The profile and cost of end-of-life care in South Africa – the medical schemes' experience

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Thesis submitted for the degree of Master of Commerce
Specialising in Actuarial Science

July 2020

Abstract

South African medical schemes spend billions of Rands each year on medical care costs for their beneficiaries near their end of life. Hospi-centric benefit design, fee-for-service reimbursement arrangements and fragmented, silo-based delivery of care result in high, often unnecessary spending near the end of life. Factors including an ageing population, increasing incidence rates of cancer and other non-communicable diseases, and high levels of multi-morbidity among beneficiaries near their end of life further drive end-of-life care costs. Low levels of hospice or palliative care utilisation, a high proportion of deaths in-hospital and chemotherapy use in the last weeks of life point to potentially poor quality care near the end of life. The usual care pathway for serious illness near the end of life acts like a funnel into private hospitals. This often entails resource intensive care that includes aggressive care interventions right up until death. The result is potentially sub-optimal care and poor healthcare outcomes for many scheme beneficiaries and their surviving relatives. Understanding the complex nature of the end of life, the different care pathways, the available insurance benefits, the interactions between key stakeholders and the multitude of factors that drive end-of-life care costs are vital to setting end-of-life care reform in motion. In order to increase value at the end of life, i.e. to increase quality and/or to reduce costs, benefit design reform, alternative reimbursement strategies, effective communication and multi-stakeholder buy-in is key.

Keywords

End-of-life care, trajectories of dying, medical schemes, care pathways, cost, quality, value, PMB's, benefit design, non-communicable diseases, curative care, palliative care, hospital, hospice, care preferences, decision-making, communication, stakeholder conflicts

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1 Introduction

All over the world, medical care costs for individuals near their end of life are high when compared to the medical care costs for those who are not near their end of life (Felder, Meier and Schmitt 2000; Hogan, Lunney, Gabel and Lynn 2001; Polder, Barendregt and van Oers 2006; Shugarman, Decker and Bercovitz 2009). Research in South Africa by Ranchod, Abraham and Bloch (2015) similarly found that medical schemes experience relatively high claims costs for beneficiaries in their final year of life. In addition to the high monetary costs of end-of-life care, research has found that often the care received near the end of life is ineffective, overly aggressive and at odds with the care preferences of individuals (Solomon, O'Donnell, Jennings, Guilfoy *et al.* 1993; Connors, Dawson, Desbiens, Fulkerson *et al.* 1995; Mack, Weeks, Wright, Block *et al.* 2010). Globally, there exists significant scope to improve care at the end of life and to reduce healthcare spending at the end of life (Cheung, Earle, Rangrej, Ho *et al.* 2015; Kavalieratos, Corbelli, Zhang, Dionne-Odom *et al.* 2016).

This research project evaluates the profile of end-of-life care in the South African medical scheme environment. The profile of end-of-life care entails the various modes or philosophies of care near the end of life, the design and delivery of this care in the medical schemes environment and the complex decision-making and interaction processes between the key stakeholders. This project also identifies factors that are associated with the relatively high claim costs experienced by South African medical schemes in respect of scheme beneficiaries near their end of life. Knowledge of these factors and of how their complex interactions may affect medical scheme claim costs may provide the opportunity for medical schemes to improve risk management, to optimise benefit design and end-of-life care delivery, and to reduce medical scheme claim costs whilst improving the quality of care and of life for beneficiaries near their end of life. This research project aims to enable the overall value derived from end-of-life care to be maximised for the key stakeholders. The value of care near the end of life is maximised when the "best outcomes are achieved at the lowest cost" (Porter 2010).

In order to contextualise this research, it is worthwhile to define the 'end of life' and 'end-of-life care', respectively. These concepts are considered in Section 2. The

various modes or philosophies of end-of-life care, their respective characteristics and definitions, their evolution over time, as well as the various settings of care are also considered in this section. Quality is one of the key components of value. The quality of care provided and the measurement thereof are also considered briefly in this section.

The other key component of value is cost. In Section 3 the medical scheme environment in South Africa is considered in more detail and the direct costs of providing end-of-life care to medical scheme beneficiaries is evaluated. Medical schemes, as the primary funding vehicle of private healthcare insurance in South Africa (Erasmus, Ranchod, Abraham, Carvounes *et al.* 2016) and the claims submitted for decedent beneficiaries over their last 24 months of life will be the key focus of this research project. These data are retrospective administrative claims data with limited clinical information. The claims data are analysed in order to identify the observable factors that are associated with the relatively high medical care costs for beneficiaries near their end of life.

Significant research has been done, globally, on the personal preferences and decisions of those at or near their end of life (Lynn and Adamson 2003; Swerissen, Duckett and Farmer 2014). The factors affecting decision-making and the complexities surrounding differing stakeholder needs are considered in Section 4.

Section 5 describes the data used for purposes of this research project, notes the limitations of the data and outlines the methodology followed to analyse the data and identify the factors associated with end-of-life care costs for South African medical schemes. The methodology followed to measure indicators of the quality of care based only on administrative data are also outlined here.

Section 6 contains the results of the data analyses performed to understand the characteristics of medical scheme beneficiaries who die and the factors associated with their medical scheme claim costs near their end of life. The key results and findings are discussed and interpreted in Section 7.

Finally, having evaluated the end of life, the available care options or pathways, their evolution, their relative and respective costs, the quality of care and quality of life (and death) that beneficiaries experience, Section 8 concludes on the findings of this research project and identifies opportunities for further future research.

The scope of this research project is limited to identifying and analysing the factors that are associated with end-of-life care costs for South African medical schemes based on a comprehensive literature review and the analysis of a sample of decedent beneficiaries' characteristics and retrospective claim costs over their last 24 months of life. This research project is a first attempt at untangling the complexities and nuances surrounding end-of-life care in the South African medical schemes environment. It sets the scene for important further research and highlights gaps in the current design and delivery of end-of-life care benefits to medical scheme beneficiaries.

The factors affecting decision-making processes of stakeholders and the quality and appropriateness of care provided are often not directly available or observable from the administrative data. Without surveying scheme beneficiaries (and healthcare providers) near the end of life, it is impossible to elicit individuals' exact preferences, or their thought- and decision-making processes. In South Africa, such research in the medical schemes environment has not been conducted and international findings from the literature review, are overlaid on the South African medical schemes environment, where applicable. A further limitation is that this research utilises only private sector (medical scheme) data, and further research is required to extrapolate the findings to the entire South African population and to the envisaged National Health Insurance framework given the vast differences between the private and public sector healthcare systems currently operating in South Africa.

The results of this project are a novel addition to research on end-of-life care in the private healthcare sector of South Africa. The impact of various illness trajectories, co-morbidities and hospital admissions on the healthcare costs at the end of life and the respective cost patterns of beneficiaries on their end-of-life journeys have to date not yet been studied in South Africa. The results of this research project can be used in scheme benefit design considerations, health policy formulation and as a basis for further research on the provision of end-of-life care in South Africa. As such, the results of this research holds importance for medical schemes and their beneficiaries, for healthcare providers in eliciting preferences and making treatment recommendations, institutions of learning in the design of their curricula, as well as

for the government in designing and delivering end-of-life care under the envisioned National Health Insurance framework currently being formulated.

2 The ‘End of Life’, ‘End-of-Life care’ and the evolution of these concepts

Death, the end of life and end-of-life care have long been topics of heated discussion, both formally in research literature, health care policy formulation and public debate, and informally, in conversation, music, poetry, etc. A significant amount of research exists surrounding the end of life and the medical care received during this final stage of life, some of which is aimed at identifying and defining the ‘end of life’ and the various modes or philosophies of end-of-life care (George 2002).

This section summarises these key concepts, defines these terms as they are used throughout this research project, and considers their evolution over time. This section also highlights the importance of quality considerations near the end of life and difficulties with measuring the quality of care.

2.1 Death and dying

It is important to consider what is meant by ‘death’ to be able to identify the end-of-life (or ‘dying’) period that precedes it. The end-of-life period, i.e. the period commencing at the point at which a person enters the dying state that eventually culminates in their death is not always straightforward to determine. Significant differences exist in the literature as to the exact definitions of commonly used end-of-life terminology (Hui, Nooruddin, Didwaniya, Dev *et al.* 2014).

George (2002) states that in most end-of-life research, researchers fail to define exactly or consistently what is meant by dying or the process of dying. At first, this might appear surprising and counter-intuitive given that it frequently is this very process being considered. However, given some thought it becomes clear that dying is a complex process and for each person the exact point of entering the dying state and the length of time spent in the dying state will be different, and depends on a myriad of factors. Each person in the dying state will have a unique set of demographic, clinical and socio-economic factors affecting their end of life trajectory (Gomes and Higginson 2006).

Some controversy and uncertainty exists even in defining the death event – the exact point at which a person transitions from being alive to dead, and the particular criteria that need to be met in order to ascertain that a death has, in fact, occurred (Youngner and Arnold 2001). Traditionally, the irreversible loss of cardiopulmonary function (i.e. when a person's heart stops beating and they stop breathing, permanently) was used to define the death event (Lizza 2006). More recently, however, due to the advent of technological interventions such as mechanical ventilation and life support (which can artificially sustain cardiopulmonary function), the definition has been expanded to be either the traditional definition *or* that of brain death (i.e. brain function ceasing permanently) (Lizza 2006).

It is clear that having multiple definitions for the same phenomenon, where one definition may not strictly imply the other, controversy, confusion and lack of consensus will abound (Youngner and Arnold 2001). However, the semantics surrounding the exact point and definition of the death event are not the focus of this research given the retrospective nature of the administrative data to be analysed. Frequently, in administrative data, death is captured as the date of cessation of cover and as such, for this research project, the exact point of death and the definition thereof is of less importance than the actual date of death. However, it is worth considering to gain a better understanding of the overall complexity surrounding the end of life.

Of greater importance and relevance to this research is the period preceding the actual death event – the period we define as the 'end-of-life' or as 'dying' - the period during which persons receive end-of-life care. Determining the inception of this period is important for a number of reasons including knowing which care interventions to administer and for measuring the quality and appropriateness of the care that was (or is being) administered (Earle and Ayanian 2006). Depending on the exact purpose either a prospective or a retrospective approach to defining the end of life can be taken (Earle and Ayanian 2006). For deciding on the goals of care and the specific care interventions that are appropriate, for deciding on the communication strategies with patients and their families, optimising quality of care, etc. a prospective determination of having entered the dying state is required – i.e. before the person has died. To this end, clinical information and the treating doctor's judgment to estimate survival times or to conclude that someone is busy dying, i.e. using prognosis, are key. For purposes

of retrospectively analysing the quality of care that *was* administered and reviewing the experience and factors contributing thereto, a more arbitrary time-based definition for the end of life and 'dying' can be used. Alternatively, clinical information then available may be used to retrospectively determine when a particular individual may have come to be in the dying state (Bach, Schrag and Begg 2004). It can thus be seen that defining the end-of-life period is important and that there are significant implications depending on how this is defined. Neither approach are without their problems and criticisms (Earle and Ayanian 2006). For purposes of this research, using retrospective data, the end-of-life period, per se, will not be identified, but scheme beneficiaries' experience over various periods prior to death (up to 24 months) are investigated.

Some research has been performed to try generalise the definition or length of the end-of-life period. However, there is no real consensus on both the length of this end-of-life period, or the inception point of this period, with some research referring to the end of life as a period measured in years and others as a period measured in hours or days at most (Hui *et al.* 2014). Another term, 'active(ly) dying', is used to more definitively describe the very last few hours or days of life (Hui *et al.* 2014).

In the US, there has been some consensus surrounding an operational definition of the end of life, especially for insurance benefit (particularly hospice care benefits) purposes and as a broad guide to health care providers when recommending treatment options (Lamont 2005; Hui *et al.* 2014). These definitions typically require the patient to be diagnosed with a life-limiting, progressive illness, which is expected to result in their death within months (often six months for insurance purposes) (Hui *et al.* 2014). This definition is suitable and easily used retrospectively, but it is vague and has been criticised for not providing health care providers with effective, unambiguous tools to use prospectively in care planning and communication, and in making care and treatment recommendations, often resulting in inappropriate interventions and care at or near the end of life (Ellershaw, Neuberger and Ward 2003; Lamont 2005). A further significant problem with the time-based definition and eligibility criteria for hospice care in the US is the requirement to forego life-sustaining treatments, frequently resulting in late or no hospice enrolment (Campion, Kelley and Morrison 2015).

In order to use the operational definition of the 'end of life' prospectively for effective and appropriate planning and decision-making, a highly accurate prognosis and a good estimate of survival time and survival probability are required (Head, Ritchie and Smoot 2005). For prospective determination, it is later shown that trying to assign a particular period is problematic and that there are more effective ways of determining that the end of life may be near when weighing up care alternatives (Highet, Crawford, Murray and Boyd 2014)

2.2 Prospective determination of the end-of-life period – challenges and potential solutions

Broad consensus exists that care in the end-of-life period should be different to the care in the period(s) preceding it (Lamont 2005). Glare, Virik, Jones, Hudson *et al.* (2003) emphasise the importance of prognosis in ensuring that patients receive appropriate disease-directed treatment prior to them being in their end-of-life period and to avoid unnecessary delays in referral to receiving hospice care once disease-directed care proves to be ineffective. However, a significant amount of research exists on the difficulties associated with accurate prognostication and the estimation of survival times (Ellershaw, Neuberger and Ward 2003; Lamont 2005; Lau, Cloutier-Fisher, Kuziemsky and Black 2007). This results in delays to patients receiving both palliative and hospice care as opposed to only intensive, aggressive disease-directed care aimed at only cure (which may be indicative of poor quality care near the end of life) resulting in suboptimal outcomes (Earle, Park, Lai, Weeks *et al.* 2003).

