In Search of a Good Death

Conversations and Contemplations Exploring End-of-life Care in the Elderly

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Declaration

I declare that this research report is my own unaided work. It is submitted for the degree of Master of Arts by Coursework and Research Report in the Department of Journalism, at the University of the Witwatersrand, Johannesburg.

It has not been submitted before for any other degree or examination at any other university.

Linda Ravenhill

Student Number: 1772863

On this 27 day of May 2020

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Abstract

There is an emerging global crisis in the delivery of end-of-life care for the elderly. In part this is due to financial considerations and in part to technological advancement: the practice of medicine has evolved to the point where hyper-medicalisation of death is frequently the norm for the elderly, often in opposition to their wishes. The impact on individuals and their families is often catastrophic; the effect on healthcare practitioners is considered by many to be no less so.

The primary purpose of this narrative is to explore the implications of this medicalisation of end-of-life in our aged. Five main themes are considered, namely: the historical trajectory of how we die; the financial, legal, ethical and societal constraints that impact the delivery of a good death; how an individual's understanding of a good death influences the care they give and receive; and, finally, what influence, if any, narrative-based medicine may have on practitioners and individuals in obtaining or providing such a death.

The narrative was informed by an extensive review of clinical and non-medical research material, relevant books and popular media, together with twenty interviews conducted with healthcare practitioners, patients, families and individuals with expertise related to the topic. It makes use of the framework of non-narrative fiction espoused in narrative medicine, in an attempt to engage the reader in a more profound way than may have been possible through a mere recounting of facts.

The work is presented in two parts. The first, an overview of the methodology and theoretical framework used in its compilation, together with a review of the emerging academic field of narrative-based medicine; the second contains the narrative work.

Index

Literature Review, Methodology and Theoretical Framework

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Literature Review, Methodology and Theoretical Framework

1. Introduction

> …our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives.
>
> Atul Gawande*, Being Mortal.*

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As the practice of medicine evolves, so, too, has the expectation that most people will, and should, live a long life. In pursuit of the ideal of longevity, however, an ever-increasing gap is emerging between technically competent medical care that prolongs life at all costs, and medical care that focuses on providing a good death for elderly patients.

The Institute of Medicine defines a good death as "…one that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes, and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassel 1997). Nonetheless, many practitioners believe they must do everything possible to extend life, regardless of the pain and suffering involved. They fear that offering comfort or palliative care may suggest they have given up or failed; it could be argued that this is a manifestation of how conventional medicine co-exists within a "persistent social attitude that denies death" (Emanuel and Emanuel 1998}

The prospect of achieving a good death within this system of care remains more an elusive ideal than a reality for many elderly patients. In the face of what Atul Gawande, surgeon and author of *Being Mortal*, refers to as the "…seemingly unstoppable momentum of medical treatment," the majority of people will end up dying in acute or hospital care, frequently against their wishes. (Wehrwein 2015; Sorrell 2018; Valente n.d.)

But dying is not a medical experience: it is a profoundly human one.

Across the board, there is a growing acknowledgement that it is time to re-think how we approach end-of-life care in the elderly; a re-balancing required to counter the relentless pursuit of the preservation of life in the face of overwhelming evidence that such a pursuit is not in the patient's best interests.

Healthcare practitioners are ill-equipped to operate within this new paradigm. Schooled in the practice of medicine that places clinical expertise above humanistic concerns, they find themselves alienated from the reality of the lived experiences of their patients and out of step with the emotional cadence that accompanies the process of death and dying.

Storytelling, which harnesses the narrative connections that bind us all, is considered by many to be a solution to this alienation of care. A narrative-based approach to medicine offers an alternative framework through which to consider the challenges encountered in the delivery of medical care, an effective method for re-humanising clinical practice and a tool through which both practitioners and patients alike can "recognise, absorb, interpret and be moved by stories of illness and death" (Charon 2004).

Rita Charon, Professor of Medicine and founder and Executive Director of the Program of Narrative Medicine at Columbia University, elucidates as follows: "As…. health care professionals and patients delve into the challenges and rewards of serious storytelling in illness, we see with new clarity deep aspects of the illness, the sick person, the situation of care, and the person who cares for the sick" (Charon 2007).

It is this facilitation that narrative offers - the ability to enable us to see with emotional clarity - that informs this work.

2. Why Discussing End-of-life Care Matters

> When Stone finally spoke it was in a quiet voice that was firm and commanded attention. He asked a question…… "What treatment in an emergency is administered by ear?" I met his gaze, I did not blink. "Words of comfort" I said to my father.
>
> Abraham Verghese*, Cutting for Stone*

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The concept of providing or facilitating 'a good death' has long been shrouded in the grey matrix of clinical decision-making: a conversation to be had in hushed tones, if at all; a process clouded by complex moral judgements; one which elicits the opposing twins of guilt and disregard.

William Osler, the father of modern medicine, himself a gerontologist, gave a speech in 1905 in which he referred to Anthony Trollope's story *The Fixed Period*, which envisages a college where men retire at 67 and, after being given a year to settle their affairs, are "peacefully extinguished by chloroform". He claimed that, "the effective, moving, vitalizing work of the world is done between the ages of twenty-five and forty" and it is downhill from then on. He is also believed to have referred to pneumonia as "the old man's friend," since it allowed elderly individuals "a quick, comparatively painless death" (William Osler 2018).

Aside from this somewhat ironic take on the process of death in the elderly, dying used to be accompanied by a set of rites and rituals. For example, *Ars Moriendi* or *The Art of Dying,* two related Latin texts created in the 1400s, offered advice on the protocols and procedures of a good death, explaining how to 'die well' according to the Christian precepts of the late Middle Ages (Ars Moriendi 2018). "Affirming one's faith, repenting ones sins and letting go of ones worldly possessions and desires were crucial and the guides provided families with prayers and questions for the dying in order to put them in the right frame of mind during their final hours. Last words came to hold a particular place of reverence" (Gawande 2014 p. 156).

These days, a swift, catastrophic illness that results in death is the exception rather than the rule. For most people, death comes only after a prolonged medical struggle with an ultimately untreatable condition (Gawande 2014).

Seventy percent of the people who were interviewed indicated that they would prefer to die at home. This is in contrast to the seventy percent of all people who will die in acute institutions or hospitals, in direct contravention of their wishes (Miller 2016). Death has become something separate from life. It is most often seen as a failure on the part of the healthcare profession, instead of a natural process. Perhaps the issue is best illustrated by this extract from *Being Mortal*, in which Gawande documents a discussion he had with a colleague:

> "I'm running a warehouse for the dying," she said bleakly. Of the ten patients in her unit, she said, only two were likely to leave hospital for any length of time. More typically was an almost eighty-year-old woman with irreversible congestive heart failure, who was in ICU for the second time in three weeks, drugged to oblivion, tubed in most natural orifices as well as a few artificial ones. Or the seventy-year-old with a cancer that had metastasised to her lungs and bone, and a fungal pneumonia that arises only in the final phase of illness. She had chosen to forgo treatment but her oncologist pushed her to change her mind and she was put on a ventilator and antibiotics" (Gawande 2014 p. 154).

The implications of this extension of life at all costs are tragic for those who experience it.

In 2008, the National Coping with Cancer project published a study showing that terminally-ill cancer patients who were put on mechanical ventilators, given electrical defibrillation or chest compressions, or admitted, near death, to intensive care, had a substantially worse quality of life in their last week than those who received no such interventions. And, six months after their death, "their caregivers were three times as likely to suffer major depression" (Gawande 2004 p. 154).

In the last decade, however, there has been a growing awareness of the issue of over-treatment of the elderly. It is driven principally, not by humanistic sentiments, but by concerns about expense. Soaring healthcare costs have become the greatest threat to the long-term solvency of most advanced nations (Gawande 2014, p. 153; Smith 2015).

In South Africa, our aging population currently comprises eight percent of the total population. It is projected that, by 2025, this elderly population will be growing at three and a half times the speed all other age groups (Joubert & Bradshaw 2003; Goodrick 2013). Whilst the exact financial implications of this age trajectory are yet to be quantified, it can safely be assumed to be considerable.

The cost, however, is far more than financial. Our system of technological medical care has utterly failed to meet the needs of the dying. The question is not how we can afford this expense - it is, as Gawande states: "…how we can build a healthcare system that will actually help people achieve what's most important to them at the end of their lives" (Gawande 2014 p. 155).

Even in developed countries, end-of-life care for the elderly, particularly the practice of palliative care, is complicated, with most public health programmes focusing mainly on preventing and treating infectious diseases and malnutrition. Studies have shown that only about six percent of all palliative care services are located in Asia and Africa (Crane 2010).

Kathleen Foley, a long-time champion of palliative care at the Memorial Sloan Kettering Cancer Center in New York, notes "a basic unwillingness to talk about the care of the dying in developed countries. What's happened in most countries is that there is so much focus on treatments and prevention that they forget to take care of the patient" (Crane 2010).

A starting point is, therefore, to get the conversation started, to attempt to restore the concept of a good death as inseparable from that of a good life, to re-humanise the process of dying by removing it from the notion of technological advancement and reverting to the principals of dignity and autonomy.

Ellen Goodman is the founder of The Conversation, an initiative that facilitates conversations relating to end-of-life care. She established it as a result of her experience with her mother, who died a protracted medical death. Goodman articulated her concern as follows:

> "Too many people we love had not died in the way they would choose. Too many survivors were left feeling depressed, guilty, uncertain whether they had done the right thing. The difference between a good death and a hard death often seemed to hinge essentially on whether someone's wishes were expressed and respected. Whether they'd had a conversation about how they wanted to live toward the end" (Goodman 2015).

Webster, Lacey and Quine concur with this in their article 'Palliative medicine - a global perspective': "We ought to give those who are to leave life, the elderly, the terminally ill, those dying slowly of AIDS and cancer the same care and attention that we give to those who enter life..." (Webster, Lacey & Quine 2007).

Only by accepting that death is inevitable, a natural sequence to life, can we consider end-of-life care that delivers on the concept of a good death. Christy Maserek, a death doula, concurs: "One thing I believe firmly is that we know how to do this," she said. "We know how to die, like every creature of nature does. We just need to get out of our own way" (Ode 2018).

3. Literature Review

> We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way.
>
> Atul Gawande, *Being Mortal*

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3.1 The History of Narrative Medicine

Storytelling in medicine is not new. As far back as Aristotle, narratives have been used by medical practitioners to teach and learn, to communicate with patients and society.

Stephen Rachman, Associate Professor of Nineteenth-Century American Literature at Michigan State University, explains: "Literature had long been used in medical instruction to promote moral, and ethical reasoning, improve communication between doctor and patient, instil a deeper sense of medical history, explore the therapeutic value of storytelling, advance multicultural perspectives and increase self-consciousness on the part of the medical practitioners" (Mildorf & Lember-Hedenreich 2013 p.17).

The practice of medicine, however, began to change in the latter half of the twentieth and early twenty-first centuries, driven for the most part by financial considerations: a change in the economics of healthcare and, to a lesser extent, by the exponential growth of technology. As healthcare responded to these changes by becoming ever more clinical and standardised, the separation between the science of healthcare and the humanity of its practice became more marked. The time-honoured inclusion of narrative as an integral part of medicine, of understanding the patient as a being with a unique lived experience who demanded personalised care, gradually gave way to the weight of clinical protocols as the drivers of such care.

So fundamental was this split between science and the humanities that in 1959 physicist and author C.P. Snow delivered his now infamous annual Rede Lecture at Cambridge University. It was entitled *The Two Cultures and the Scientific Revolution.* In it, he referred to "…a gulf of mutual incomprehension and mutual lack of sympathy that had grown up between literary intellectuals on the one hand and natural scientists on the other" (Snow n.d.).

While Snow's contention was reasonably well accepted at the time, a few years later it became the subject of furious debate when literary critic F.R. Leavis launched a scathing critique of Snow's assertions, arguing that the Rede Lecture showed "….no evidence of any scientific training or rigorous scientific habit," and "…was intellectually as undistinguished as it was possible to be" (Snow n.d.). Be that as it may, Snow's thinking around the matter took hold in the popular consciousness of the time, and remains a turning point in the post-modern rupture between science and literature, a schism that continues to this day.

The years 1950 to 1990 were marked by rapid developments in clinical medicine. Many of the treatments we take for granted today occurred during this period of clinical advancements, such as hip replacements, beta-blockers, artificial hearts and pacemakers. Innovations included the first liver transplant; the discovery of polio, mumps and measles vaccines; the invention of cardio-pulmonary resuscitation (CPR); and the development of insulin pumps, to mention but a few. These advances all contributed to our modern-day expectation of improved life care and extended life expectancy (Timeline of medicine and medical technology 2018).

Concurrent with these rapid technological advances was a growing concern about the weaknesses of standard clinical practices and their impact on both the quality and cost of patient care in the United States (Lewis & Oland 2004) The old system of the doctor making house-calls and the corner pharmacist dispensing advice in addition to medication was fast falling out of favour in the face of the relentless pursuit of standardised healthcare and its obvious bedfellow, cost control.

In 1990 a young internist at McMasters University named Gordon Guyatt floated the idea of 'Scientific-Based Medicine', which he defined as, "…care that integrates individual clinical expertise with the best available external clinical evidence from systematic research" (Guyatt 1990). It was an approach he hoped would prove to be a response to the perceived weaknesses of standard clinical practices and would bring more certainty to clinical decision-making.

Initially his idea was not widely accepted, but having renamed his concept ’Evidenced-Based Medicine’ or EBM, his paper was eventually published in 1991, paving the way for what it has become the *de facto* standard for the practice of modern medicine (Roger & Sur 2011; Duke University Archives 2018). While its advocates believe that EBM in the managed care setting provides “standards that have the potential to provide the best medical care at the lowest cost”, it placed the science of medicine – clinical studies and treatment algorithms - at the centre of care, effectively ‘othering’ the patient from their illness (Lewis & Oland 2004).

“Many patients feel abandoned by their doctors, dismissed in their suffering, disbelieved when they describe their symptoms or objectified by impersonal care. …. [S]adly, patients have come to reconcile themselves to a forced choice between attentiveness and competence, between sympathy and science” (Charon 2006 p. 21).

So catastrophic were the unintended consequences of the singular evolution of healthcare to the new model of care, that a growing school of medical practitioners, most notably Professor Rita Charon, began reviewing a way to counter its effects. “A scientifically competent medicine alone cannot help a patient grapple with the loss of health and find meaning in illness and dying” (Charon 2006 p. 21).

Richard Horton, editor of the medical journal *The Lancet*, as quoted in Philip Day’s book *Health Wars,* concurred with this sentiment, commenting that there is a “…schism in medical practice that is at the heart of the present challenge to medicine. The solution is to discover a way to reconnect doctor to patient through a bridge of common understanding and shared ways of knowing about disease. We need nothing less than a new philosophy of medical knowledge” (Charon 2006 p. 39).

In 1990 Professor Charon was instrumental in establishing a new field in medicine which she termed narrative-based medicine” or NBM: a direct means, she believed, of counteracting the effects of evidenced-based medicine. Charon defines narrative-based medicine as "medicine practised with the skills of recognizing, absorbing, interpreting, and being moved by the stories of illness." She terms this a “new frame” for medicine, believing that it “…can improve many of the defects of our current means of providing (or not) medical care” (Charon 2006).

Charon believed that, along with their growing scientific expertise, doctors need the expertise to listen to their patients, to understand as best they can the ordeals of illness, to honour the meanings of their patient’s narrative of illness, and to be moved by what they behold so that they can act on their patient’s behalf. She believed that medicine which is practised with narrative capacities would lead to more humane, more ethical and perhaps more effective care (Charon 2006 pp. 3, 11).

In more recent times Charon’s ideas have taken hold, facilitated in part by the rise of physician-centred narratives such as those penned by Oliver Sacks and Atul Gawande, who have successfully demystified disease through popular narrative. More recently, Felice Aull, founder of the Literature, Arts and Medicine Database, pointed out that medical training is currently undergoing significant changes, whereby

> … [A paradigm of detached concern is being replaced by one of engagement, affiliation, reflective practice and emotional resilience. Doctors are increasingly expected to be able to understand their patients more holistically and also be aware of their own bias and preconceptions so that they can deal creatively with the ambiguities inherent in their work (Mildorf & Lember-Hedenreich, p. 18).

As Rachman argues (as quoted in Mildorf & Lember-Hedenreich p. 18), the study of literature “makes the language of medicine, doctors, patients and disease entities – the cultural frame of illness – visible”.

3.2 How does Narrative Medicine influence the Practice of Care?

Literature about medicine may be all that can save us.

Andrew Solomon (Solomon, 2017).

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"An illness narrative tells us not only about a specific medical case but about the intensive, ultimate and most authentic reality of life or death of a person." This belief is central to Victor von Weizacker's work of on psychosomatic medicine, and the basis on which he demanded the inclusion of the patient's experience into the medical endeavour (Kalitzkus & Matthlessen 2009).

As proof of the effectiveness of narrative in patient care, a study done on two hundred and thirty-four cancer patients looked at a narrative group (patients who wrote a story about their pain), a questionnaire group (who filled in a McGill Pain Questionnaire), and a control group. While pain intensity was similar across all the groups, patients whose narratives had a high emotional impact experienced significantly less pain than patients whose stories were less emotional. Indeed, both stories provided contexts that helped to understand and share the experience of illness. This is referred to as narrative empathy, and many believe that the process can aid in decision-making and improve overall outcomes for patients (Rosti 2017).

In the words of Greenhalgh and Hurwitz (quoted in Kalitzkus & Matthlessen, 2009), "Narrative provides meaning, context, perspective for the patient's predicament. It defines how, why, and what way he or she is ill. It offers, in short, a possibility of understanding which cannot be arrived at by any other means".

