interact with one another, creating a system which is not suited to early, or any palliative care.⁽⁷⁴⁾

De Vader *et al.* showed that many of these barriers can be mitigated by a brief educational intervention. However, time and relational barriers persisted. Relational barriers include difficulty establish rapport and relationships with patients in the ED and family dynamics causing difficulty in decision-making at times of stress. In view of these difficulties in initiating palliative care in the

emergency department and the importance of doing so, there has been a move towards an evidence-based approach that is applicable in the emergency context.^(13,19,33,40,106)

Acute care staff may be comfortable in dealing with their own mortality, but that may not be enough. Parish *et al.* in a study in Australia on acute medical ward nursing staff found that even when nurses had a strong will and desire to deliver quality palliative care, it was not always achieved. This seems to be because of lack of education leading to sub-optimal assessment of patients with palliative care needs and inadequate documentation. Other barriers, previously discussed, also were mentioned, including competing priorities of different patients.⁽¹⁰⁷⁾

Ellershaw and Ward, in a clinical review article, summarised the barriers to providing end-of-life care, the effect on patients and families and suggestions on how to overcome these barriers. The barriers to diagnosing dying include hope that the patient may improve, lack of a diagnosis to work with, not realising (or not admitting) that treatment is proving futile, disagreement about the patient's condition, not recognising certain key symptoms and signs, lack of prescribing knowledge, lack of communication skills, concerns about withholding and withdrawing treatment, fear of shortening life, poor decision-making related to resuscitation, cultural and spiritual barriers, as well as medico-legal concerns. The effects of these barriers can be devastating. Patients and families may not realise that death is imminent. Patients may stop trusting their doctor when their condition is clearly deteriorating but this fact is not being acknowledged. Patients and families may get mixed messages from the team. This may result in an undignified death, with poor symptom control and possibly unwanted, futile CPR; leaving patients and families dissatisfied with care and predisposing families to complicated bereavement.⁽⁶⁷⁾

Even when adequate education, basic palliative care and early referral is achieved, a busy emergency unit, with many different patients competing for attention, is still far from an ideal space to spend one's dying hours. Several solutions to this problem have been suggested and implemented over the years. Pedley and Johnston, in a letter to the editor of *Emergency Medicine Journal* describes admitting terminal patients into a side ward of the short-stay unit of their department, after consensus was reached that further active treatment was futile and discussion with the family. They found that families appreciated the extra privacy and that prompt delivery of palliative care led to satisfactory outcomes. They advocate for the judicious use of the short stay ward (still in the ED) for palliative care, as opposed to referral for speciality admission.⁽¹⁰⁸⁾

Thus, in the emergency unit, doctors and nurses who are not necessarily well versed in palliative care and terminal care, have to initiate and/or complete this important task of caring for a dying patient. Tools had to be developed to assist them in giving appropriate care.

The Liverpool Care Pathway

As mentioned in the introduction, the Liverpool Care Pathway, or LCP, was an integrated care pathway developed with the aim to help health care professionals, even ones not usually involved in care of the dying, achieve a high standard of care in these patients.^(35,109) Many units, including emergency departments, implemented the pathway, or modified it for use in their own setting. At first, the results seemed overwhelmingly positive. Units who had implemented published before and after studies, quality control cycle audits, and qualitative studies showing better care being rendered, with lower costs and higher staff satisfaction.^(60,110)

Paterson had adapted the LCP for the emergency unit and seemed to have very favourable results, in terms of file audit and staff satisfaction.⁽¹⁰⁹⁾ Veerbeek *et al.* in a multi-centre, controlled before and after study showing that the LCP contributed to the quality of documentation and symptom control.⁽¹¹¹⁾

Large scale implementation of the LCP started in the late nineteen nineties, and by 2000 it was declared a NHS Beacon for good practice.⁽¹¹²⁾ However, there was some concern in the literature about the way all these improvements were being measured. In a letter to the editor of Palliative Medicine, Sanjay Shah pointed out the high likelihood of selection bias in favour of the integrated care pathway in before-and-after type studies. He also pointed out that caring for dying patients make up a small proportion of most acute care physicians' workload, and that may not be reasonable to expect these acute care doctors to maintain skills required for excellent care towards the end-of-life. He urged further robust research into the efficacy of the LCP but pointed out the difficulties with conducting a randomised controlled trial in the setting. In the absence of this possibility, he suggested post death analyses of units with and without the LCP implemented.⁽¹¹³⁾

In 2008, Rotter pointed out that "*...the evidence base is not conclusive enough to provide a replicable framework for all pathway strategies.*"⁽³⁷⁾

In 2009, media frenzy ensued in the British media. Families were claiming that their loved ones were being put on the pathway prematurely and that it was hastening death. Some families were not counselled when their loved ones were put on the pathway and some people improved, leading to an outcry.^(38,114–116)

Several investigations into the safety and efficacy of an integrated care pathway at the end-of-life have been published. Chan and Webster conducted an updated Cochrane review in 2013. They included all randomised controlled trials (RCTs), quasi-randomised trial or high-quality controlled

before-and-after studies comparing use versus non-use of an end-of-life care pathway in caring for the dying in their review. They identified 2042 potentially relevant studies but none met inclusion criteria, other than the 920 studies identified in a 2010 review. They could not find any high quality evidence justifying the use of the pathway and considering the concerns about the safety of the pathway, their current recommendation is against the use of such pathways. This review was conducted prior to the publication of Costantini's cluster randomised control trial on the LCP .A discussion on the Costatini trial follows below.⁽¹³⁾

Norman Lamb MP, Minister of State for Care Support, also asked a committee, chaired by Baroness Julia Neuberger, to investigate to Liverpool Care Pathway. Their findings were published in a report called "More care, less pathway". Their investigation included a review of the academic literature, written submissions from the public and hospital staff that had used the pathway, inputs from professional bodies, review of complaints received by the NHS. The committee had four public participation meetings, where members of the public could share their input and ask questions.^(39,116)

The report started off by citing confusing terminology to be a large part of the problem. "End-of-life care", for example starts when a person is believed to be in the last year of their life. The care that this kind of patient will require is quite different from what he or she will need in their last few hours. The lack of clarity may lead to people being started on the pathway inappropriately.⁽³⁹⁾ Even the term "pathway" may let families feel that their loved one is being forced down a road to death which, although not accurate, can be very distressing. Furthermore, the concern with professionals using the "pathway" was that it was being applied as a set of absolute rules. This was never the intent of the clinicians who developed the LCP. Death is such a personal experience that care for each person has to be individualised.⁽³⁹⁾

The report looked at the lack of high quality evidence for the pathway and described the difficulty in diagnosing imminent death accurately. However, it confirmed that implemented properly, the pathway will help patients die with dignity and peace. It highlighted the implementation and decision-making difficulties, making the overall policy inappropriate. This is in line with what Edmonds *et al.* suggested in 2009 BMJ editorial that the problem is not the underlying principles of the LCP but the difficulties in implementation.^(39,106)

The report led to the phasing out of the LCP as a standard of care of dying patients in 2013. During the hiatus of policy that ensued, a cluster randomised control trial to compare the LCP to standard health care practice was published by Costatini *et al.* The study was rigorously randomised and had a primary endpoint of a quality of care toolkit score after the death, judged by completion of toolkit

interview with a family member 2-4 months post bereavement. The intervention did not result in a significantly different toolkit score, either compared to the pre-intervention control (at the same sites) or the control group. However, of the nine secondary outcomes, two (control of breathlessness and respect, dignity and kindness) showed improvement in the intervention group. This study was used to emphasise the need to phase out the LCP. However, the authors may not have agreed with this development. The authors mention several limitations to their study, and these limitations, they suggest, may have led to the under-estimation of the pathway's effect. A great limitation is related to the difficulty in assessing a complex intervention unblinded (it would be extremely difficult to blind such a complex intervention) in a complex system context. They calculated that for a power of 80%, they would need to include 20 research sites. They only had 16, which translates into an under-powered study. There was a significant difference in response rates between the family members of the intervention and control groups, with fewer control bereaved family members agreeing to be interviewed. The authors surmise that they may have not agreed to be interviewed as their grief may be complicated, thus leading to type 2 bias under-estimating the pathway's effect. The study included all patients dying of cancer in the selected wards. Some of these patients may not have been in the traditional dying phase and would have not needed the integrated care pathway. Also, the integrated care pathway did lead to improvements in score, but had not reached significance. If the study was adequately powered, the positive effects may have reached significance. According to the study, no negative effects were associated with the pathway. They concluded that one cannot discount the *"... the important continuing role for inpatient hospices and specialist palliative care units, in which the total culture of care (environment, staffing, procedures and philosophy) differs from that in hospitals"* They also advocate for specialist palliative care teams to be available around the clock, as well as the availability of "good practice hospice wards" within acute care hospitals.⁽¹¹⁷⁾

Current recommendations in end-of-life care

The Neuberger report had many recommendations, related to terminology, diagnosis of dying, documentation, communication and good practice, including clinical adjustments that were needed. It also called for the entire health system and society to change their approach to dying. These recommendations led to a policy statement called "One chance to get it right" with the "five priorities of care" quoted in the Introduction chapter. This is viewed as one current standard of practice.^(39,40)

Practically, they recognise the difficulties that can be encountered in diagnosing dying and stress the importance of regular reassessment of patient condition. It is important to communicate that the

provider believes the person is entering the dying phase but also that this will be reassessed regularly. It iterates the importance of offering food and drink, as appropriate. Currently no diagnostic tool for the diagnosis of dying is endorsed. Communication is underlined as a crucial part of care and is to include to dying person and their family. In addition, shared decision-making is crucial. Family needs are to be met, if possible. Lastly, the individual nature of a care plan is described, including the need for shared decision-making.⁽⁴⁰⁾

Food and hydration was the basis of many of the complaints related to the LCP.^{(21,39,40,106)(118)} The statement encourages the offering of food and drink and assisting eating. This may often just be done for comfort, if hydration needs are being met. However, being unable to take orally may be one of the signs of the dying phase, and communicating this to families and putting them at ease may be an important part of the care offered.⁽¹⁵⁾

“One chance to get it right” comments that good record keeping is not specific to end-of-life care, and thus it does not offer any specific guidance on note keeping. However, with the phasing out of the LCP, there is no change in documentation when the dying phase is entered (as was the case with the LCP), so there is less chance of confusion.⁽⁴⁰⁾

The underlying concern is the general lack of palliative care training of general doctors and nurses. This issue has been addressed earlier in this chapter, and “One chance to get it right” also acknowledges this gap.⁽⁴⁰⁾

With regards to medication use, these are the recommendations

“All medications, including anticipatory medicines, must be targeted at specific symptoms, have a clinical rationale for the starting dose, be regularly reviewed, and adjusted as needed for effect.”

“The reason for any intervention, including the use of a syringe driver, must be explained to the dying person and to those important to the dying person. Other than in exceptional circumstances, this should be done before it is used.”

“The likely side effects of specific interventions, especially those that may make the person sleepy, must be discussed with the dying person to enable them to make informed decisions, and explained to those important to the dying person if the person wishes.”⁽⁴⁰⁾

The most commonly used drugs at the end-of-life include morphine (a well-known opioid analgesic), low-dose haloperidol (a potent anti-psychotic with anti-emetic action that works well for multi-modal nausea and vomiting), hyoscine butyl bromide (an anti-muscurinic agent used as anti-sialogogue) and midazolam (a short-acting benzodiazepine).⁽¹¹⁹⁾ These medications can all be

administered subcutaneously via syringe driver. Data is available for the safe administration of up to three medications in the same syringe driver at a time.⁽¹¹⁹⁾

Acute Palliative Care Units (APCU)

“A PCU should be a monument not to the incurability of some disease, but to the dignity of man.”⁽⁴²⁾

In 1976, Balfour Mount described a Palliative Care Service as a potential solution to the problem of sub-optimal terminal care in a hospital in Montreal, Canada. The service consisted of an acute palliative care ward, a home-based care service and a consultation service to other wards. He considered many of the obstacles to good palliative care already discussed - reluctance talking about the approaching death, prioritizing other patients over the dying patient the increasing isolation of patient at the end of their lives – all rooted in a deep discomfort in the knowledge of mortality.