Many factors affect the level of certainty that accompanies any prognosis, e.g. new/experimental treatments, variability in past survival times or in efficacy of treatments, optimistic bias on both the part of the health care provider and the patient, specific patient characteristics, e.g. age, sex, diagnosis, current level of functional ability and the manifestation of symptoms and co-morbidities, etc. (Lamont and Christakis 1999). Functional ability, as used here, refers to the relative level of an individual's ability to perform independently basic activities of daily living such as eating, being physically mobile, dressing themselves, etc. (Lamont 2005). Various measures of functional ability exist, e.g. the linear Karnofsky Performance Status (KPS) where a score of '0' means being dead and '100' means being fully functional,

or the Eastern Co-operative Oncology Group (ECOG) six-point scale with '0' being fully functional and '5' being dead (Blagden, Charman, Sharples, Magee *et al.* 2003).

Given the complexities surrounding accurate prognostication outlined above, Ellershaw, Neuberger and Ward (2003) have extended the vague insurance definition, outlined earlier, to include a number of additional clinical signs and symptoms to simplify identifying when someone suffering from cancer *might* be dying. The justification for this is to give healthcare providers more clarity regarding the care considerations that may be appropriate for their patients, i.e. treatments alternative to or complementary to those aimed purely at curing their patients' diseases. These signs and symptoms include considering the gradual shift to becoming bedbound, losing consciousness more frequently or being semi-comatose, a loss of appetite, weight loss and struggling to eat or take oral medications. For people suffering from progressive heart failure Ellershaw, Neuberger and Ward (2003) also include some additional signs and symptoms as indicators that death may be imminent. These include: heart failure admissions being more serious than in the past, no identifiable or reversible cause for the heart failure, the patient is already receiving the optimum level of medication, renal function is deteriorating and changes to drugs don't have the desired effects within two or three days. Similarly, for other seriously ill patients not suffering from cancer or progressive heart failure, various clinical signs and symptoms can also be considered to help identify approaching or imminent death and when a shift in care goals should be considered. These are contained in the 'Supportive and Palliative Care Indicators Tool' (SPICT^{TM}). These signs and symptoms include: unplanned hospital admission(s), low functional status, dependence on others for care, significant recent weight loss, a high symptom burden despite ongoing treatment, and the communication of a desire to receive palliative care (SPICT 2018). The SPICT^{TM} tool was developed in 2010 by a collaborative team from NHS Lothian and The University of Edinburgh (SPICT 2018).

Echoing Ellershaw, Neuberger and Ward (2003), Lamont (2005), found that clinical symptoms are powerful predictors of impending death, in addition to the patient's current functional status and their health provider's estimate of survival time. It is shown that considering these common predictors of survival time together, improves the accuracy of prognoses significantly regardless of the individuals'

primary diagnosis (Lamont 2005). These, used in conjunction, remove some of the subjective bias the health care provider may have, but improves on the rigid, objective estimate based only on performance status statistics (Lamont 2005).

When ranking the predictive power of these predictors independently, a person's functional status is the strongest of these predictors, and the health care provider's estimate of survival time is the weakest, as they tend to over-estimate survival times systematically. However, the higher a person's current functional status, the weaker the prediction of survival time (Chow, Harth, Hruby, Finkelstein *et al.* 2001). A KPS score of less than 50 has been found to indicate a survival time of less than 8 weeks (Lamont 2005). Regularly measuring the KPS and considering the patient's clinical indicators and the doctor's estimate of survival time, the prediction of death should become more accurate, especially with increasing imminence of death, which can allow for better communication, planning and administering of end-of-life care (Lamont 2005).

Given the difficulties identified with exact prognostication, it is encouraging that recent literature suggests that this may be of less importance than merely identifying whether a patient is exposed to a significant enough risk of death so as to evaluate or re-evaluate goals of care as well as the ensuing treatment options (Highet *et al.* 2014). Hence combining clinical indicators, performance status, the doctor's estimated survival time and the guidelines in the SPICT^{TM} tool, conversations about care pathways and goals of care can be initiated timely, thus avoiding late or non-referral to palliative care and hospice services, and interventions not aimed specifically at cure can be incorporated into patient care early on to maximise stakeholder value (Lamont 2005; Highet *et al.* 2014). Unnecessary hospitalisations and ineffective curative interventions can thus be minimised and care can be aligned with patients' expectations and preferences.

2.3 Retrospective analyses

Bach, Schrag and Begg (2004) argue that arbitrarily choosing a time period to consider and the selection of the population of decedents introduces bias into retrospective analyses of the end of life. Teno and Mor (2005) acknowledge these shortcomings, but highlight the problems associated with prospective approaches, e.g. accurate

prognostication, hence arguing the importance of and value in using both methods, respectively. For certain purposes and in certain circumstances, a retrospective approach will be advantageous, e.g. for considering the experience and costs incurred by decedents using administrative data. Administrative claims data is retrospective in nature with limited clinical and prognostic information (Iezzoni 1997).

Allocating decedents to trajectories of dying and analysing their experience is one example of a retrospective analysis, given a chosen end-of-life time period. "Trajectories of dying" are a broad, systematic classifications of a sample of decedents according to their resource utilisation and given their respective diagnoses/illnesses (Lunney, Lynn, Foley, Lipson *et al.* 2003). It will be useful to look at the various trajectories of dying and to determine how treatment varies (or should vary) by the respective trajectories of dying. Each trajectory of dying exhibits a unique pattern of individuals' physical function declining over time, their likely resource utilisation and which treatment(s) may be optimal at different stages within their respective trajectories of dying (Lunney *et al.* 2003).

Looking retrospectively at deaths that have occurred in a sample of Medicare (the federal social health insurance system in the US predominantly covering citizens aged 65 and older) beneficiaries, Lunney, Lynn and Hogan (2002) identifies four main trajectories of dying. 92 per cent of the deaths in the observed sample could be attributed to one of these four trajectories (Lunney, Lynn and Hogan 2002), and hence provides a robust framework into which we can classify and analyse the claims and death data analysed in this research project.

These trajectories are: 1) "Sudden death" (roughly 7 per cent of the deaths in the sample), characterised by a high level of functional ability right up until death with death occurring suddenly, or at most over a number of days. 2) "Terminal illness" (cancer diagnosis only, accounted for roughly 22 per cent of the deaths in the sample), characterised by a high level of function ability, declining rapidly over a few weeks to a few months prior to death. 3) "Organ failure" (mainly deaths due to congestive heart failure and chronic obstructive pulmonary disease, accounted for 16 per cent of the deaths in the sample), characterised by a gradual decline in functional ability, often over a number of years, accentuated by drastic dips in functional ability and subsequent recoveries until an exacerbation without a subsequent recovery (death) occurs. Any

one of these exacerbations are potentially fatal, but significant uncertainty exists. Over time and with declining functional capacity, the likelihood of the next 'event' or exacerbation of the condition being the fatal one, increases (Murray, Kendall, Boyd and Sheikh 2005). It can be seen from the nature of the "Organ failure" trajectory that trying to prospectively determine the end-of-life period and/or when death will occur presents significant challenges, emphasising the need for concurrent curative and palliative care to optimise patient outcomes and the quality of care. 4) "General frailty" (covering diagnoses such as dementia, stroke, Parkinson's, pneumonia, etc. accounted for 47 per cent of the deaths in the Medicare sample). "General frailty" is characterised by a very gradual decline in functional ability, often over many years, starting from a low base, with the patient suffering multiple co-morbidities such as chronic conditions, but no specific terminal illness or definite organ failure is present, i.e. general old age and its associated decline in functional ability over time.

As illustrated by these main trajectories of dying it is clear that the end-of-life period differs significantly by trajectory, and even within trajectories (Lunney, Lynn and Hogan 2002). The circumstances surrounding each death within each trajectory are unique, be they clinical, personal, setting and mode of care, psychosocial, etc. and as a result the exact end-of-life period and end-of-life care needs for each dying person will be inherently unique (Murray *et al.* 2005).

Lunney, Lynn and Hogan (2002) used a sequential profiling system to classify deaths using the unique diagnosis code which accounted for the most Medicare claims in the twelve months preceding death for each individual decedent. "Sudden deaths" were identified first (decedents who had less than USD$2000 worth of Medicare claims during the twelve months prior to death), then deaths due to terminal illness, i.e. "Cancer" diagnoses, were identified, then deaths due to "Organ failure" and finally, deaths due to "General frailty" were identified. Deaths where the main diagnosis codes are for conditions that infrequently cause death, the decedent is grouped as "Other" – roughly eight per cent of the deaths in their sample.

In another study looking at a sample of deaths in Canada focusing on the medical care costs associated with each trajectory, Fassbender, Fainsinger, Carson and Finegan (2009) used cluster analysis and the use of expert opinions to classify the deaths in their sample to corresponding trajectories of dying. Their classification of deaths

resulted in similar proportions of deaths in each trajectory when compared to the study by Lunney, Lynn and Hogan (2002).

Next we look at defining 'end-of-life care'.

2.4 End-of-life care

End-of-life care, simply put, is the care (medical or otherwise) that a person in the dying state receives, whether this period has been identified and acknowledged or not, and regardless of the aims of this care. End-of-life care can also extend beyond the point of death of the patient to the families and caregivers to offer support and assistance with the bereavement process (Hui, De La Cruz, Mori, Parsons *et al.* 2013).

The concept of 'end-of-life care' has seen numerous transformations over the last five decades, as well as the emergence of new terminologies and definitions (Bennett, Davies and Higginson 2010). It is easy to get bogged down in the intricate details and subtle distinctions between the multitude of terms that are used to describe 'end-of-life care' in the literature today: terminal care; supportive care; palliative care; hospice care; comfort care; usual care; hospital care; curative care; etc.). For ease of reference, this research project focuses on two core philosophies or modes of care – curative care on one end of the spectrum and palliative care on the other. This is to avoid any confusion that could result from having similar, yet distinct terminologies and definitions (as is used throughout the literature).

Curative care, as a care philosophy, is characterised by disease-directed treatments focused on curing the underlying illness, attempting to undo part or all of the damage caused by the condition or to prevent the condition from worsening and further threatening an individual's normal function (WHO 2011). It often involves aggressive and invasive procedures and/or treatments and comes with a very high price tag (Connors *et al.* 1995; Felder, Meier and Schmitt 2000). Multiple terms exist in the literature for 'curative care' or versions thereof (acute care, intensive care, disease-directed care, usual care, hospital care, etc.), but for purposes of this research paper the term 'curative care' will be used to refer to any form of care aimed at curing or preventing the worsening of conditions/illnesses. The most common disease-directed care relates to care and/or interventions in a hospital setting (Gott, Ingleton, Bennett and Gardiner 2011). It is important to note that palliative care can also be (and is

frequently) administered in a hospital setting, but that significant challenges exist in initiating palliative care and the transition from a curative to a palliative care approach in-hospital (Campion, Kelley and Morrison 2015).

Palliative care, (and more recently, the term supportive care[1]) on the other end of the spectrum, represents a multi-disciplinary care philosophy focused not on cure but on providing comfort and enhancing the quality of life at any stage in the disease progression (Hui *et al.* 2013). Hospice care is a sub-component of palliative care, administered either at home or in a facility offering hospice services, at the very end of life – in the final months, weeks, days and hours of life. The goals of hospice care are similar to that of palliative care, but due to the operational definition and strict eligibility criteria used for insurance purposes in certain territories, the time period of hospice care tends to be very short – usually a few days to a few weeks (Billings 1998; Odejide 2016)

Palliative care does not directly aim to alter the course of any disease. Rather, palliative care focuses on the provision of a comprehensive service to patients facing serious illness, including: relieving the pain and symptoms patients experience, psychological support and education for patients and their families about how their disease is likely to progress and what they can expect. Palliative care further extends to the bereavement process and to care for the caregivers/family members after the death of the patient (Billings 1998; Rome, Luminais, Bourgeois and Blais 2011). Palliative care involves a multi-disciplinary team consisting of doctors, nurses, auxiliary healthcare professionals, e.g. a physical therapist, a psychologist, and chaplains/social workers to deliver the wide range of medical and supportive care services that patients and their families and caregivers require at or near the end of life (Fennell, Prabhu Das, Clauser, Petrelli *et al.* 2010).

The settings in or at which end-of-life care may be delivered are at one's personal home, in hospital, at a care home (frail care facility/nursing home) or at an inpatient palliative care facility, and with approaching death there may be one or more transitions between these care settings (Van den Block, Deschepper, Bilsen, Van

[1] A more modern term for palliative care stemming from the stigma that palliative care is synonymous with end-of-life care and/or hospice care resulting in a hesitance for patients to opt for palliative care and providers to recommend it (discussed later).

Casteren *et al.* 2007). Curative care is typically associated with care in hospital as the equipment and human resources required are not readily available at the other care settings, whereas palliative care is typically associated with home-based or hospice-based care settings/services. However, the value of offering palliative care in hospital (even in intensive care units) and in care home settings to improve patients' quality of life is increasingly being recognised and offered (Kelley and Morrison 2015).

As can be seen from above, the two care philosophies have vastly different aims at the end of life. Curative care involves trying to stave off or prevent death, whereas palliative care acknowledges death and aims to ease the transition into it, maximising the quality of remaining life. As noted earlier, timeous identification of the end-of-life period and communication thereof (and of the available care options) to patients and families is important to initiate a shift in focus from cure to care and support to ensure that patients receive optimised care at or near their end of life (Lamont and Christakis 1999). However, it has been argued that neither care philosophy, in isolation, may be completely appropriate (Kelley and Meier 2010; Dalgaard, Bergenholtz, Nielsen and Timm 2014). These authors analyse the benefits of early palliative care interventions alongside disease-directed treatment. The benefits include: improved symptom control, better quality of life, less intensive care near the end of life, lower levels of anxiety and depression and even increased survival periods (in a study performed by Temel, Greer, Muzikansky, Gallagher *et al.* (2010) on persons with advanced lung cancer).