3.3 What are the Literary Devices used in Narrative Medicine?

Telling stories of illness is the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe. This voice is embodied in a specific person, but it is equally social, taking its speech from the post-modern times we live in. The voice of the ill person is made possible by modernist medicine, but it cannot be contained within modernist assumptions, particularly those about medical professional domains, and narrative surrender this dominance requires.

Arthur Frank, *The Wounded Storyteller*

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Medical narratives are attempts to bridge the gap between the science of medicine and the philosophy of care. They are concerned with portraying people as multi-dimensional characters who exist within defined societal fabrics, rather than a collection of signs and symptoms. They differ from healthcare journalism, which, typically focuses on reportage - a relating of facts and objective recording of information – engaging a more in-depth, immersive process which deploys the tactics of literary fiction to deliver individual stories.

To critically appraise narrative medicine, it is necessary to establish its place in 'the' grand narrative', to understand its origination and reflection of accepted narrative techniques. To do so requires a return to the ancient Greeks.

Although he is not as important to modern medicine as Hippocrates, Aristotle made a significant contribution to the theory of Greek medicine. Aristotle, however, was not only a physician and biologist, he is also considered the father of the modern narrative. In his 347-342 B.C treatise, *Poetics*, he put forward the so-called 'seven golden threads' of storytelling, namely plot, character, theme, diction, melody, décor and spectacle, which form the foundation for all narrative. He believed in the central role of tragedy in a narrative, stating that

> Tragedy is essentially an imitation, not of persons but of action and life, of happiness and misery. All human happiness or misery takes the form of action; the end for which we live is a certain kind of activity, not a quality. Character gives us qualities, but it is in our actions - what we do - that we are happy or the reverse. A tragedy is impossible without action, but there may be one without character (Foundation of Narrative Theory: Aristotle's *Poetics*, n.d.).

Essentially then, if one applies the devices of Aristotle's Seven Golden Threads to the genre of medical narratives, they can be considered as creative non-fiction.

Tom Hallman, Pulitzer Prize author, posits that from a pure storytelling perspective, nothing comes close to the potential of the medical world. "It's a remarkable place, one that makes readers think and feel. Within this world they see the range of humanity – hope and fear, science and faith, brilliance and doubt" (Hallman T. , n.d.).

To explore the use of fictional devices as deployed in medical non-fiction narratives, one need look no further than the New Journalism of Tom Wolfe. The genre combined journalistic research with the techniques of fiction writing in the reporting of stories about real-life events. Wolfe believed that by employing the accepted fictional devices of narration, scene, dialogue, voice and point of view, to real-life stories, that realism provided "a psychological process which resulted in a shock of recognition that served to involve the reader emotionally in the work. He believed that the unique power of realistic fiction, was in the stimulation of emotional response" unknown author? (Literary Journalism and Tom Wolfe, n.d.).

So what then of the form and structure deployed in medical narratives?

Katheryn Montgomery Hunter, Rita Charon and John Coulehan (as quoted in Mildorf & Lember-Hedenreich, 2013, p. 17) put forward, in their *Study of Literature in Medical Education,* that there are three possible conceptual models for medical narratives:

> An *ethical approach* which focuses on moral reflection. It considers images of healers in literature, cultural perspectives on illness, and the moral dimension of every patient-physician encounter. The *aesthetic approach* which emphasises the literary skills of reading, writing and interpretation using them in the service of medical practice. The *empathetic approach* which aims to enhance the ability of care workers to understand the experiences, feelings and values of another person.

Often illness narratives follow specific, pre-defined patterns that are common in literary texts. In his seminal work *The Wounded Storyteller,* Arthur Frank identifies at least three types of narrative trajectories: the *restitution narrative,* in which illness is eventually overcome, the *chaos narrative*, which leaves the patient helpless and desperate; and the *quest narrative*, which allows the patient to use his or her experience to go in search for some deeper meaning in life. Frank points out that most public illness stories are quest narratives (Mildorf & Lember-Hedenreich 2013, p. 12).

So much for the types and forms of medical narrative, but what of its features and how do they reflect the genre of creative non-fiction narratives? Rita Charon identified five narrative features of medicine, namely: *temporality, singularity, causality/contingency, inter-subjectivity* and *ethicality*. She believed these to be the bedrock of clinical practice, but also the bedrock of narrative practice.

> *Temporality:* refers to time, specifically for the purpose of storytelling, to the "positioning of a narrative in a continuum." Humans to struggle to come to terms with time – their existence, the many battles against immortality - leading Charon to conclude that time is medicine's necessary axis and its irreplaceable ingredient. Concerning narratives regarding end-of-life, it is this temporality that drives the urgency of the narrative forward (Charon 2006 p. 43).
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> *Singularity*: What distinguishes narrative knowledge from universal or scientific knowledge is "…its ability to capture the singular, irreplaceable or incommensurable." Gerard Genete, the French structuralist who christened the field of narrative study, articulated it thus: "No story replicates any other story." While there may be similarities in clinical presentation, no one person's lived reality can ever be the same as another. Each person's story is unique and therefore, invaluable (Charon 2006 p. 45).
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> *Causality/Contingency*: To have a narrative it is necessary to have a plot. Each event is linked to another event. Peter Brookes, Professor Emeritus of Comparative Literature at Yale University, posits that "Illness is a story. It has characters, it has dialogue, it follows a plot, it has a voice." One event is causally linked to another in delivery of the whole, much like human life (Charon 2006, p. 48).
>
> *Inter-subjectivity*: Refers to the situation that occurs when two subjects or two authentic selves meet. Charles Taylor, as quoted by Charon, writes "One cannot be a self on one's own". Literary scholar Barbara Herrnstein Smith defines narrative discourse as 'Someone telling someone else what happened." Narrative acts always join one human to another. Herein lies their power to transform people and situations (Charon 2006 p. 53).
>
> *Ethicality*: According to Charon, there are "obligations incurred in narrative actions – the ethicality of the very act of writing and reading. In writing stories of illness, there are consequences not only in books but in ordinary lives. The act of reading a story confers upon the reader a great or sacred trust.

> There is a peculiar and unexpected relation between the affirmation of universal moral law and storytelling, which is particularly important in the discussion of illness and death" (Charon 2006 p. 58).

Professor Louise Rosenblatt, who developed a revolutionary approach to reading and the teaching of literature with the 1938 publication *Literature as Exploration*, suggested that (as quoted in Roen & Karolides, 2005), the reader does not remain untouched through the act of reading, but rather "becomes open to the fundamental transformation by virtue of having read".

It is this evolution, this fundamental transformation that narrative fiction offers to the reader, one that is "informed by reading, writing, telling and receiving stories, that invites one to be moved by the stories of illness and promotes a healing relationship with patients, colleagues and the self" (Rosti 2017).

4. Narrative Purpose

A rapidly ageing global population, existing within a society where death denialism is entrenched, and a culture within which life-at-all-costs is the de facto position has led to a situation where there is a codified system of hyper-medicalisation of end-of-life care in the elderly. The consequences of this phenomenon are far-reaching and, many believe that if they are not addressed, may, in the long term, pose one of the most significant public healthcare crises we have experienced in modern times.

The primary purpose of this narrative is therefore is to explore and better understand how end-of-life care is experienced by the individual, their family, their caregivers (including healthcare providers), and other, associated stakeholders, such as workers in care facilities, within the current healthcare system.

Principally, the interest lies in exploring the concept of a good death and how an individual's understanding of what a good death is manifests in how the elderly are treated as they enter the final stages of their lives, and what the implications of that process may be for all involved.

The secondary purpose of this narrative is to explore the use of narration - the act of telling and listening - as a means of effectively communicating and interpreting these end-of-life challenges through its inherently humanising impact on both physicians and laypersons.

5. The Narrative Approach

I chose to adopt a narrative approach for this exploration of end-of-life care in the elderly, as I believe the strategy of applying fictional techniques to non-fiction medical narratives allows the reader to engage with the story in a more profoundly emotional way than may have been possible through a mere recounting of the facts of an illness. It fulfils the requirement outlined by Wolfe for literary non-fiction - that it be an immersive, realistic experience.

My intention was to write this narrative in the first person, utilising the story of my father's death together with my experience as an Intensive Care nurse, as a springboard to explore the larger narrative.

Link required here.The various research themes identified were explored through the secondary narratives of my interviewees. Where this was not possible, I drew on existing literature to provide the necessary context.

I have devised the narrative in a short story format. Each theme is explored as its own 'mini-narrative' with the golden thread –the exploration of what makes for a good death - connecting them to the broader theme.

A combination of scene-by-scene development, narration and dialogue were used throughout to foster a sense of intimacy between the reader and the subject matter.

By approaching my research in this manner, I hoped to overcome the reluctance of both laypersons and medical practitioners to discuss end-of-life care, and, if not enabling them to reach a conclusion, at the very least to encourage conversation and dialogue concerning the issues raised.

6. Narrative Themes

It is not possible in a restricted narrative to offer a comprehensive review of the multitude of issues that play into the complexity of hyper-medicalisation and death.

This work is therefore restricted in scope to five themes:

- The historical context of end-of-life care; how we got to where we are, what the impact of our current approach to elder care has been and continues to be, with regard to the delivery of a good death.
- What end-of-life care, looks like to different people, a good death, in particular, to the individuals themselves, their families and caregivers, as well as to the healthcare practitioners involved in their care;
- The financial, emotional and physical impacts of our modern approach to elder care;
- The ethical and legal constructs regarding end-of-life care and their impact on delivering a good death for the individual;
- A review of whether or not the inclusion of a narrative-based medical practice would enhance or hamper the delivery of end-of-life care for the elderly.

7. Methodology

This narrative was compiled using qualitative research methods. The research instruments used included desktop research and semi-structured, one-on-one interviews.

The desktop research, which took place over nine months, involved an extensive review of clinical research articles, research into related subject matter, public comment and positioning papers.

During this process, it was determined that remarkably little content was available that explored the South African context, therefore many of the inferences in this thesis are, by default, an extrapolation of scant local data against the international body of work.

7.1 Desktop Research and Literature Review

In recent times the subject of end-of-life care, in part fuelled by the multi-faceted crises regarding the care of aging populations, has produced considerable growth in both clinical and popular literature related to end-of-life care. These books and articles informed this narrative and helped to form its theoretical background. They include the following:

- *Book reviews:* A number of books have been published in relation to end-of-life care, which has proved influential in turning the public's gaze to issues around age care. Principal among these is Atul Gawande's ground-shifting work *Being Mortal*. Seminal texts were reviewed by authors such as Rita Charon, Arthur. W Frank, Kathryn Montgomery Hunter, Oliver Saks, Henry Marsh and Abraham Verghese, all of whom are driving the discussions around the use of medical narrative in both clinical and popular literature.

- *Reviews of clinical articles:* An extensive review was conducted of clinical medical literature from a range of professional publications, covering topics such as clinical medicine, bio-ethical and legal issues related to end-of-life care. Additionally, both *The Lancet* and the *British Medical Journa*l have supplements dedicated to literature in medicine, which proved invaluable in formulating the narrative framework of this essay.

- *Reviews of non-clinical articles:* Research reports were consulted from organisations such as the World Health Organisation, and the Pew Research Institute, together with publications such as *The Economist*, which dealt with the economics and societal impact of ageing and end-of-life care..

- *Media articles:* There is a growing international awareness in the popular press regarding elder care and end-of-life care, The *New York Times*, the *Washington Post*, the *Huffington Post* and the *Guardian*, have recently dedicated considerable space to articles on this topic. Locally, the *Daily Maverick*, the *Cape Times* and a few other online publications have begun to cover stories related to elder care in our society. These articles provided an additional source of information, in particular, on how end-of-life care is perceived in popular culture.

7.2 Interviews and Discussions

This narrative is told through the exploration of individual stories to illustrate the various themes under consideration.

The interviews were conducted in informal settings to encourage open dialogue that might have been inhibited in a more clinical setting. The interviewees were either experts on the themes I wished to explore, or could offer narratives around the subject matter. The questions were structured to reflect the research and current sentiment, while the interviews themselves were grouped in thematic rounds, enabling me to verify and expand on each conversation and engage with respondents in a manner that extended beyond simple question and answer sessions.

The interview subjects included the following:

- One-on-one healthcare professional interviews: The following healthcare professionals participated in this narrative: a gerontologist at a local practice, a professor of medicine at a major academic hospital, two intensivists heading up Intensive Care units, a surgical registrar, two intensive care registered nurses, a bio-ethicist who specialises in end-of-life care, a state forensic pathologist, a matron in charge of a local retirement home in Johannesburg, and two nursing sisters at Hospice SA.

- One-on-one interviews with individuals associated with end-of-life care for the elderly but who are not professional healthcare workers, including:
    - A death doula
    - A theologian from the Jesuit order who has an interest in the ethical considerations of passive and active euthanasia, and has written extensively on them.

- One-on-one interviews with representatives from the following institutions, to provide insight into the non-health related impact of advanced elder-care:
    - A healthcare funder institution
    - A financial institution involved in retirement planning
    - A lawyer involved in end-of-life care issues
    - A healthcare economist.

- Individuals and their families:
    - Apart from my own story, I interviewed four families who were willing to discuss their experiences of elder-care and end-of-life care.

A copy of the interview schedule for each of these subject groups has been attached as Appendix 3, 4, and 5 respectively (pp. 67–69)

8. Ethical Considerations

In her paper *The ethics of narrative: A return to the source,* Sue Greenburg wrote, in relation to narrative ethics in non-fiction storytelling,:

> If there is a single thing that distinguishes literary journalism from other forms of reporting, it is the use of narrative rather than expository prose. This involves the dramatisation of actions that have consequences. In the case of non-fiction storytelling, the consequences are not invented but real; or at least, verifiable (Greenburg 2014).

It is the awareness of these 'real consequences" that informed the process of obtaining and documenting information for this narrative. In keeping with generally accepted ethical principles, the narrative is as truthful as possible and was approached sensitively in all instances, with respect for the wishes of those who were interviewed.

To ensure the ethical integrity of the narrative, ethical clearance was obtained from the Human Research Ethics Committee (Medical) at the University of Witwatersrand, with the clearance number M180922**,** attached as Appendix 1 (p.65). This narrative is bound by the strictures of that process.

Where requested, the names of the participants have been changed to protect their identities. Such instances have been indicated in the footnotes. A copy of the consent form has been attached as Appendix 2 (p.66)

9. Theoretical Framework

This narrative follows the format of a "quest narrative" as identified by Arthur Frank, discussed previously in section 3.3. To reiterate, a quest narrative is the most common form of illness narrative as it allows the patient or practitioner the opportunity to use their experience to go in search of some deeper meaning in life. The framework was informed by Rita Charon's narrative-based medicine approach, which encourages the use of fictional devices in the delivery of non-fiction based medical narratives.

The use these devices offered an opportunity to explore both the individual's experience and the science of medicine within a creative, humanistic framework, ensuring that these narratives are simultaneously engaging, informative and impactful.

Arguably, the greatest strength of the narrative technique resides in the opportunity offered to create an intimate relatability between writer and reader, encouraging the reader to engage further, to want to understand more and, possibly and to care more, in a way that a factual recounting could not.

10. Conclusion

There is an acknowledged crisis in elder care, globally and locally. That crisis is multi-factorial – financial, medical and social - but most importantly, it is a human crisis, one which affects every person at some point, whether as caregiver or patient.

While conversations and discussion regarding end-of-life care have in modern times have been considered unpleasant and best hidden, or spoken of in whispers in private, there is a pressing need to re-introduce the concept of a good death as part of a good life. To do that, there is a need for open and honest dialogue, a removal of the natural barriers to the discussion of death in order to search of solutions that deliver on the desires of the individual at the end of their lives.

This narrative reached no definite conclusions other than that an individual's death is precisely that – individual. Many of the concerns regarding the monetisation of death in the elderly as a driver of hyper-medicalisation have been validated. Many considerations that may not have been apparent in the initial crafting of this research, including legal impediments and the lack of education regarding end-of-life issues, became apparent during the interviews, those with the healthcare practitioners in particular.

The growing use of narrative medicine techniques among clinical practitioners, together with the rise in patient illness narratives, may offer the most effective platform to explore difficult subjects in a way that connects us all – that of storytelling.

While asking healthcare practitioners to comment on this did not help reach any definite conclusion regarding its use, the overall consensus was that, at the very least, a narrative of this nature would provoke conversation and possibly facilitate more consideration regarding end-of-life care than is currently afforded it.

In Search of a Good Death

Conversations and Contemplations Exploring End-of-life Care in the Elderly

Chapter 1: In every Ending there is a Beginning

> How long has she got? I hate this question. It's almost impossible to answer, yet people ask as though it's a calculation of change from a pound. It's not a number - it's a direction of travel, a movement over time, a tiptoe journey towards a tipping point...
>
> Katherine Mannix, *With the End in Mind*

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It's not like you see in the movies.

Death, that is.

The odds are slim that it's a *Grey's Anatomy* experience - sombre physicians gathered around the dying person's bedside, doe-eyed interns quietly comforting the sobbing family, the dulcet tones of a flat-lining monitor underscoring the drama.

And if you're elderly, it's even less so. Death then is often a slow trajectory of multiple dying moments, played out over years, with ever-increasing insults visited on frail, aging bodies.

I was pulling into the parking lot of the hospital on a sunny Highveld winter afternoon when my Dad died.

"Linda, its Vusi. The engine. It just stopped. It couldn't anymore."

It was not how I'd imagined his end would be.

I'd thought – arrogantly, I now realise - that with my years of ICU experience, I could help give my Dad what I thought of as a 'good death'; one which reflected what he wanted: pain-free and surrounded by the people he loved and who loved him.

At eighty-seven years of age, you might say his death couldn't have been unexpected. But that doesn't tell the whole story. Philip Roth wrote in his book *Everyman* that "Old age isn't a battle: old age is a massacre" (Bailey 2006). I think my dad would have agreed. The last fifteen years of his life were characterised by a series of unfathomable medical interventions, a carousel of endless doctor visits and ICU admissions, the last of which left him wheelchair-bound.