They had multiple premises on which this project was founded. Initially, they focused on the medical, emotional and spiritual needs of dying patients, as well as their families’ needs. They acknowledged that a feeling of isolation contributes greatly to suffering. They considered patients dying on a general ward distressing to everyone involved. They understood that realistic hope is crucial at the end-of-life, and used this to facilitate advanced planning (they also had the option to discharge into their own domiciliary service). They understood how crucial it is for dying patients and families not to feel deserted by the hospital service they had come to know and trust. This is why an acute palliative care unit inside the hospital, staffed by specifically trained nurses, doctors, social worker, physiotherapists and occupational therapists, as well as many allied professionals and volunteers could adequately address the need of this special group of patients.⁽⁴²⁾

In the unit, they encouraged family members to take active part in the patient’s care. Hospital regulations were relaxed with regards to visiting hours, and children and even pets were allowed to visit. Routine nursing interventions were cut down. Follow-up for bereavement care was offered to family members close to the patients. This article describes an acute, hospital-based palliative care unit that integrated well with the surrounding medical community.⁽⁴²⁾

More recently, Rigby *et al.* studying oncology patients, found that opening an acute palliative care unit, decreased the number of emergency oncology admissions, and decreased the length of stay on the general oncology ward. This meant that the patients with higher palliative care needs could have those needs met by the specialist palliative care team, while saving on resources and opening up beds for elective admissions on the general oncology ward.⁽⁷²⁾

Other units have had similar experiences. Eti *et al.* studied their APCU in New York City, USA, and found data suggesting that their unit provided cost effective, acute care for patients with chronic life-limiting illnesses, as well as dying patients needing intensive symptom management.⁽¹²⁰⁾

Kellar *et al.* described their experience of opening a hospice inside an acute care facility in an academic hospital in Chicago, USA. They looked at demographics and referral patterns. Most of their patients came from elsewhere inside the hospital. They also studied family satisfaction. Their mailed surveys had a 42% response rate. The overwhelming response was very positive, embracing the quiet environment and specialised nursing at their loved ones' end.⁽¹²¹⁾

The South African Context

South Africa suffers from the so-called quadruple burden of disease. This is because of the high incidence of infectious diseases, such as HIV/AIDS, maternal and peri-natal morbidity and mortality, trauma, as well as the increasing burden of non-communicable disease.^(32,122)

Palliative care services in South Africa (and Cape Town specifically) has traditionally been provided by non-governmental organisations (NGO) mainly focused on people suffering from cancer and HIV/AIDS. The concept of providing palliative care in state hospitals, as well as for patients suffering from other life-limiting diseases, is one that has only developed in recent years.^(32,43)

In 2013, at the African Palliative Care Association/ Hospice Palliative Care Association Conference, several African Health Ministers agreed to a consensus statement which earmarked a new era for palliative care in Sub-Saharan Africa. The consensus statement included 1) the need to develop robust policies, to both strengthen the health system, but also to integrate palliative care into hospital- and community-based health services. 2) To make palliative care part of national health budgets, to ensure sustainability of palliative care services. 3) To ensure accessibility and availability of appropriate medications and technologies, especially opioid analgesia. 4) To promote education in palliative care, both pre-service and in-service training and capacity-building. 5) The sharing of palliative care best practice, both in clinical practice and education. 6) Ensuring provision of palliative care to vulnerable groups, like children and disabled people. 6) Strengthening of partnerships across Africa (including governments and other stakeholders) to promote the sustainability of palliative care and quality improvement at all levels.⁽¹²³⁾

As Harding *et al.* wrote in 2010, it becomes evident that globally, but even more so locally, palliative care has to operate in an ill-defined niche, negotiating resource constraints, evolving treatment

options, a complex policy and political environment, and the mandate to provide care that is based on best evidence.⁽¹²⁴⁾

Emergency medicine is one of the newer specialities in South Africa, having only been recognised as a speciality in 2003⁽¹²⁵⁾. EDs are run by staff with great variation in training –according to Clarke, more so than other specialities, especially considering how recently Emergency Medicine became recognised as a speciality. Some are very recently qualified, and some very experienced.⁽¹²⁶⁾

McFarlane adds that, in addition to problems inherited from the previous political regime, infrastructure also varies widely, with newer hospitals having excellently designed units, often with some more private rooms, whereas older units suffer from overcrowding and poor patient flow. This means that many EDs in South Africa are unpleasant places in which to receive care, especially for people nearing the end-of-life with complex needs.^(43,126,127)

Our rainbow nation also means that often health care professionals need to care for people of different heritage. This can cause considerable distress to the health care practitioner, the patient and the family, as people may have conflicting agendas for what need to happen towards the end-of-life. Gysels *et al.* explains that culture influences every person's experience of their illness and impending death.⁽¹²⁸⁾ Bullock published a paper in 2011 exploring the difference between white and black Americans that revealed that older black patients are more likely to perceive barriers to advance care planning than their white counterparts. She also identified that white Americans value individualism, independence, self-reliance and future-orientedness, while black Americans value collectivism, interdependence, inter-connectedness and present-orientedness. Considering these differences, it becomes clear that the family's importance at the end-of-life is heightened in certain cultures.⁽¹²⁹⁾ Crawley *et al.* in an article outlining the culturally-sensitive approach to patients acknowledges that Western Medicine itself is a cultural system and that healthcare providers must remember that the emphasis on patient autonomy and informed consent which is central to this culture may seem foreign and inappropriate in many other cultures. They conclude that respecting one's patient does not equate to forcing them to make decisions that they wish their families to make.⁽¹³⁰⁾ Graham *et al.* performed a qualitative cross-sectional study in urban, peri-urban and rural Eastern Cape, studying the views of traditional healers on a "good death". They found that many traditional healers were reluctant to manage the dying process, because of fear of blame for the death and the concern that death may negatively impact on their practice. However, they agreed that there is need to manage psycho-social distress at the end-of-life, that death is a family affair (with many patients finding comfort, restoring relationships and giving a verbal will at the death bed), and that continuing care of the deceased individual and the bereaved family is essential. Some

traditional beliefs make talking about dying a taboo, as it may hasten death. This important, local article stresses the importance of being patient-centred and culturally sensitive, to build a care plan that will be suitable to the individual.^(131,132)

Resource implications

Early identification of terminally ill patients and introduction of palliative care appears to reduce costs.⁽¹²⁾ Gómez-Batiste *et al.* in a descriptive-observational, prospective, longitudinal, multicentre study in Spain, looked at resource consumption in patients diagnosed with terminal stage cancer (n=395) for sixteen consecutive weeks. The findings were compared with a similar study conducted in 1992. Compared to the historical data, there was a significant move away from acute hospital admissions and towards palliative care admissions, reduced hospital length of stay, increased home deaths and fewer presentations to the ED. The cost saving compared to historical data was profound. Most of the saving was related to fewer and shorter hospital admissions.⁽¹³³⁾

According to Leadbeater and Garber, in the UK, about 20% of hospital bed-days are taken up by patients receiving end-of-life care.⁽⁵²⁾ This makes up the bulk of spending on healthcare at the end of life. With current trends continuing (i.e. more hospital and fewer home deaths), it is expected that this spending will increase by another 25% by 2030.⁽⁵²⁾ However, they suggest that if government invests in palliative care infrastructure and service now, they can increase the number of good, community-based deaths and curb the spending.^(40,52)

Lack of palliative care services in the government healthcare sector of South Africa leads to unnecessary expenditure. The unmet needs of these patients not only lead to poor care for them, but regular recurrent visits to the ED. Admissions follow, substantially driving up costs.⁽³²⁾

DesRosiers *et al.* conducted a study comparing the first 56 deaths after a novel palliative care support intervention in a Cape Town hospital and compared it to 48 historical controls. They found a significant lowering in number and length of admissions, and a significant increase in home deaths achieved, leading to a cost saving of \$622 per patient in 2012/13. This study was well-controlled to reduce bias, and currently unique in our context. The service they provide is predominantly outpatient-based, and the current study aims to describe the impact that an inpatient unit in the same system has made.⁽³²⁾

Chapter Three: Methodology

Rationale of study

There is limited information about the role of an acute palliative care unit in a resource restricted setting such as South Africa. This study aims to evaluate the outcomes of a service introduced in Groote Schuur Hospital and describe a care model that can be applied in other hospital settings. It aims to pave the way for follow-up studies assessing the impact on families and staff, as well as the actual cost implications of such a hospital palliative care unit.

Aim & objectives

Aim:

To evaluate aspects of care in the end of life unit at Groote Schuur Hospital.

Objectives

1. Design a questionnaire based on the validated Liverpool Care Pathway to audit the elements of end of life care rendered at the Groote Schuur Palliative Care Unit
2. Describe the patient population of the Groote Schuur Palliative Care Unit demographically and record outcomes.
3. Make recommendations on any areas of concern identified by the audit

Study design and setting

The study was a retrospective folder review carried out in the recently opened palliative care unit in Groote Schuur Hospital (GSH). The folders were reviewed by a single researcher (CR) between April and July 2014.

Study population

All patient records of patients admitted to the palliative care unit at GSH between 1 April 2011 and 31 May 2013 were included in the study.

Sampling

The entire series of patient records during the specified time was included. Patients were excluded if there was no documentation of admission into the palliative care unit during the specified time. Patients who received palliative care in other wards were excluded. Patients who were referred to the palliative care unit, but were dead on arrival to the unit were included in the study.

Data extraction tool

The data collection sheet proposed has been developed in consultation with supervisors and colleagues, based on the literature surrounding end-of-life pathways and piloted on three folders from the patient population.^(22,31,35,67,106,109)

This was done with on-going consultation to ensure the feasibility of collecting the data that is proposed.

The areas covered in the data collection sheet include demographics of the patient population, length of stay, outcomes, initial and repeat assessment of the patients, comfort measures taken in the unit, psychological measures, spiritual measures, communication and bereavement care given in the unit.

Demographic data was recorded onto the data extraction sheet next to chronological number. This included sex, age and diagnosis of patients admitted into the ward.

Time of stay was estimated from nursing records –the time of admission into the unit (not arrival at GSH) to discharge or death. Death was used as the cut off, not time of removal of the body.

Outcomes were recorded as death in the unit, death en route to the unit, transfer home for end-of-life care, transfer to another institution for end-of-life care, or transfer to another speciality for further care if improvement occurred. If referred to a specialty, but death still occurred during the same admission, this was recorded. If the patient improved enough to go home from, this was recorded.

The initial and repeat assessment of patients included whether current medication was reassessed, inappropriate medications were discontinued, and whether as required medication for pain, vomiting, agitation and secretions were prescribed. It also looked at whether antibiotics and blood tests were discontinued, whether there was a clear “Do not attempt resuscitation” order and whether unnecessary nursing interventions were discontinued. These variables were recorded as “yes”, if the goal was achieved, “no”, if the goal was not achieved, or “variance”, if it was not

achieved, but for a good reason (e.g. the goal was inappropriate to the specific's patient's care). The variables were recorded as achieved if there was any documentation suggesting that the outcome was achieved at any time during the admission.