Throughout this research project, reference is made to sub-optimal care and outcomes. Care is deemed to be sub-optimal in cases where the aims thereof cannot realistically be achieved, i.e. ineffective interventions at the end of life which are aimed at curing or undoing the underlying illness or trauma that aren't expected to be successful (Mobley, Rady, Verheijde, Patel *et al.* 2007). Even when curative interventions are clinically appropriate, care may still be sub-optimal where other dimensions of care (other than those focused on the disease itself) are not holistically considered and addressed (Steinhauser, Christakis, Clipp, McNeilly *et al.* 2000). These include the spiritual, mental, social and support dimensions of care. Hence, sub-optimal care refers to care at the end of life which is overly aggressive, misdirected and/or financially unjustifiable; care that does not align with the goals and needs of

the patient and/or their loved ones; or care that fails to offer the infrastructure, support and environment needed to facilitate a good death (Emanuel and Emanuel 1998; Wenger and Rosenfeld 2001). At the end of life, care that is optimal is care focused on, inter alia, pain relief and symptom control, comfort, affirming or strengthening relationships, achieving peace with oneself and any relevant deity, and maximising the quality of remaining life (Steinhauser *et al.* 2000).

We now look at what defines high quality end-of-life care and what care may be appropriate given that someone may be dying.

2.5 End-of-life care – quality considerations

The means by which a person arrives at their end-of-life (trauma, terminal illness, frailty, etc.), together with the many personal (age, sex, religion, etc.), and other factors (setting of care, doctors, loved ones, etc.), will influence which mode of care is optimal and which mode of care is actually received (which research has shown are oftentimes not the same) (Lunney *et al.* 2003; Frost, Cook, Heyland and Fowler 2011).

A significant amount of international research exists on determining which philosophy of care (or combination of philosophies) may be appropriate during different phases of illness, being cognisant of patients', their families', doctors' and funders' specific, and sometimes opposing needs. These needs may be opposing due to the different stakeholders having different preferences, and viewing different factors, e.g. pain management, the fulfilment of dying wishes, the use of intensive care, mental awareness etc., as being more (or less) important at the end of life (Steinhauser *et al.* 2000). Differing stakeholder needs and/or perspectives may result in different stakeholders seeking, recommending/offering and paying for (or being willing to pay for) different care or treatment interventions at the end of life. It is clear that significant conflicts of interest or principal-agent issues may exist when it comes to stakeholder decision-making near the end of life. The different stakeholders, their interests and the factors affecting their decision-making are considered in more detail in Section 4.

Connors *et al.* (1995) report that many patients hospitalised for life-threatening conditions die receiving high levels of unwanted care achieving little more than prolonged suffering. These care interventions tend to be expensive, are often invasive,

and may result in extended periods spent in hospital (Smith, Coyne, Cassel, Penberthy *et al.* 2003).

The personal circumstances and preferences/biases of the patients, their families and their health care providers will influence which care philosophy or combination of curative and palliative care is optimal, and which is actually received (Weissman 2001). A blended approach to care will be more focused on being curative in nature, initially, then gradually transitioning to being more palliative as the patient's circumstances change and disease progression advances, and hence the level of certainty over prognosis, improves. Schofield, Carey, Love, Nehill *et al.* (2006) suggest that this is likely to be the best approach to end-of-life care, regardless of primary diagnosis and current level of disease progression. They argue that palliative care should gradually be introduced with disease progression, and not be seen as a care intervention that is only offered from that point where the decision is made to cease curative care interventions.

Frequently, even if the prognosis for a patient is terminal with little or no chance of recovery or for improvement, patients still receive expensive and ineffective curative care interventions. Possible reasons for seemingly inappropriate care near the end of life include: overly optimistic prognoses and subsequent non-/late-referral to hospice, concerns about receiving insufficient medical care in hospice, denial of death's imminence and a hope of recovery. Furthermore, conflicts between patients, their families and their doctors, perverse financial incentives, poor communication, a lack of understanding of the implications of aggressive care, etc. can result in sub-optimal care near the end of life (Wright and Katz 2007; Wright, Zhang, Ray, Mack *et al.* 2008). Implications of such aggressive care near the end of life may result in increased and prolonged suffering for patients with ineffective pain and symptom control, a reduction in overall quality of life and a worsened bereavement experience for the patient's close relations (Connors *et al.* 1995; Wright *et al.* 2008).

A prominent feature of the South African medical schemes environment is the legislative requirement for all schemes to cover a common set of benefits, the Prescribed Minimum Benefits (PMB's), at cost without any limits or co-payments (Department of Health 1998). In this environment, a potential, additional reason for such aggressive treatment regardless of whether death's imminence is appreciated or

not, may be that the treatment falls within this PMB's package. These PMB's tend to be hospi-centric and provider driven in nature (Kaplan and Ranchod 2015) without any readily available or easily accessible palliative care benefits/resources. This coupled with a general ignorance about end-of-life care options and alternatives and a general avoidance of talking about and planning for death paints a bleak picture about how beneficiaries progress on their end-of-life journeys (Kirshbaum, Purcell and Nash 2011). PMB's and their impact, in their current form, on treatment recommendations and eventual decisions will be analysed in Section 3, which covers the South African medical scheme environment.

When it comes to the use of intensive care, one in five Americans die in an intensive care unit (ICU) of a hospital (Angus, Barnato, Linde-Zwirble, Weissfeld *et al.* 2004). The quality of life of a patient spending their final days in an ICU intuitively feels much lower than that of a person spending their final days in a comfortable setting. Being connected to whirring machines with multiple tubes protruding from their body in a brightly lit room surrounded by strangers can't compete with being at home, with the symptoms and the pain associated with terminal conditions being managed and being surrounded by loved ones (Gawande 2014). However, a more rigorous measure than intuitive feel, with objective indicators of quality of care and quality of life is required to gauge whether the care that patients receive at the end of life is optimal.

Measuring the quality of care and the quality of life, especially near the end of life, when many factors need to be considered, is a complex task. Steinhauser, Bosworth, Clipp, McNeilly *et al.* (2002) propose a quality measurement tool, 'QUAL-E', comprising of five key domains, each including a number of factors considered to be important indicators of quality of life near the end of life. These five domains are: 1) the completion of life, 2) preparation for death, 3) symptom and pain management, 4) interaction with the healthcare system, i.e. knowledge of and control over the condition and treatment options, and 5) social support. It is important that these domains are considered prospectively for seriously ill patients and in communicating and recommending care/treatment to these patients at appropriate times so as to ensure that they are most likely to opt for and to receive the optimal care as the end of life draws near. Steinhauser *et al.* (2002) and Ostgathe and Voltz (2010) further identify

the domains of mental, social, spiritual, religious and cultural well-being at the end of life as being important considerations to ensure that good quality end-of-life care is given to individuals. Taking a multi-disciplinary approach to delivering end-of-life care including access to a psychologist, social worker and chaplain near the end of life may assist in addressing distress in each of these domains near the end of life.

It is important to develop and test a set of objective quality measures in the medical schemes environment specifically around the delivery of end-of-life care to gauge the quality and cost of different care pathways for individual beneficiaries along different trajectories of dying. Earle *et al.* (2003) performed a comprehensive literature review, held focus group sessions and interviewed an expert panel to help identify indicators of poor quality care near the end of life. The top ranked indicators for poor quality of care include: chemotherapy for cancer patients in their last weeks of life (or starting new chemotherapy regimen near death), death in hospital, frequent hospital admissions, a 'high' number of days in hospital/ICU before death and no/late hospice enrolment. These indicators, barring for starting a new chemotherapy regimen are observable and can be measured from the retrospective administrative data used in this research project. It is important to note that the absence of these indicators of poor quality care near the end of life does not necessarily imply high quality care near the end of life.

Earle *et al.* (2003) also identified indicators of good quality end-of-life care, and these included: the availability and use of multidisciplinary care teams, continuity of care between providers, good communication including shared decision-making (between providers, patients and their families) and the use of advance directives, and effective pain and symptom management. These indicators are not observable from the administrative data, but should ideally be taken into account when performing any evaluation of the quality of care provided near the end of life.

2.6 The evolution of end-of-life care

Understanding the evolution of end-of-life care and the contributing factors thereto, and how this care is likely to evolve further, may yield further insights into distinguishing between care that is optimal and care that is suboptimal. Utilising this knowledge may assist in achieving the aim of maximising value for the key

stakeholders involved in end-of-life care, particularly beneficiaries near their end of life. The key stakeholders and their relationships are discussed in Section 4.

2.7.1 Changes to life expectancy and cause(s) of death

Over the last century and a half, death, the end of life and care at the end of life has seen significant shifts. Global life expectancy in the late 1800's was barely thirty years[2]. In 2015, the global average life expectancy at birth was around 71.5 years (Feigin 2016) – a more than twofold increase in life expectancy.

There has also been significant shifts in the most common causes of death. The most prevalent causes of death in the late 1800's were communicable diseases associated with poor hygiene, poor nutrition, cramped living conditions and virtually no effective medical interventions/treatments. These diseases included pneumonia/influenza, tuberculosis and gastrointestinal infections (Quora 2017). Death was most prevalent in infants or children under the age of five years (Riley 2001). Death at advanced ages was uncommon in the late 1800's as very few people lived long enough to die "old". Today, the majority of deaths occur at advanced ages. In the book, *Global burden of disease and risk factors,* by Lopez, Mathers, Ezzati, Jamison *et al.* (2014), it is reported that more than fifty per cent of the global deaths in 2001 were of people aged sixty and above. With the global phenomenon of ageing populations and decreasing age-standardised mortality rates, the proportion of deaths at advanced ages has been steadily on the rise (WHO 2015; Feigin 2016). Today, globally, most of the deaths are as a result of non-communicable diseases, with heart disease, cancer and respiratory disease being the top three causes of death (Feigin 2016). In fact, non-communicable diseases such as these caused over seventy per cent of all deaths in 2015.

Many of the communicable diseases responsible for the majority of deaths in the nineteenth century became preventable and/or treatable, and death was, on average, postponed to older ages. The reduced mortality attributable to communicable diseases

[2] The Economist. (2017). A better way to care for the dying. Available: https://www.economist.com/news/international/21721375-how-medical-profession-starting-move-beyond-fighting-death-easing-it-better?fsrc=scn/fb/te/bl/ed/endoflifecareabetterwaytocareforthedying (accessed: 24 January, 2018).

resulted in the observed shift towards non-communicable diseases becoming more and more prevalent causes of death, globally. As cardiovascular disease and cancer became more prevalent, further assimilation and dissemination of knowledge and research led to a greater overall awareness of, and better management and treatment of chronic and serious illnesses such as these, accounting for most of the mortality improvements in the developed world during the second half of the twentieth century (Preston 2015). However, with better treatment and hence declining mortality from chronic conditions, plus increasingly unhealthy dietary habits and sedentary, stressful lifestyles, the incidence and prevalence of these non-communicable chronic conditions has been on the rise, globally (Jakovljevic and Milovanovic 2015). In the local, South Africa context, a similar shift in cause of death from communicable to non-communicable diseases is being observed (Joubert and Bradshaw 2006; Delobelle, Sanders, Puoane and Freudenberg 2016). The burden of disease in South Africa and the impact of non-communicable diseases and lifestyles on medical scheme claims costs are considered in more detail in Section 3.

2.7.2 Implications for end-of-life care

Prior to the 1900's, illness/disease typically had a rapid and unexpected onset and affected people of all ages, especially infants and young children. Death (or recovery) typically followed soon after the onset of illness, i.e. illness was typically not characterised by protracted periods of sickness and/or disability (Bern-Klug, Gessert and Forbes 2001). Back then there were no modern hospitals and doctors, or private and/or social medical insurance like available today, and access to any form of medical care often restricted by availability, affordability and distance (Shapiro and Field 1993). The early hospitals or 'poor houses' were not places of medical care, like today, but rather places where the destitute went to seek refuge and the seriously ill and the mentally unstable were quarantined. At these institutions rogue surgeons could experiment with new and often fatal technologies, and test new theories and practices on people about whom no one would ask too many questions (Young and Kroth 2017). As a result most people preferred to be cared for in their own homes, and most families preferred to care for their ill loved ones, personally, with little to no formal medical intervention (Bern-Klug, Gessert and Forbes 2001).

However, with the large epidemiologic transition in the first half of the twentieth century the United States and Europe (the more developed regions) saw major shifts from death at younger ages (due to predominantly infectious diseases) to death at older ages (predominantly from chronic conditions) (Tomes 1990; Quora 2017). The developing regions followed suit, albeit at a much slower rate and only decades later (Cohen 2000). The development of antimicrobial agents, vaccinations and other preventative and curative treatments and technologies during the twentieth century further reduced the spread of and numbers of deaths attributable to infectious diseases (Cohen 2000). As a result, changes gradually occurred to the setting(s) of care and in the mode(s) of care for the ill and for the dying.

The stigma around the care that hospitals or other institutionalised settings could provide started to change. These institutions became places where the sick could seek treatment and the expectation of the care in these institutions became that of cure, instead of the expectation of mistreatment and of hastened death (Stevens 1989; Young and Kroth 2017). Standardised treatment protocols and structured training programmes for healthcare providers gradually became commonplace (Rothstein 1987). Government policy and funding of healthcare became national priorities in many countries and health insurance came into existence (Ross 2002). Over the last century, and currently, hospital footprints grew significantly, and still are, more healthcare professionals are getting educated in an ever-increasing number of medical schools and as a result, more and more people have gained access to high quality healthcare through either state or private provision (Rothstein 1987; Stevens 1989; Ross 2002). This, together with other factors, including: changes in family structures, globalisation and the societal role of children in the care of their parents, have resulted in death shifting from private homes to hospital settings and then, later, to formalised care institutions, e.g. nursing homes (Wilson, Smith, Anderson, Northcott *et al.* 2002; Gomes and Higginson 2008; Broad, Gott, Kim, Boyd *et al.* 2013).

In recent, years, there has been some reversal of this trend with the recognition that care aims at the end of life should be different to care aims at any other life stage, irrespective of age. This has led to the emergence of palliative care as a new philosophy of care over the last seven decades (Fallon and Smyth 2008). The emergence of palliative care has facilitated more deaths at home, greater hospice enrolment, national

end-of-life care strategies in the US, the UK and in other territories, and early discussions regarding care and treatment preferences (Flory, Young-Xu, Gurol, Levinsky *et al.* 2004; Gomes, Calanzani and Higginson 2012). However, this reversal has been slow, and globally, the current state of death and dying still leaves much to be desired and is far from being optimal.