A gentle, proud family man, married for nearly 60 years, a lover of music and a voracious reader, he slowly crumbled, to the point where he asked what the point was of carrying on.

The afternoon he died, as I removed the drips, catheters and shunts that accompanied his death, I felt a deep, visceral sadness, but also a blistering sense of outrage.

We had, as a family, discussed the possibility that he would not survive his surgery. We had everything in place: living wills and Do Not Resuscitate orders. But when it came right down to it, it made no difference to the way he died.

Once he had developed septicaemia, which did not respond to initial aggressive treatment, it was apparent that further intervention was hopeless. But for all my knowledge and experience, I was helpless in the face of the tide of unstoppable medicalisation.

We called a family conference to discuss my dad's wishes with the intensivist in charge of his care. We offered the necessary signed documents, requested that all interventional care be stopped, and that my dad simply be provided with comfort care.

There are moments in your life which define you. What happened next is mine. Having heard us out, the intensivist gave a small shrug, and to my mind, a seemingly-dismissive laugh before commenting, "We are not in the business of killing people in this unit. We don't stop care."

And that was last we saw of him, for the nearly two weeks it took my dad to die.

And he died in agony.

He was dialysed, he had central lines, arterial lines and nasogastric tubes inserted. He had to be restrained to stop him pulling those out, his hands pulled so tight against the bars of his bed that I often found them cold and mottled-purple, small friction wounds oozing from where he had rubbed his wrists raw. He was given a plethora of cardiac drugs, renal drugs and a cocktail of antibiotics: a lethal combination which only made matters worse. It was only by threatening legal action that he was not taken back into surgery or ventilated.

All that was missing from my dad's care was medication for the indescribable pain he must have been in. That came only when I insisted it be given, and was accompanied by warnings that the morphine would kill my father so they could only dispense 'very little'.

It could not, even in the very marginal definition of the phrase, be described as 'a good death'.

While I sat at his bedside during the long hours of those grim weeks, I observed the other patients in that ICU. All were octogenarians. All, besides my father, were ventilated. Some had been there for months. Very few had any hope of recovery, yet were subjected to a plethora of pointless medical interventions.

The manner of my father's death, together with these observations, gave voice to a question I had long pondered during my medical career and more recently, as a caregiver. What is the price of this 'life-at-all-costs' approach, this unrestricted medicalisation of end-of-life care? When did philosophies such as 'we not in the business of killing someone' become permission a free pass for extending life beyond reason and against a patient's wishes? How have we fallen so far from humanity, that this is purported to be 'medicine'?

Talking about death makes people profoundly uncomfortable. Death denialism is our default. Yet there is no escaping it: its part of the human journey. In our post-modern society, however, it appears that only if we are incredibly lucky does it occur in the manner we would choose.

When we met to discuss this work, state pathologist, Professor Ryan Blumenthal asked: "Why are you so fixated on death in old age? Age makes no difference to death. Death can occur at any age. What really matters is whether we die fast or whether we die slow. That's all there is to it."

But I believe the elderly do die differently from younger people, and the manner of their death bears more scrutiny than is currently afforded it. This narrative reaches no conclusions. I'm not sure you can reach a conclusion about death, other than what the wise Munchkin Coroner in the Wizard of Oz intoned of the Wicked Witch "…she's not only merely dead, she's really, most sincerely dead"(Movie Quotes, n.d.).

Catherynne Valente wrote (as quoted in Valente n.d.) in her book *Radiance*: "A tale may have exactly three beginnings: one for the audience, one for the artist, and one for the poor bastard who has to live in it."

I'm not sure which beginning is yours, but I invite you to step into the void and explore the ending of a Good Death with me.

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Chapter 2: What's Epicurus Got To Do With It?

The death rate remains 100% and the pattern of the final days, and the way we actually die are unchanged. What is different is that we have lost the familiarity we once had with that process, and we have lost the vocabulary and etiquette that served us so well in past times, when death was acknowledged to be inevitable. Instead of dying in a dear and familiar room with people we love around us, we now die in ambulances and emergency rooms and intensive care units, our loved ones separated from us by the machinery of life preservation.

Katheryn Mannix, *With the End in Mind*

Dying is not an event; it is a phenomenon to be understood existentially.

Heidegger

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Once it was unusual for someone to die of old age.

As sixteenth-century French Renaissance philosopher Montaigne observed, (as quoted in Montaigne M. D., 2016). "To die of age is a rare, singular and extraordinary death, and so much less natural than others: it is the last and extremist kind of dying; and the more remote, the less to be hoped for".

Fast forward to the twenty-first century and we now not only live longer, we expect to do so. According to the Economist's Quality of Death Index, by 2030, the number of people aged 65 and older - the accepted definition of 'old' in developing countries - is projected to reach one billion. Put into perspective, that is one in eight people. Indeed, the last 20 years have seen a rise in the category of the 'oldest of the old' which refers to 80-plus-year-olds, indicating that it is one of the fastest-growing age segments across all countries (The Economist Intelligence Unit 2015 p. 11; World Health Organisation, n.d. ; Anderson-Randbug, Petersen, Rabine & Christensen p. 35).

While these figures do not accurately reflect the situation in Africa, where the accepted definition of 'older' or 'old' is 50 years and above, here, too, life expectancy is increasing. In South Africa we've added ten years to our lifespan over the period 2002 to 2018. The average woman can now expect to live to 67 years, the average male 61 years (World Health Organisation n.d.; Statistics SA, pp. 4,6).

In large part, this increase in longevity is due to the extraordinary advances in medical technology that occurred in the early part of the twentieth century. The way we live has improved immeasurably. Arguably the same cannot be said for how we now die.

With a multitude of ground-breaking drugs, devices and therapies at our disposal, death is now seen as a failure and something to be fought against at all costs. This is a philosophy of the medicalisation of life which has fundamentally shifted the trajectory of dying in our societies.

The term 'medicalisation' entered popular discourse in the 1970s and refers to

> …the process by which human conditions and problems come to be defined and treated as medical conditions, and thus become the subject of medical study, diagnosis, prevention, or treatment (Van Dijk, Faber & Tan 2016).

Hyper-medicalisation, as an extension of that definition, is considered the 'unnecessary medical expansion' of medical care.

Ivan Illich, the Roman Catholic priest, philosopher, sometime anarchist and prominent critic of Western culture, placed the concept in the front and centre of the medical care debate in his 1975 essay entitled 'Medical Nemesis.'

Never one to hold back on his critique of the relentless industrialisation of our society, Illich railed against the "….indirect sickening power of the healthcare profession", which is exercised by "…transforming pain, illness and death from a personal challenge into a technical problem, which fundamentally prevents individuals from dealing with their human condition. Medicine," he went on to say, "… isn't here to serve human health, it's only interested in itself...It makes more people sick than it heals a state of affairs." In his opinion, it amounted to no less than "man-made misery" (Illich 1975).

He wasn't the first to put forward these critiques; one physician of that time is reported to have pointed out: "There are already more radical thinkers within the ranks of medicine than Illich, and they understand more about biology." But he [Illich] was probably the most vocal, and many physicians of the day agreed with him (Geiger 1976).

Did his criticism help? Sadly, it was not the call to action he would have liked. More than twenty years later, we have failed to shift the needle even fractionally; if anything, things are worse. Physicians are now

> …schooled in such a way that they believe they must do everything to prolong life regardless of the pain and suffering involved, and fear that offering comfort care may suggest they have given up or failed (Valente n.d.).

How have we arrived at this acceptance of the hyper-medicalisation of care? As with all things, to understand where we find ourselves, it is important to understand where we came from.

In the Beginning

The word death originates from the Old English word *'dēaþ'*, which is in turn derived from the Proto-Germanic '*dauþuz'*, meaning the "process, act, condition of dying" (Google Dictionary, n.d.).

Among hunter-gatherers, death was often abrupt, the result of disputes or predation. Life expectancy was no more than 30 years, and how members of these primitive societies faced their mortality related directly to their beliefs about the after-world.

This after-world was not necessarily seen as a benign place. The Khoisan people of Southern Africa, for example, believed death was an unnatural phenomenon and viewed the spirits of the dead as vengeful entities, to be avoided at all costs. The death of someone within the community would occasion the vacating of an entire village to escape the wrath of the dead, and the elderly were often abandoned to avoid the bad luck that would inevitably follow their deaths (Itumeleng 2017).

Some primitive societies believed that death was simply "a change in existence in which the soul passed to another realm" (San Filippo 2006 p. 5). A 'good' death was therefore seen as one that did not incur reprisals from angry spirits, and the community was responsible for performing the sequence of rituals to avoid the disasters attendant on a 'bad' death.

The Ancients

The belief in an afterlife and its effects on the living continued to define the attitudes and beliefs in ancient societies to a lesser or greater extent.

The first significant shift in Western beliefs can be traced to 200 BC and the rise of three schools of philosophy - the Stoics, the Sceptics and the Epicureans. These schools shaped ways of thinking about the world through to the advent of the Roman Empire and of Christianity (Carr 2017).

In these societies, death was considered heroic, something to aspire to in the quest for a higher state of knowledge. How you lived your life was believed to influence how your death journey played out.

Although now reduced by many to the justification of the unrestrained pursuit of pleasure, it could be argued that it was Epicurus' philosophy of hedonismthat provided us with the earliest articulation of a good death. He believed that two self-imposed beliefs made our lives unhappy or painful: the first, that the gods would punish us for our bad actions; the second, that death was something to be feared.

The gods, he contended, did not directly concern themselves with human affairs. As a result, we need not fear punishment from them. Furthermore, he believed there would be no pain once the sentient body expired. Consequently the fear of death was groundless, and its continued expression was the cause of all human neurosis.

His ideas should give us comfort, but humanity and medical science have travelled a long way since then, and the fundamentals of Epicurean philosophy appear to have been lost.

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Chapter 3: Everybody Wants to go to Heaven, but No One Wants to Die

Death comes with a crawl or he comes with a pounce,
And whether he's slow, or spry,
It isn't the fact that you're dead that counts,
But only, how did you die?

Edmund Vance Cooke*, How Did You Die?*

No one wants to die. Even people who want to go to heaven don't want to die to get there. And yet death is the destination we all share. No one has ever escaped it. And that is as it should be, because Death is very likely the single best invention of Life. It is Life's change agent. It clears out the old to make way for the new. Right now the new is you, but someday not too long from now, you will gradually become the old and be cleared away. Sorry to be so dramatic, but it is quite true.

Steve Jobs, *Stanford University Commencement Address, 12 June 2005*

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The rise of Christianity from the sixth century onwards marked the second identifiable shift in attitudes towards death and dying, a shift distinctly at odds with Epicurean philosophy. The promise of the eternal afterlife, so favoured by the ancients, was replaced by the threat of eternal damnation. Consequently, 'saving ones soul' took on extraordinary significance.

The most useful framework we have for considering the evolution of death and dying in Western societies is the work of medievalist and historian Philippe Ariès. In *Western Attitudes Toward Death From the Middle Ages to the Present* (Ariès 1974) he identified four distinct periods.. In the first, between the sixth to the early twelfth centuries, death was considered a normal part of human existence and there were well-established rituals associated with the dying process. Most often death was a community affair, with family and neighbours in attendance and the dying person in control of the way their end played out. Ariès called this period the 'Tamed Death'.

The second period, commencing in the latter part of the twelfth century, he termed 'Ones Own Death'**.** During this time, Ariès maintained, death became more personal and less about the community. In keeping with the concept of a heavenly afterlife, people believed that the way they lived their lives would affect their final residence in the eternal stations of heaven or hell.

If you buy into Ariès' theory, at this point, the West was still 'comfortable' with death. It was considered part of life. We had our beliefs, we had our rituals, and we were still mostly in control of how we died.

All that was about to change.

Originating in the dry, arid, desert regions of Central Asia in the mid-thirteenth century, travelling down the Silk Road, carried aboard ships and trade caravans, transmitted by fleas and delivered straight to the heart of the European capitals, the Plague is said to have decimated the Eurasian and European populations, wiping out a jaw-dropping estimate of seventy to two hundred million people over five years (History.com 2019).

In the face of this catastrophe, it's no surprise that European society began to suffer extreme anxiety regarding death and dying. It was in response to this death anxiety that the *Ars Moriendi or Art of Dying* is purported to have been written - a text which was to become crucial in shaping our modern religious death rituals. It offered practical and religious advice, informing the dying about what to expect, prescribing prayers, actions, and attitudes that would lead to a good death and the individual's subsequent salvation. While its author remains a mystery – the most likely authors were two Dominican churchmen – it still forms part of the

Christian faith, and its integration into modern practices can be evidenced in deathbed ceremonies such as the administration of last rites in the Roman Catholic religion (Duclow n.d.; New Catholic Encyclopedia n.d.).

Following the religious reforms of the early sixteenth century, the teaching and practices of the Catholic Church were called into question and the Protestant faith arose, extending the conversation on ways of dying, offering comfort and allaying fears of death (Honor & Flemming p. C11). This evolution heralded the arrival of the third of Aries historical periods: ‘Thy Death’.

From the late seventeenth to the twentieth century, death was no longer considered a normal part of life. People still participated in death socially and ritualistically, but as mourners rather than witnesses.
It is significant that the idea that natural death should only come in old age first appeared during this time. According to Ivan Illich, it was a class-specific phenomenon, driven by the wealthy bankers of the day who demanded that their doctors do everything to keep death at bay (Illich 2003 pp. 920, 921). This demand was driven by the high mortality rate among the young during the Victorian era, when “…three children out of every 20 died before their first birthdays, and those that survived infancy could not expect more than 42 years of life” (Taylor 2018).

The Victorians thus became obsessed with the idea of a ‘Good Death’. They idealised the notion of an end slow enough to give the dying the chance to say goodbye to their families and to prepare themselves spiritually. Grief was ritualised and elaborate ceremonies surrounded a loved ones send-off. Not to observe these was considered a societal and moral failure (History.com: Victorians and the Art of Dying, n.d.). Queen Victoria famously donned funeral black after her beloved Albert died, a dress code she never deviated from for the forty years she remained alive and on the throne (Waugh n.d.). Indeed, my uncle tells the story of how *my* great-grandmother donned the black ‘weeds of mourning’ after her husband died. She would, in his words, “bear down on him like a vengeful angel, her black dress coat flapping in the breeze,” scaring his seven-year-old self into good behaviour and multiple nightmares. She, too, never relinquished her mourning dress till the day she died.

By the end of the nineteenth century, the winds of change were blowing through Europe. The influence of religion was weakening, medical advances were on the rise, and the First World War, the defining force for how we practise medicine today, was cresting the horizon. Its impact would reverberate around the globe long after the fields of Flanders had greened over.

This is Aries’ fourth and final period, the period in which we now find ourselves: our ‘Forbidden Death’. It is in this era where the dying man no longer presides over his death, that the scene is set for the de-humanising of our dying process.

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Chapter 4: The House of God

We turn to our doctors to tell us how long we have left, what pain we might feel at the end, what things we can do to extend our life, should we fight or surrender. In our war on dying, doctors play arbiter, judge, healer, general emperor. How did we get to a place where we have placed far too many roles and far too much pressure on one human?

Michael Hebbs*, Let's talk about Death over Dinner*

The main source of illness in this world is the doctor's own illness: his compulsion to try to cure and his fraudulent belief that he can.

Samuel Shem*, The House of God*

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The elderly gentleman had been admitted the previous night following a hit-and-run incident. Although he was grievously injured, the 87-year-old had been holding his own for the preceding 24 hours.

I was starting my shift as unit leader that night, 23 years old, having recently achieved my life-long ambition of becoming an Intensive Care nurse in the field of trauma medicine. It was at the height of apartheid violence, which had some painful lessons to teach me, but professionally I loved the adrenaline rush of emergency medicine.

I remember reassuring my patient's wife and daughter that if he survived the next 24 hours, he might recover. If I am honest, I never thought he had a chance, but I couldn't face saying that to his wife. So I did what many healthcare professionals do when faced with these difficult situations: I hid behind 'the medicine.'

Walking into his cubicle a while later I saw that we were in trouble. The monitor showed an increasingly rapid pulse, his blood pressure was dropping quickly, the veins in his neck were distended. A quick listen with a stethoscope confirmed my suspicion: muffled heart sounds. He was exhibiting the classic signs of cardiac tamponade - a medical emergency that arises when fluid, usually blood, seeps into the space between the pericardium lining of the heart and the heart muscle, stopping the heart from pumping efficiently, eventually leading to cardiac arrest.

I called the Surgical ICU upstairs, requesting the surgical registrar assess the situation as a matter of urgency. I had no sooner put down the phone than alarms rang from the patient's room. Grabbing the crash cart, I started to resuscitate him, even though I was aware that he was unlikely to survive, given his age and the extent of his injuries.

The moment the surgical registrar and his team entered the room, the sense of urgency ratcheted up. A sixteen-gauge needle was rammed into the patient's heart to release the accumulated blood. Vial after vial of adrenaline was pumped into his central line, units of blood were ordered and chest drains were inserted as his fractured ribs punctured his lungs. Eventually, his chest was cracked open and open-heart massage commenced. Despite it being obvious that the patient's frail body could not take the drastic medical intervention being meted out, the registrar refused to stop.

An hour later, it was finally over. My patient was officially declared dead.

I was traumatised by what had happened. I could not justify the level of over-treatment my patient had been subjected to. I struggled for a long time to come to terms with the fact that I had been party to that travesty. Ultimately. the experience contributed to my decision to leave the profession.

Years later, I read a passage in Michael Hebbs' *Let's Talk about Death over Dinner* that perfectly articulated what I had felt that night. In the book, an emergency doctor is asked to comment on being required to resuscitate an elderly person, even when she knew it would not change the outcome. She said the following: "We're causing so much trauma to a frail person's chest when, realistically, every doctor in the room knows the outcome will be death - regardless of whether we do CPR for ten minutes, one hour or three hours. The patient's ribs are cracked and their final moments are traumatic. They are surrounded by doctors, not their children. That's not a good or dignified death" (Hebb 2018 p. 66).