With regards to the CPR order, documentation was often poor, with no explicit "Do not attempt resuscitation" order, but if clear proxies (e.g. "no intravenous lines, no nasogastric tube", or "no re-intubation") were used, it was documented as partially achieved.

It was recorded whether a syringe driver with subcutaneous medications was commenced, as well as what medication was administered in the syringe driver. Dosages of medication were not recorded.

Repeat assessment was recorded as whether any mention was made within the notes with regards to assessment of pain, agitation, secretions, nausea and vomiting, and medication given or altered at any time during the admission. . These variables were recorded as "yes", if the reassessment was done, "no", if the reassessment was not done, or "variance", if it was not done, but for a good reason (e.g. the patient had died before there was time to reassess).

Comfort measures were recorded as mouth care, urine output charting, pressure care rendered and bowel care rendered at any time during the admission. . These variables were recorded as "yes", if the measure was achieved, "no", if the measure was not achieved, or "variance", if it was not achieved, but for a good reason (e.g. the measure was inappropriate to the specific's patient's care).

Psychological measures were documented if any mention of comforting, counselling and future planning was made. This included assessing family needs at the end of the patient's life, including whether the death should take place at home, in the hospital or another institution. These variables were recorded as "yes", if the measure was achieved, "no", if the measure was not achieved, or "variance", if it was not achieved, but for a good reason (e.g. the measure was inappropriate to the specific's patient's care). However, this measure could not ascertain when psychological care and comfort were given (non-verbally and environmentally), but not recorded.

Communication was assessed. If a patient's and their family's primary language was Afrikaans, English or isi-Xhosa, it was documented that it was possible to communicate with them, as these are the main three languages in the Western Cape. This information would be found from the admission slip. If their primary language was something else, this was documented as possible communication difficulty.

If there was documentation that a health care professional has counselled the patient and/or family with regards to diagnosis and being in the dying phase, this was recorded as such.

If family members left their numbers and designated who is to be contacted in the emergency situation, this was recorded. If there was a note that family members were given information about the ward and visiting hours etc., this was recorded. If the patient's community health centre or general practitioner referred them to GSH, or if a speciality other than Emergency Medicine admitted them into the unit, then it was documented that the primary care providers were aware of the admission. If there was documentation of any general practitioners being contacted by the doctors or ward staff from the unit, this was also recorded.

If the plan of end-of-life care was discussed with patients or families, this was recorded. However, this variable often had to be assumed from the same documentation as whether the diagnosis and prognosis discussed. These variables were recorded as "yes" if clear communication was achieved, "no" if not. If the patient was too ill to communicate with them, this was documented as "comatose".

Spiritual measures were recorded as achieved if a spiritual counsellor spent time with the patient and/ or family, or if a nursing entry documented spiritual care being offered. It was documented whether the patient's religious tradition was known and recorded, and whether a religious leader was contacted and/ or visited them in ward. There was also a space to record if spiritual reassessment and care was offered later in the admission. These variables were recorded as "yes", if spiritual care was documented as rendered, or "no" if not. However, if patients were too ill to communicate, this was also documented as "comatose", as spiritual needs could not adequately be assessed.

The next group of variables dealt with the handling of family needs after the death of the patients.

If the patient did not die in the unit, these were recorded as not applicable. Bereavement care was documented as offered if there was any mention of the unit being in contact with the family after the removal of the patient's body, or if they were counselled at the death bed. These variables were recorded as "yes", if the goal was achieved, "no", if the goal was not achieved, or "variance", if it was not achieved, but for a good reason.

Refer to appendix A to see an example of the data collection sheet.

Admission selection and record collection

An Information Technology clerk helped to locate the correct patient numbers. Folder numbers were obtained from the Clinicom data management system (a patient administration system, used to track folders and enable billing) that the hospital uses.⁽¹³⁴⁾ Another programme, called Impromptu, was used to find the specific folders. Impromptu reports for all admissions in the hospital during the specified time were obtained. Of the output received, a pivot table was drawn for the relevant ward and unit. The list of folder numbers was sent to the author, who forwarded it to the research assistants at the medical records department. They then drew the folders as requested by the list. Once all the initial folders were processed, they looked for the missing folders two more times.

Data collection

Initially, folders were compared against the folder list that was generated. Folders were excluded if they were not on the list or no record was found inside them of any palliative care unit admission during the specified time period.

Initially, the researcher would do a quick review of the folder to confirm admission into unit and establish if any documentation was missing e.g. doctor's notes. If this was the case, it was documented on identification spread sheet, but the folder was not excluded if admission into unit is confirmed. Nine folders were excluded, as no record was found indicating any admission into the unit during the time frame. Eight folders were found to have important information missing. Of these, one was completely empty, three were missing nursing records, and four were missing doctor's notes. The information available was extracted from these, and a note made of information that was not available. During analysis, this missing information was left blank.

Next, the folder number was recorded onto an identifying spread sheet, separate from the list of folder numbers and names gained from the IT department, as well as the data collection spread sheet. Folder numbers were recorded next to the chronological number in which data was extracted. Data was then extracted into the data extraction spread sheet as described earlier. Missing data was recorded as a blank on the data sheet.

Premises of data extraction

Data was collected in the research room in the records department at GSH. Folders were not removed from GSH property. The records department is an access controlled area.

Ethical considerations

Beneficence and non-maleficence

Beneficence is defined as the obligation to improve the welfare or well-being of others. Non-maleficence is closely related to beneficence and indicates the obligation to avoid affliction or harm.⁽¹³⁵⁾

This study aimed to describe current practice, thereby improving care and minimizing mistreatment of a vulnerable group of patients and families.

There was no direct interaction with patients or staff in this research, and so no direct benefit was possible. However, the knowledge gained can inform future practice, thereby promoting better care for patients needing palliative care in the acute care setting and empowering staff to give this care.

Because the research assessed attention to essential elements of end-of-life and clinical competence, it is important to stress that the staff will be protected from punitive measures. The research aimed to describe current practice and make recommendations, not to punish staff.

Autonomy

Autonomy is the individual's right to self-determination. It has two broad sub-sections – informed consent and confidentiality.^(135,136)

Informed consent

Informed consent requires competence and voluntariness in deciding. Before this can happen, there needs to be the sharing and understanding of information.⁽¹³⁶⁾

Written permission was obtained from the Groote Schuur's Chief Executive Officer to conduct the folder review once the proposal was passed by University of Cape Town Human Research Ethics Committee. See appendices B and C.

As no direct interaction with living people was proposed, there was no individual informed consent taken.

Confidentiality

Confidentiality of information in a folder review needs to protect both the patients involved and the staff rendering care.

Confidentiality in this study was ensured by the following measures 1)Patient identification list is kept separate from information gathered 2)Staff names was not recorded 3)Information recorded and stored onto a password protected laptop 4) Back-up of information is on Spider Oak, a locally encrypted cloud storage facility.

Unprocessed data will be stored by the author for at least five years, after which it will be permanently deleted.

Justice

Justice refers in principle to fairness. There are three aspects of justice to consider, namely, legal justice, rights-based justice and distributive justice.⁽¹³⁷⁾

All patients have the right to appropriate health care. Just because cure is highly unlikely in the patients referred to the palliative care unit, does not mean that they do not deserve impeccable health care. This study aims to draw attention to this right of patients at the end-of-life, thereby protecting and upholding the right to medical care.

Distributive justice is always relevant in a resource limited setting such as Groote Schuur Hospital. However, the interventions proposed by palliative care is likely to free up very limited resources from patients who do not stand to benefit from them and render appropriate care to these patients.

Data analysis

The data were collected into a Microsoft Excel spread sheet and analysed with Small Stata 13.0. Numerical variables included age and length of stay. These were analysed using summary descriptive statistics to establish mean, median, standard deviation, interquartile range, minimum and maximum values. The Shapiro-Wilks test was applied to ascertain the distribution of the ranges. The Shapiro –Wilks test is a test of normality in frequentist statistics, using the null hypothesis.⁽¹³⁸⁾

All the other variables were analysed as categorical. These included whether current medications were assessed, whether as required medication for pain, vomiting, agitation or secretions were prescribed, whether blood tests were discontinued, antibiotics were discontinued, whether a CPR order was in the file, whether unnecessary nursing interventions were cut, whether a syringe driver was ordered and commenced, what medications were administered via syringe driver.

A Kaplan-Meier Survival Estimate and a Cox Proportional Hazards Analysis were performed to investigate whether administering four medications via syringe driver had any effect on time to death. The Kaplan-Meier method is a non-parametric method to estimate empirical hazard, survivor and cumulative distribution function. In it, data is ordered by ascending times to the “event” (death in this analysis).^(139,140) The Cox Proportional Hazards Model for Censored Data is a semi-parametric method for adjusting survival rate estimates to quantify the effect of predictor variables (having four medications in the syringe driver in this analysis).⁽¹⁴¹⁾

Communication measures were assessed in terms of health care providers speaking the patient’s language, awareness of the diagnosis and of dying for both patient and family. It also dealt with whether a family contact person was recorded and whether the family was given hospital information. Spiritual measures established spiritual needs recorded and religious tradition recorded. Several chronic diseases were recorded as being as present and not present. The patient population often had more than one diagnosis, but all diagnoses were recorded if present. The patients’ ages were converted into age categories for comparison. Age category one was age 0-30 years, two was 31-50 years, three was 51-70 years and four was 71 years and older.

Categorical variables were plotted as one-way or two-way tables. Percentages of totals were calculated. Two-way tables plotted outcomes versus the individual disease profiles, hypertension versus massive stroke, previous stroke versus massive stroke, malignancy present versus malignancy absent, hypoxic brain injury versus being post cardio-pulmonary resuscitation and age category versus length of stay. All other categorical variables were analysed using one-way tables.

Age category was tabulated against mean length of stay, and a Kruskal-Wallis equality-of-rank test and Pearson chi-squared test applied to ascertain whether there was a significant difference in length of stay between the different age categories. The Kruskal-Wallis equality of rank test is a non-parametric test comparing several random samples. The null hypothesis in the test is that all the samples’ distribution frequencies are equal. If the test is significant, one can make multiple comparisons between the samples.⁽¹⁴²⁾ The Pearson chi-squared test is a test applied to two sets of categorical data to establish whether observed differences may have arisen by chance. It is reported in terms of a probability (p) value. If the p value is less than 0.05, the test is deemed significant, i.e. there is more than a 95% chance that the difference is not just due to chance.⁽¹⁴³⁾

Some categorical variables (e.g. known hypertension and massive stroke) were plotted against each other to ascertain whether they were related. Pearson’s chi-squared test was applied to see whether the association was significant.

Repeatability / reliability

All the records were assessed by the same researcher. If there was concern about incongruences between folders, the older folder was rechecked. For example, when it was soon found that is often not a clear “Do not resuscitate” order in the folders, a third category of “proxy DNR” was created and the previous folders checked and recorded as such.