Institutionalised or hospitalised deaths are often quoted as deaths involving significant amounts of pain and suffering, intensive, aggressive and often ineffective medical interventions and a general lack of alignment of care interventions with patient preferences (Singer, Martin and Kelner 1999; Teno, Clarridge, Casey, Welch *et al.* 2004; Heyland, Dodek, Rocker, Groll *et al.* 2006).

Palliative care can be integrated with usual hospital-based care, adding an additional layer of support to the patient and their loved ones (Kelley and Morrison 2015). Palliative care can equally be extended to a home or nursing home setting, culminating in hospice care at or near the end of life when life-sustaining treatments can offer no further benefit (Quill and Abernethy 2013). It is important to note that hospice care is not palliative care, but rather a subset of the palliative care service offering.

It has become apparent that nursing home care, as an alternative to or as a step-down from hospital care, also did not fully meet the palliative care needs of patients (Meier, Lim and Carlson 2010). Common problems identified with nursing home care include: staffing shortages, a general lack of palliative care training, untreated pain and symptoms, poor communication and a high chance of hospitalisations with unwanted medical interventions near the end of life (Ersek and Wilson 2003; Meier, Lim and Carlson 2010).

The modern hospice movement started taking shape in the mid-1960's, and this and the subsequent evolution of palliative care is attributed to the work of Cicely Saunders (1918-2005) who undertook to study pain, its manifestation and the effective treatment thereof (Clark 2007). Prior to this very little was understood of pain and it was deemed to be an inevitable and uncontrollable aspect of disease and as a result was frequently overlooked in the treatment of patients (Seymour, Clark and Winslow 2005).

Opioids were found to be very effective in treating pain, however a general stigma against opioid use due to fears of abuse and addiction often resulted in the management of pain and symptoms taking the back seat when it came to treating seriously ill persons and their illnesses (Clark 2007).

With an increasing recognition of the importance of pain and the management thereof, and with the hospice movement gaining traction as the preferred mode of care for those dying of cancer, the term *palliative care* was born, coined in 1975 by Dr Balfour Mount (Clark 2007). In 1987, palliative care/medicine was recognised as a sub-speciality of general medicine in the UK, and in 1995, it was recognised as a stand-alone medical speciality in the UK. New Zealand and Australia recognised palliative care as a speciality in 1998 and the US, more recently, in 2008[3] (Clark 2007). In South Africa, non-governmental palliative care services started in the 1980's and in 2017 the National Policy Framework and Strategy for Palliative Care was approved by the National Health Council (Gwyther, Krause, Cupido, Stanford *et al.* 2018).

Palliative care and the focus of this fledgling medical speciality on quality of life, patient autonomy and –choice, and its easy integration with usual curative care measures has resulted in it rapidly becoming the benchmark of high quality care for the seriously ill, globally. However, the evolution of care at the end of life is far from complete (Lynch, Connor and Clark 2013).

Significant challenges exist in delivering palliative care to all those who will benefit from it. On a global level, these challenges include (but are not limited to, and are not independent of each other): 1) low levels of palliative care development and health policy recognition; 2) poor integration of palliative services with usual care; 3) significant healthcare resource constraints (human, infrastructure, medication and monetary resources); and 4) an ever-growing burden of lifestyle and other diseases (Clark 2007; Connor and Sepulveda Bermedo 2018). In South Africa, the recent release of the National Policy Framework and Strategy for Palliative Care represents a big step forward for palliative care integration in South Africa (HPCA 2017).

[3] At the time of publishing, the US recognition of palliative care as a standalone medical specialty was imminent, and has since been recognised as such

With the advent of death-defying new technologies and medicines, the shift of care at home to care in institutions occurred almost naturally and a fundamental change in attitudes and perceptions towards illness, mortality and medical care occurred – society as a whole has become death-denying (McConnell, Moules, McCaffrey and Bouchal 2012). The problem is systemic in nature, resulting in the world's healthcare systems, especially hospitals, operating on this premise – illnesses are seen as curable manifestations and death as a phenomenon that need not be succumbed to, yet (Al-Qurainy, Collis and Feuer 2009). Medical professionals are trained to diagnose and treat and, at the core, fight illness. It may be seen as failure to accept that an illness is terminal and to refer a patient to palliative or hospice care (Gardiner, Cobb, Gott and Ingleton 2011). The unwillingness to admit that death is near and the only likely outcome highlights the existence of a stigma towards the use of palliative care and a perception that palliative care is synonymous with end-of-life care (Shen and Wellman 2019). The WHO updated their definition of palliative care in 2002 in order to break the direct link with end-of-life care and to increase the remit of palliative care to all serious illnesses (Gott, Seymour, Ingleton, Gardiner *et al.* 2012). The stigma and associated problems with it, persisted, resulting in the emergence and the use of the term 'supportive care' with measured success (Dalal, Palla, Hui, Nguyen *et al.* 2011). The terminology may have changed, but the definition and scope of the services offered may not have, however, the new terminology does allow for an expansion of services offered – at least relative to the perceived level when compared to the term 'palliative care' (Dalal *et al.* 2011; Hui *et al.* 2013). This research report uses the term 'palliative care' throughout.

The education of medical professionals on the end of life, end-of-life care and on the communication of these complex, uncomfortable topics are lacking (Gibbins, McCoubrie and Forbes 2011), however, great strides have been made and some basic supportive, palliative (and/or end-of-life) care training is incorporated in most undergraduate medical syllabi in the developed world (Horowitz, Gramling and Quill 2014). In South Africa, palliative care training is provided through the South African Nursing Council as well as through tertiary institutions such as the University of Cape Town and the University of the Witwatersrand, with a number of other palliative care initiatives and training programmes countrywide (Harding, Bristowe, Downing,

Gwyther *et al.* 2019). That said, the wheels of change turn slowly and the general acceptance of and the full integration of supportive/palliative care into usual acute care for the seriously ill will still take a significant amount of time, especially in the developing world (Ddungu 2011; Lynch, Connor and Clark 2013).

In the developed world, the pressure of ageing populations confronted with multiple chronic co-morbidities, and a rising number of annual deaths, healthcare systems are struggling to provide the level and quality of care required for those at or near their end of life (Gott and Ingleton 2011). South Africa, too, faces similar challenges in both the public and private sectors (Joubert and Bradshaw 2006; HPCA 2017; Council for Medical Schemes 2019). Furthermore, there are limited availability of infrastructure and human resources to deliver palliative and end-of-life care to those who need it and will benefit therefrom (Aldridge, Hasselaar, Garralda, van der Eerden *et al.* 2016; Sharkey, Loring, Cowan, Riley *et al.* 2018).

The availability of palliative care is limited (sometimes even non-existent) in significant parts of the developing world; financial and infrastructural resources are severely strained and education and research is minimal (Ddungu 2011; Lynch, Connor and Clark 2013). For these reasons it is necessary that strong emphasis be placed on the need for and importance of informal and community-based palliative and end-of-life care in developing regions to assist in meeting the needs of those at their end of life whilst formal resources, capacity and infrastructure aren't yet available (Harding and Higginson 2005). The medicalisation of the dying process has greatly shifted the focus from care at home or in the community to care in institutions (Horsfall, Noonan and Leonard 2012). However, evidence exists of community capacity and the willingness and skills to care for the dying and achieving better outcomes and better meeting patients' needs (Horsfall, Noonan and Leonard 2012; Kellehear 2013).

In South Africa, for the entire population, at least 44 per cent of deaths occur in-hospital (Bradshaw, Pillay-Van Wyk, Laubscher, Nojilana *et al.* 2010). It is further estimated that at least fifty per cent of those who die in South Africa could benefit from palliative care intervention leading up to death (HPCA 2017). South Africa is classified as a level 4a (preliminary integration) country when it comes to palliative (and hospice) care integration with mainstream medical care provision (Lynch, Connor

and Clark 2013). This means that South Africa has developed significant capacity for palliative care delivery in terms of education, training, availability of palliative care resources, etc. and what is left is to achieve full integration is to facilitate and ensure access to palliative care for those that need it.

A further controversial, yet prominent, evolutionary element of the end of life is the debate around the deliberate ending of life. Assisted dying is beyond the scope of this research project as it is not permitted in South Africa, but given the evolution of thought on the topic, globally, it is worthwhile to consider briefly. It is worth noting that access to effective palliative care can significantly reduce the need for assisted dying as a result of the effective management of pain and symptoms, but lack of access to such palliative care and the existence of forms of suffering that cannot (yet) be controlled makes room for arguments about the necessity of assisted dying (Quill and Battin 2004). However, in territories where effective palliative care is readily available and utilised, less than one per cent of persons die receiving aid in dying (Quill and Battin 2004).

Various forms of assisted dying exist, euthanasia (administered directly by the healthcare professional) or assisted suicide (indirectly administered by the healthcare professional) (Radbruch, Leget, Bahr, Müller-Busch *et al.* 2016). For both of these, the ending of life may be active (administering the treatment to end life), passive (withholding treatment to sustain life), voluntary (with the patient's consent) or involuntary (without the patient's consent). Involuntary assisted dying is illegal everywhere, i.e. it constitutes murder (Materstvedt, Clark, Ellershaw, Førde *et al.* 2003). In some territories, euthanasia (the Netherlands, Belgium and Luxembourg) or assisted suicide (Oregon, Washington, Vermont, California, Montana, Colorado, Canada and Switzerland) is permitted, and more territories are following suit (Radbruch *et al.* 2016). Reasons for legalising assisted dying, despite the clear ethical and moral conundrums they pose include recognition of patient choice and autonomy when faced by unbearable pain and suffering caused by terminal illness (Fontalis, Prousali and Kulkarni 2018).

Having considered the end of life and the various modes or philosophies of care near the end of life as well as their evolution, and contextualising the research project,

the following section outlines the South African medical schemes environment and the demand for healthcare by medical scheme beneficiaries.

3 Demand for healthcare in the medical scheme environment in South Africa

Demand for healthcare goods and services are driven by both demand-side and supply-side factors (Schulz 2005). Demand-side factors include demographic factors such as ageing populations and clinical factors such as increasing burdens of disease due to chronic non-communicable diseases, etc. (Council for Medical Schemes 2019). Supply-side factors influencing demand include provider behaviour, technological advances, insurance coverage, the availability and access to care, etc. Stakeholders' behaviour, including provider behaviour, and decision-making is considered in Section 4. Separating out demand- and supply-side influences on claim costs are not straightforward and are frequently inter-linked. Below, we briefly consider the South African medical schemes environment and the factors in this environment that may contribute to the high healthcare expenditure observed and, particularly, the healthcare spending near the end of life.

South Africa has dichotomous private and public healthcare systems with an inequitable split of resources between them. Per capita expenditure by persons in the private sector is tenfold that of persons in the public sector and seventy per cent of human resources for health work full time in the private sector (Mayosi and Benatar 2014). Medical schemes cover around sixteen per cent of the South African population. The remaining 84 per cent of the population is reliant on out-of-pocket private healthcare expenditure, the public healthcare system or the informal healthcare system, i.e. traditional or spiritual healers and/or medicines, or on a combination of these (Caldis, McLeod and Smith 2001; Erasmus *et al.* 2016). Around 68 per cent of the population is wholly reliant on the public healthcare system (Ataguba and McIntyre 2012). Medical scheme membership is predominantly concentrated in the top two income quintiles of South Africa, i.e. 71 per cent of scheme membership is from the highest income quintile and sixteen per cent of the membership is from the second highest income quintile (Ataguba and McIntyre 2012). The focus of this research project is on the private funding of cover for healthcare through medical schemes in South Africa.

Medical schemes are the dominant insurance vehicle for private healthcare expenditure (Erasmus *et al.* 2016). They are mutual, not-for-profit organisations, owned by the members and regulated by the Council for Medical Schemes (CMS) in accordance with the provisions as set out in the Medical Schemes Act of 1998 (Department of Health 1998). The Medical Schemes Act in conjunction with other regulations as are published in the Government Gazette from time to time sets out the rules governing medical scheme registration, administration, management, and the requirements of schemes' benefit offerings. Medical schemes operate on the basis of a number of social solidarity principles, namely community rating, voluntary and open enrolment and a prescribed universal minimum benefits package referred to as the Prescribed Minimum Benefits (PMB's) (McLeod and Ramjee 2007).

The 'business of a medical scheme' as set out in the Act is the provision of indemnity-type insurance benefits for healthcare expenditure incurred by scheme beneficiaries (Department of Health 1998). Based on this definition, traditional long- and short-term insurers may market and sell health insurance policies which do not offer indemnity-type benefits that encroach on the 'business of a medical scheme' – i.e. the demarcation of medical scheme business (Erasmus *et al.* 2016). The benefits of these 'health insurance' products are typically of stated amounts, either an overall lump sum (e.g. critical illness products, disability cover, etc.), a per diem amount (e.g. hospital cash products) or an income (income protection or long-term care cover). However, these health insurance products make up a relatively small proportion of the private healthcare funding and insurance markets (Erasmus *et al.* 2016) and are beyond the scope of this research project.

3.1 Medical care costs at the end of life

A recent study in South Africa has shown that, on a risk-adjusted basis, in the final year of life, medical scheme beneficiaries experience significantly higher medical scheme claims than in non-final years of life (Ranchod, Abraham and Bloch 2015). The amount claimed by the beneficiaries in their final year of life was found to be 3.3 times higher than compared to the year prior to the year of death (Ranchod, Abraham and Bloch 2015). This is consistent with findings in the US where around 25 per cent of annual Medicare costs are as a result of spend on persons in their final year of life,

whereas only around 5 per cent of these Medicare beneficiaries die annually (Hogan *et al.* 2001). From the above studies, it is evident that medical costs for decedents are significantly higher than the corresponding costs for survivors in any given year.

The total cost per individual beneficiary (irrespective of their proximity to death) will depend on the type of care and the intensity of the care that the beneficiary receives as well as the length of time for which the care is required. Another recent study in South Africa shows an increasing rate of hospitalisation together with an increasing average length of hospital stay, particularly for people aged 65 and above (Erasmus and Kean 2018).