Coincidentally, that year, 1991, marked another milestone in my medical career. I received my first copy of a banned book. Smuggled home from London, strapped to the waist of one of my dearest friends to avoid detection, it was excitedly delivered to me, slightly curved and sweat-stained from its fourteen-hour journey, but no less precious for that.

And the title of that book? *The House of God* by Samuel Shem (Shem 1985).

First published in 1978, the book takes a satirical look at the practice of medicine, showcasing the psychological harm caused by the dehumanisation of medical care, principally in the elderly. The storyline follows a group of medical residents through their residency at a fictionalised hospital – the House of God. The main protagonist, Roy Basch, is supervised by a doctor known only as the Fat Man.

The Fat Man contests that the diagnostic procedures, treatments, and medications received by elderly patients, referred to as Gomers – an acronym for Get Out My Emergency Room - actually harm these patients instead of helping them. While most of the other medical residents are being taught to do everything in the pursuit of life at all costs, the Fat Man teaches Roy that the only way to keep the patients in good health and to make sure that he survives psychologically is to break the official rules and *do nothing.*

The House of God helped me understand that my experience was not unique, but was happening in hospitals and emergency wards across the globe. It also was the first time I encountered the term 'Good Death'.

Defined by the Institute for Medicine, a good death is one that is "free from avoidable distress and suffering for the patient, family and caregivers, in general accord with the patient's and family's wishes and reasonably consistent with clinical, cultural, and ethical standards" (Gustafson 2007). While generally accepted, the definition has come in for considerable criticism, notably that there can be "no such thing as an external criterion of a good death, that it is an individual experience, restricted to the dying and their families" (Meier et al. 2016).

Dying in our modern-day is, however, very rarely restricted to the individual and their families. To understand why, we need look no further than the two world wars.

World War One fundamentally changed the shape of societal grief, mourning and dying, steering us full steam ahead into Philip Ariès' 'Forbidden Death'. More than seventeen million people perished across Europe during the four years it took to end that war. It has been described as the first mass killing in history. Simultaneously, in a world filled with ironies, war is good for all kinds of advancement, not least in medicine. Dr Mary Merritt Crawford, the only woman doctor at the American Hospital during the war, noted that: "…war brought death and destruction, yet also opened the path to progress. A war benefits medicine more than it benefits anybody else. It's terrible, of course, but it does" (Hampton 2017).

World War One introduced us to anaesthesia, antiseptics, motorised ambulances, treatments for typhus and sepsis, Alexander Fleming's accidental discovery of penicillin – although that only came into its own in World War Two - blood transfusions, orthopaedic and facial reconstructions and advances in modern dentistry, to mention but a few (Bennet 1990).

The First World War also marked a difference in how we grieved.

As a matter of policy, the government of Britain did not repatriate the bodies of the soldiers killed on foreign soil. Gone was the orderly death so cherished by the Victorians, where the process of mourning was entrenched in society and seen as pivotal to a good death. Open displays of grief were frowned upon.

Mourning was to be conducted privately in the interests of “public morale and social solidarity.” Death that occurred outside of the battlefield was moved “…from the family home to the hospital, funeral home and crematorium” (Jalland 2018).

The Second World War marked

> …an even deeper break with the past than the First. The change in cultural norms affecting family bereavement was more intense, widespread and long-lasting. Open and expressive sorrow was strongly discouraged in favour of a pervasive model of death-denial and privatised grieving which became entrenched in the nation’s psyche for the next thirty years (Jalland 2018).

The World Wars also changed where we died.

Prior to 1945, we tended to die at home. A rise in societal consciousness brought about by World War Two, accompanied by economic imperative, changed that. In America, the Hill-Burton Act was signed into law by Harry S. Truman in 1946, making funding available to construct a vast network of hospitals, not only to provide healthcare but also employment for the soldiers returning home. In the UK, the National Health Service was established in 1948 in an attempt to “…universalise the best care and not simply act as a safety net for the poor” (Campbell 2016).

Here in South Africa, we were not untouched by this shift of care from home to hospital. Baragwanath Hospital, today the largest hospital in the Southern Hemisphere, was built by the British during the war to provide healthcare services for their soldiers injured in the Middle East Command (Baragwanath Hospital, Soweto, 2013).

Increasingly rapid developments in clinical medicine marked the twenty years following the World Wars. Many of the treatments we take for granted today were initiated during this period: hip replacements, beta-blockers, artificial hearts and pacemakers. Other developments included the first liver transplant, the discovery of polio, mumps and measles vaccines, the invention of cardio-pulmonary resuscitation (CPR), and the development of insulin pumps. These all contributed to our modern-day expectation of improved care and extended life expectancy. (Timeline of medicine and medical technology, 2018)

So rapid were the advances that we needed to relook at what it meant to be dead.

For the first time, machines could keep people alive long after their bodies lost the ability to do so. In 1968 a committee at Harvard Medical School, established to review this situation, recommended that brain death become the standard definition for what it meant to be dead. That definition remains in place today (The Economist*,* When Death is not the End, 2016; Goila AK & Pawar M T 2009).

Dr Seamus O’Mahony, author of the most devastating critique of modern medicine since Ivan Illich, describes the years from 1950 to 1970 as the ‘Golden Years of Medicine’, with many doctors agreeing there was more “curing of diseases, patients were mostly grateful and respectful, and doctors had clearer roles and more power and status” (Smith , 2019).

Golden they may have been, but with better care came an unintended consequence. “Dying stopped being a part of life,” says Dr Joaquim Madrenas, professor of Microbiology, Immunology and Medicine at the University of Western Ontario (Von Aderkas & Levine 2011).

Whereas healthcare was previously the purview of the individual – the doctor who made house calls and was solely responsible for the care of his patients – now there were many players involved in the care chain, including government, care facilities, medical insurers and Big Pharma – the so-called medical-industrial complex - and those players had interests beyond the mere provision of care, not least of which was the management of costs.

Not only did we transfer responsibility for our care to these players, but in the words of Prof Alan Williams, as a society we began to pursue life-at-all-costs which, he argues, implies that "... no one should be allowed to die until everything possible has been done. That means not simply that we shall all die in hospital but that we shall die in intensive care" (Henwood 1999 p. 36).

But what of the future?

While no one has a crystal ball, it is safe to say that the next thirty years will be even more dramatic in terms of medical advances. Artificial Intelligence, robotic diagnostics, remote surgery, digital medication, DNA manipulation and precision medicine all point to a world in which it is conceivable that the average age of our elderly will extend to a hundred years or more.

We are now "…caught up in a medical juggernaut driven by a logic of its own, one less focused on human suffering and dignity than on the struggle to maintain vital functions" (Clark 2002).

I take some comfort from the 2017 UK report into 'The Changing Face of Medicine and the Role of the Doctor in the Future', which states that: "…the doctor of the future will be an expert on people, compassionate and caring, with a holistic approach that incorporates the use of new technologies. (British Medical Association 2017).

One can only hope.

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Chapter 5: There’s Something about Mary

In the past few decades, medical science has rendered obsolete centuries of experience, tradition and language about our mortality and created a new difficulty for mankind: how to die.

Atul Gawande, *Being Mortal*

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Dame Mary Beard, Britain’s best-known classicist, wrote a piece in the *Guardian* entitled *Exit Strategies,* in which she stated, “…of all the ideas we have inherited from the classical world, the very worst is the myth of a 'good death’ … we would be kidding ourselves if we thought that, in the end, our addled bodies would be able to seize the opportunity for some witty last words, as the ancient myth suggests. There will be no cleverly choreographed deathbed scene; almost certainly we will be in pain, and not in control” (Beard 2009).

I’m not sure if she was referring to the hyper-medicalisation of death or not, but this chapter is not about Mary Beard. It is about Mary, my friend Katherine’s mother, who undoubtedly would have agreed with Dame Mary’s sentiments.

When I first met Mary, she was a bright, sprightly, whirlwind of a seventy-year-old. A retired teacher, she still offered remedial classes for children with learning difficulties. She had a fabulously quick wit and wonderful sense of the ridiculous, which often left us convulsed in laughter; a love for all things musical and literary and a large, sloppy dog named Harry, whom she adored above all things.

She had outlived her husband by nearly twenty years. He had died of pancreatic cancer when Katherine was still in high school. Never prone to hysteria or self-pity, she was explicit in what she wanted at the end of her life.

I recall a conversation the three of us had during my ICU training, in which Mary told Katherine and me in no uncertain terms that if it did not cause her family too much distress, she wanted to die at home. She had a horror of being resuscitated and kept alive if there was no hope of recovery. She and I made a pact that if she ever ended up in my ICU, I would do everything in my power to ensure that her wishes were respected.

Life happened. I travelled overseas. Katherine married and moved to another city. It was a good ten years before we reconnected, and by then Mary had moved in with Katherine and her family. Katherine said she loved having her mom around for her children to grow up with, and they adored her.

The last time I saw Mary, she was nearly 89. We took advantage of the hot summer weather to sit in the garden – she in the sun and Katherine and I in the shade – reminiscing about ‘the old days.’ The twinkle in her eyes was still there, her sense of humour intact. But I could see, as I had with my father, that she was tired.

She wasn’t sick. She was, in her words, in ‘disturbingly good health’.

She was just old.

Her eyesight was failing and her hearing was fading. She could no longer listen to her beloved music or read the books that gave her so much pleasure. While she was still mobile, it was becoming increasingly tricky to navigate everyday life.

Some time after that visit, Mary was admitted to hospital with pneumonia. According to Katherine, she was very frail, but mentally still ‘as sharp as a tack’.

One day, when Katherine was away from her bedside, Mary suffered a cardiac arrest. Despite her clearly articulated wishes and Do Not Resuscitate Order (DNR), the medical team swung into action. She was resuscitated, ventilated and moved to the ICU unit.

When Mary eventually regained consciousness and realised what had happened, Katherine recalled, tears streamed down her face. She was inconsolable.

Six weeks later she was back home, but she was never the same. She seemed to give up on life. She was distraught at having been resuscitated against her wishes, a process which had broken two of her ribs, leaving her in extreme pain, causing respiratory issues which lasted for the remainder of her life. The healthy woman who had never taken more than a Panado now had medications for her heart, for her blood pressure, for her gastric reflux – a condition caused by her other medications. Most humiliating of all, she had to take a diuretic, which made frequent toilet visits necessary. This process was so onerous that she was eventually forced to wear adult diapers. She refused to leave her wheelchair - meant to be a temporary measure – and lost interest in trying to walk to, or even sit in her beloved garden.

Mary wanted to die, but she couldn't. Medicine and good genes were keeping her alive.

During a routine visit to her physician, he pronounced himself 'happy' with her condition, allegedly remarking, "It's going to take an asteroid to bump you off, Mary."

Fast forward five years and Mary was now 94. She was bedridden, requiring round-the-clock care, completely blind and unable to hear much, with or without her hearing aids. Still mentally alert, her life must have been unbearable.

One morning, Katherine was struggling to get Mary to eat. In desperation, she admonished: "If you don't eat, mom, you can't take your medicine" - a remark Katherine says she'll regret for the rest of her days. Mary made the connection. She refused all food and liquids, except for the odd sip of tea. It took three weeks for the end to come. And it was grim.

When Mary began Cheyne-Stoking, a slow, stop-start breathing that often accompanies the dying process, Katherine panicked and despite all her best intentions, called the emergency services.

The young paramedic who attended to the call took one look at Mary and told Katherine her mom was close to the end, reassuring her that what was happening was normal. If they took her to hospital now, he advised, she would be put in a starched green gown, dripped, drugged, shoved onto a gurney and placed in a sterile ward environment, all to prolong the inevitable.

Then he did something remarkably kind, if not extraordinary. He offered to stay with Katherine until her mom died. He phoned her doctor, got permission to give Mary some form of pain control to keep her comfortable, and true to his word, sat in the room with Katherine and her mom.

An hour or so later, Mary finally got her wish. I do not think Mary's death can in any way be classed as a good death, but things could have been much worse had it not been for the wisdom of that twenty-something-year-old paramedic.

What was appalling are the lengths that Mary had to go to, to be allowed to die.

While this story is an exploration of the medicalisation of death, it felt appropriate, in the interests of balance, to offer a glimpse of an alternative to the medical standpoint. For this, I turned to death doula Odette Green, who practises out of Cape Town.

A death doula is a non-medical person trained to care holistically for a dying individual and their family at the end of life. They are as old as time itself, but as radical an innovation in our current process of dying as any medical technology. According to the website www.doulagivers.com, people are "readily embracing this new area of end-of-life planning, and the practice is rapidly gaining momentum" (DoulaGivers 2017).

Death doulas are here, they say, to re-teach us the forgotten art of dying naturally.

I asked Odette what her thoughts were concerning how the elderly die in our current environment:

> The alienation that we have now - of people dying alone, in institutions - is a very modern thing. I would say that even as late as the 1940s people still died with their families. But what has happened is we have taken the humanness out of dying. But why take the dying, shove them to one side, and leave them to die on their own, with little or no support?

At the time, Professor Ryan Blumenthal's question about my apparent obsession with death in the elderly was still preying on my mind, so I asked Odette if she thought there was a difference in the way older people died.

"Yes, I do. So if you are talking about people older than 'three score years and ten', they are aware that they are coming to the end of their lives. They are aware that they have had their quota. Many are frail. What they would prefer is not to die in pain, and on their own terms, whatever those may be. But,' she clarified, "it depends on what kind of life they've lived. Some elderly people want to continue their lives because they're not finished yet."

I was interested to learn her views on the apparent trend that the medical fraternity now controls the moment and process of our deaths: "In all honesty, I don't think any doctor or court on the planet should have the right to tell you what to do at the end of your life. If someone wants to die, that is their choice. If they don't, that's also their choice."

Then she told me this story, which offered an insight into why she does what she does, while simultaneously illustrating the extremes to which people – and here I include not only medical professionals, but also family members – will go to, to extend life.

> My father was a diabetic. He had been unwell for a long time. One day, when he pulled his sock off, a bit of his foot came away with it. He obviously had a huge infection. He got sicker and sicker. He wanted me to instruct his medical team that he wanted the infection, by this time septicaemia, to kill him. He did not want any more care. So I communicated that to the doctor.

She paused before continuing.

> Instead of listening to me – because I was the youngest daughter, I think – they went to my sister and my father's brother, and together they had him declared medically unfit to make his own decisions. They kept him alive for eighteen months while he slowly lost bits and pieces of his body. He was in the hospital for seventeen of those eighteen months. His medical bills were eventually over R2.5 million, which, fifteen years ago, was an exorbitant amount. But eventually, he managed to die.
>
> How did they [the doctors] get to decide that? Why would you make someone suffer like that? It's beyond comprehension. My sister was here recently. It's the first time we have connected since my father's death. It's taken us fifteen years to get to a place where we could do that."

I could not begin to imagine how that must have affected her and her father.

"You know, when I discussed my father's wishes with my husband, I fell apart. My husband asked me: 'Is this about you, or your father? Because if it is about your father, then you have to abide by his wishes.' And then, to have my sister and the doctors go against that...I cried many, many tears. And then I cried some more."

I offer these two stories, together with my father's story, to illustrate the impact of relentless medical intervention in end-of-life care on the elderly and their families. Death can be traumatic. For those left behind, it's often tragic. But it is a natural phenomenon, and somehow, in our relentless pursuit to 'cure', we have forgotten that. We have forgotten how to die.

As Samuels Shem's character Roy in *The House of God* reflected:

> We were putting into these gomers our fear of death, but who knew if they feared death? Perhaps they welcomed death like a dear long-lost cousin, grown old but still known, coming to visit, relieving the loneliness, the failing of the senses, the fury of the half-blind looking into the mirror and not recognizing who is looking back, a dear friend, a dear reliever, a healer who would be with them for an eternity, the same eternity as the long ago, before birth (Shem 1985 p. 343).

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Chapter 6: Fail to Plan, Plan to Fail

It is the fate - the genetic and neural fate - of every human being to be a unique individual, to find his own path, to live his own life, to die his own death.

Oliver Sacks

When a patient is severely ill, he is often treated like a person with no right to an opinion. It would take so little to remember that the sick person too has feelings, wishes and opinions and has- most import of all - the right to be heard.

Elizabeth Kübler-Ross

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"It all starts with a living will, doesn't it?" I was visiting Margie Waterford[1], retired head of caregiving at a non-profit organisation that provides care and accommodation for the elderly and member of the now-defunct Living Will Society of South Africa.

A midwife by trade, Margie left England in the 1950s in search of adventure, finding work and love on Zambia's Copper Belt. She and her husband migrated to South Africa in the 1960s, where she raised her family and spent much of her working life advocating for and taking part in care of the elderly.

Now, well into her seventies, she epitomises 'active' retirement, having simply swopped her day job for a whirlwind of charitable activities that would exhaust people half her age. I knew that she spent much of her time assisting members of her retirement community in compiling their living wills. I was interested to learn more about her experiences.

"If you don't know what you want, you don't tell your family, and there's no record of it, how can you expect anyone to respect your wishes? You'd be horrified how few people have one, or want to talk about it. Even at our age!" She commented wryly. "I always tell people, you've only yourselves to blame for what happens to you if you don't have a living will."

Margie's comments echo what Michael Hebb claimed in his book, *Let's talk about Death over Dinner*:

> People are bankrupting their families, and for little good reason: most of them don't even want expensive, extreme life-prolonging measures, but they haven't talked to their families about their preferences, and no-one has asked (Hebb 2018, p. 5).

But could it be that simple?

Decide what you want, communicate it to your family, write it down, sign it to make it legal, make sure everyone knows where you keep your document and a good death is assuredly within your reach.

I still had that persistent question, one that's bothered me ever since my encounter with the physician who treated my dad, namely, why the medical team refused to respect my dad's living will. I am not alone in this concern.