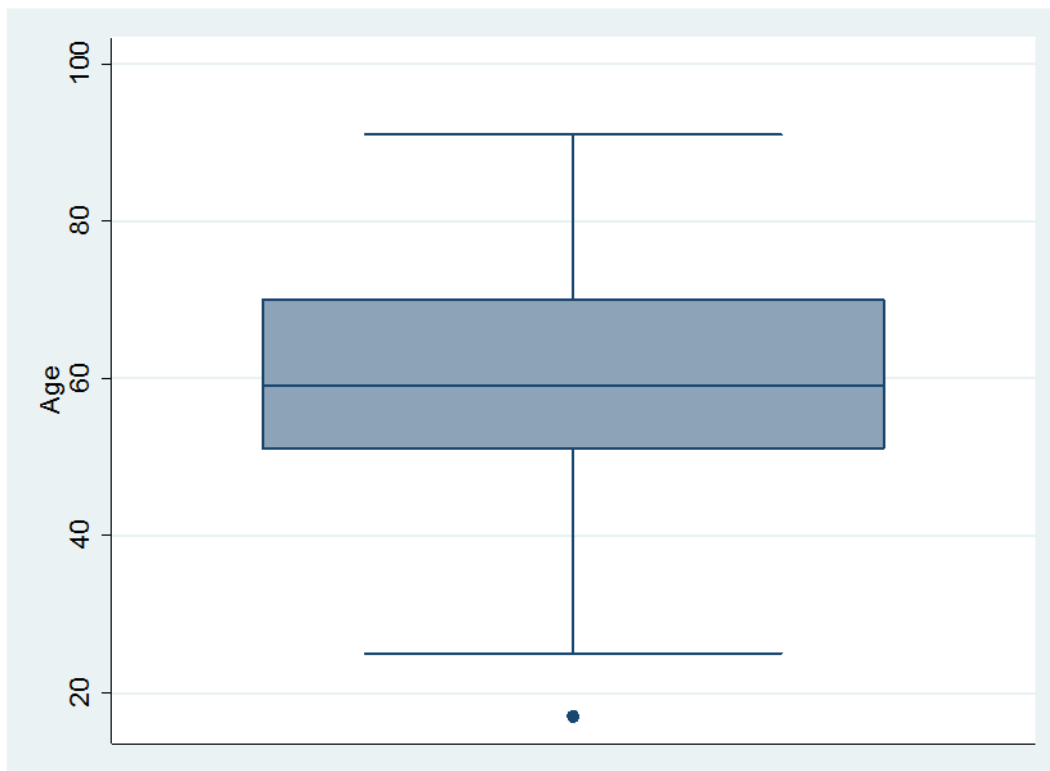
Chapter 4: Results

A total of 176 eligible folders were identified. Nine folders were not found after three attempts. There were 167 folders included in the initial review. Nine folders were excluded, as there was no record found of admission into the palliative care unit. Thus, the response rate was 94.89% and the exclusion rate 5.39%. This made the number of folders included in the study 158. Eight of these folders had significant missing documentation, but were still included in the study.

Demographics

Age

The mean age was 59.49 years (95% CI 56.76 – 61.53) Standard deviation 15.15, minimum 17, maximum 91 years. Shapiro –Wilks test showed a normal distribution of the series. See graph 1.



Graph 1: Age range box-and-whisker plot

Areas of referral

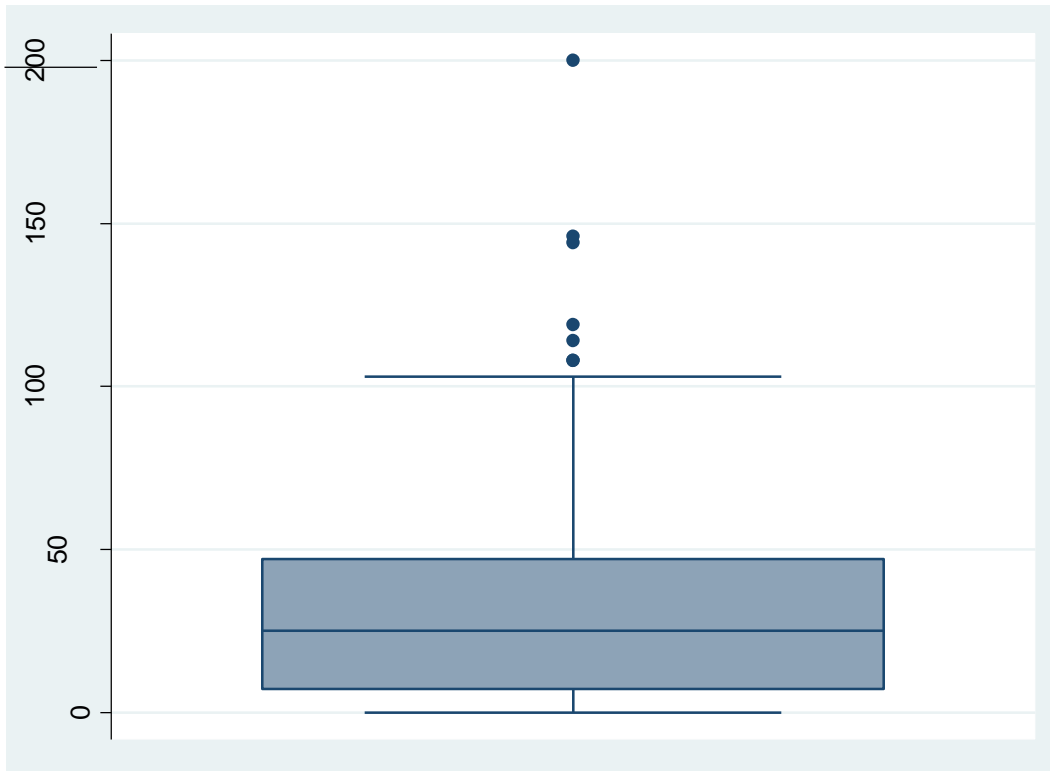
Table one summarises all areas of referral. All patients admitted from outside Groote Schuur Hospital were admitted via the Emergency Department.

Area of referral	Number of patients
Self-referral	114
Community health centres across Cape Metropole	17
District hospitals (GFJ, VHW, Wesfleur)	10
Regional hospital (NSH)	3
Other areas in GSH	5
GP practice	3
Private hospital	1
Local hospice	1
Old age home	1
International hospital	1

Table one: Areas of referral to the unit

Duration of admission

The median length of stay was 25 hours (IQR 7-47), minimum 0 and maximum 200 hours. Shapiro-Wilks test showed a skewed distribution of the series. See graph 2.



Graph 2: Length of stay box and whisker plot

Exclusion of outliers still showed a non-normal distribution, according to the Shapiro-Wilks test.

Gender was evenly distributed, with 78 females and 79 males admitted to the unit during the audit.

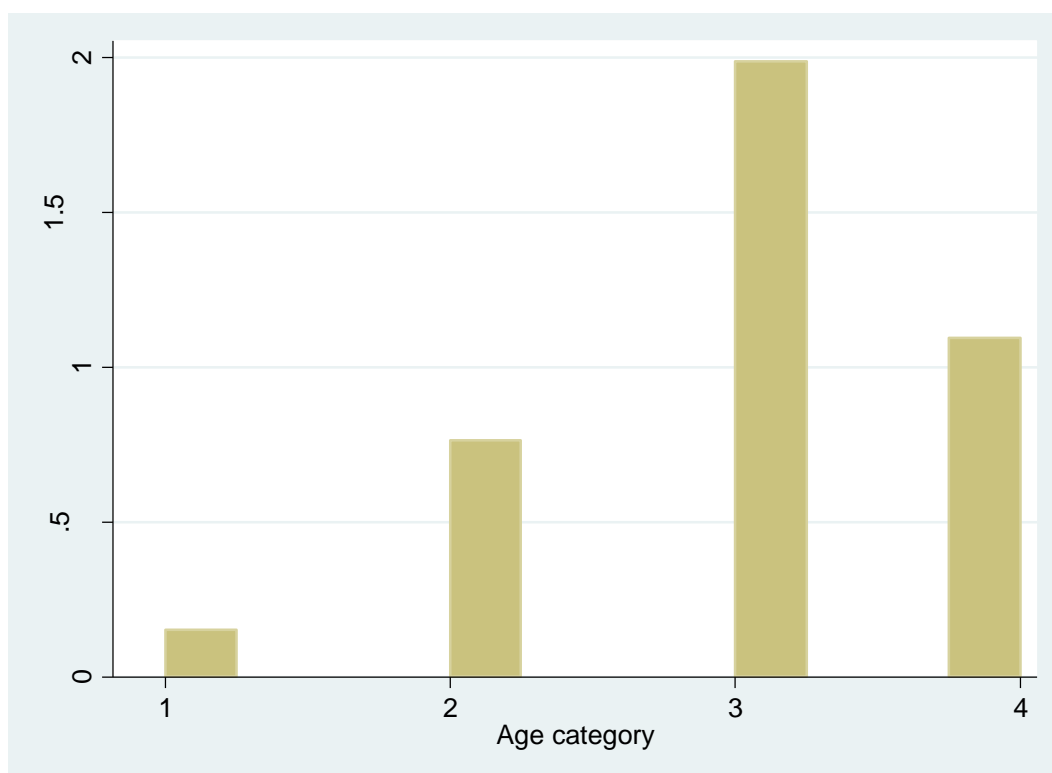
Six patients (3.82%) were under the age of 30 years. Thirty patients (19.11%) were between the ages of 31 and 50 years. 78 patients (49.68%) were between the age of 51 and 70 years, while 43 patients (27.39%) were older than 70 years. See graph 3. Table two compares the age categories in terms of average length of stay. Older groups were likely to stay for significantly longer ($p=0.03$).

Age category	n	Mean age (years)	Mean length of stay (hours)	Kruskal-Wallis Equality-of-Rank test rank sum
< 30 years	6	25.67	17.21	351.00
30-49 years	30	41.33	31.68	2372.00
50-69 years	77	59.03	29.61	5404.50
>70years	42	77.72	41.72	3962.50

Table two: Age category versus mean length of stay

Chi-squared test = 9.050 with 3 d.f. ($p = 0.0286$)

Chi-squared test with ties = 9.053 with 3 d.f. ($p=0.0286$)



Graph 3: Age distribution of patients, per age category

1= under 30 years, 2= 30-49 years, 3= 50-69 years, 4=older than 70 years

Diagnoses

Sixty patients (38.22%) were admitted with a known diagnosis of malignant disease, where-as 97 (61.71%) of patients with palliative care needs did not have any known malignancy. Of the patients known with malignancy, 28 (46.67%) were not diagnosed with metastatic disease and 32 (53.33%) did have metastatic disease. Refer to table three for the breakdown of the different malignancies.

Cancer subtype	Number of patients	%
Lung	17	28.33
Colo-rectal	7	11.67
Breast	6	10.00
Cervix	5	8.33
Haematological	4	6.67
Oesophagus	4	6.67
Brain	3	5.00
Pancreas	3	5.00
Head and neck	2	3.33
Renal	2	3.33
Prostate	2*	3.33
Gastric	2*	3.33
Bladder	1	1.67
Gallbladder	1	1.67
Uterine	1	1.67
Unknown primary	1	1.67
Total	60+1	100+1.67

Table three: breakdown of malignancies

Many patients were known with multiple co-morbidities. For ease of analysis, all these were listed separately, but in looking at these results, it is important to bear in mind that one patient could be suffering from more than one of these diagnoses. Hypertension was previously diagnosed in 60 (38.22%) of the patients. Diabetes mellitus was present in 28 (17.83%) patients. As reported earlier, malignancy was present in 60 (38.22%) of the patients. Chronic obstructive airways disease was present in 11 (7.01%) patients. Only one patient (0.64%) was known to be suffering from asthma. Fifteen patients (9.55%) were HIV positive, of these five (33.33%) also had active TB. Six patients (3.82%) had TB; five of them (83.33%) were co-infected with HIV. Eleven patients (7.01%) had had a previous stroke, three (1.91%) had epilepsy and five (3.18%) were suffering from end-stage

dementia. Cardiac failure was present in 14 patients (8.92%). Seven patients (4.46%) had abused alcohol chronically. 46 (29.30%) of the patients admitted during the audit had suffered from massive strokes, often haemorrhagic in nature, and not amenable by neurosurgery. Of these patients, 25 (54.35%) were known hypertensive patients ($p < 0.05$). End-stage renal failure (not for dialysis) was present in 30 (19.11%) patients. Hypoxic brain injury was present in 11 (7.01%) patients; eight (72.73%) of these patients had received cardio-pulmonary resuscitation (CPR). Sepsis was present in 25 (15.92%) of the patients, often complicating other life-limiting diagnoses e.g. aspiration pneumonia post massive stroke. "Other neurological" diagnoses included delirium, seizures and neuro-glycopenic brain injury. "Other neurological diagnoses" were present in 23 patients (14.65%). "Other" diagnoses included hypothyroidism, schizophrenia, Down's syndrome and other associated diagnoses, not necessarily related to the acute life-limiting event. There were 35 patients (22.29%) with "other" diagnoses.