Some medical interventions at the end of life yield little benefit to the patient whilst being extremely costly (Chochinov and Janson 1998). It is thus important when considering efficiency and cost savings that beneficiaries do not receive unnecessary and unwanted medical interventions near their end of life that do not meaningfully extend life and/or improve the quality of life for the beneficiaries. To this end, it is important that medical schemes aim to facilitate access to optimal care at the end of life through their benefit design, reimbursement arrangements, benefit communication and an increased emphasis on early planning for end-of-life care. This may allow and incentivise medical professionals to make optimal recommendations for treatment and care insofar possible given the significant levels of uncertainty and rapidly changing circumstances of individual beneficiaries nearing their end of life. Furthermore, this will also allow for optimised decision-making by the beneficiaries themselves or by their proxies near the end of life.

It is important to note that end-of-life care planning should not be a once-off exercise, but rather, a dynamic multi-stakeholder process that keeps pace with the patients' ever-changing personal circumstances. The importance of end-of-life care planning is highlighted by Detering, Hancock, Reade and Silvester (2010) having shown that it results in better end-of-life care for the patients and also a better experience at the end of life for their surviving relatives.

A large amount of international research exists on the financial implications that approaching the end of life have for patients, their close relations and for the funders of the end-of-life care received by patients. However, in South Africa, research surrounding the funding of end-of-life care and the factors associated with end-of-life

care decisions and costs are sparse. Below, the potential impact of particular elements of the unique legislative environment, the structure of the industry and medical scheme benefit design on claim costs for beneficiaries near their end of life are considered. Following this, the impact of chronic non-communicable diseases on medical schemes' claims experience are briefly considered.

3.2 Prescribed Minimum Benefits

All registered medical scheme benefit options are required to provide at least the PMB's, at cost at the point of delivery, to all beneficiaries should they require treatment for any of the legislated PMB's. The only exceptions are PMB-exempt benefit options, but these are beyond the scope of this research project. The PMB's include 270 diagnosis and treatment pairs (DTP's) plus the management and treatment of 25 chronic conditions as well as evacuation and care in the event of an emergency (Department of Health 1998). This includes unlimited cover for hospitalisations, specialist consultations, medical tests, medication, etc. for any condition/event defined as a PMB. The PMB's themselves in their design are hospi-centric (Kaplan and Ranchod 2015) and the increase in spending on PMB's over time has far exceeded the increase in spending on non-PMB's as well as the consumer price index (Council for Medical Schemes 2016, 2019). Additionally, the legislation surrounding full payment for PMB's may create perverse incentives for providers to commit various forms of fraud, waste and abuse, e.g. performing unnecessary medical services, up-coding services (submitting claims for higher cost services/medication, etc. than what was actually provided), submitting false claims, etc. further driving up medical scheme claim costs (Legotlo and Mutezo 2018).

Over and above the hospi-centric nature of PMB's and the incentives created for providers given the legislative framework, schemes' direct or even indirect interpretation of the PMB's in the design of scheme benefits can have further unintended cost and care implications at the end of life. The PMB DTP's are set out in Annexure A of the Medical Schemes Act. One particularly relevant DTP that lends itself to misinterpretation is defined as having diagnosis: "Imminent death regardless of diagnosis", with treatment defined as "Comfort care; pain relief; hydration" (Department of Health 1998). This DTP is likely intended as the catch-all end-of-life

benefit which alludes to covering 'alternative' treatments to the 'usual' curative in-hospital treatment, e.g. palliative- and/or hospice-related care. However, this definition as it currently stands is vague and lends itself to misinterpretation. It does not explicitly define exactly the diagnosis nor the treatment parameters within this DTP. Furthermore, no mention of eligibility criteria for this DTP nor the period or circumstances under which beneficiaries are eligible to continue receiving this particular treatment are specified. The vague wording and lack of information on this DTP may have resulted in medical schemes not offering targeted end-of-life care benefits or not explicitly communicating their coverage for end-of-life care benefits to their beneficiaries. The end-of-life DTP is not diagnosis-specific and the treatment responsibility is also not aimed at any specific provider or setting of care, whereas the other DTP's are more clearly defined, and/or need less clarification about what best practice medical treatment for the particular diagnosis is. As a result, even when the end of life is 'imminent', it may happen that a better-defined, equally applicable DTP care pathway is pursued, irrespective of whether this may result in more expensive and/or suboptimal care aimed at cure even when cure is no longer possible. Even if explicit end-of-life care benefits are available, utilisation thereof depends on whether doctors/beneficiaries are aware thereof, and depends on the doctor, the beneficiary and the beneficiary's relatives' preferences for care, and on these stakeholders' interactions over time in making care recommendations and treatment decisions. Stakeholder interactions are considered in section 4.

Encouragingly, in recent years, some medical schemes have started offering specific end-of-life care benefits that involve multi-disciplinary care teams, advanced care planning and individually co-ordinated care plans for seriously ill beneficiaries[4]. These benefits are still in their infancy and are continually being refined based on emerging experience and with help and input from the Hospice and Palliative Care Association of South Africa[5]. These benefits are currently structured as once-in-a-lifetime benefits, only accessible at the end of life, and only available to beneficiaries with end-stage cancer who meet strict eligibility criteria, who forego curative treatment

[4] https://hpca.co.za/download/discovery-healths-advanced-illness-benefit/

[5] HPCA. (2019). HPCA. Available: https://hpca.co.za/palliative-care/who-qualifies/ (accessed: 14 November, 2019).

and are referred by their treating doctors. The problem herewith is that palliative care and hospice-based services are accessed very late in the disease trajectory, if at all, and a significant part of the benefit of early palliative care intervention is lost (Dalgaard *et al.* 2014). However, the significant risk to medical schemes of widening benefit eligibility where home or nursing services are included is the risk of having to pay for long-term or frail care services for extended periods of time. These are typically specific scheme exclusions due to the 'social' rather than 'medical' nature of this care and the threat they pose to the financial sustainability of medical schemes. A way to trigger palliative intervention early in the trajectory of serious, life-limiting illness without the high financial risk to schemes is to incorporate consultations and advanced care planning benefits with a palliative specialist upon diagnosis of serious illnesses into scheme benefit designs.

The CMS is currently undertaking a PMB review in which significantly more focus is placed on the importance of the provision of palliative care to those who need it. This is amongst other key PMB priorities requiring urgent attention, e.g. addressing the quadruple burden of disease experienced by South Africans (Council for Medical Schemes 2016). This should go a ways towards highlighting the need and importance of integrated palliative care for all beneficiaries with serious illness and facilitating access to this care. Implementation of the revised PMB package is expected by 2022 (Council for Medical Schemes 2019).

There are many factors particular to the medical scheme environment beyond the interpretation and application of PMB's that further interact and impact on the high level of medical scheme claims costs, extending particularly to end-of-life care costs. These include, but are not limited to fee-for-service reimbursement mechanisms, limited value-based provider contracting and reactive rather than proactive managed care interventions aimed specifically at the end of life, and the incomplete regulatory framework resulting in anti-selective behaviour (Competition Commission South Africa 2019). A further factor affecting the demand for medical goods and services (on both the demand- and the supply sides) in the medical schemes environment are benefit design considerations, i.e. what is covered, who is eligible for particular benefits, who may provide these, etc. (Kaplan and Ranchod 2015). Below, we briefly consider the fee-for-service environment as a driver of medical scheme claims costs

and the role of managed care organisations and value based contracting in managing demand for both the demand- and supply-side drivers of costs, and maximising the value of care for medical schemes and their beneficiaries.

3.3 Fee-for-service reimbursement, managed care and value-based contracting

Medical schemes in South Africa typically reimburse providers of medical goods and services on a fee-for-service basis (Competition Commission South Africa 2019). In the 2018/19 CMS Annual Report it can be seen that almost 77 per cent of hospital payments were made on a fee-for-service basis with the remainder being on the bases of alternative reimbursement models, per diem rates or fixed global fees (Council for Medical Schemes 2019).

A fee-for-service environment rewards providers of medical goods and services based on the volume of high-cost goods supplied and services rendered thus perversely incentivising providers to over-service beneficiaries and to place greater emphasis on the use of higher-cost goods and services in treatment (Competition Commission South Africa 2019). This is termed supplier-induced demand and has frequently been cited as a major driver in healthcare utilisation and hence healthcare costs in the medical schemes environment (van den Heever 2015). The impact of supplier-induced demand is likely to manifest at all levels of healthcare delivery where fee-for-service reimbursement exists and this may be especially true for the end of life given the concentration of scheme expenditure in hospital and on PMB's near the end of life.

The Health Market Inquiry into the private healthcare sector in South Africa calls for the establishment of a supply-side regulator and a move away from fee-for-service reimbursement models to reduce fragmentation and inefficiencies in the private healthcare sector (Competition Commission South Africa 2019).

Medical schemes utilise services and clinical management programmes provided by managed care organisations to assist with managing their overall risk and to ensure appropriate, cost-effective care for their beneficiaries. These services and programmes include, but are not limited to, the use of pre-authorisation for planned hospitalisations, disease management programmes, high-cost case management, treatment protocol formulation, formulary formulation and implementation, etc. (Kaplan and Ranchod 2014). Managed care interventions have had success in managing utilisation of

healthcare, preventing downstream costs and even in improving quality of care and care outcomes (Kongstvedt 2013). Near the end of life, value for the key stakeholders could be improved significantly with more proactive (early identification of beneficiaries and palliative care integration with curative care) rather than reactionary (high-cost case management) managed care interventions. This requires a shift from the traditional fee-for-service reimbursement arrangements to more value-based contracting solutions that incorporate multi-disciplinary care teams and individualised care plans. The increased value is realised both from a cost and quality perspective - medical scheme claim costs can be reduced and the quality of care, life and of death for beneficiaries near their end of life can be improved. The use of such multi-disciplinary structures with appropriate incentives has shown success internationally in the delivery of high-quality, cost-effective end-of-life care (Luckett, Phillips, Agar, Virdun *et al.* 2014; Fendler, Swetz and Allen 2015). However, significant challenges exist in the regulation of healthcare providers in South Africa regarding the establishment of multi-disciplinary group practices (Competition Commission South Africa 2019).

3.4 Social solidarity and anti-selection

The social solidarity principles upon which medical schemes are based, i.e. voluntary and open enrolment and community rating creates an environment that opens schemes up to anti-selection (Ramjee and Vieyra 2014). Anti-selection occurs in an insurance environment when an asymmetry of information between an insurance company and an individual can be utilised by the individual to their advantage. Individuals typically have more information regarding their state of health and their health-related behaviour than the insurance company (Erasmus and Kean 2018). Normally this does not represent a significant problem to the insurance company as it can underwrite each individual to gauge the level of risk and decide on the level of cover and/or the level of premiums to compensate for the risk, or it may decline cover altogether. However, denying coverage and charging for individual risk is disallowed by medical scheme legislation in South Africa, thus encouraging rational individuals to select (legally) against medical schemes by opting out of medical scheme cover whilst young and healthy, and opting for cover at older ages or when ill (Ramjee and Vieyra 2014).

Schemes have limited means with which to protect against this anti-selection, e.g. waiting periods (twelve-month condition-specific, and three-month general waiting periods), age-related late-joiner penalties and the various managed care tools and techniques highlighted above (Hutcheson 2011). The intention of the social solidarity principles are to prevent the ill and elderly from being denied cover and ensuring affordable, equitable access to care for those that need it through age and health-related cross-subsidisation. The higher expected claims for sicker beneficiaries are thus subsidised by the contributions of healthy beneficiaries (Ramjee and Vieyra 2014). In an environment where cover is mandatory, these cross-subsidies are effective and overall contributions can, in theory, be kept affordable. However, in a voluntary environment, all things equal, selection will result in healthy individuals opting out of cover, the risk profile worsening year-on-year, and contributions increasing unsustainably year-on-year, as is happening in the South African medical scheme environment (Ramjee and Vieyra 2014). Furthermore, the requirement to pay for PMB's in full greatly affects the affordability of medical scheme cover as it sets a high minimum cost of offering cover (Kaplan and Ranchod 2015). Increases in the cost of offering PMB's and hence contributions, effectively force beneficiaries at the lower end of the market out of medical schemes over time (McLeod and Ramjee 2007).

The public healthcare system in South Africa is plagued by a lack of infrastructure and human resources, outdated technology, long waiting times and generally poor quality of care (Mayosi and Benatar 2014). The private sector healthcare in South Africa delivers high quality care, but at a very high price tag putting out-of-pocket payment for care, especially specialised and in-patient care out of reach of the majority of the population (Barber, Kumar, Roubal, Colombo *et al.* 2018). The risk of catastrophic medical expenditure in the private sector and the poor quality of care in the public sector makes scheme membership a logical option for seriously ill persons with the means to pay the monthly contributions. This may be worthwhile even after applying late-joiner penalties (a penalty that remains in force for life) and waiting periods (expiring after three and/or twelve months, depending on the specific type of waiting period(s) applied). In exchange for known contributions, beneficiaries have access to unlimited cover for PMB's and significant cover for specialist care in private hospitals. It is clear that significant scope for anti-selection

exists in this voluntary environment with limited means of protecting against it. This anti-selective behaviour may be exacerbated near the end of life when the costs of managing chronic conditions, unplanned hospitalisations, emergencies, etc. become untenable for individuals and/or their families and medical scheme cover is taken up.

3.5 Chronic non-communicable diseases as a driver of healthcare demand

Globally, chronic, non-communicable diseases are increasingly affecting populations and the healthcare systems. The incidence and prevalence of these diseases are on the rise and so are the costs managing and treating these conditions (World Health Organization 2011). Developing countries are experiencing an epidemiological transition whereby the leading causes of death are shifting from communicable to non-communicable diseases (Kaplan, Spittel and David 2015). The situation in South Africa is no different – 43 per cent of all deaths are caused by non-communicable diseases (Pillay-van Wyk, Msemburi, Laubscher, Dorrington *et al.* 2016). The developed world experienced this transition decades ago.