A 2017 article in the *Economist* entitled '*A better way to care for the dying*', reported that

…sometimes, even when relatives know a loved one's wishes, they cannot make sure they are granted. Between 12% and 24% of those who had lost someone close to them said that the patient's wishes had not been carried out. Between 25% and 38% said that friends or family had experienced needless pain.

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[1] Name changed on request of interviewee

Across the whole survey, most people rated the quality of end-of-life care as ‘fair’ or ‘poor’ (The Economist 2017).

In contrast to these findings, there is a growing body of research which shows that people who *did* discuss their end-of-life wishes with their clinicians experienced a far better outcome. La Cross, a small town in Wisconsin, USA, is the probably the poster child for this school of thought. As far back as 1991, the medical leaders in this small rural community set in motion a county-wide campaign to get medical practitioners to discuss end-of-life wishes with all their patients. In addition to the immensely positive emotional impact, it appeared that these discussions decreased the end-of-life costs in that small county to half that the national average (Severson 2012).

I was curious, given Margie’s background, what her practical experience had been with the medical fraternity around the implementation of a living will. I prefaced my question by stating that, until recently, I had been a huge proponent of living wills. They just made sense. But my experience had shown that they made very little difference to the end-of-life care received in hospital, since many practitioners appeared to ignore or discount them.

She appeared taken aback by my observation. ‘Well, I guess that does happen, but at least it’s a start.” She paused a moment before saying contemplatively, “But to answer your question, I think it might have something to do with the legal issues.”

Legal issues? I had not considered that aspect. Cynically, I believed it all came down to the money. Specifically, that the way our medical aid schemes are required by law to pay for certain types of care meant that the various players involved in that care stood to make significant amounts of money by delivering extensive treatments in end-of-life situations. My opinion was not pure speculation. There is research in the US that shows that as much as 25% of all Medicare spending is on 5 % of patients in the last few months of their lives, *with little apparent benefit* (Gawande 2014 p. 153). But had my thinking been myopic, framed by my personal opinion and experience?

I was even more committed, after my conversation with Margie, to get to the bottom of the issue, and now I had a direction to focus on: the law. I started my search by asking Dr Google to pull up information on the two most important documents we have in our arsenal against hyper-medicalisation, namely living wills and Do No Resuscitate (DNR) orders. Could the reason, as in all things, be more nuanced?

A living will – a document different to your actual will – is intended to guide your family and healthcare providers regarding your wishes in situations where, medically speaking, you cannot recover or are no longer able to make your own medical decisions.

According to the Living Will Association of South Africa (ironically, now defunct), four conditions need to be met for a living will to be valid: (i) you must be eighteen years or older when you write your living will; (ii) you must be mentally capable at the time of compiling the will; (iii) a healthcare practitioner must be sure that you are fully informed of your condition and the treatment choices before signing the document and were not unduly influenced to do so; and finally, (iv) a healthcare practitioner must be sure that you did not change your mind after you wrote the directive (AED Attorneys 2019).

Well, that’s tricky.

In an end-of-life care situation, when a healthcare practitioner has just come into contact with an elderly person, say in an emergency room, how can they possibly ensure points two to four? Does that invalidate the living will?

Do Not Resuscitate (DNR) orders, on the other hand, are precisely what they say. They detail under what circumstances you are not willing to be resuscitated. Importantly, ‘resuscitate’ here refers to Cardio Pulmonary Resuscitation or CPR and not to other treatments such as pain relief, medicines or nutrition.

According to David McQuoid-Mason, Professor of Law at the Centre for Socio-legal Studies at the University of KwaZulu-Natal, DNR orders should be followed in the following circumstances: where the patient has a living will, or makes an informed decision to refuse CPR; where the medical fraternity make a clinical judgement that restarting the patient's heart and breathing would be futile – for example, if they had an irreversible condition - and finally, when, after discussions with the patient, their family or both (as the situation dictates), an agreement is reached that the benefits of CPR are outweighed by the burdens and risks involved (McQuoid-Mason 2013).

It seemed pretty clear, but I could also see it being fraught with issues when it came to implementing a decision in this regard. 'Futile' according to whom? 'Outweighed by the burden and risks' according to whom, and by what standards?

I was starting, reluctantly, to have some sympathy for the medical practitioners. It was more complex than I could unravel. I needed to call on outside expertise, and I had just the people in mind.

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First up: Michael, a financial advisor at a well-established financial management company. A sixty-something survivor of and sufferer from Hodgkin's lymphoma, he is no stranger to the conversation about death.

I was sure he had some insight into the issue, as his firm functioned as estate planners and executors of people's wills.

"Well, mainly, you should know that people don't plan for death," he offered. "They believe they're not going to die…not yet. You cannot believe the number of clients we come across that don't have their affairs in order. I refuse to do anything with a new client until we resolve the issues around their will. And that includes having a living will."

In his experience, then, did a living will work out for most of his clients? Had the medical fraternity, by and large, respected his client's wishes? "Absolutely not!" he scoffed. "We have had to put a clause in our documents that says we've followed your request to include a living will, but bear in mind, in this country, most doctors will not follow through with your request."

Did he have an opinion on why that was the case? Was it a legal concern? A moral one? Financial? "Well, they say it's the Hippocratic Oath. But that's all BS. Oh, and in case they get sued. At least that's how I understand it."

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Michael confirmed what I had discovered, but I was still none the wiser as to what the actual impediments to respecting a living will could be. To complete the puzzle, I needed a medico-legal opinion.

Jeanne[2] is an attorney who specialises in health law, policy and medical ethics. I had worked with her early on in my career and respected her measured, calm demeanour and extensive experience. Over the years I had attended many of her ethics lectures and I could think of no better person to help me understand the complexities of this particular puzzle.

Before I could arrange a meeting with her, a chance encounter with an old acquaintance gave me more food for thought.

It was the 'trauma blues' uniform that first drew my attention that afternoon as I waited for a relative in the canteen of a local hospital. To my delight, I realised it was someone I knew. I hadn't seen Karen[3] since I left South Africa to travel in the early 1990s, but she had been much more than an acquaintance. An ICU nursing sister par excellence, she was also a lecturer, flight sister and renal transplant co-ordinator. She'd been the

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2,3 Names changed on request of the interviewee reason I'd become an ICU nurse. As we chatted, she explained that she was now the matron in charge of a retirement home, and was at the hospital to ensure her patient received the care she was asking for.

I asked what the problem was with her care. "Well, she's 82 and really together mentally, but she's battling to eat." This is a situationthat is not uncommon in the elderly.

"We decided as a care team, with her and her family, that a PEG (percutaneous endoscopic gastrostomy or feeding tube) would help. She was more than capable of managing it and it would give her a better quality of life."

So far, so good. Even I could not detect hyper-medicalisation in that intervention.

"But when we got here [to the hospital] they wanted her to sign the blood transfusion permission form. She refused, saying if things went wrong, she had a living will and a DNR and did not want to be resuscitated in any way."

Karen's patient was not unique in her decision not to accept blood products. And she most certainly was not unusual in her living will and DNR requests, but what happened next was telling.

"The anaesthetist said that, unless she agreed to receive blood, he wasn't prepared to do the surgery. He called the surgeon, who said the same thing. "

It seemed, on the face of it, to be a storm in a teacup. Inserting a PEG is a common, quick procedure, with minimal risk, so the odds of her receiving a transfusion were slim. But the implications were a little more complicated.

"You and I both know what happens if things go wrong," said Karen, clearly angry now. "She's 82. If she needs to be resusc'd, and it doesn't go well, she'll spend weeks, maybe months in ICU, before they send her to High Care. Till the money runs out and then they send her home to die. It's a disgrace."

I needed to know how it ended. What did she do?

"Oh it's simple," Karen said. "She signed the damn documents. But I managed to get them to let me go into theatre with her, to make sure that, worst come to worst, her wishes will be respected. As soon as we're done, I'm getting her the hell out of here and back to the home so I can take proper care of her."

This was patient advocacy on another level.

But what of those people who don't have a Karen or a caregiver who is either experienced or (can I say it?) strong-minded enough to stand up for their patient's rights? What about the countless other octo- and nonagenarians languishing in ICUs across the country, receiving unwarranted treatments? I had seen some of the consequences in the ICU in which my dad died, but I was starting to realise, following my encounter with Karen, that even I had not fully comprehended the magnitude of the problem.

I hoped that Jeanne could help bring some perspective to the complexities.

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"I'm not sure if I can offer anything regarding the hyper-medicalisation of death and dying," Jeanne said when responding to my request for an interview. "It's not really my field of expertise."

As it turned out, far from not having anything to contribute, my discussion with her proved a turning point in my journey. I asked what her legal opinion was regarding living wills and the problems I had encountered relating to their implementation.

"Well, at the moment, there's no official legislation that makes a living will legally enforcable, and that is a big part of the problem," Jeanne confirmed.

According to Jeanne, there is a document currently before Parliament that is designed to address this issue. However, as with the contentious Euthanasia Bill, which also applies to this discussion, neither had been passed at the time of writing this narrative.

In the absence of any legal dictate, the document most health practitioners abide by is the Health Professions Council of South Africa's (HCPSA) Withdrawal of Care Guidelines, which are aligned to our Common Law. These state, in a nutshell, that you can't help someone die, which, arguably, a living will could be construed as doing (The Health Professions Council of South Africa 2016).

I asked Jeanne if she thought that was the sum of it, this concern shared by practitioners that they are not acting within the letter of the law if they abide by living will. Instead of the agreement I was expecting, she took a long moment to answer, clearly mulling something over, before offering this somewhat cryptic comment: "I think there are scenarios where there are agendas at play, with people being kept alive…. or not."

Jeanne's hesitation brought home the seriousness of our discussion. We were entering sensitive territory, something that is not openly spoken of. I understood her discomfort.

Now that it was on the table, she clearly had more to say:

> I was recently involved in one case where the family insisted their elderly mother be kept alive, despite indications that she was not going to recover. And the very real fear that doctor, or in this instance, the team of doctors, had was that they would get sued if they did not go all out in her care. So they simply complied with the family's wishes. She was ventilated for nearly *a year* before she died.

It was not only family pressure that played a role in this travesty. What Jeanne said next confirmed my worst suspicions: "And you know, as long as there is a third-party payer, who is going to pull the plug? If the family is paying directly, it's a completely different situation. But if there's a Prescribed Minimum Benefit (PMB) at play, you are obliged to continue care."

What Jeanne was referring to was the legal obligation medical aids and insurers, otherwise known as third-party payers, have to cover to specific health services. These are the so-called 'prescribed minimum benefits' or PMBs: they include all life-threatening emergencies, some two hundred and seventy conditions that, if left untreated, would severely affect the patient's quality of life, and twenty-five common chronic conditions (Council of Medical Schemes n.d.).

It is under this PMB umbrella that treatments such as ventilation and dialysis, arguably the most common of all medical interventions in end-of-life care of the elderly, are reimbursed. There is no enforced cut-off point for this type of medical intervention, and their implementation is entirely at the discretion of the prescribing doctor. At least, this is the situation in private healthcare.

Despite having my instincts somewhat validated by what Jeanne had disclosed, this knowledge unsettled me deeply. It was difficult not to conclude that there was a correlation between hyper-medicalisation and the unrestricted, legally-required reimbursement of that medicalisation.

Ira Byock, a well-known palliative care advocate, commented in an *Economist* report that:

> The reason that assisted suicide laws are polling so well these days is that the public has a well of fear, anger and distrust about the care they will receive and how they and their families will die. And the hard truth is that this is well-founded (The Economist Intelligence Unit 2015 p. 49).

Based on my conversation with Jeanne, it appeared he is correct in his assertion.

It was time to talk to the people at the heart of the issue. Time to interview the Intensivists.

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Chapter 7: But You Took an Oath

The original oath still resonates, particularly the phrase: “I will utterly reject harm and mischief,” which is commonly misquoted as ‘First do no harm…….’ For me that fits perfectly with not over-diagnosing, not over-treating, and sharing decision making

Dr David Warriner*, Clinical Fellow at the Academy of Medical Royal Colleges, London* (Oxtoby 2016).

I don’t think any doctor should swear any oath. We are not royalty or priests, but health professionals doing a job, regulated by law and the GMC. That should be enough.

Dr Clare Gerada*, General Practitioner, London* (Oxtoby 2016).

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Michael the financial advisor’s words regarding the Hippocratic Oath had struck a chord.

Originating in the Fifth Century BC, compiled by Hippocrates, the father of medicine, the medical oath is one of the oldest texts in history. In 1948 it was modernised for the twentieth century by Dr Louis Lasanga and recently updated in 2019 to include “additional protection of the environment that sustains us” (Lasagna, 1964). While there is much debate regarding the relevance of the oath in modern medicine and many institutions no longer require their graduates to swear to uphold it, most practitioners still seem to agree with its guiding principles.

A closer reading of the 2019 rendition offers some pertinent advice regarding life, death and hyper-medicalisation, specifically:

> I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism.
>
> Most especially, I must tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God. (Chaney 2018; Hippocrates n.d.).

I’ll be keeping these injunctions mind when I’m conducting my interviews.

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James Greagan [4] is the Head of Critical Care at a private hospital. At any given time, he told me, more than three-quarters of his patients in the ICU were over the age of 80. When I interviewed him, his ICU was 100% full. Given the average age of most of his patients, he was perfectly positioned to answer my questions.

What did he, as an intensivist, believe a good death looked like for the oldest of the old?

“Well the ICU environment is different to the ward, so you need to remember that. But for me, a good death is where the patient is comfortable.” And he believed strongly that part of the process of making the patient comfortable required practitioners to take the time to talk through the prognosis and the options with the family. “Depending on how you, the doctor, play this, it has a huge impact on the lives of the family going forward.”

He continued:

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[4] Name changed on request of the interviewee

> ICU is not a one-day game. It’s important to tell the family they can defer a decision to discontinue care for a few days. By doing that you give them a chance to come to terms with what is going on and, should you decide to pull the plugs – well, we don't pull plugs – but should you choose not to escalate care - then the family is less traumatised. When a family can walk away without guilt, that’s part of a good death. Well, that’s my philosophy, anyway.

I told him about my experience of my dad’s death and the fact that our requests not to escalate care were brushed aside. Even now, two years after my dad died, I struggled to come to terms with what had happened. Grief and guilt are not comfortable bedfellows. “I live with the guilt,” I told James. “That I didn’t intervene more actively, and ultimately fight harder.”

He was kind enough to try to comfort me: “Linda, the outcome would have been the same, regardless of what you did or didn’t do.”

We moved on to the topic of living wills. James believed they were often not specific enough for an ICU environment, and that might result in a lack of understanding by the patients and their families. The biggest fear most people had was not being able to take care of themselves and of existing as ‘a vegetable’. They thought that having a clause in their living wills which said ‘Do not resuscitate me’ would prevent that happening.

Here, according to James, was where things become very grey.

He explained. “So say you’ve had a heart attack, and we can give you an angiogram, restore blood flow and get your heart functioning again. You'll come off the ventilator and have a good quality of life for years. But your living will says ‘do not resuscitate’. And this type of intervention *is* considered resuscitation. What do we do then?”

Then, too, he’d seen that people changed their minds when it came down to it, so practitioners had to be alert to that and make sure no one was forced to do anything they did not want to do. “The elderly are so vulnerable,” he concluded.

How, then, did he approach situations where a living will or DNR hadto be considered? How did he make decisions around the level of care he provided?

It was all about context, he told me and illustrated what he meant: “The first thing you have to do is determine what the patient was like prior to ending up in your unit. What was their level of functionality, what was their quality of life? Then you have to look at their disease process. Can we reverse that, and, if we do, will the patient be able to function as they did before? And if we can’t get them back to their starting point, how do the patient and the family feel about that?

“It’s a very individual process. You can follow the guidelines, but really, I guess, as you get more advanced in your career, we all come at it differently. It’s our own bias we bring to the table. It’s a human thing.”

Given his measured stance concerning end-of-life care, why did he think many of his peers had such resistance to the withdrawal of care, or to merely providing comfort care for elderly patients? Did he think it was a moral issue? A financial issue? Or something else?

“I don't know. But I guess your whole training is to keep alive or heal, but sometimes you can't heal,” he mused. “I think some people do find it very difficult not to escalate care. And often your decisions,” he hesitated before continuing, “are also about family pressure…”

I asked him how that affected him.

“Let me tell you about a recent experience we had here in this unit. An elderly gentlemen came in, having suffered a mild stroke. He needed to be ventilated, but the scans showed that the damage was minimal and the odds of him returning to full functioning were really good. Not guaranteed, but good.”

The ICU team had a good relationship with the patient’s daughter, he went on. They explained that her father had a good chance of recovery, and on that basis, she was comfortable to continue treatment. Three days after the gentleman's stroke, his other two daughters arrived from overseas, and then the trouble began. They disagreed with the youngest daughter, stating that their dad was well into his eighties, and should be allowed to go in peace.

James said they did everything they could do convince the older daughters that their dad was making good progress and would recover with minimal fallout from the stroke. But they were having none of it.

"The one daughter said she had come all this way, and she wasn't coming back for a funeral when he eventually did die. So they out-voted the younger daughter."

James was forced to take him off all treatment and move him from the ICU to a regular ward.

It was apparent how deeply this case affected him. After a long pause, he continued.

"He died about three weeks later. I don't know. Maybe it looked like we were over-reaching in our care, but I truly believed with a few simple interventions, he would still be here and functioning well. We were all traumatised, and I don't even want to know how the younger daughter is coping."

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Dr Andrew Corous[5] is a specialist physician and sub-specialist geriatrician in full-time private academic practice. He heads up the department of geriatric medicine at a local university. He is one of a handful of geriatricians in the country - indeed, Medpages, the country's largest private medical database, lists only twelve geriatric medicine specialists on their books, a frightening statistic given our aging population[6] (MedPages, n.d.).

Who better to talk to about end-of-life care in the elderly?