Diagnosis	Number of patients	%
Hypertension	60	38.22
Diabetes Mellitus	28	17.83
COPD	11	7.01
Asthma	1	0.64
HIV/AIDS	15	9.55
TB	6	3.82
Previous stroke	11	7.01
Massive stroke	46	29.30
Epilepsy	3	1.91
End-stage Dementia	5	3.18
Cardiac Failure	14	8.92
Chronic Alcohol Abuse	7	4.46
End-stage Renal Failure	30	19.11
Hypoxic Brain Injury	11	7.01
Sepsis	25	15.92
Other neurological	23	14.65
Other	35	22.29

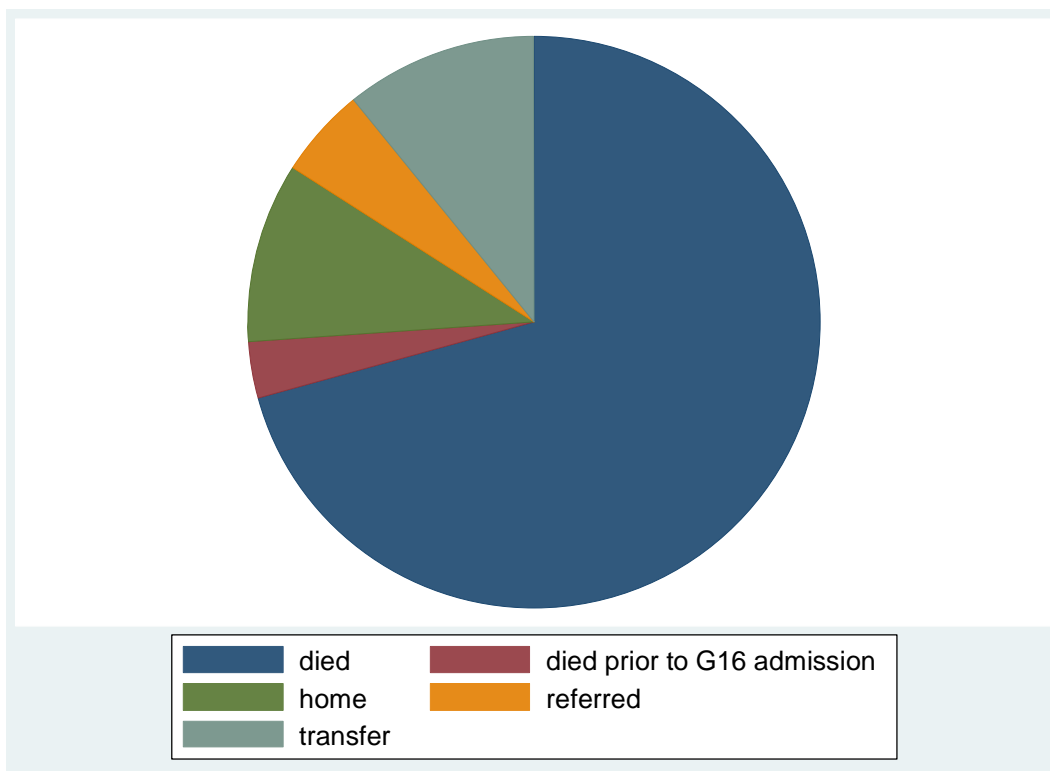
Table four: non-malignant diagnoses

Outcomes

Table five summarises general outcomes for all the patients admitted to the unit.

Outcome	Number of patients	%
Died in the unit	111	70.70
Died prior to admission to the unit	5	3.18
Went home	16	10.19
Referred back to specialities	8	5.10
Transferred to step down facility	17	10.83
Total	157	100

Table five: Outcomes of patients admitted to the unit. Also refer to graph 4



Graph 4: Outcomes

Disease specific outcomes are summarised in table six. Many patients had multiple co-morbidities.

Outcome	Malignancy	Massive stroke	ESRF	HPT	DM	Asthma/COPD	CCF	Epilepsy	HIV/AIDS	Hypoxic brain injury	Sep-sis	Alcohol Abuse	Dementia	TB	Other neuro	Post CPR
Died in unit	38	32	25	42	21	9	12	2	13	9	16	4	5	6	12	6
Died prior to admission to the unit	1	2	0	1	0	1	0	0	0	1	1	1	0	0	0	1
Went home	6	6	3	6	3	1	1	0	0	1	5	1	0	0	4	1
Referred back to specialities	5	2	1	4	1	0	0	0	0	0	0	0	0	0	2	0
Transferred to step down facility	10	4	1	7	3	1	1	1	2	0	3	1	0	0	5	0
Total	60	46	30	60	28	12	14	3	15	11	25	7	5	6	23	8

Table six: disease-specific outcome. Many patients had multiple co-morbidities

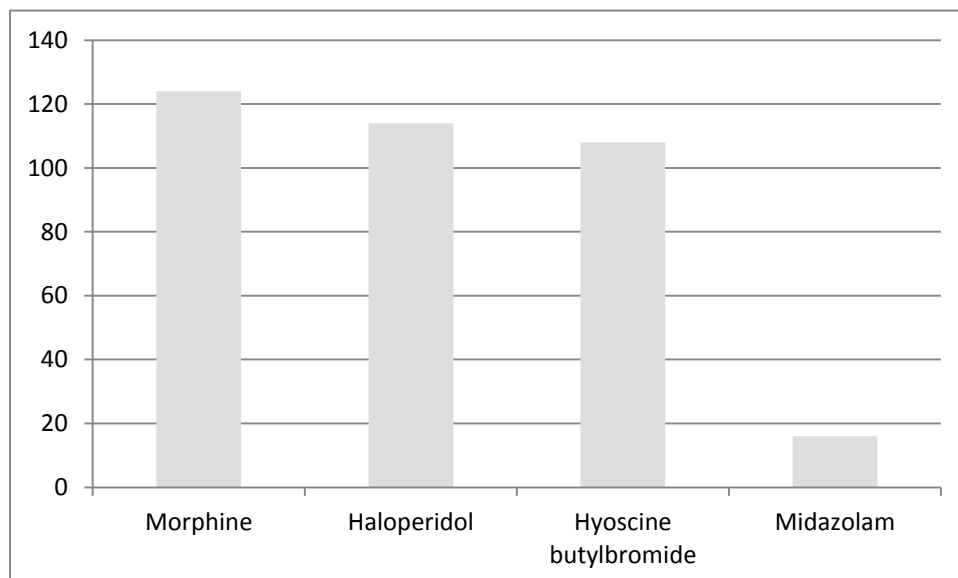
Care offered in the unit

Medication

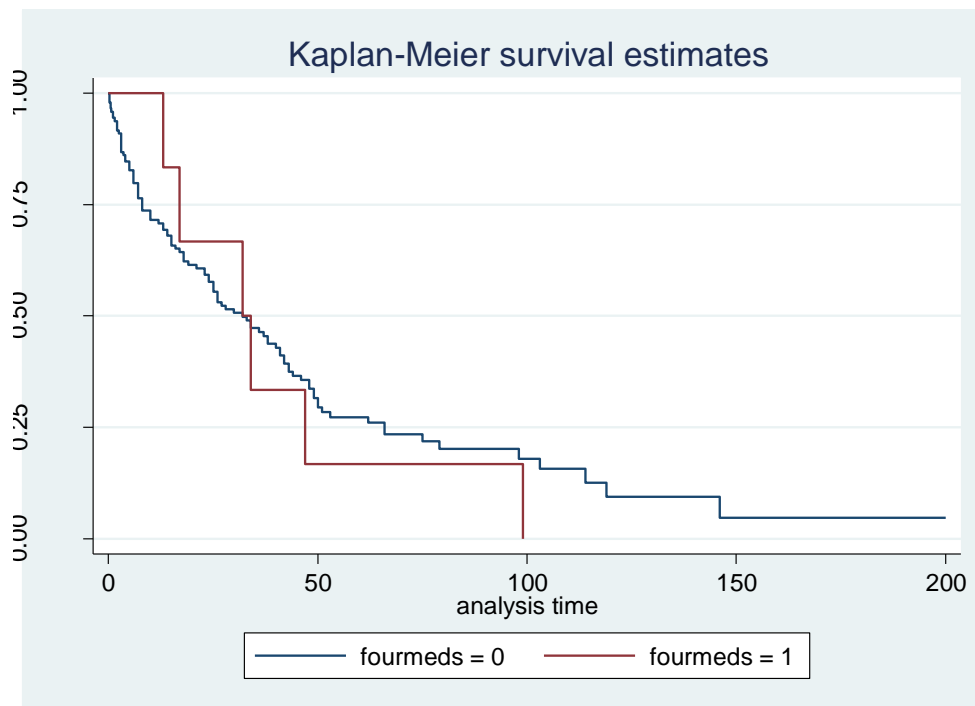
Medication was reassessed in 146 (96.05%) patients, unnecessary medications were discontinued and the subcutaneous route of administration was prescribed where appropriate.

In total, 128 (81.53%) patients admitted to the palliative care unit had all oral medications stopped and a subcutaneous syringe driver prescribed. However, five (3.91%) patients prescribed subcutaneous medications died before arrival at the unit, and thus did not have the syringe driver commenced. Syringe drivers were prescribed to contain morphine in 124 (96.88%), haloperidol in 114 (89.06%), hyoscine butylbromide in 108 (84.34%) and midazolam in 16 (12.50%) of patients. No syringe driver contained more than four medications.

Six patients had four medications in their syringe driver. Their mean length of stay in the unit was 40.33hours, median 33hours, SD 31.26446, IQR (17- 47) Shapiro-Wilks showed a normal distribution. Kaplan-Meier Survival Estimate and Cox Proportional Hazard Model found no significant impact on time to death by having four medications in the syringe driver ($p = 0.669$, Hazard Ratio 1.197 Confidence Interval 0.52 - 2.73). Diagnoses of patients with four medications included metastatic uterine carcinoma, end-stage renal failure (hypertension, diabetes), massive stroke (hypertension), metastatic gastric carcinoma and HIV, as well as status epilepticus and cardiac arrest, with hypoxic brain injury after return of spontaneous circulation. Data capture did not capture whether these patients had one or two syringe drivers running. See graph 6.



Graph 5 Medications used in syringe driver



Graph 6 Kaplan-Meier curve of survival times

Fourmeds = 0 Patients with <4 medications in syringe driver

Fourmeds = 1 Patients with 4 medications in syringe driver

“As required” analgesic medications were prescribed in 83 (54.61%) patients.. The agent prescribed was usually indomethacin suppositories. No breakthrough doses of morphine were prescribed, rather if patients were assessed as in pain in later assessments (see later), morphine dosage in the syringe driver was increased.