Today, most people die at advanced ages – global life expectancy at birth has surpassed 71 years (Wang, Naghavi, Allen, Barber *et al.* 2016). Age-standardised death rates at all ages have significantly reduced, globally, due to improvements in medical technology, care interventions and pharmaceuticals which have significantly reduced the numbers of deaths due to communicable, maternal and neonatal, and nutritional disorders (Moraga 2017). Non-communicable diseases account for more than 72 per cent of deaths, globally (Moraga 2017). Furthermore, age is highly correlated with the level of chronicity (Shlisky, Bloom, Beaudreault, Tucker *et al.* 2017).

The most common non-communicable diseases are cardiovascular disease, cancer, chronic respiratory disease and diabetes (Habib and Saha 2010). Near the end of life, complications resulting from chronic conditions (potentially exacerbated by the existence of multiple chronic conditions in some individuals) and treating these conditions may result in more frequent hospitalisations, longer hospital stays and more bouts of intensive care during these hospitalisations (Palladino, Tayu Lee, Ashworth, Triassi *et al.* 2016).

In the medical schemes environment, the PMB's include full payment (subject to certain rules, e.g. using a designated service provider, etc.) of a defined list of chronic conditions (the Chronic Disease List or CDL). More comprehensive options may include cover for additional specified chronic conditions. Schemes generally require beneficiaries to inform the scheme and provide proof of the chronic condition in order to qualify for these PMBs. This is known as chronic 'registration' or 'authorisation' with the scheme. Certain chronic condition registration is also accompanied by enrolment on a chronic condition management programme, e.g. HIV/AIDS and cancer. This is to ensure that the beneficiary manages their condition well by taking medication timeously, going for regular tests, check-ups, etc. and to avoid exacerbated medical costs and further complications downstream. The administration and management of these programmes falls under the scope of the scheme's managed care arrangements. Chronicity and the impact of chronic conditions on end-of-life care costs are considered in more detail later in this research report.

In the next section, the key stakeholders, their interactions and their thought- and decision-making processes within the medical schemes environment are considered.

4 Stakeholders, decisions and conflicts near the end of life

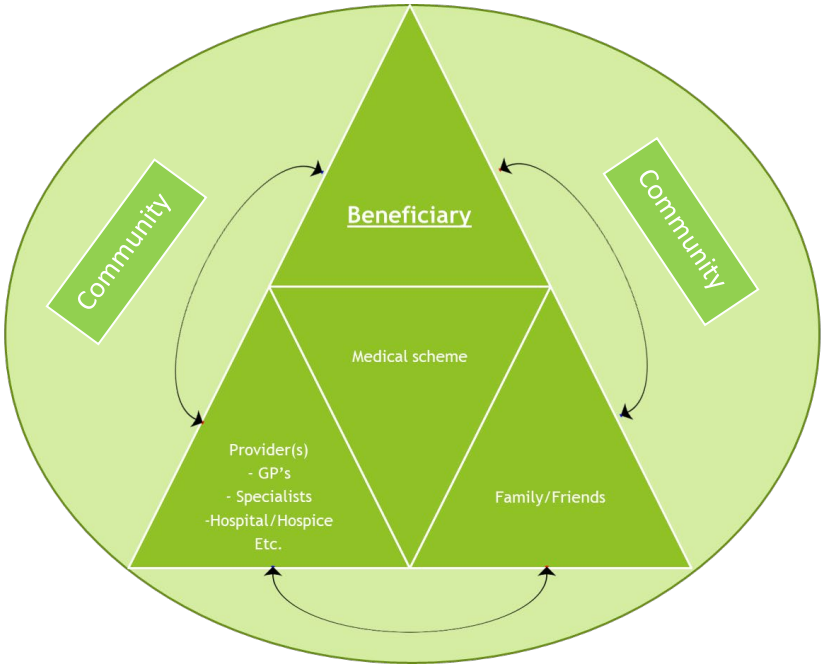
When it comes to the end of life, no two people have the same backgrounds, characteristics and preferences, and no two people make decisions in exactly the same way. The following is a high-level exploration of the behavioural and other factors contributing to the complexity surrounding decision-making in end-of-life situations, focusing on the unique aspects in the South African medical scheme environment and the key stakeholders (and their respective needs) therein. The factors considered here are not exhaustive. Neither is the discussion around the multiple layers of interaction between stakeholders in the continuum of care and disease progression over time. Local as well as international literature on conflicts between stakeholders and decision-making are considered below.

Numerous stakeholders play instrumental roles in end-of-life care decision-making, the provision of care and the funding thereof. It frequently happens that these stakeholders have opposing interests or conflicting needs resulting in an additional layer of complexity surrounding end-of-life care decision-making and care provisioning (Weissman 2001; Frost *et al.* 2011). The complex interaction between stakeholders may a go a ways toward explaining the stakeholders' observed behaviour and their decision-making in the face of serious, life-limiting illnesses.

4.1 Key stakeholders

Figure 4.1, below, illustrates the key end-of-life care stakeholders in the end-of-life care universe, and depicts the various interactions between them, e.g. communication, the flow of funds and the provision of care and support.

Figure 4.1 – The End-of-Life care universe



Beneficiaries are scheme members and/or the registered dependents of the scheme members entitled to receive scheme benefits in accordance with the benefit rules of the particular medical scheme. They sit at the top of the pyramid within the end-of-life care universe depicted in Figure 4.1, as they are the benefactors of the care and those for whom the quality of care, life and death are to be optimised.

In the centre of the pyramid is the medical scheme as the funder of the end-of-life care given the competitive and legislative environment in which medical schemes in South Africa operate. The role of medical scheme service providers, e.g. administrators and managed care organisations were considered briefly in Section 3. These service providers are not considered as separate stakeholders in this section and are considered together with medical schemes.

The base of the pyramid consists of the providers (and settings) of end-of-life care and the relatives/friends of the beneficiary that support the beneficiary near their end of life. The support they provide may be emotional, financial and/or in a caregiving capacity. Within this end-of-life universe, the greater society or community within which beneficiaries find themselves and the prevailing culture and attitudes of the persons within these communities also influences the type and intensity of care as well

as the care decisions and transitions between settings of care near their end of life. For example, in poorer or more rural communities where formal care resources like specialists and private hospitals are more limited, there may be a greater proliferation of informal or community-based care programmes or initiatives than in more urban or better-resourced communities. Similarly for smaller, more close-knit communities, greater emphasis may be placed on community involvement in care for the seriously ill (Byock, Norris, Curtis and Patrick 2001).

All stakeholders are inter-connected (to a more or lesser extent depending on each individual beneficiary's circumstances) in the provision of and the decisions made surrounding the end-of-life care the beneficiary receives.

4.2 Preferences, communication, benefits and decisions

There are many factors that impact on a beneficiaries' choice (or lack of choice) regarding the care they receive at the end of their life including: demographic factors such as age, sex, race and geographic location, state of mind, cognition, degree of physical impairment, religion, doctors' recommendations, family preferences, etc. (Frost *et al.* 2011). Financial factors, insurance and level of education/awareness will also have an influence on the decision-making near the end of life. Frost *et al.* (2011) argue that decision-making at the end of life is "contentious". This is partly because of the complex interaction between stakeholders and the factors they consider important at the end of life (Steinhauser *et al.* 2000). Another contributing factor is the significant amount of uncertainty that accompany the end of life and how perspectives change with level of awareness and with changes in circumstances over time (Lau *et al.* 2007). Uncertainty may also translate into hope and unrealistic expectations regarding the effect of curative interventions, given technological advances and a tendency (by both providers and beneficiaries) to err on the side of optimism with prognoses and estimates of future survival times (Lamont 2005).

Effective communication about care preferences and illness trajectories is a useful first step to reducing the level of conflict between the key stakeholders, to reduce uncertainty and to improve decision-making near the end of life. Effective communication helps to address societal ignorance and fights any stigma associated with the end of life and has been shown to shorten the length of hospital stays, to

significantly reduce end-of-life care costs, to increase patients' quality of life near their end of life and helps to facilitate an improved family bereavement experience (Wright *et al.* 2008; Curtis, Treece, Nielsen, Gold *et al.* 2016; Keeley 2017). Identifying that communication gaps and inefficiencies in the delivery of end-of-life care exists, is straightforward; however, addressing them poses an entirely different set of challenges. Some challenges surrounding effective end-of-life care communication are outlined below.

A beneficiary's religious or cultural orientation may preclude conversations about death or make such conversations inappropriate (You, Downar, Fowler, Lamontagne *et al.* 2015). Beneficiaries may refuse to accept poor prognoses and as a result not engage in end-of-life care discussions or care planning with providers and/or family members. A doctor or specialist may avoid the topic in order to maintain hope or may, him- or herself, be uncomfortable/inexperienced with such communication. Equally family members may avoid the conversation with the beneficiary or fail to convey to providers the treatment preferences of a loved one when they are unable to do so themselves (You *et al.* 2015).

Advanced care planning has been effective in encouraging discussions around care goals and documenting care preferences, helping to address some of the communication gaps identified in end-of-life care decision-making (Emanuel, von Gunten and Ferris 2000). However, research has shown that documenting preferences does not necessarily result in them being adhered to (Prendergast 2001). Significant problems with advanced directives are that they are once-off in nature and are often forgotten or misplaced after the initial directive is drawn up (Perkins 2007). Another problem with advanced directives is the significant, and often unanticipated, changes in circumstances between the time of drawing up the advanced directive and the time when it is meant to be acted upon, and the resulting (often drastic) change in personal preferences (Fagerlin, Ditto, Hawkins, Schneider *et al.* 2002). Researchers use prospect theory to explain this phenomenon and its impact on decision-making – as prospects change, preferences change (Winter and Parker 2007). The theory reads as follows: when a person is in good health, the distinction between life in poor health and death is small, and the preference is an expressed wish to avoid intensive, life prolonging interventions that will cause further pain and suffering. Conversely, when

a person is in poor health, the distinction between further life in poor health, and death, is greater, meaning that life-prolonging treatment may be more acceptable and even desirable (Winter and Parker 2007). It is thus recommended that advanced care planning should be an ongoing process of engagement that focuses on preparing patients and their families for making difficult decisions and eliciting care goals so that at that time when a crisis occurs and important, difficult decisions need to be made they can be made in good time (Perkins 2007; Sudore and Fried 2010). It is clear that effective communication and ongoing engagement between key stakeholders is paramount to end-of-life care decisions. However, communication is only one aspect of conflict and decision-making in the end-of-life conundrum. Another significant consideration is the actual scheme benefits to which the scheme beneficiaries are entitled.

There is a proliferation of medical schemes and individual benefit options within medical schemes. The design of these are complex, with beneficiaries who don't understand their benefits and/or are unaware of their benefit entitlements (Kaplan and Ranchod 2014). This lack of awareness and understanding disempowers beneficiaries in the decision-making process (Competition Commission South Africa 2019). It is possible that beneficiaries are unaware of which care alternatives or complements exist, and which of these may be optimal near their end of life given their unique circumstances and the uncertain way in which their end-of-life period will unfold.

4.3 Third-party payer dynamics

Scheme beneficiaries themselves don't pay directly for the medical goods and services they consume (other than for out-of-pocket payments, co-payments or for medical care that is excluded from scheme cover) and are thus not incentivised to consider the cost of such treatment, nor to seek the most cost-effective services – this is referred to as the third-party-payer problem (Edmeston and Francis 2012). This, together with a lack of detailed medical knowledge on the part of the beneficiaries results in further disempowerment of scheme beneficiaries when it comes to medical care decisions whereby they assume a more passive role in making treatment decisions (Say, Murtagh and Thomson 2006; Longtin, Sax, Leape, Sheridan *et al.* 2010). Passive decision-making means expressing a preference to not be directly involved in making care and

treatment decisions and accepting the doctor's treatment recommendations (Robinson and Thomson 2001). Passive decision-making by beneficiaries may result in them receiving higher cost medical care and treatment that does not necessarily improve health outcomes, and at the end of life, potentially resulting in worse outcomes (Adams and Drake 2006; Oshima Lee and Emanuel 2013). This highlights the importance of shared and empowered decision-making at all levels of care, but particularly at the end of life where an understanding of care preferences and goals and the quality of life should supersede merely keeping someone alive.

The proliferation of scheme options and complex benefit designs also presents challenges for providers - it is impossible for all doctors to know exactly which benefits are provided by which schemes and options and which beneficiaries are entitled to which benefits, how much of these benefits and when beneficiaries are entitled to them. The PMB's (the base package that all schemes and all options need to cover in full) and their impact on claims were touched on in the previous section. Cover for intensive medical treatment for serious conditions and emergencies requiring hospitalisation (which are frequent near the end of life), most often fall within the legislated PMB's. Providers may be more likely to admit beneficiaries to hospital (resulting in intensive and expensive treatment), knowing that this care is covered as a PMB and will be fully paid for by the scheme. This is further exacerbated by the fee-for-service reimbursement mechanism and provider incentives to potentially over-service beneficiaries (considered in the previous section) (Competition Commission South Africa 2019). The extent to which providers deliberately over-service beneficiaries and unnecessarily admit them to hospital is unclear. There is however some consensus that this is widespread and driven to an extent by the regulation surrounding the payment of PMB's (Ramjee, Abraham, Kaplan, Taylor *et al.* 2013; Erasmus and Kean 2018; Legotlo and Mutezo 2018).

For the reasons above, amongst others, intensive treatment in-hospital near the end of life may be sought despite being sub-optimal and despite the beneficiary having access to and cover for other complementary or palliative care benefits that may be more, or at least, equally, suited to their personal circumstances.