He was in a rush when we met. He'd been busy with a new admission and was running two hours late for our interview. It was after 6 pm by then, and he still had ward rounds to attend. I felt guilty for taking up his time and offered to come back another time, but he waved me towards his office.

I started our interview by clarifying that I was aware that hyper-medicalisation was probably more a private healthcare issue. Immediately, he stopped me. "It's more than a private healthcare problem. It's also a state problem. We see patients who have hopeless prognoses selected by some enthusiastic doctors for unbelievable treatment, even in the state sector."

It was clear he had strong feelings on the subject. What, then, did he have to say to the comment: "I'm not in the business of helping people die, I'm in the business of saving them."?

"Well, that's just nonsense," he said. "That's not saving anyone. Doctors are taught terribly. We're all egomaniacs who don't listen to the patients and don't take the time to give them information to help them make the best decisions for themselves."

So, given that a living will is where most people would record decisions regarding their end-of-life wishes, was I correct in assuming he was a proponent of them?

"In my opinion living wills are sacrosanct. You tell me what you want, and if you are not in a position to tell me, here is a piece of paper where you wrote down what you wanted when you *were* compos mentis. Why would I not respect that?"

"Some say it's around the concern of being sued," I countered. "That the law is not set up to protect the rights of the practitioner in cases where a dispute arises regarding the implementation of these wills."

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[5] Name changed on request of the interviewee

[6] MedPages Data represents mostly practitioners in Private Practice. The actual figure may differ from this tally.

“Sued for what?” he retorted. “Respecting your patient's wishes? That's ridiculous. But what's wrong with death? It's inevitable. And besides, the doctor didn't kill the patient. Illness killed the patient.”

He continued: “That's the problem in this country. You can ask some child who's involved in your care to dictate what happens to you, but *you* can’t control what happens to you.”

He had a point.

How did he manage his patients then? What did he advise them regarding living wills? “I always tell my patients the most important thing is to make sure your family knows what you want if you have a living will. Because mostly it's the nice gentleman who came to change the light bulb who signs the document and the family have no idea of what the patient wants. That causes a lot of problems.”

Andrew also believed that many living wills are vague. “A living will is not a one-pager. It’s a couple of pages long so you can describe various scenarios and what you want to happen to you in each. And you get your whole family to sign it. The problem,” he continued, “is how you define end-of-life. And that’s absolutely individual.” He explained further: “So, for example, if you’ve got chest pain from an irregular heartbeat. We can give you a bit of sedation and some cardioversion (shock therapy), and you'll feel much better. In my mind that’s not a resuscitation, that’s just making you more comfortable. Would you accept that level of intervention then, even though strictly speaking, we are resuscitating you?”

That’s exactly what James had said: it’s a grey area.

I asked if he had any final comments before we finished our interview. It turned out he did.

“You know, just because you have a living will doesn't mean you aren't entitled to healthcare. It just means you have chosen the level of comfort you want. The bigger issue in end-of-life care in the elderly is that we're bleeding money on a few fancy interventions that have a limited effect, ultimately, for these patients. That’s the real issue. That’s what you should be looking at.”

I intended to do just that. But I had one more interview to conduct.

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When I talked to James and Andrew, one of the issues that came up was that of pain management in end-of-life care. James confirmed that pain management and conversations around the death process received about the same amount of exposure in the undergraduate curriculum: almost none.

For insight into this issue, I turned to the president-elect of Pain SA, Doctor Sean Chetty. Sean is a specialist anaesthesiologist and deputy Head of the Department of Anaesthesiology & Critical Care at Tygerberg Hospital and Stellenbosch University.

When asked what he believed the reasons were for the excessive medical interventions in end-of-life care in the elderly he had this to say: “I think a big part of the reason in the private sector is certainly that there is an incentive for it. As you know, medical aids are obliged to pay for ICU care.”

“But,” he reflected “I don’t think that’s an entirely fair representation. As intensivists, we are trained to save people, but we are also trained to know when it's futile. That’s our responsibility, not the medical aids’.”

Andrew said we were bleeding money on a few fancy interventions that would probably have limited effect. Did he agree? Personally, he told me, he wanted to do everything for his patients. But for him, there were limits, regardless of how difficult those decisions were.

"We need to ask whether going overboard with a 95-year-old patient so they can walk out of the ICU, back to a home where they live alone with their caregiver, getting sent money from their kids overseas – is that worth it? To the patient?"

He also alluded to the considerable financial costs we are incurring as a society, with this life-at-all costs philosophy.

"If you are pouring hundreds of thousands of rand into a patient where care is futile, you are not only putting enormous strain on the family but on the entire health system. And when you do that over and over again, healthcare becomes less affordable for everyone."

I wonder what he makes of living wills in this context. Does he think they help or hinder?

"Unfortunately, in South Africa, the law states that living wills have no legal standing. So whether you are in state or private, you practise defensively to make sure you don't set yourself up for some medical liability. Until the law changes, I don't think that's going to change."

"I do, however, think," he went on, "that when you have good communication with the family, you can get the same result as a living will."

I sensed a 'but' coming, and it did.

"But, in ICU we are very wary of the potential for the family benefiting from the implementation of a living will. I've experienced that."

Both James and Andrew had expressed similar concerns. It opened up an entirely separate debate, one I was not sure I was ready to contemplate just then.

"To answer your original question, though, about why we are experiencing this excessive medicalisation, I think in the state sector we decide to terminate care much sooner because it's a resource issue. So keeping a 95-year-old ventilated for five more days helps no one, and there is no incentive to do so. But in private, keeping a patient ventilated for five days…..well, that's a lot of money you're going to be making."

There it was again. Whatever way you look at this debate, money had to be factored in. Whether concerning the payment for excessive care or the family benefiting from a living will, there was no escaping the financial implications of hyper-medicalisation in the elderly.

"We need to humanise the argument around end-of-life care," he concluded. "Until we get that point, nothing is going to change. We should be focusing on the quality of life, rather than trying to prolong the end of life."

What, then, is his professional definition of a good death? "Even if you are in hospital, a good way for anyone to die would be to have your family around you, talking and interacting. And if we're talking pain control, we don't necessarily have to take away all the pain - just make it so that the patient is lucid and can interact with their families. What's the point of being comatose?"

Did that reflect his personal definition of a good death?
"I think a good death is a death that that person wants .... so you know, maybe a skydiver says I want to go out in a blaze of glory and jump and smash into the ground." He laughed. "But a good death is very, very personal for each individual. I think a general trend would be that you shouldn't have to suffer. Whatever your definition of suffering is...."

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My suspicions regarding how our medical care reimbursement process significantly facilitates the hyper-medicalisation of death had been validated. However, in terms of the actual act of withdrawing care, there was a very real human cost to the healthcare practitioners responsible for implementing those wishes, which added another layer of intricacy to the issue.

I met Ian[7] at a medical conference. When he heard the topic of my narrative, he offered to chat to me about his experiences. A recent medical school graduate, now interning on the surgical registrar programme of a prominent teaching hospital, he had been on call for nearly thirty-six hours when we managed to find a rare moment of downtime to grab a coffee in the hospital canteen. Judging from the state of his surgical greens, it had been a long, hard shift.

I asked him how he handled end-of-life conversations with the elderly and their families.

"I haven't a clue how to do that. Discuss pulling the plug, I mean. Part of the reason is we're not taught how to in med school. If you're lucky you'll have a few hours role-play, but that's more of drag and a bit of a laugh because it's not real to you. And it couldn't be further from what you're interested in as an undergrad."

In this, he confirmed what Sean and James had said, that their training focused more on 'fixing' people than on having conversations around dying.

Ian continued, "It's about doing everything in my power to help you live. How the hell can I start a conversation about wanting *to* do nothing to help? How do you tell a family you've essentially given up?"

He shrugged resignedly "When there's chaos all around you, and you're running from patient to patient, crisis to crisis, battling with no drugs and broken equipment, after a 36-hour shift who has the time to have a conversation about death, particularly when the means to save someone are right in front of you? How am I supposed to do that? How can you teach somebody to do that?"

How, indeed?

I had started this series of interview with the Hippocratic Oath ringing in my ears. Speaking to Ian brought to mind a sentence in the oath which, to me, is the most sacred: "Above all, I must not play at God."

No one I interviewed had given me the impression they were playing God. Quite the opposite. I believe they, too, grapple with this complex, multi-faceted issue, which goes to the very core of our humanity. But perhaps, on reflection, both the profession and the patients would be better served by the codification of another Hippocratic edict, namely: "Cure sometimes, treat often, comfort always"

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[7] Name changed on request of interviewee

Chapter 8: It's All About the Money, Honey

Another day older and deeper in debt
Oh, Saint Peter don't you call my name, 'cause I can't go….I owe my soul to the company store.

Ernie Ford*, Sixteen Ton Tennessee*

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My conversations with the intensivists had challenged many of my preconceived beliefs. I had not fully understood the murky middle ground that straddles the gap between achieving a good death and the legal and moral factors that came into play when attempting to attain such an end.

And yet I still could not shake my inherent belief that money plays a significant part in hyper-medicalisation of end-of-life care. Bill Clinton was not wrong when he strode to victory in 1992 US elections on the back of his now-infamous campaign slogan "It's the economy, stupid" (Ironically his other campaign slogan was "Don't forget healthcare") (Wikipedia: It's the economy, stupid n.d.).

The costs of care, however, are not only monetary. There are social and emotional considerations that must be taken into account in any debate related to illness and death, perhaps more so in elder care.

I'd known Anne for almost nine years. Like me, she was the sole carer of two of her elderly relatives – her mother and her father-in-law. Her mom had Crohn's disease, which had required numerous surgical and complex medical interventions. She'd had multiple falls, two of which resulted in hip surgery. In addition to this, she suffered from the evil twins of hypertension and hypercholesterolemia. On average, she was admitted to hospital five to six times a year, never for a short stay.

Anne's father-in-law, on the other hand, had Alzheimer's and, at 82 years old, was diagnosed with an aggressive form of cancer, which a previous doctor chose to treat with chemotherapy, leaving him further debilitated and frail. Both of them lived with Anne and her family. She supported them financially, covering their medical aids, caregivers, accommodation, food and living expenses. Their monthly costs – on a good month, one without a crisis – were more than R40,000.00

Did I mention that Anne was self-employed? Now factor in those costs against a background of spending a significant number of hours managing her elderly parents' care, hours when she could have been earning but wasn't, and the financial and emotional strains become apparent.

So here's another conundrum, in a story littered with them. To pay for 'good' care for your elderly relative, you need to earn money. Lots of it. But you can't earn the money you need to, because you are too busy delivering care.

"I'm not sure how much longer I can carry on. I haven't even saved for my own retirement yet. I'm broke. *And* I'm still helping my kids find their feet," She confided to me.

Anne's story illustrates one of the most under-reported challenges of our current times: the burden of the Sandwich Generation. It's a ridiculously apt description; on the one hand conjuring up idyllic summer days filled with fun; on the other a tight squeeze, an uncomfortable compression, a messy situation. The term was coined back in 1981 by US social worker Dorothy Miller to "…describe women in their 30s to 40s who were 'sandwiched' between young children and ageing parents, as their primary caregivers" (Tarantine 2014).

While caregivers may now be slightly older - we are currently between 45-60 years old - and the gender equation has shifted somewhat, the fact remains that nearly ten million people over the age of 50 are caring for their ageing parents (Geewax 2012). In South Africa, where only 6% of people can retire independently of others, becoming part of the sandwich generation is a likelihood for most of us (Williams 2018).

The impact of this phenomenon is not only economic. A body of research conducted in the US over a twenty-five-year period showed that family caregivers are at risk for a wide range of problems, including physical and mental health issues. Indeed, caregivers have a 63% higher risk of mortality than non-caregivers (Carter 2008). So significant is this effect that some believe the caregiver crisis should join the ever-growing list of public health crises. Whether you subscribe to that or not, you cannot discount the substantial burden of end-of-life care on these individuals.

"You know," said Anne "Sometimes it's just all too much. I'm resentful all the time. I don't mean to be. But the truth is, I am. I feel like my life is an endless series of hospital appointments and bills. Every time we go to another specialist, we get referred to another specialist, and on and on it goes. And then there's guilt heaped on you if you try and pull back on any treatment. It's relentless. I'm exhausted. And I can't see it ending any time soon. I feel terrible for even saying that because the end means just that. The End. And that's not what I'm saying. It's just too much."

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Anne represents the individual face of the caregiver crisis and its implications, but what does the picture look like for society at large?

Globally, the stats are staggering. Of the roughly 150 000 people who die every day, two-thirds die of age-related causes (De Grey 2007). And they are not dying at home. The majority of older people are dying in hospitals, undergoing care that, to all intents and purposes, should be deemed futile, at huge cost to the individual, the family, the caregivers and society as a whole.

If you subscribe to the theory that money makes the world go round (or its counterpoint- money is the root of all evil), then it becomes imperative to quantify the so-called 'burden of disease' in the elderly, and that starts with a review of what we are dying from as we age.

According to the *Economist*, globally, non-communicable diseases such as heart disease and diabetes will account for more than three-quarters of the deaths of the projected one billion people expected to reach sixty-five and older by 2030 (*The Economist* Intelligence Unit 2015 p. 7). Here in South Africa, the stats concur, with the 2018 Morbidity Report showing that in the age group sixty-five-plus, cerebrovascular disease is our leading underlying cause of death, followed closely by diabetes and hypertensive disease.

If we then look at where we die in terms of place, 43.2% of all elder deaths take place in hospitals. James Greagan illustrated this in the interview reported in the previous chapter, when he stated that, at any given time, 85% of the people in his ICU were octogenarians. And that care does not come cheap. Researchers Bion and Strunin observed: "…[I]t costs twice as much to die in an intensive care unit as it does to survive" (Statistics South Africa 2018 pp. 11,16,20,28; Clark 2002).

So, what do we get in return for the money we spend? Not much, if you believe the 2015 Quality of Death Score report. The report, which looks at affordability of care, specifically palliative care for the dying, puts South Africa at a dismal forty-fourth of the eighty countries reviewed when it comes to the Affordability of Care Index.

And we're not even achieving good care, in the end, for that cost. We are a shocking thirty-fourth out of the eighty countries in the Quality of Death Score (The *Economist* Intelligence Unit 2015 pp. 14, 37).

It appears that we can't even pay our way to a good death.

As an economy with a multitude of societal concerns, all justified in clamouring for attention and financial assistance, how are we going to manage these healthcare challenges, the burden of which, if not addressed, could cripple our already strained healthcare system?

And there’s another kicker. It turns out that, out of eighty countries surveyed, South Africa, unbelievably, is third in the world, behind Japan and Ukraine, to exhibit the phenomenon of simultaneous growth in the number of elderly combined with a significant population decline. (Why Population Aging Matters: A Global Perspective 2017 p. 14).

Practically, not only do we have a growing elderly population with an increasingly complex disease trajectory, existing in an environment where the cost of care is rapidly escalating, but we have fewer people who can pay for it, or the necessary resources.

Why is no one paying closer attention to these startling facts?

They should be. Professor Sean Morrison, System Chair of Geriatrics and Palliative Medicine at Mount Sinai Hospital in New York, put it bluntly: “The continued growth of the older population, coupled with their increasing need for healthcare as death approaches, presents one of the largest public health challenges in history” (Morrison, 2005).

Could this lack of attention be intentional? Or is it just that as a society we have so many other issues that the aged are relegated to the margins in the hope that, by natural attrition, they eventually go away?

I was determined to find out.

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After weeks of phone calls, emails and calling in favours, I was struggling to find a medical aid willing to meet with me. I had all but given up when luck and a chance call put me in touch with Ellen Parker[8] and Janet Reading[9].

Ellen is a doctor who has a Masters in Health Economics and specialises in bioethics and health law. She heads up the clinical services department at a large medical aid company. Janet is a registered nurse, heading up the advanced illness and compassionate care programs at the same organisation.

In preparation for our meeting, I scoured their medical aid’s annual reports for the last three years and found no mention of the elder-care challenges.

A search for information regarding end-of-life care directs you to palliative care services, listed as Compassionate Care and Advanced Illness Benefits, both of which are tagged for the treatment of oncology patients. Interestingly, in 2019, the Compassionate Care Benefit, which, according to the brochures, offers access to psychosocial support, pain management, nursing care and home oxygen, has a once-off life-value of R 62,000.00.

A once-off lifetime value. That would have just about covered my father’s nursing care for two months.

I decided to cut to the heart of the matter with my first question. Did they, as a medical aid, believe they were in part responsible for the hyper-medicalisation and delivery of futile care that the elderly were receiving at the end of their lives?

“Well maybe, but that’s perhaps not the best place to start,” Ellen answered. “With the elderly, it is just more obvious than with other groups. They do get a lot of non-beneficial care. You are pretty certain they are not going to get up and leave the ICU. But, to be clear, it’s not only happening in private.”

Both Ellen and Janet, it turned out, trained at the Charlotte Maxeke Hospital. Ellen recalled that even thirty years ago the same things were happening.

“Patients got resusc’d. People did things to them - broke their ribs, kept them there for another day or two. And for what? Nothing was gained. You asked yourself: ‘Why are we doing this?’ It didn't sit well with me.”

8,9 Names changed on request of the interviewee

She believed that a significant reason for the high level of futile care is because no one is honest with the family. Janet agreed with her. “You know we talk about the doctors not doing the right thing, but we experience a lot of resistance from the family. I would say it's almost fifty-fifty.”

I was interested to know how they, as funders, came to that conclusion. It turned out it was based mostly on the resistance to palliative care, and in particular to pain control, that they encountered. Some family members believed that giving morphine to a patient equated to attempting to euthanase them. And in private, the doctors were nervous about withdrawing care in favour of palliation in case they got sued. “This is where the whole problem arises.’ Ellen continued. “We are not asking you to actively kill people. Just to stop non-beneficial care. And every single day these two things are mixed up.”