“As required” medication for agitation or anxiolytics was prescribed for 89 (58.55%) patients.. Lorazepam was the most commonly used agent.

Eight (5.26%) patients were prescribed “as required” medication for nausea and vomiting.

Nineteen (12.50%) patients received an “as required” prescription for secretions.

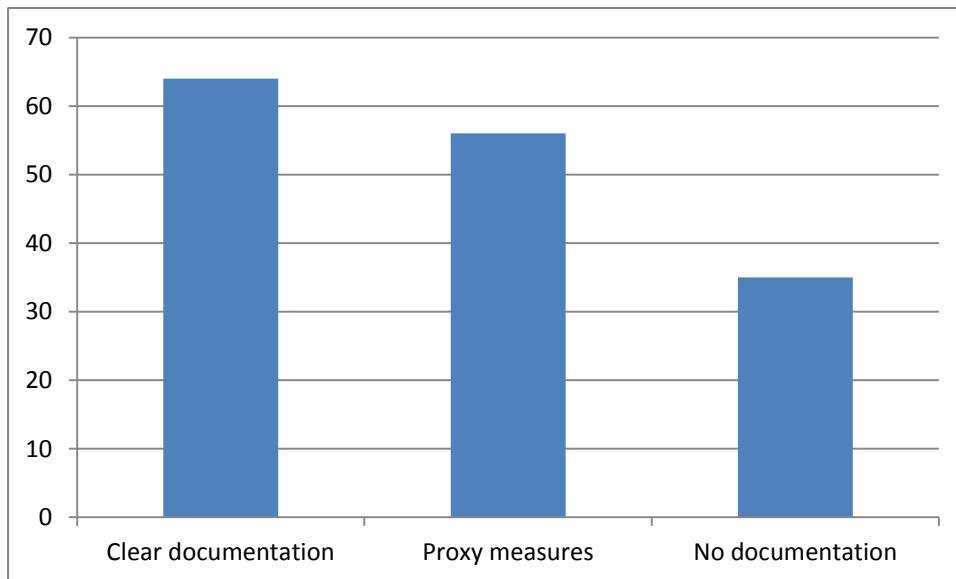
Blood testing was discontinued in 146 (94.81%) patients.

Unnecessary nursing interventions were discontinued in 139 (90.85%) patients. This includes four hourly vitals. Pressure care was continued.

Cardio-pulmonary resuscitation (CPR)

No formal policy documents relating to CPR or “Do not attempt resuscitation (DNAR)” were found in any of the folders. Groote Schuur Hospital has a policy regarding this decision. See appendix D.

There was a clear order written in the notes to not attempt CPR in 64 (41.39%). Proxy measures indicating that active resuscitation is not appropriate were present in 56 (36.13%) folders. No clear instructions with regards to CPR were found in 35 (22.58%) folders. Graph 6 summarises these findings.



Graph 7: CPR documentation

Repeat assessments

As mentioned earlier, in the methodology section, there was no clear timeline for assessing repeat assessments. The literature suggests four hourly assessments.⁽¹¹¹⁾ If any mention was made at all about the parameters assessed, then the assessment was recorded as achieved.

Table seven summarises the physical care and reassessments rendered in the unit.

Reassessment	Pain	Agitation	Secretions	Nausea/ vomiting	Mouth care	Pressure/ comfort care	Urine output chart	Medication Reassessed /adjusted	Bowel care
Yes	113 74.83%	112 74.17%	81 53.64%	16 10.60%	69 45.70%	127 84.11%	117 77.48%	120 79.47%	10 6.62%
No	7 4.67%	17 11.26%	49 32.45%	113 74.83%	60 39.74%	7 4.64%	15 9.93%	12 7.95%	119 78.81%
Died too soon to reassess	21 11.26%	22 14.57%	21 11.26%	22 14.57%	22 14.57%	17 11.26%	19 12.58%	19 12.58%	22 14.57%

Table seven: Physical care in the unit

Communication

Ability to communicate clearly was assumed if the patient or family's first language was Afrikaans, English or isi-Xhosa. This was the case in 63 (41.25%) patients and 142 (93.42%) of families. Eighty-one (53.29%) patients were too sick to communicate with. Difficulty with communication was present in 8 (5.26%) patients and 10 (6.58%) families.

Notes in patients' files indicate that 57 (38.00%) patients and 136 (90.67%) families were aware of the diagnosis. However, 80 (53.33%) patients were too sick to communicate the diagnosis or treatment options during the admission. Thirteen (8.67%) patients and fourteen (9.33%) families were not documented as being aware of the primary diagnosis.

Documentation was that 26 (17.33%) patients and 121 (81.21%) families were aware of the patient being in the dying phase of their illness. It was found that 94 (62.67%) patients were too ill to communicate. Twenty-eight (18.67%) patients and 26 (17.45%) families were not documented of being aware of the dying phase being entered. Two patients were not actively dying.

There was documentation that the plan was discussed with 30 (20.13%) patients and 123 (83.11%) families. The care plan was not discussed with 88 (59.06%) patients, on account of them being too ill. It wasn't documented that the plan was discussed with 31 (20.81%) patients and 22 (14.86%) families. Three (2.03%) families were not reachable, but efforts to contact them were documented.

Table eight summarises the communication documentation in the unit.

		Able to communicate	Aware of diagnosis	Aware of dying	Plan discussed
Patient	Yes	63 (41.25%)	57 (38.00%)	26 (17.33%)	30 (20.13%)
	No	8 (5.26%)	13 (8.67%)	28 (18.67%)	31 (20.81%)
	Too ill for communication	81 (53.29%)	80 (53.33%)	94 (62.67%)	88 (59.06%)
Family	Yes	142 (93.42%)	136 (90.67%)	121 (81.21%)	123 (83.11%)
	No	10 (6.58%)	14 (9.33%)	26 (17.45%)	22 (14.86%)
	Unable to reach family				3 (2.03%)

Table eight: Communication in the unit

Psychological support

Documentation of patients receiving psychological support and comfort was found in 18 (11.92%) folders. No documentation with regards to psychological support was found in 111 (73.51%) folders. It is not possible to comment on whether the 22 (14.57%) patients who died shortly after admission received psychological support, as this measure was not formally documented.

Documentation of family members being psychologically supported or comforted was found in 41 (27.15%) folders.

Documentation of family members' needs being addressed was found in 76 (50.33%) folders.

Documentation of family members being given hospital information, and specific information with regards to the palliative care unit was found in 84 (55.63%) folders.

A specific family member who could be contacted in case of emergency and/or death was documented in 134 (88.74%) folders.

The patient's primary care team or doctor was aware of the admission in 67 (44.37%) of cases. However, not one of them was documented as informed when the patient had died.

Spiritual care

Spiritual needs were documented and/or addressed in 42 (27.81%) patients. Documentation of 95 (62.91%) patients suggests that they were too sick to communicate with. No mention is made of spiritual care in 14 (9.27%) patients' folders.

A religious tradition was identified in 76 (50.33%) patients and of them 8 (10.53%) had a religious leader contacted or visiting them.

Subset of data relating to patients who died in the Palliative Care Unit

The 41 (26.11%) patients who did not die in the unit are excluded from the rest of the results.

In 111 patients who died in the unit, their death recorded in the folder. No documentation of laying out procedures was found in any folder. Documentation was found that 106 (93.81%) families were informed of legal procedures related to registration of the death, undertakers and burial. In six cases (5.31%), staff from the unit was unable to get hold of the family. In one folder (0.88%) no mention was made about information given to the family related to the death's aftermath. In two folders, the information was missing.

The necessary documentation was given in all patients who died in the unit. Hospital policy regarding patients' belongings was followed in 44 (38.94%) of cases.

As mentioned earlier, no primary care doctors were informed of the patients' death.

Bereavement support (aftercare) was rendered in 15 (13.27%) cases.

Summary of results

In summary, 158 patients were admitted to the unit during the research period. Most of the patients admitted were self-referred to the ED from home. All of the patients had a decision made to withhold or withdraw life-prolonging treatment.

Mean age was 59.49 years. The bulk of the patients were in the 50-69 years age category. Patients in the older age categories stayed in the unit significantly longer than the younger age categories. Median length of stay in the unit was 25 hours.

Malignancies, along with hypertension were the two commonest diagnoses. Patients without malignancy made up the bulk of the population. Multiple co-morbidities were present in most patients.

One hundred and sixteen patients died during the index hospitalisation. Sixteen went home for home-based palliative care, eight were referred back to specialities with potentially reversible factors and seventeen were referred for palliative care in a step down facility.

Medication was reassessed in 146 of patients, and 128 patients were prescribed subcutaneous medication via syringe driver.

No formal DNAR documents were completed, but documentation or proxy was found in 120 (77.52%) of folders.

Most (90.67%) of families were documented as being aware of the diagnosis and prognosis. Patient were less aware, with 57 (38%) documented as aware of the diagnosis and 26 (17.33%) being aware of dying. This is mostly attributed to the patients being too ill to effectively communicate.

Psychological support and spiritual care was poorly documented overall.

Bereavement was also poorly documented.

These results will be discussed further in the following chapter.

Chapter Five: Discussion

Demographics

The demographics of the patients admitted to the unit were different from similar units described in the literature.^{(9,42,72,73,77,108,121).}

Age and age distribution

The demographics differed from the literature in age distribution. More patients were dying in the 50-69 year old age group than the elderly population. This differs from studies from the first world.^(3,45,107) In a similar study done by Parish *et al.* in Australia, all the patients were elderly.⁽¹⁰⁷⁾

Area of referral

Most patients arrived at the Emergency Department self-referred from home in extremis, and for most the decision was made to withhold or withdraw treatment. This correlates with the descriptions of van Tricht *et. al* and Le Conte.^(23,24,31) There were fewer in-hospital referrals than other units of a similar nature, and often the referrals were not specifically for end-of-life care

Considering how many in hospital deaths tend to be anticipated, and the fact that a longer hospital stay is associated with a higher chance of dying an expected death, it is of concern that in-hospital referrals are not occurring. This may be explained by the fact that the unit is being run by the ED doctors, as a formal palliative care team is only being formed currently. Current policy precludes admission into the unit from patients already admitted into a ward hospital bed. This policy reflects the current staffing situation in the unit.^(29,78,79)

Length of stay in the unit

One of the concerns in the creation of this unit, as well as the literature on end-of-life care pathways, is the difficulty in accurately diagnosing dying.^(12,39,40,106) Inappropriate diagnosis may lead to prolonged stays in an acute unit such as this, or families feeling that death is being hastened. Considering the data, it emerges that, for the most part, the diagnosis was accurate and/or future planning was initiated as soon as the patients were admitted. Thus, with the exception of a few outliers, the median stay length was just over one day. Older people were significantly more likely to stay longer in the unit. This may be related to societal beliefs regarding care and diagnosing terminal decline more easily in older patients (and in patients with malignancy)^(12,29,31,78,79,144,145) Also, 5% of patients either improved enough or had an acutely reversible cause of their symptoms and were

referred back to various specialities for management. This underlines the importance of regular reassessment, even if it seems that the patient may die soon.⁽³⁹⁾

Diagnoses

It is of note that more patients had palliative care needs from non-malignant disease progression than malignancy. This unexpected result may be explained by the oncology team still admitting its own palliative care patients in the oncology ward, and that the NGO hospices tend to meet the needs of cancer patients in the community. However, cancer, together with hypertension was the most common diagnosis in the population.