The concept and interpretation of quality can further affect beneficiary decision-making. A common misconception exists that more expensive healthcare means higher

quality healthcare or conversely, that lower cost care means substandard care (Weisbrod 1991; Hibbard, Greene, Sofaer, Firminger *et al.* 2012). The concept of diminishing returns (that may even become negative) can be borrowed from economic theory. This concept means that the more of something one receives, the lower the marginal utility that they derive from each additional unit thereof (Greene and Baron 2001), and that there may be a tipping point after which the 'benefits' of additional units actually decrease the overall utility, i.e. causes harm (Chochinov and Janson 1998; Greene and Baron 2001). This may be especially true for complex goods or services such as healthcare interventions near the end of life where quality (and utility) are often not directly observable and cost is erroneously used by some as a proxy for quality, irrespective of whether the care is appropriate or achieves better outcomes (Hibbard *et al.* 2012). Near the end of life, ineffective care is one such example where additional spending adds no additional utility or benefit, but may very well cause harm (Kompanje, Piers and Benoit 2013). Beneficiaries (and even providers) may incorrectly assume that the more expensive or intensive the care, the better the value and the higher the quality thereof is. This may not be true given that more intensive/aggressive care near the end of life potentially results in reduced quality of life and poorer outcomes for patients and their families (Connors *et al.* 1995). It has also been shown that increased spending does not necessarily result in better healthcare outcomes or even in extended survival times (Fisher, Wennberg, Stukel, Gottlieb *et al.* 2003).

Beneficiaries may also be of the conviction that they are entitled to more expensive care (if given alternatives) at any given time they become ill if they had been contributing to the medical scheme for years during which they were healthy and not claiming any benefits. When choosing between care pathways at the end of life (or at any time), these beneficiaries may place a higher personal value on the more intensive, more expensive care without fully understanding the implications of their end-of-life care preferences and eventual decisions. The extent to which this rationalisation or entitlement may exist for beneficiaries in the medical schemes environment, and its effect on claims costs is unknown and not easily quantifiable without observing and surveying beneficiaries and care providers directly.

4.4 Agency issues and conflicts of interest

The existence of agency issues in healthcare presents clear conflicts of interest, especially in end-of-life care decision-making. These conflicts potentially arise between any of the care provider(s), the beneficiaries, the close relations and/or the medical schemes. The existence of agency issues and other conflicts of interest may result in beneficiaries eventually receiving care that is sub-optimal in some respect near their end of life, resulting in a combination of unnecessary pain, suffering, feelings of anger and frustration, depression, etc. and receiving care that is contradictory to their preferences, stated or otherwise (Weissman 2001).

At the end of life, a beneficiary may not be physically or cognitively able to make decisions when alternative care pathways need to be considered. The proxy decision-makers for the beneficiary may have different considerations and/or needs to those of the beneficiary when making end-of-life care decisions on their behalf (Parks, Winter, Santana, Parker *et al.* 2011). Making end-of-life care decisions for loved ones carries a significant emotional burden (Braun, Beyth, Ford and McCullough 2008) and frequently a bias exists towards favouring interventions aimed at cure, especially when there is unresolved family conflict surrounding the choice of care interventions (Parks *et al.* 2011).

Doctors may also in some circumstances recommend treatments knowing that these may not be fully appropriate as found in an investigation by Solomon *et al.* (1993). This investigation also found that doctors often felt that the treatments they were offering their patients were excessive. Reasons for this overtreatment of patients may be because of the doctor not knowing what the patients' preferences for treatments are, a fear of under-servicing patients or of being uncertain about what is ethical or what the law requires, etc. (Solomon *et al.* 1993). Weissman (2001) additionally puts forth that doctors may recommend overly aggressive treatment because they are wary of destroying hope for the dying patient and their loved ones. Doctors themselves may harbour strong religious or cultural convictions resulting in a stigma against foregoing curative care instead of rather opting for more palliative measures (Wilkinson and Truog 2013). Furthermore, doctors may fear being ostracised by their peers by recommending less aggressive treatment (Weissman 2001). Another reason for offering intensive interventions near the end of life may be that there are significant

legal risks involved in withholding or not authorising certain treatments, and/or reputational risk in being seen to withhold certain curative measures, even at the end of life (Meisel, Snyder, Quill and Panel 2000). The inherent uncertainty near the end of life, technological or experimental interventions and individual convictions potentially cause providers to err on the side of caution – favouring intensive, life-prolonging or curative care interventions near the end of life.

Finally, another factor driving decisions and highlighting the existence of agency issues in the provider-patient relationship is the existence of a profit motive for the provider. An economic conflict of interest exists in the fee-for-service environment whereby the doctor or specialist may directly benefit from the care they recommend and administer as opposed to referring the beneficiary to a different care provider (Gray 1997). Unfortunately, this may result in a provider purposely administering inappropriate, ineffective care near a beneficiary's end of life. There also exists conflicts of interest between the providers of care and the medical schemes as third party funders of the care. The use of managed care techniques and treatment protocols by medical schemes may be seen by providers are a direct undermining of the trust between them and their patients (Gray 1997). Rapidly rising medical costs and frequently reported poor care outcomes, however, have necessitated the development and use of managed techniques as a means to try and contain costs and improve patient outcomes (Kongstvedt 2013).

It is clear that significant conflicts of interest exist - some apparent, some more sinister and some more subtle. It is the confluence of this multitude of factors, the complex interactions between stakeholders and the significant information asymmetries and uncertainty, which may result in these conflicts of interest. The literature suggests that decision-making near the end of life by patients, their family members and their doctors are often, in hindsight, inappropriate resulting in patients often receiving sub-optimal care near their end of life (Frost *et al.* 2011). Inappropriate decision-making is often driven by a failure to recognise, understand or acknowledge death's imminence, cultural values and beliefs, desperation and hope, fear of acting immorally or legal repercussions, etc. (Weissman 2001). Medical schemes and their managed care service providers can play a significant role in facilitating effective

communication, aligning stakeholder incentives and removing some of the contention in the end-of-life decision-making processes.

5 Data and methodology

5.1 Credibility and representivity of the data

The data analyses performed for purposes of this research project comprises of retrospective analyses of a sample of decedent medical scheme beneficiaries' medical scheme claims incurred during their last 24 months of life. The analyses also considers these decedents' demographic characteristics to further evaluate the observable factors that impact on their overall end-of-life care claims costs.

The sample contains a total of 24 980 medical scheme beneficiaries that died in the calendar years 2016 and 2017, representing around 12 500 deaths per respective calendar year under investigation. The decedents represent about 0.5 per cent of the total number of beneficiaries exposed to the risk of death per calendar year from the subset of the overall medical schemes' population to which the decedents belonged at their time of death. This means that there were a total of around 2.7 million exposed beneficiaries per calendar year in the population to which these decedents belonged. The greater population to which the decent beneficiaries in our sample belong represents around thirty percent of the total medical schemes industry in South Africa, i.e. thirty per cent of the roughly 8.9 million medical scheme beneficiaries in South Africa (Council for Medical Schemes 2019). Given the proportion of the medical schemes industry covered by the sample, the analyses and results are expected to be representative of the experience of the greater medical schemes industry in South Africa. This should be interpreted with caution as some of the smaller medical schemes in the industry may have demographic profiles and claims experience that differs significantly from that of the sample analysed. Furthermore, differences in benefit designs, scheme and option sizes, geographic concentrations, etc. between schemes and options may result in different overall experience when compared with that of the sample under investigation.

No explicit adjustments are made for different benefit designs between schemes and between different benefit options within schemes. Different benefits designs between schemes and options are expected to have an impact on individual beneficiaries' total claims costs. However, given the common set of PMB's on all medical scheme options (Kaplan and Ranchod 2015) and the hospi-centric nature of

these PMB's and specifically care at the end-of-life (Ranchod, Abraham and Bloch 2015), the effect of different benefit designs between schemes and options are likely to be muted at the end of life. In addition, this research project analyses the total claims submitted, as opposed to the total claims paid, which will further reduce the impact of differing benefit designs on the overall claims experience. The difference between the claims submitted and the claims paid are less than ten per cent of the overall claims for decedent beneficiaries in the sample.

The total claims incurred by all exposed lives in the population to which the decedents belonged (the 2.7 million lives) amounts to around R40 billion per annum during these two calendar years (Council for Medical Schemes 2019), whereas the overall claims for the decedent beneficiaries in the sample over their last year of life amounts to around R4 billion per annum (in 2017 monetary terms). This means that, for the population under consideration, around ten per cent of total claims incurred by all exposed lives are incurred by the 0.5 per cent of beneficiaries that die each year. Stated otherwise, this reads as follows: claims costs for beneficiaries in their final year of life are more than twenty times greater than for beneficiaries not in their final year of life, on average. Medical scheme claims costs for beneficiaries in their final year of life are thus significantly subsidised by the contributions of those not in their final year of life. The high relative level of expenditure on beneficiaries nearing their end of life warrants an investigation into the factors that potentially drive this observed experience.

While an attempt is made in this research to be comprehensive in the identification and analyses of end-of-life care cost drivers, there are many forces and factors at play, some subtle and invisible, and others less so. It is not impossible that some factors may have been overlooked, or that the nuances of their interaction with other factors may have been incorrectly or too simplistically interpreted. Where deemed appropriate, recommendations are made, and areas that require further research or require substantiating evidence are identified. This research project is a first step towards unpacking and understanding the complexities, the challenges and the gaps in delivering end-of-life care to beneficiaries of South African medical schemes.

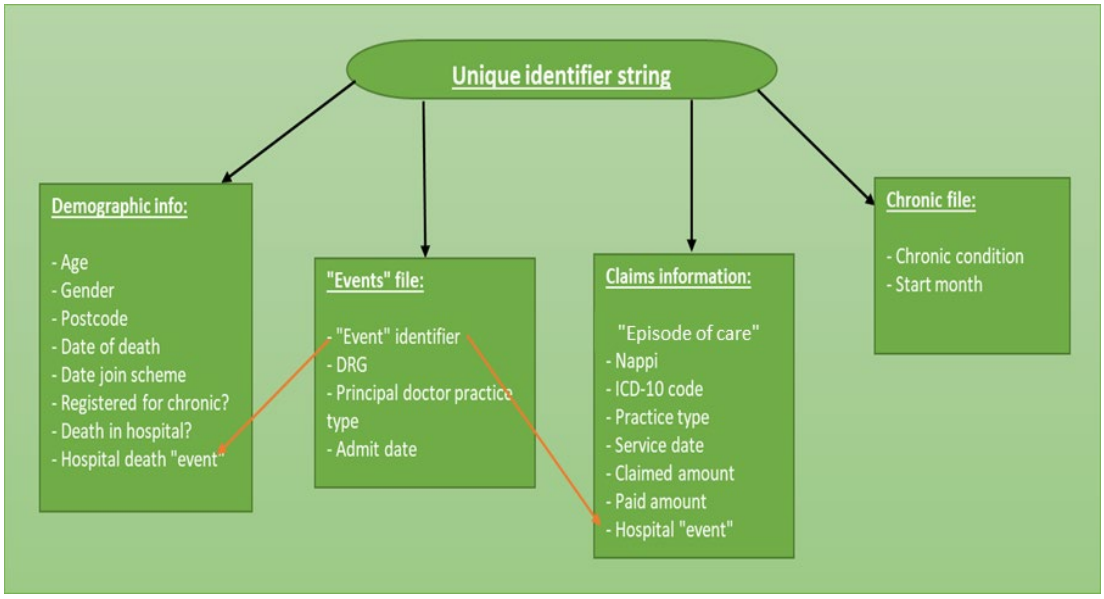
Next, the data analysed are considered, followed by a description of the methodology employed in the analyses.

5.2 Description of the data

Full claims data for the sample of medical scheme beneficiaries that died during the period under investigation (calendar years 2016 and 2017) are analysed. All medical scheme claims submitted to the scheme for these beneficiaries during their last 24 months of life are included in the data. The data extraction was done in July 2018. Given a period of greater than six months following the last death, it is reasonable to assume that the claims data are fully run off at the time of the data extraction. All data are fully de-identified and individual beneficiaries have been assigned unique number/character strings that link them to their individual claims, their demographic information, their hospital events and chronic condition authorisation data across a number of data sets. The claims data consists of some 26 million individual claim lines. The data analyses are performed using Microsoft SQL Server Management Studio (a database application) to summarise and group the data and to do high-level manipulations, and Microsoft Excel (a spreadsheet application) to perform the detailed analyses and to construct the figures and tables presented in this report.

Figure 5.1, below, illustrates the various data sets and the links between them.

Figure 5.1 – Data files



The key variables are the unique identifiers for each beneficiary and for each unique hospitalisation and chronic authorisation. The demographic data supplied for each decedent beneficiary includes their age at death, date of death, sex, postal code (indicating his or her area of residence), chronic registration indicator and the duration of their scheme membership. Further, the claims information includes the monetary amount (in Rands) of the claim submitted to the scheme and the monetary amount paid by the scheme, respectively, per claim line. An ICD-10[6] code as well as the specific 'episode of care'[7] (and its description) that a claim belongs to is contained in the claims file, per claim line. An 'episode of care' is broadly defined as the set of health services delivered during some time period to treat a particular condition or a particular event requiring medical intervention (Peterson, Grosse and Dunn 2019). This may consist of one or more hospitalisations, follow-up visits, medication, etc. that falls within the scope and definition of the particular 'episode of care' (Jackson, Walsh and Abecassis 2016). The claims file also included a NAPPI[8] code and a procedure code together with descriptions of these, the practice type of the providers and an in-hospital indicator plus a unique in-hospital 'event' identifier for claims occurring during each hospitalisation, for each individual claim line.

The unique hospital 'event' identifiers can be cross-referenced with an 'events' data file. This file contains the details of the admission and discharge dates, the Diagnosis-Related Group (DRG[9]) description for each hospital 'event', the admitting doctor practice type and a link to the individual beneficiary's unique identifier for each hospitalisation the beneficiary had during their last 24 months of life. The chronic file contains authorisation data for chronic conditions, including the actual chronic condition and the start date of each chronic authorisation for each individual decedent beneficiary.

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[6] International Classification of Diseases (10th revision) or ICD-10 is a coding system used to classify/code all diagnoses, symptoms and medical procedures.

[7] 'Episodes of care' are defined by statistical parameters using an 'episode' grouper. The details of and methodology followed by the 'episode grouper' (proprietary information) is beyond the scope of this research project.

[8] A NAPPI code is a unique identifier for consumables or surgical products used in delivering healthcare and allows for the identification of individual items billed for in a fee-for-service environment

[9] DRG's or diagnosis-related groupings refers to a standardised system of hospital patient classification depending on diagnosis (based on ICD-10-coding).