I saw my opportunity. “Actually, can we chat about your Compassionate Care benefit? It indicates that you will pay a one-time-only payment in ‘the face of imminent death.’ How do you, as a funder, make that judgement call – ‘imminent death’ - and how did you get to the exact figure of R62,000.00?”

According to Ellen, the figure and the one-time-only parameter were based on the disease trajectory of patients with cancer, where it was much easier to predict how long a person would survive. Typically, it covered the last two months of palliative care.

And there was the issue for the elderly again.

“The elderly die in slow increments, not in defined timelines. What happens when the lifetime amount is used up?” I asked.

Ellen acknowledged that it was a problem. “Previously, yes, it was gone. But nowadays, when the benefit is up, we do have discretionary powers to give more.”

And then a much more poignant issue was put on the table.

“But we are not going to advertise that,” she continued. “Because what people want - old people - they really just want assistance with daily living. Things like cooking and helping with cleaning. But that’s not nursing. That’s not a scheme’s responsibility.”

On a humane level, perhaps more than anything else I had heard, this was the saddest.

It appeared from this conversation that some elderly people, struggling to live out their last years with dignity, were turning for help, not to their families, many of whom had left the country or simply did not care – or to communities, which, let’s face it, were marginally interested at best, but to their medical aids, for this final gift of care.

Could there be a greater indictment of our society?

I digested this for a few moments before circling back to my original question. Given all that we had discussed, particularly around palliative care, did they believe the system of third-party payment was responsible for the hyper-medicalisation of end-of-life care? Was the system failing the very people it was supposedly there to help?

“I don't think we could say we failed, or our goal is to say no one dies in an acute facility. Because if they did and there was no futile care, then that would already be a big step forward. The daughter’s not traumatised. The mother didn't have millions of tubes, wasn’t linked up to the ventilator, and then no one knew when to switch it off. So we averted all that. You can’t think of it only one way. Sure it was in the hospital, but it was a good death.”

My discussion with Ellen and Janet clarified several issues and put some new considerations on the table, not least that it’s not only the reimbursement model of private care that creates problems in the delivery of end-of-life care but how we, the families who pay for that funding, expect to have it implemented.

And the discussion highlighted a subject I had until now not addressed, namely that of palliative care. Could a change in care philosophy hold the key to obtaining a good death for the elderly? Could it help ease the financial, social and emotional burdens of delivering that death?

Was Katherine Sleeman, clinical lecturer in palliative medicine at King's College, London, correct when she said: "People have woken up to the fact that we may be able to save money overall for society by investing in dying better"? *(The Economist* Intelligence Unit 2015 p. 14).

Or is the reality more what Andrew Corous believed, namely: "If you are poor in this country, you are okay, you have State Healthcare. If you are rich you are okay, you can buy your care anywhere. But if you are middle-class, well, then you have a problem."

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Chapter 9: Pain-free Days, Peaceful Nights

In all such cases, death is certain, the timing isn't. So everyone struggles with this uncertainty - with how, and when to accept that the battle is lost.

Atul Gawande*, Being Mortal*

A paradigm shift of viewing palliative care or hospice as a gift instead of seeing it as giving up has the potential to change the way we experience advanced age.

Lisa J. Shultz*, A Chance to Say Goodbye: Reflections on Losing a Parent*

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'Pain-free days and peaceful nights': I can't claim credit for the title of this section. It was Janet from the medical aid who used the phrase in our interview to illustrate her belief system around palliative care. It resonated with me when she said it, and I felt it summed up perfectly the next part of my journey.

When I first mentioned that I was going to write about a 'Good Death', most people assumed that I was going to do a story either about palliative care or euthanasia. Initially, neither was going to feature prominently, focused as this work is on the hyper-medicalisation of death. Following my discussions with the medical aid, however, I started to wonder if I had missed the point. Whether the counter to the medicalisation issue was indeed palliative care? It certainly seemed worth a closer look.

Long associated with end-of-life care in cancer patients, there is much confusion and consequently much resistance in the minds of the public to palliative care, and to Hospice in particular. As Janet put it, people hear the word 'hospice', and they feel that you have given up. Far from giving up, as mentioned previously, a 2010 study at Massachusetts General Hospital found that people who engaged with a palliative care specialist and entered a hospice earlier lived, on average, 25% longer than people who did not (Gawande 2014 p. 177).

It is not only the public who are resistant. The *Economist* article *A better way to care for the dying,* quotes one of its interviewees, Dr Ikegami, as saying: "Doctors often neglect palliative care, which involves giving opioids for pain, treating breathlessness and counselling patients …….. It does not seek to cure." As a result of its non-curative stance, he concluded, "…it is seen as what you do when you give up on a patient" (Economist 2017).

Part of the issue, I suspect, may arise from the loose aggregation of the terms 'hospice' and 'palliative care' when it comes to describing end-of-life intervention. While they may overlap, there are subtle differences between the two.

Hospice is "….reserved for terminally ill patients when treatments are no longer curative, during the last six months of life." It focuses on the comfort and quality of life, helping the patient "get most out of their life with the time they have left." Palliative care, on the other hand, is a part of hospice care but is not restricted to terminally-ill patients. It can be used in all areas of medical practice where a patient is receiving treatment for an illness and has a strong focus on pain management. (Pillars of Hospice and Palliative Care 2018).

In South Africa we are aligned with global thinking. We have a National Policy Framework and Strategy on Palliative Care and, to guide healthcare practitioners, the HPCSA launched their Palliative Care Guidelines in August 2019 (Healthcare Professions Council of South Africa 2019; National Department of Health 2017).

Everything on paper appears to endorse its adoption. It even makes financial sense, with some research indicating the reduction in costs obtained by shifting end-of-life care from acute to palliative at almost 60% (Eduardo & Dalal 2017). And yet, concerning the elderly, we fall far short of actually delivering that on that care philosophy.

The problem appears to be that old age is not an illness. Many elderly die as a natural consequence of aging. And often that dying process is incremental, with peaks of wellness and troughs of illness shaping its trajectory. It is almost impossible for healthcare practitioners to determine when the end may be and to implement palliative care as they may have done with a terminally-ill cancer patient. As a result, many elderly find themselves trapped on a seesaw of care, with practitioners, on the one hand, going all out to 'cure' them of their illness, and on the other, removing treatment completely when it appears further medical intervention is futile.

It is this unpredictability, this inability to define the course of death, that shifts the treatment paradigm from palliative to withdrawal, and segues us neatly to the crux of the euthanasia debate in elder care.

Euthanasia is defined as "the practice or action of one person deliberately or intentionally killing another, not because of threat or punishment for a committed crime, but rather to bring about a painless and gentle death" (Strohwald 2014 pp. 9, 10).

There are two forms of euthanasia: passive euthanasia, which takes place by omission, such as withdrawing life-prolonging medication, and active euthanasia, which occurs by commission, or an actual act, such as injecting a patient with a lethal dose of morphine.

You may recall from my earlier discussion with Jeanne, the healthcare lawyer, that the Euthanasia Bill has not yet been passed by Parliament. In the absence of a Bill, actions which are deemed to be euthanasia fall under our Common Law, and thus acts of active euthanasia are considered to be murder. Passive euthanasia is more challenging to quantify, but no less fraught with issues.

So much for the law. What of the new HPCSA Palliative Care Guidelines, which offer guidance to the healthcare practitioners in these matters? A first reading proved encouraging:

> It is for the patient, and not the health practitioner providing palliative care, to determine what is in the patient's best interests.
>
> Treatment can legally and ethically be withheld or withdrawn if the patient refuses further treatment, further treatment is futile, or if it is no longer in the patient's best interests (e.g. when treatment merely prolongs the dying process.
>
> Palliative care treatment where life is shortened as a side effect is not regarded as unlawful or unethical provided the patient or their surrogate has given informed consent.

These pointers seemed straightforward and somewhat heartening, with their clear focus on what the patient wants. They even appeared to offer the healthcare practitioner a 'get out of jail free' card should they abide by their patient's living wills.

That is, until you consider the section in the same document which deals with euthanasia, unhelpfully titled "Non-Maleficence and Palliative Care." It states:

> Respecting patient autonomy, however, does not mean that patients are entitled to illegal, unethical or medically inappropriate treatment simply because they have requested it.

And then this nail in the coffin, so to speak:

> At present, South African courts have acknowledged that both euthanasia and doctor-assisted suicide are fundamentally incompatible with a practitioner's role as a healer, and a practitioner guilty of either is regarded as having acted unethically and unlawfully. (Healthcare Professions Council of South Africa 2019 pp. 9,10,14).

So, on the one hand, the Guidelines say it is the patient's right to refuse treatment and should you, the practitioner, abide by those wishes and your patient life is 'shortened', you won't be held responsible. On the other hand, even though it is the patient's right, that doesn't mean you can do as they ask, and if you do, you may be guilty of unlawful conduct. There is very little clarity here. Medically inappropriate? Unethical treatments? Again, by and large, these are instances of moral judgement and are wide open to interpretation.

Unravel that at your peril. I turned to Father Anthony Egan.

Jesuit priest, well-known academic, often controversial but always through-provoking, he has written and consulted extensively on the subject of euthanasia and its application in both law and medical bio-ethics. He had this to say in response to my questions:

> There is no more sacred human right than being able to decide when and where you die. We should have the space to determine that at a certain point we've had enough. Whether that's to say 'Doctor I'm not taking that treatment' or something else.

"But," he was quick to qualify "I believe it's more a case of 'I don't want to be forced to be alive' than 'I want to decide the exact specifics of my death.' And I do not believe that any healthcare practitioner should be compelled to act on your wishes."

The latter part of his statement took the wind out of my sails somewhat, but morally, I could see his point.

He was unequivocal in maintaining that there was a difference between killing someone or letting them go, and it was in understanding that difference that most of the confusion regarding euthanasia occurred.

He offered this example:

> Let's consider the contentious issue of nutrition and hydration. It may well be that in some cases, that level of care is futile. You are merely prolonging the inevitable at the cost of the patient. Ethically you should discontinue or withdraw that care. *But* you do that, *not because someone is old*, but because they have been clinically certified brain dead. If someone is conscious and you are withdrawing nutrition and food, there is no doubt. That's active euthanasia. That's killing someone.

Were there instances in which he thought active euthanasia was appropriate, I wondered?

> I think we have to find a balance. It's pointless getting into a froth about these issues. On a spiritual level, sometimes to value your life, you have to end it. And that, for me, is in cases of untold pain and suffering.

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Untold pain and suffering. That reflected the answer the majority of people gave when I asked what they feared most about death – dying in pain. While the means to prevent that from happening are readily available, there remains a strong resistance on the part of the healthcare practitioners to do so.

As Janet, who heading up her medical aid's compassionate care benefit, told me, they see the resistance on the scripts that they receive for patients on their programme, where everything is prescribed for the patients except for morphine. "It's interesting," she said. "I met with a palliative doctor last week, and he said that nursing staff have refused to implement his palliative pain treatment regime because they think it amounts to euthanasia. Palliative care is a mind-shift and we are not there yet."

Dr Sean Chetty, in his capacity as head of Pain SA, agreed with Janet's assessment:

> I think the issue is complex. Pain management spans every one's discipline, not just palliative care. The problem is everyone thinks that someone else is dealing with it, and in the end, essentially no one is dealing with it. So the patient dies in pain. But I want to stress again, that getting pain down to a lower level is not what's important here [in end-of-life care]. Reducing the pain to improve the quality of your life at the end, is what really matters.

Quality of life at the end. Pain-free days and peaceful nights. Sadly, from everything I'd heard, it seemed we have some way to go to deliver on that promise to our elderly, regardless of whether we implement a palliative philosophy in our care system or not.

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At the beginning of my journey, one of my first interviews exposed a significant flaw in my thinking. I had sat down with my dear friend Cheryl to discuss her mom's death, which happened peacefully in hospital, calling into question my belief that hospital deaths were always traumatic and to be avoided at all costs.

Now that I was some way into my research, my discussions regarding palliative care had brought her story to mind. Her intimate account of her mom's death is perhaps the best example of what Andrew Corous had said on the subject of palliative care: "No one wants to be palliated. They just want care."

Here is Cheryl's story.

> My mom was hospitalised with a bowel obstruction. She was 92-years-old and up till then, on no medication whatsoever. She was struggling to eat, was very swollen and in pain. She had all the tests, but the medical staff couldn't put their finger on the problem. The only option left was surgery. The specialist told us that, in all honesty, he did not think she would survive that.
>
> My dad, who'd had cancer, had always said there comes a point where you draw the line, where you stop treatment. And my mom, after hearing what the specialist had to say, decided it was enough - she did not want any further treatment. The specialist agreed to respect her wishes. He said they would continue to monitor her and, if something less invasive came up that would help, they would revisit it. If she were in pain, they would make her comfortable, and she could stay in the hospital. We would take it day by day.
>
> So that's what we did. The staff were very supportive. Nothing was forced on her that she did not want. At the bottom of the nursing chart, it just said TLC (tender loving care).
>
> I was with her when she died. It was the first time I had seen a death. It was all very quiet. The curtains were drawn, nobody fussed and nobody chased me out. And afterwards the family came and they all went to say goodbye…It was a good end.

I asked how her experience of her mother's death had influenced what she wanted for her own end-of-life.

> Well, I haven't given it much thought, to be honest. But if you ask me how I would like to kick off ...quickly I guess!"

She laughed before considering the question further.

> Would I die at home? Maybe not. It's difficult for the family at home. Somebody else can deal with me, the physicality of it all. Hopefully, I could go somewhere where they would be nice to me in my last hours. Hopefully, I won't lose my sense of humour. But I wouldn't try to hasten it, I don't think. Unless it went on and on. I take my father and mother's stance – there comes a point when you need to call it.

Cheryl's story brought home to me that perhaps it's not the place that matters, but how we die and who is with us when we do. And that 'how' is undoubtedly a factor of communication and respecting the patient's wishes, as Chery's experience clearly illustrates.

I don't know if the specialist who treated her mom had any training in palliative care; whether he based his decision on an experience-honed world view, or simply followed his moral compass. But I do know that he gave Cheryl and her family a precious gift - a guilt-free, peaceful, 'good death' for her mother.

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Chapter 10: Talk, Talk

People die only once. They have no experience to draw on. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come.

Atul Gawande*. Being Mortal*

It is as if a conspiracy of silence has settled upon us, like a curse on a village, and we have forgotten that we know how to have this dialogue about death.

Michael Hebbs*, Let's Talk about Death over Dinner*

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Acclaimed Nigerian writer Chimamanda Ngozi Adichie articulated the impact of storytelling as follows:

"[S]tories matter. Stories have been used to dispossess and to malign. But stories can also be used to empower and to humanise. Stories can break the dignity of a people. But stories can also repair that broken dignity" (Adichie 2019).

I started this journey with the intention of understanding the beliefs and practices that contributed to the challenges of achieving a good death for the elderly, in an environment which, to all intents and purposes, is structured to avoid death at all costs. Taking my lead from Professor Rita Charon and the Narrative Medicine movement, I wanted to explore her assertion that "Storytelling, which harnesses the narrative connections that bind us all, is considered by many as a solution to this alienation of care" (Charon 2004).

Could something as elementary as storytelling change the trajectory of an individual's death in a clinical, medicalised setting? Could it, in the words of Adichie, 'restore dignity' to the elderly in their last moments?

Literature and medicine, once so twinned, fell out of sync in the early part of the twentieth century. CP Snow, novelist and chemist, posited in his infamous 1959 Rede Lecture, that "a gulf of mutual incomprehension" had developed between "literary intellectuals on the one hand and natural scientists on the other" (Snow n.d.).

I had, consequently, expected my storytelling premise to be dismissed out of hand in the evidence-driven world of medicine. What I found was more surprising. It appeared that storytelling remains at the heart of scientific endeavour. Robert Burton, in his article *Our brains tell stories so we can live* put it thus:

> Science is in the business of making up stories called hypotheses and testing them, then trying its best to make up better ones. People and science are like bread and butter. We are hardwired to need stories; science has storytelling buried deep in its nature. The methodology of science remains one of the great advances of humankind. Its stories, properly told, are epic poems in progress, and deserve to stand alongside the great stories of history (Burton 2019).

And there is definitive scientific evidence that gives credence to both Charon and Burton's assertions. It turns out that storytelling activates the reward system in the limbic area of our brain, the area responsible for emotions, memories and stimulation. Furthermore, it has been found to increase the production of the hormone oxytocin, which you may be more familiar associating with new mothers rather than death and dying. (Lazauskas & Snow 2018; Pappas 2015,).

It appears that we are hardwired to care. We have, apparently, just forgotten how.

But how does storytelling facilitate conversations about end-of-life care? Here, too, there has been considerable research. Jenny Mandelbaum, in a piece entitled *Storytelling in conversation,* concluded that the story itself is not the complete process, but is intended to provoke conversation (Mandelbaum 2012).

All told, it indeed would appear that, through its ability to invoke empathy and encourage conversation, the 'simple' act of storytelling may assist in changing the public and healthcare professional's attitudes towards end-of-life care.

On paper, it all adds up. But practically? There was only one way to find out.

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I posed my question to James Greagan:

> So can storytelling, medical narratives, act as a way of re-humanising medicine? If doctors knew people's backstories, do you think it would make any difference? Would it change what type of treatment you gave your patient? Would you care more? Would you spend more time with the family, talking to them? Or do you think it clouds the waters?

He took a long time to answer. I understood how left-of-field this was for a physician schooled in science, whose everyday experience involves decisions of a complex, clinical nature. I would hazard talking about 'stories' was not high on his agenda.

> Well I can't speak for anybody else, but a few things come to mind. The number one reason why we refer to the 'COPD with influenza in Bed 3 who is on isotropes and has acute kidney failure' as opposed to Mrs Wallace who is 87, with the big family and a birthday coming up, is because it does make it easier to deal with things. It's an emotional job. Dehumanising things is a protective mechanism. I think that's why we do it.