Most patients had more than one diagnosis, affirming that, in non-cancer palliative care especially, it may be very difficult to distinguish what diagnosis is causing the final decline. This concurs with the literature on illness trajectories discussed in the literature review chapter.^(52,57,146)

The cancer subtype diagnoses that patients were admitted to unit with which, broadly reflect the top cancer causes of death published by the Cancer Association of South Africa in 2014. Nine out of the top ten causes of cancer deaths from the statistics are represented in the top ten cancer subtypes in the unit. The exception was liver cancer, which was not represented in the study population.⁽¹⁴⁷⁾

Massive (usually haemorrhagic) strokes were the next most common diagnosis in the group. There was a significant association between a known hypertensive diagnosis and having a massive stroke, ($p=0.007$). Of note is that only 9.55% of the patients admitted during the study period were dying of AIDS, compared to Kellar's 27% in a U.S. hospital in the nineties. This may add evidence to the effectiveness of ARVs.⁽¹²¹⁾

Outcomes

Death occurred in 116 patients during their admission to the unit. Of those, five had actually died by the time they reached the unit from the emergency department. These five patients may have benefitted from a unit that is closer in proximity to the ED than the unit was, or being kept in a side room in the ED, something that the current infrastructure does not support.⁽¹⁰⁸⁾ Ten per cent of patients went home for end-of-life care. This is in keeping with the trend of fewer than one in ten home deaths projected by Gomes and Higginson⁽⁴⁵⁾, but this may be skewed by the fact that only folders of patients who were admitted to the unit was assessed. Many more patients may have gone home from the ED without referral to the unit.

Care offered in the unit

The unit being assessed was opened in April 2011. This was during the time of major uncertainty and reform with regards to end-of-life care described in the literature review chapter. Integrated care pathways were never introduced in the context of this unit. The aim of this unit was to focus on patients and their families, and provide sensitive, appropriate care.

Medication

One of the goals of the LCP was to get syringe drivers set up within four hours of the doctor's orders.⁽¹⁵⁾ The syringe driver is a commonly used drug delivery tool used extensively in palliative care.^(15,148) The syringe driver was prescribed in 128 (81.53%) of patients in the unit. This is in line with current recommendations.⁽⁴⁰⁾ However, many patients and families are often wary of the syringe driver, and clear communication about its role is crucial. "One chance to get it right" states that the syringe driver should only be used when symptom control demands it, and the reason and potential side effects should be discussed with the patient and their loved ones.^(40,149) When patients were on a syringe driver, morphine was not anticipatorily prescribed for breakthrough pain. In several cases, the doctor was contacted as the nurses assessed the patient to be in pain, and breakthrough doses were prescribed. This is of concern, as we have established that pain is often under-recognised and undertreated.^(68,76) Morphine, haloperidol and hyoscine butyl bromide were the commonest prescribed drugs in the syringe driver, in line with current practice. Midazolam was only used in 16 cases. This is in line with the recommendation to limit the routine use of sedatives, unless clinically indicated and discussed with relevant stakeholders.⁽⁴⁰⁾

Six patients had four medications in their syringe driver. Data capture did not record whether they had one or two syringe drivers running. Current recommendation is to combine two or three drugs, but occasionally more drugs can be used.⁽¹⁵⁰⁾ To assess whether any harm was caused by administering four medications in one syringe driver, a Kaplan-Meier Survival Estimate and Cox Proportional Hazards Model were performed. This showed no significant impact on the time to death by administering four medications in the syringe driver ($p=0.669$). The hypothesis was that if harm was caused to patients already so sick that they are considered dying, the time to death may decrease. This was not found to be the case.

DNR Orders

Refer to appendix D for the Western Cape Government's policy on DNR. The form requires very specific information on what care is not indicated. It states clearly that all other care should be given. This is important, as the literature shows that very often; a DNR order leads to reduced overall care. This is also why many doctors are reluctant in giving DNR orders.⁽⁹⁵⁾ In the current study, there was not one DNR form completed. There were orders in the notes relating to not attempting CPR, inserting naso-gastric tubes and intravenous lines in nearly 80% of cases, but no formal policy-led documentation. This may be problematic in many ways. Documentation in the notes may still lead to reduced care. Documentation may not be noticed at times of crisis. The decision may not be adequately discussed with the patient and the family. There may be a breakdown in trust if this important matter is not approached honestly and sensitively.^(100,105,151) Conversely, keeping notes simple, and not having more forms filling up folders may be useful in streamlining documentation and care.⁽²⁶⁾

In more than 20% of cases, there was no documentation related to CPR. This is of concern, as palliative care is not equal to "Do Not Resuscitate". Both concepts are separate, important, and need to co-exist.

Repeat assessments and physical care

The commonest reason for repeat assessments not being done was that the patient had passed away since the initial assessment. This was the case in 22 (14%) patients.

Assessments of pain were performed at least daily in 113 patients. A limitation of the data collection tool was that no clear timeline was specified for repeat assessments. Lack of formal pain assessment tools and timelines is of concern, as pain is often under assessed and undertreated at the end-of-life.^(33,67,68,116)

Repeat assessment of agitation was documented in 112 patients. This is in line with current recommendations, to have patients comfortable, but not over-sedated.⁽⁴⁰⁾ However, it is difficult to assess retrospectively whether the patients or families may have felt overly sedated. Routine sedation was not given, according to current recommendations.⁽⁴⁰⁾ More than half the population was assessed as too ill to discuss prognosis and plan. This correlates with research documenting the incidence rates of delirium as high as 88% near the end of life.⁽¹⁵²⁾

Repeat assessment of secretions was documented in just over half of patients. Mention was made even if patients did not have excess secretions. If one looks at the prescribing of hyoscine butyl

bromide in the unit, which is to decrease secretions, it seems that anticipatory prescribing of the anti-sialagogue decreases the so-called “death rattle”.⁽¹¹⁹⁾ Secretions are a common problem at the end-of-life, but may be more distressing to the family than the patient.^(15,119)

On the other hand, mention of nausea and vomiting was only made when the patient was actively vomiting. The patients on syringe drivers tended to have low-dose haloperidol administered, which helps to treat this distressing symptom, so one can hope that nausea was not common. However, it is impossible to assess the symptom burden of nausea retrospectively.⁽¹¹⁹⁾

The aim of mouth care is prevention and treatment of unpleasant symptoms. It consists of preventing a dry mouth by oral sips or rinsing, dental hygiene and preventing chapped lips by applying an emollient. This was done in nearly half of patients in the unit. This is uncomplicated care that can greatly enhance comfort at the end-of-life.⁽¹⁵⁾

Pressure care and turnings for comfort continued in 84% of patients. This is good nursing practice. Only seven patients lacked documentation of pressure care. Comfort care becomes a top priority at the end of life.⁽¹⁵⁾

Urine output was also well documented.

Most patients who stayed in the unit longer than a day had their medication reassessed.

Bowel care was done in ten patients. Constipation is a common problem in palliative care, and untreated, can lead to pain, bowel obstruction and overflow diarrhoea.⁽¹⁵⁾ However, in the terminal phase, treatment is only indicated if it causes distress.⁽¹⁵³⁾

Communication

Communication is a crucial part of any relationship, but no more so than the caring relationship at the end of life. If one has to pinpoint the main factor why so many families were unhappy with the Liverpool Care Pathway, poor communication would have to be it.^(39,116) In the research population, initial discussions were documented in most cases, but the families who were not immediately contactable often became distressed on arrival at the unit. In nearly 20% of cases, the families did not realise that their loved one is going to die soon – either because they did not understand or was not contactable at the time. Documentation by doctors having these difficult conversations is clearer in the initial notes, than follow-up discussions. All patients were initially assessed in the ED, and that is where most of the initial discussions took place. Follow-up discussions would have taken place in the unit itself, and taking into account staffing pressures, documentation declined accordingly. Thus, one can conclude that documentation could improve, especially if the unit had full-time staff.

South Africa is a multi-lingual country, and miscommunication is common. Although language was assessed, it is hard to comment whether all interactions had clear communication, as patients, family members, doctors and nurses could all speak different languages (especially if they were English, Xhosa and Afrikaans) and communication difficulty would not have been recorded. This is probably related to the tool being developed in a country with one major spoken language, English, and any deviation from this would have been easier to document.^(15,35)

The patient's primary care team or doctor was aware of the admission in over 40% of cases. However, not one was informed once their patient had passed away. This is a symptom of a care system based on Community Health Centres (or "Day Hospitals") where patients wait in line to see doctors, and doctor-patient relationships are difficult to maintain. However, there is scope for informing the patient's general practitioner where they were involved in care; there is even a section on the death notification form generated by the hospital software.

Psychological care

Psychological support systems, with social workers and psychologists are not easily accessible at short notice in the South African State Health Care system. Psychological support to patients was not well documented. This does not mean that it did not occur, and possibly the nurses working in the unit takes it as a given role to support their patients. Psychological support to family members was slightly better documented (27% of family members).

Documentation of family needs being addressed was more consistently executed. This included the giving of hospital information, and how the unit differs from normal hospital admission. It was also documented if family members needed to go home, needed employers' notes and how they would like to be contacted.

Spiritual care

Psychological and spiritual support was offered by nurses and volunteers in the unit. This is a crucial part of nursing in this context, but nurses need to be trained and given adequate time to perform this part of their duties. Moving the patients into an acute palliative care unit frees up nurses from competing interests and provides an environment more conducive to dignified dying.^(26,42,154) Ross, in a review article on spirituality in nursing found that most nurses (especially in oncology and palliative care) were well equipped to identify and assess spiritual needs in their patients. However, the response to this need is often inconsistently executed and nurses need someone to refer these patients to.⁽¹⁵⁵⁾ Half of the patients had a documented religious tradition identified, but only eight had a religious leader visiting them. This may also reflect the difficulty of providing end-of-life care

far away from the patient's home community.^(42,52) Groote Schuur Hospital does have a chaplain, and including him in the team to coordinate this part of the service, may lead to improved spiritual care.

Bereavement support

The team in the unit were well equipped to deal with the patients' bodies quickly and efficiently, while allowing families to say culturally appropriate goodbyes. However, the lack of feedback to primary care, where appropriate, and bereavement support is of concern. However, this may be a case of poor documentation rather – bereavement care is not documented well, but performed.

Chapter Six: Conclusion

“...palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care;”⁽⁴⁷⁾ World Health Assembly. Strengthening of palliative care as a component of integrated treatment within the continuum of care. EB134R7

The health systems in Sub-Saharan Africa, and South Africa specifically, are experiencing a change in demands that palliative care can help address. The combination of the quadruple burden of disease, as well as significant resource constraints, requires that cost-effective care at the end-of-life become a standard of practice.⁽³²⁾

This study reported on a unit offering end-of-life care in the context of the Cape Town Metropolitan area State Health Care system. A unit such as this one has not been available in this context until recently. The current study aimed to describe the unit and evaluate the care offered there, as this had not been done previously.

The author designed a questionnaire (data capture sheet) based on the Liverpool Care Pathway to audit the elements of end-of-life care rendered at the Groote Schuur Palliative Care Unit. This objective was achieved, although data capture had some problems, including the difficulty to ascertain whether an action was required or not.

The patient population of the Groote Schuur Palliative Care Unit was described demographically and outcomes were recorded. This contributes valuable evidence to help define the role of such a service in the context of state healthcare in Cape Town.

The third objective of the study was to make recommendations on any areas of concern identified by the audit. Several recommendations can be drawn from the data presented. These will be discussed in the following section.

A word on terminology is required here. The unit is called the “Palliative Care” unit, and palliative is certainly at the core of the service offered, but palliative care refers to a broader milieu of care. The care offered in this unit is end-of-life care, or even more specifically, terminal care.^(14,39,40) In spite of this unit aiming to provide care at the very end of life, more than a quarter of the patients admitted to the unit during the research period left the hospital alive.

Palliative care can assist in addressing many complex issues in the current health care system. In this study, we described an acute palliative care unit in a context where such a service was not available previously. Most of the patients admitted to this unit had palliative care needs in the absence of malignancy. The care in the unit is aimed especially at providing care at the end-of-life. The need in the health care system for an integrated palliative care approach is bigger than what the unit can offer currently. Integrating an outpatient service may reduce the need for admissions to a unit such as this.⁽³²⁾

Limitations

This study had several limitations. The retrospective nature makes it difficult to comment on uptake of the service. It is thus difficult to ascertain whether patient still died expected deaths in the emergency department, with or without unmet palliative care needs. This may have led to selection bias and only the patients with adequate care being referred to the unit, with others stills suffering elsewhere. However, the aim was to describe and evaluate the care in the unit, and that was achieved.

The final death event in patients who often had many co-morbidities was not recorded.

Related to the retrospective nature of the study, was difficulty data collecting reliably. It was impossible to know for sure whether patients were still having underdiagnosed symptoms or unmet needs. No formal symptoms scores were used in the documentations. It is well described that nurses may document care as “good”, even when symptom management is sub-optimal.⁽¹⁴⁵⁾ Also, as the author collected all the data herself, there was no discussion in cases of uncertainty whether a parameter was achieved or not.

Data was not triangulated with family member and staff interviews, which could have offered a more comprehensive assessment of the participants’ care.^(29,107)

Due to the retrospective nature of the study and the lack of formal assessment tools, psychological care may have been grossly underestimated.

There was no group to compare the data to, e.g. a similar number of patients dying in the ED before the unit opened, or still dying in the ED, or patients dying elsewhere in hospital during the study period. Without contextual comparison, it is hard to comment on whether the opening of this unit has improved care or not. The feeling is that the care offered is comparable with current literature’s recommendations in many areas, and these findings point to good care, but without comparison in

the same context, the level of evidence is contestable. Studies like this one are also known to favour the intervention.⁽¹¹³⁾

No formal costing data was collected. Once again, this would have been useful in terms of a before and after study.

Recommendations

“Care at the end of life should be an indicator of the performance of health systems”⁽¹⁴⁵⁾

1. The term palliative care unit is not completely suitable for the service offered there. Renaming the unit an “Acute Palliative Care Unit” will emphasise the short-stay nature of the ward, the emergency focus, as well as the service offered there.
2. Establishment of a Palliative Care Team at Groote Schuur Hospital. This interdisciplinary team can consist of a Palliative Care specialist, a medical officer, specially trained nurses, a social worker, counsellor and occupational therapist, chaplain, as well as volunteers. The team can be consulted for complex palliative care problems, even in the context of acute care specialities still being responsible for the patient’s care. To echo the WHA consensus statement discussed in the literature review, “...*palliative care is an ethical responsibility of health systems, and that it is the ethical duty of health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured, and that end-of-life care for individuals is among the critical components of palliative care;*”⁽⁴⁷⁾

An integrated team approach would be a good approach to achieving this goal, as Mount described in 1976.⁽⁴²⁾

3. Development of palliative care policies and implementation of palliative care guidelines to guide staff in providing excellent palliative care. This will include more comprehensive assessments of symptoms, more holistic care, improved documentation and more clear and honest communication.^(29,39,40,47,156)
4. Further research in acute care and palliative care in Cape Town. Possible areas to look into include before and after controlled studies, cost analyses and qualitative research with staff and families describing the barriers to palliative care in the emergency setting, family needs at the end of life and staff experiences in this setting.

5. Implementation and correct completion of forms, according to the Western Cape Government “Do Not Resuscitate” Policy, circular H153/2013 ⁽¹⁰⁵⁾

Considering the impact made by another state hospital-run outpatients-based palliative care intervention in recent years, there is scope for implementation of a similar (outpatients-based) model at Groote Schuur Hospital.⁽³²⁾ This should complement the care offered in the unit and help in reducing the need for acute admissions by improving advanced care planning and supporting families and patients in the community. This can have more far-reaching effects than just reducing admissions and associated cost. It is a step in the direction advocated for in the first world by Leadbeater and Garber, as well as Hospice UK. To quote Leadbeater and Garber’s report *“To allow people the deaths they want, end of life care must be radically transformed...”* There is urgent need for further research on the cost implications and efficacy of this kind of intervention.

The model of care described in this unit can provide excellent palliative care in a resource-restricted environment and could be implemented elsewhere in Sub-Saharan Africa.

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Appendix A: Sample Data extraction sheet

Data was captured directly onto a Microsoft Excel Spread Sheet, to reduce transcription error. This “data sheet” was adapted from the original spread sheet for easier perusal.

Patient number	Sex	Age	Age category =IF(BB3<30,1, IF(BB3<50,2, IF(BB3<70,3,4)))	Length of stay in hours	From where	Exact location	Outcome

Diagnosis	HPT	DM	Asthma	COPD	CCF	Epilepsy	HIV

Malignancy	No malignancy	Old CVA	Massive CVA	ESRF	Hypoxic brain injury	Metastases	Sepsis	Alcohol abuse

Dementia	TB	Other neuro	Post CPR	other	Cancer subtype

current meds assessed	PRN pain	PRN vomit	PRN agitation	PRN secretions	Discontinue blood test	Discontinue antibiotic	CPR order	Nursing intervention cut

Syringe driver	Morphine	Haloperidol	Buscopan	Midazolam

Communication language patient	Communication language family	Aware of diagnosis patient	Aware of diagnosis family	Aware of dying patient	aware of dying family

spiritual need patient	Religious tradition	Religious person contacted	spiritual need family

How to inform death	Family given hospital information	Primary care aware of patient's admission	Plan discussed patient	plan discussed family

Assess pain1	assess agit1	assess secr1	assess nv1	mouth care1	urine1	Medication1	pressure1	bowel1

psych pat1	psychfam1	spiritual1	fam needs1	GP death

laying out	record death	special procedure	family informed re legal etc	hospital policy re belongings	necessary documentation given	Bereavement support

**Appendix B - University of Cape Town Human Research Ethics
Committee Approval letter**



10 September 2013

HREC REF: 550/2013

Dr C Robertson
Palliative Care
Public Health & Family Medicine

Dear Dr Robertson

PROJECT TITLE: AN EVALUATION OF CARE IN THE END OF LIFE UNIT AT GROOTE SCHUUR HOSPITAL

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

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

Approval is granted for one year until the 30th September 2014

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/research/humanethics/forms)

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

Please quote the HREC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

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 Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki 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.

s.thomas

Appendix C - Groote Schuur Hospital Research Approval letter



Western Cape
Government

Health



GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bernadette Eick

E-mail : Bernadette.Schmitz@westerncape.gov.za

Dr C. Robertson
Palliative Care
Public Health & Family Medicine
MEDICAL SCHOOL

E-mail: bothmacara0@gmail.com

Dear Dr Robertson

RESEARCH PROJECT: An Evaluation of Care in the End of Life Unit at Groote Schuur Hospital

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research.

Please note the following:

- a) Your research may not interfere with normal patient care
- b) Hospital staff may not be asked to assist with the research.
- c) No hospital consumables and stationary may be used.
- d) **No patient folders may be removed from the premises or be inaccessible.**
- e) Please introduce yourself to the person in charge of an area before commencing.
- f) Please discuss the study with Dr Peter Raubenheimer before commencing.
- g) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
- h) Confidentiality must be maintained at all times.

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

Yours sincerely

DR BERNADETTE EICK
CHIEF EXECUTIVE OFFICER

Date: 12th March 2014

C.C. Mr L. Naidoo

Dr R. Kirsten

Dr P. Raubenheimer

G46 Management Suite, Old Main Building,
Observatory 7925

Tel: +27 21 404 6288 fax: +27 21 404 6125

Private Bag X,
Observatory, 7935

www.capegateway.gov.za

Appendix D- Western Cape Government Circular H153 /2013
Do Not Attempt Cardio-pulmonary Resuscitation Policy



Office of the DDG: Chief Of Operations

REFERENCE: 16/4

ENQUIRIES: Dr EH Engelbrecht

For Attention: Chief Directors, Directors, District Managers

CEO's and Facility Managers: Institutions

Chairpersons of the Provincial Clinical Governance Committees

Circular H 153 /2013

GUIDELINES ON THE IMPLEMENTATION OF THE DO NOT RESUSCITATE ORDER FOR ADULTS

1. Aim of the policy:

A provincial guideline on the procedure to be followed when initiating a "Do Not Resuscitate" order on an adult patient

2. Purpose and reason

This guideline will ensure that healthcare providers document in detail the circumstances surrounding a decision taken not to resuscitate a patient. The document is placed in the patient's folder and is therefore a medico-legal record for the protection of healthcare providers.

3. Implementation guideline

The form is double sided with the entry fields on the front page and the instructions on the reverse side of the page. It should be completed whenever a "Do Not Resuscitate" order decision is taken and has to be reviewed regularly during that admission. The order will only be relevant to the current admission.

4. For enquiries

Please ensure adequate consultation with the senior clinician in charge of the patient. Further support or queries are to be directed to the manager of the institution. For enquiries regarding the contents of this circular, please contact Dr Hein Lamprecht at hl@sun.ac.za, or telephone nr. 021 938 9803.

DR B ENGELBRECHT
DDG: CHIEF OF OPERATIONS
DATE: 2013-09-17

20th Floor, 4 Dorp Street, Cape Town, 8001
Tel: +27 21 483 3478 fax: +27 21 483 5920

P O Box 2060, Cape Town, 8000
www.capegateway.gov.za

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION FORM



Western Cape
Government

GOVT ER

Patient sticker

Ward.....

Consultant in charge:.....

DNAR – Do Not Attempt Cardiopulmonary Resuscitation

Date of DNAR order:

Time of DNAR:

In the event of cardiac or respiratory arrest no attempts at cardiopulmonary resuscitation (CPR) will be made. All other appropriate care and treatment will be provided.

1. Does the patient have capacity to make an informed decision about CPR? If "Yes", go to box 2		<input type="checkbox"/> Y	<input type="checkbox"/> N
If "No", are you aware of a valid advance directive refusing CPR which is relevant to the current condition?		<input type="checkbox"/> Y	<input type="checkbox"/> N
If "Yes", go to box 6.			
If "No", go to box 2.		<input type="checkbox"/> Y	<input type="checkbox"/> N
All decisions must be made in the patient's best interests and comply with current law.			
2. Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests?			
3. Identify specific actions not to be taken.			
Cardiopulmonary resuscitation	<input type="checkbox"/>	Intubation & Ventilation	<input type="checkbox"/>
Inotropes	<input type="checkbox"/>	Other	<input type="checkbox"/>
4. Summary of communication with patient, patient's relatives or friends.(Document in clinical notes)			
5. Names of members of the multidisciplinary team contributing to this decision:			
6. Senior doctor completing this DNAR order:			
Name:	Position:	Speed dial:	
Signature:	Date:	Time:	
Name of nursing staff DNAR order communicated to:			
7. Endorsement by consultant:			
Signature:	Name:	Date:	
8. Should organ donor be considered for this patient?		<input type="checkbox"/> YES	<input type="checkbox"/> NO
(If yes, please contact your local transplant co-ordinator)			