He continued:

> I also think that's how medical students have been taught, certainly in my day. And there's no healing for the healer, is there? It's not like we have regular debriefing sessions and you have to see the counsellor every three months. If you don't distance yourself to an extent, you won't survive.

It was clear to me then, the very real toll his work took on him.

> It's difficult. I chat with my patients, and I joke and try and get to know them a bit. And some of their stories are amazing, what they've done. But to be honest, it makes it a lot harder. If they get better, it's great. But if they don't do well….But to go back to the medical narratives and patient's stories specifically, I think it's important, but it's got its negatives and limits.

When I posed the same question to Sean Chetty, asking whether he thought understanding patient's life stories would change the way healthcare practitioners engaged with those patients, he was unexpectedly positive:

> Oh, absolutely. It's very easy to make rash decisions when there is no humanity attached to it. As soon as you say 'This could be my mother lying here', all of a sudden it makes you empathise rather than sympathise. I think that helps people manage these scenarios."

I told him that he was the only person in my discussions who had said that. He seemed surprised and then after some thought, offered:

> So I would say that in the ICU, a coping strategy is definitely to disconnect. It helps you deal with things, especially when there is a barrage of loss of life. But it also removes you from caring, and I think it can make you callous.

He gave a small laugh "Not that I'm great at that. I'm so emotionally attached to my patients that I can't disconnect. But I think that when you lose your humaneness, that's when you need to leave healthcare."

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James Greagen had raised the issue of what medical students are taught, or not rather not taught, as a reason why they struggle to have these difficult conversations. I asked Andrew Corous, in his capacity as head of a geriatric medicine department, to provide some insight into the training the medical students received.

"Well, that's easy," he quipped. "There is nothing taught at Med School. Well, next to nothing. Even if there was time allocated. Who do you get to discuss it with the students? Who is comfortable discussing death?"

"But," I persisted, "Would it help if more was taught, or do you think it's really only experience that makes a difference?"

This was his response:

> It *would* help because just having conversations about things makes you think about them. Most students, however, have never seen a death. So they don't understand. And death is a failure when you're a medical student. Death is actually a success in some cases because it's inevitable; the suffering's ended, the patient's comfortable. The problem is, students don't see it that way.
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> And if we do have a discussion, it's mostly related to that guy who got the court to give his doctors permission to kill him. Because half of them [the students] believe in euthanasia, but they work in a country where it's illegal. And they need to get that.

What about the families, the public? Did he think storytelling would help encourage more conversations? I mention the global phenomena *Being Mortal*, in which Atul Gawande, renowned surgeon-writer takes a look at how people can better live with age-related frailty, serious illness and approaching death.

> Well, maybe. But people only remember the good things. Don't give them statistics. Then you've lost them. So the 90-year-old who fell and broke his hip, went home the next week and he's fine; they'll remember that. The other one thousand 90-year-olds who didn't live last past three months? No-one wants to hear that.

"Actually", he concluded, "people don't want to know how you die. It's left to the doctors. And that's why people die full of tubes in ICU."

Just out of curiosity, I asked if he had read Gawande's book. To which he responded "I don't need to read it. I live it."

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State Pathologist Professor Ryan Blumenthal is an extremely accomplished professional. Over and above his medical qualifications and academic status as a professor of forensic pathology, he holds a doctorate from the Faculty of Engineering and the Built Environment from the University of the Witwatersrand. He has written four novellas to date and is currently busy with his fifth.

I had seen him talk at a few medical conferences and was engaged by his energy and sense of humour. When I found out he had spent some time in the UK working in elder care, I was eager to interview him for this narrative.

We managed to find a gap to meet in his incredibly busy schedule. Like Jeanne, the healthcare lawyer, my meeting with Ryan informed much of my thinking around this topic. You may recall that it was Ryan who challenged me on why I was writing about death in the elderly when death is the same for all of us. We chatted about his experience in the UK and how, when he was working in elder care in that system, they were encouraged to have end-of-life conversations with their patients, and how necessary he believes those conversations were. Given his experience, I wondered if could explain the reluctance of the medical fraternity as a whole to engage on this issue with their patients. He had this to say:

> Back in the day, when I was a medical student, minimal emphasis was placed on ‘death rehearsal’, for want of a better word. It is slowly entering the curriculum, but by no means is it what it should be. I think end-of-life preparation is so important. Like pilots on a flight simulator. You need to ask the tough questions, like who do you want at your funeral, who do you want by your side when you die, do you have any regrets, who do you want to tell you love, with whom do you want to make peace with, are so important. But none of this stuff is discussed. Even when I was in practice, the doctor would think the nurse was talking to the patient, and the nurse thought the doctor was talking to the patient and, in the end, no-one was talking to the patient, and the patient died alone.
>
> But it’s not exactly cocktail conversation, is it? Even in forensic pathology. If I take my current situation, there are only fifty-six pathologists in this country, so it feels like I've been on the front lines for a while now. It's a luxury to discuss end-of-life care.

It was Ryan who introduced me to the magical book *The Story of San Michelle* by Axel Munthe. Set in the 1800s, the book reflects many of the issues we still deal with today regarding euthanasia and end-of-life care. One passage in particular stood out for me, which I think perfectly sums up the healthcare practitioners dilemma.

In the book, the protagonist, a young physician, visits the island of Capri and fantasises about spending the rest of his days there. He has a dream in which he makes a pact with a ‘tall figure wrapped in a rich mantle’. In return for being gifted a magical life on the island, he is asked to renounce his ambition, to be stripped of all that made him great, and to sacrifice his future as a great physician. After pleading and negotiating with the figure for some time, the young man implores: “Will you at least leave me pity? I cannot live without pity if I am to become a doctor.”

To which the figure responds: “Yes, I will leave you pity, but you would have fared much better without it” (Munthe 1929 p. 15).

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Chapter 11: So in the End

Endings matter. Not just for the person, but perhaps even more for the ones left behind.

Atul Gawande*, Being Mortal*

Because I could not stop for Death
He kindly stopped for me
The Carriage held but just Ourselves
And Immortality.

Emily Dickenson*, Because I could not stop for Death*

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When I first presented my proposal for this project, one of the lecturers asked: "What are you hoping to prove?"

The question caught me off guard. I had not thought of proving anything. I had hoped to explore and understand the complexities surrounding the issue and maybe, if I was lucky, to gain some insight for myself and others in a similar position. I'm not sure you can prove anything about death, other than it is most absolutely, most definitely final.

But I did learn a few things. Principally, that a good death is a very individual matter. I had thought everyone would want to die at home and not in a hospital. I was wrong. I had believed that modern medicine had lost its compass and become clinical and dehumanised. Then I met people delivering care who disproved that theory and were as horrified by what was happening as I was.

I believed money was at the heart of the hyper-medicalisation issue, but I learnt that it was much more multi-faceted. I thought living wills were binding. I learnt they are only the first step in your planning and mean nothing without conversations with your physicians and family.

I had thought people would turn away from the topic in social settings like dinner parties and lunches with friends. Instead, I found my conversations often stretched far into the night.

And I have been consoled by much of what I've learnt. From James Greagan and Sean Chetty, clearly so deeply committed to offering their patients comfort in their last moments, I have felt my faith in medicine inching back. From Ryan Blumenthal, I learnt that some people still believe in the ancient art of healing. From Karen Botha, I learnt some people care deeply for the elderly and do as much as they can to ensure that their wishes are respected.

I have learnt that it is possible to achieve a good death in this hyper-medicalised environment, but it is not easy. We are aging and we are not aging well. So many medical advances have been extraordinary, but the consequences are often not.

When Peter Fenwick, the neuropsychiatrist and neurophysiologist renowned for his studies into end-of-life phenomena was asked how we can achieve a good death, he said, "You need to prepare for death like you prepare for an exam" (Thanatos TV 2018).

So if there is a conclusion to be reached, perhaps it is just that.

To achieve a good death takes work.

Only a lucky few get by these days by happenstance. You need to think about what you want, and you have to plan to achieve it. And, most importantly, you have to communicate your wishes to the people who will be responsible for your last moments, be they family, caregivers or medical personnel.

As when you write an exam, however, sometimes it's your day and everything goes to plan and sometimes nothing does and you fail. That's life. Or in this case, death. From what I have learnt, at least if you plan and talk things through, the odds are stacked in your favour.

That said, the last words in this narrative belong to Michael, the financial advisor, who, when asked what he believed a good death looked like, responded:

> Probably the best death is the one you don't know about. It just happens. It is a scary thought, though, you know, what happens after death? Don't let anybody tell you they're not scared. It's the unknown. My belief is very simple. You don't go anywhere, you don't become anything. As David Block says, we're all just space dust. The scary thing is, I guess, what if we're wrong?

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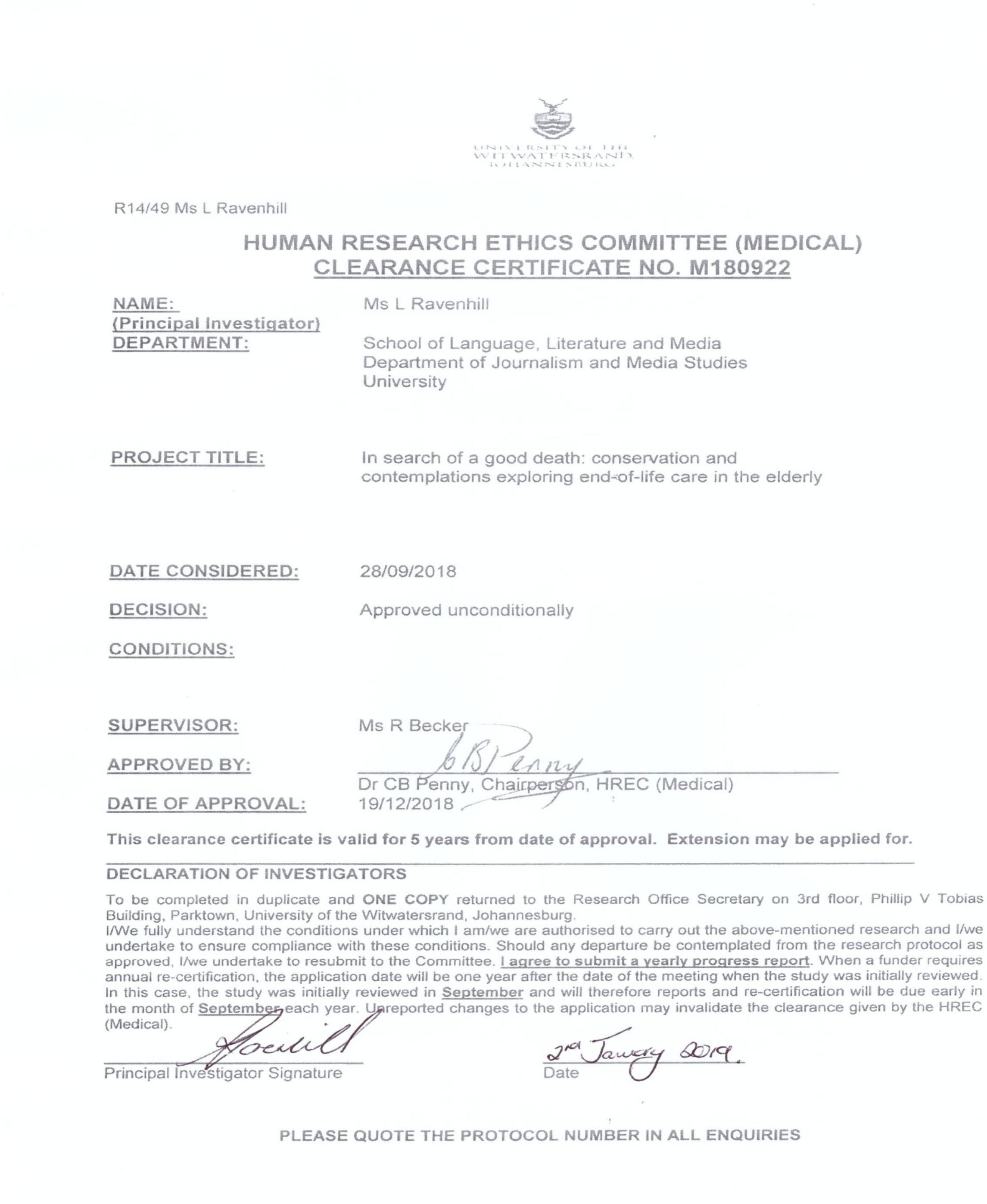
Appendices

Appendix 1: Human Research Ethics Committee (Medical) Clearance Certificate



UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

R14/49 Ms L Ravenhill

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M180922

NAME: (Principal Investigator)	Ms L Ravenhill
DEPARTMENT:	School of Language, Literature and Media Department of Journalism and Media Studies University
PROJECT TITLE:	In search of a good death: conservation and contemplations exploring end-of-life care in the elderly
DATE CONSIDERED:	28/09/2018
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms R Becker
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	19/12/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. I agree to submit a yearly progress report. When a funder requires annual re-certification, the application date will be one year after the date of the meeting when the study was initially reviewed. In this case, the study was initially reviewed in **September** and will therefore reports and re-certification will be due early in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

2nd January 2019.
Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 2: Interview Consent Form

Title of research project	In Search of A Good Death: Conversations and Contemplations exploring end-of-life care in the elderly
Name of principal researcher	Linda Ravenhill
Postgraduate course	Masters in Journalism and Media Studies
Department	University of the Witwatersrand School of Journalism and Media Studies
Department contact details	+27 11 717 4028, journinfo@wits.ac.za
Nature of the research	This narrative intends to explore end-of-life care in the elderly, in relation to its meaning, challenges and resolutions.
Participant's involvement	To provide context for, and stories concerning the topic of the research.

I ……. agree to participate in this narrative research project. The purpose of the narrative research been explained to me and I understand what my participation will involve.

I understand that no reimbursement will be received for my participation in this research, nor will any reimbursement be attributable to the principal researcher as a product of this research. You are free to withdraw your participation in this project at any time, with no repercussions.

I have read this consent form, and the study information document and had the opportunity to ask questions about the project. I understand that any information I may provide to the researcher will be kept in and reported in, in the strictest of confidence

I therefore give consent as follows:

I request that my participation remain anonymous	Yes	No
I agree that the researcher may use quotes or narratives in this research report that I have provided during my interviews, taking into account my request that my participation remains anonymous.	Yes	No
I understand that I am under no obligation to take part in this project	Yes	No
I understand that I have the right to withdraw from this project at any stage with no repercussions	Yes	No

Signature of Participant ……….……………………………………………………

Name of Participant ……………………………………………………………

Signature of person who sought consent ……………………………………………………………

Name of person who sought consent ……….……………………………………………………

Date of Consent …………………………………………………………….

Appendix 3: Healthcare Provider Interview Questionnaire

In Search of a Good Death: Conversations and Contemplations exploring end-of-life care in the elderly

Healthcare Provider Interview Questionnaire

Below are the broad questions that the healthcare provider may be asked in relation to this study. As it is a narrative journalistic piece, it may be that from time to time, additional information may be asked, in response to feedback from the interviewee.

The research will take the form of personal unstructured interviews in an informal setting of the interviewee's choice. The types of questions that will be asked will include but not be limited to:

1. What does a good death mean to you as a healthcare practitioner?
2. What is your personal belief system regarding a good death?
3. What is your experience as a healthcare provider of end-of-life care in the elderly within your practice/institution?
4. In your opinion, what are the challenges that occur in the delivery of end-of-life care for the elderly within your practice/institution?
5. What impact, if any, do you think the current system of delivering end-of-life care in the elderly has on you as a practitioner*?*
6. Would you agree that there is hyper-medicalisation in end-of-life care, and if so, why do you think that is?
7. What were you taught in your initial training regarding death and death preparation? Did it have an impact on how you practise medicine?
8. Are you familiar with Narrative-based Medicine, and, if so, do you think it has a role to play in our modern-day practice?
9. Do you have any general insights concerning this study that you would like to discuss?

**Follow through questions will be posed based on specific feedback*

Appendix 4: Subject Matter Expert Experience Questionnaire

In Search of a Good Death: Conversations and Contemplations exploring end-of-life care in the elderly

Subject Matter Expert Experience Questionnaire

Below are the broad questions that the subject matter expert may be asked in relation to this study. As it is a narrative journalistic piece, it may be that from time to time, additional information may be asked in response to feedback from the interviewee.

The research will take the form of unstructured interviews in an informal setting of the interviewee's choice.

The types of questions will include but not be limited to:

1. What is your experience regarding the elderly, and in particular, end-of-life care?

2. In your opinion, what are the - (insert *as applicable – finance, legal, religious/social*) challenges that occur in the delivery of end-of-life care in the elderly?
    a. *Follow through questions based on specific feedback*

3. What impact, if any, do you think the current system of delivering end-of-life care in the elderly has?
    a. *Follow through questions based on specific feedback*

4. Do you think the current system of delivering end-of-life care in the elderly can be improved? If so, please provide more detail?
    a. *Follow through questions based on specific feedback*

5. What does a good death mean to you personally?

6. Do you have any general insights concerning this study that you would like to discuss?

Appendix 5: Individual Experience Questionnaire

In Search of a Good Death: Conversations and Contemplations exploring end-of-life care in the elderly

Individual Experience Questionnaire

Below are the broad questions that will be posed as part of the individual experience narrative.
As it is an investigate journalistic piece, it may be that from time to time, additional information may be asked in response to feedback from the interviewee.

The research will take the form of personal unstructured interviews in an informal setting of the interviewee's choice. The types of questions will include but not be limited to:

1. What has your personal experience been with end-of-life care in the elderly? *('Tell me your story' narrative approach)*

2. What the impact of this experience been for you and your family - emotionally, financially and physically?
   (These will be adapted depending on the narrative question under consideration)

3. What is your personal belief system around a good death? Has that changed or been influenced based on your experience?

4. Do you have any general insights concerning this study that you would like to discuss?