Summary statistics and reasonability checks performed on the data

First, the distribution of deaths by calendar month are considered for reasonability. This is illustrated in figure 5.2, below.

Figure 5.2 – Distribution of deaths per calendar month

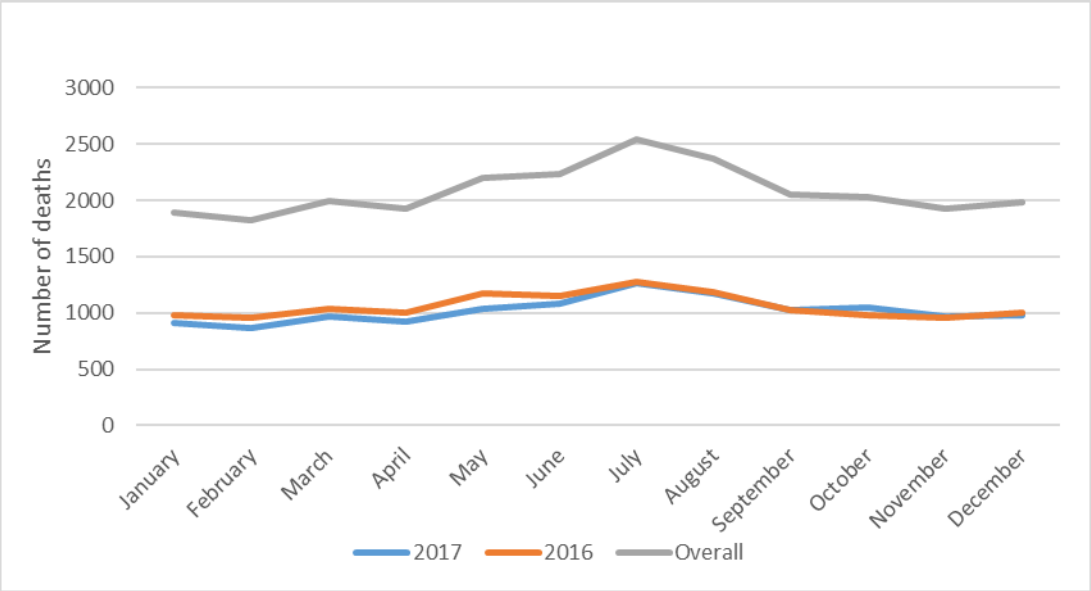
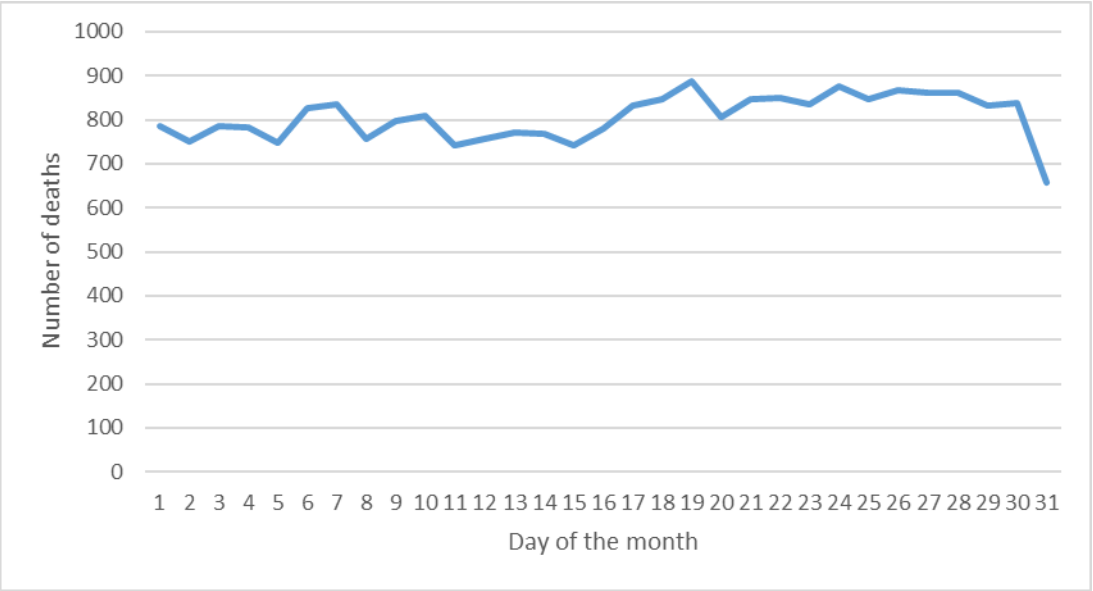


Figure 5.2 shows that there is some variation between calendar months. On average, approximately 1 000 beneficiaries in the exposed population die each month in both calendar years. July sees the highest number of deaths and February sees the lowest number of deaths. The calendar year patterns do not differ significantly.

Next, as a reasonability check on the recording of the dates of death, the distribution of deaths per day of the month is considered. This is shown in Figure 5.3, below.

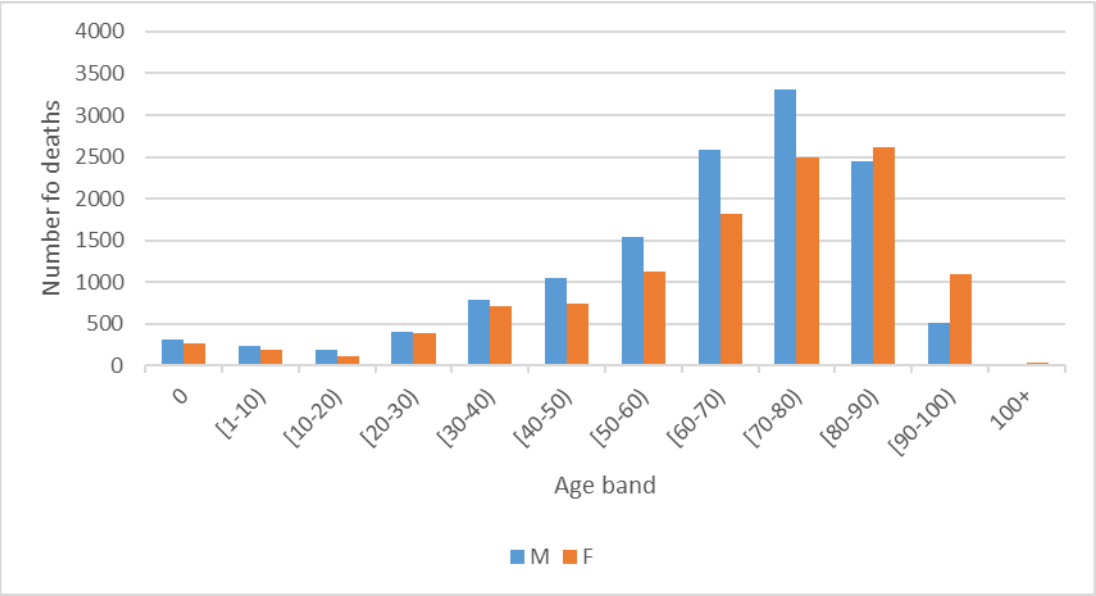
Figure 5.3 – Distribution of deaths per day of the month



It can be seen from Figure 5.3 that the number of deaths per day (across both calendar years) range from around 750 to around 850, with the second half of each month experiencing a slightly higher average number of deaths than the first half of each month, on average. This may be due to random variation. The 31st has a lower number of deaths, as expected, as some months only have thirty days. Overall, the distribution seems reasonable, and there is no evidence of clustering of days of death, particularly at the end of any particular month. Cessation of cover for reasons other than death, e.g. resignation from scheme membership, normally occurs at the end of any particular month.

Next, the demographic characteristics of the sample of decedent beneficiaries are analysed to gain an understanding of the profile of the lives that have died during the period under consideration. Figure 5.4, below, shows the distribution of deaths by age and sex across the two calendar years.

Figure 5.4 – Number of deaths by sex and age band at death



The profile of the decedent beneficiaries is in line with expectations – a relatively higher number of neonatal deaths (age '0' in Figure 5.4) than child deaths, and increasing numbers of deaths with increasing age, dropping off significantly at extreme ages given the low number of beneficiaries exposed at these ages. The split between males and females is also reasonable with a higher proportion of male deaths (54 per cent male, 46 per cent female).

Table 5.1, below gives a breakdown of the deaths by average and median ages (rounded) by sex of the decedent beneficiaries.

Table 5.1 – Age of decedent beneficiaries

Average age (years) at death:	
Males	63
Females	66
Overall	64
Median age (years) at death:	
Males	68
Females	71
Overall	70

A difference of about 3.5 years in the average age at death between the two calendar years is observed. Similarly, the median age at death also shows this discrepancy – 68

years in 2016 vs 71 years in 2017. Upon further investigation it was discovered that there were more neonatal deaths in 2016 than in 2017, bringing both the average and median age at death in 2016 down; and in 2017, there were more deaths at more advanced ages (age eighty and above), pushing the average and median age at death in 2017 up. Given the size of the dataset and number of deaths in each year (around 12 500 deaths per annum), such fluctuation can reasonably be expected to occur. The shape of the distribution of deaths across the two years are broadly similar and follow that of Figure 5.4, above. The overall average and median ages at death, across both calendar years were around 64 years and seventy years, respectively.

5.3 Data limitations

The data analysed in this research projects have a number of limitations. The data contains age-last-birthday for each decedent beneficiary and the exact ages (i.e. date of birth) of the beneficiaries are not available. On average, this means that the beneficiaries that have died are six months older than suggested by the data.

Also, the claims data contains all the details of procedures, medications and consumables claimed for, but no details on the exact cause of death are available. At best, these have to be inferred from the episodes of care and the ICD-10 codes assigned to the claims data. Given the large number of episodes of care and ICD-10 codes and the number of combinations of these for each beneficiary (each claim line is assigned an episode of care/ICD-10 code), such inference are only approximate. Furthermore, the limited clinical information contained in the claims data means that there is no prognostic information (functional status, symptom burden, doctor's prognoses, etc.) that can be used to evaluate definitively the appropriateness and quality of care as was provided. Inference needs to be made based on a number of generalised indicators of quality that are measurable from the data which only potentially implies good or poor quality care.

The claims data contains fields for the claim amounts submitted and the claim amounts paid. Depending on the specific scheme and option and the benefit rules thereof, some claims may be rejected (or only partially paid) by the medical scheme. A number of reasons exist for rejecting (or only partially paying for) claims. These include overall cover limits having been reached, a co-payment or an exclusion

applying, etc. Where limits and co-payments apply, the amounts claimed will be higher than the amounts paid. As a proportion of total claims submitted, the paid claims are approximately 93 per cent. This does not materially affect the overall claim amounts and the conclusions drawn from the analyses. The analyses that follow uses the 'claims submitted' amounts when considering the overall and average claim amounts for the sample of beneficiaries. This reduces the effect that different benefit designs have on claim costs near the end of life, as noted earlier.

Furthermore, the claims data only contains claims submitted by providers (or the beneficiaries themselves) to the medical scheme and excludes any out-of-pocket medical expenses incurred by the beneficiaries that have not been submitted to the medical scheme. These may include fees for private nursing or residential frail care which are typically not covered by medical schemes in South Africa. Furthermore, over-the-counter medications and other day-to-day benefits such as GP or dentist visits may also not be covered on certain plans. Out-of-pocket medical costs incurred by beneficiaries are beyond the scope of this research. It should, however, be borne in mind that scheme exclusions or limits on some benefits may drive higher utilisation of other scheme benefits, e.g. the in-hospital benefits. Benefit design was considered in some detail in Section 3.

Hospice services in South Africa are offered on a charitable basis to provide the necessary end-of-life care and support to indigent individuals (HPCA 2019) and hence hospices frequently fail to bill medical schemes appropriately for the services they provide to scheme beneficiaries. This is despite some schemes offering cover for hospice benefits and billing structures having been put in place to reimburse hospices for the services they provide to medical scheme beneficiaries. The utilisation of hospice services by scheme beneficiaries in the sample of deaths are investigated in a later section, but it should be borne in mind that actual utilisation may be higher than what is observed from the claims data due to potential irregular billing. It is more likely that in-patient hospice care are billed for as opposed to hospice care home visits.

5.4 Special cases/errors identified in the data

Some 520 beneficiaries (around two per cent) had claims dated before their recorded date of joining the scheme. This is investigated and it became apparent in the analyses

that some scheme beneficiaries had terminated their membership within the 24-month period preceding their death and had then had subsequently reinstated their cover prior to death. This means that they did not enjoy cover for the full 24 months and had claims before their final entry date to the scheme, relating to their prior membership. These beneficiaries are considered to have entered the scheme on their final cover reinstatement date and all claims and exposure prior to their final join date are excluded from the analyses.

A number of beneficiaries also had claims recorded after their respective dates of death. These claims only amount to 0.16 per cent of the overall claims for the sample of decedents and are thus immaterial for purposes of these analyses. The death data are accurate in as far as the death dates recorded by the Department of Home Affairs are accurate. The medical scheme administrator uses the Department of Home Affairs death database to scrub the date of death for purposes of their records. This was performed prior to the data being extracted for purposes of this research project. A number of reasons may explain why there are claims recorded after the date of death, e.g. service dates incorrectly captured, either by accident or by intent, inexperience of provider in billing resulting in errors, etc. Section 7.2.1 considers the billing practices of hospices, in particular.

Some dialysis claims for decedents in the 2016 calendar year were very large (unrealistically so) and a factor of 100 times greater than the amount paid for these claims. Upon investigation it appeared that the claims submitted for these procedures were recorded in ZAR cents and not in ZAR Rands, and the claim amounts are adjusted downward by a factor of 100 to correct these errors. This affected less than two per cent of dialysis claim lines submitted for the 2016 decedent beneficiaries and amounts to just over two per cent of the overall claim amounts submitted.

The hospital ‘events’ file contained a number of anomalies, e.g. discharge dates after the date of death, or multiple events in periods that overlap. A possible explanation for the overlap in periods for different ‘events’ may be that the DRG was updated following the initial admission to hospital after more information became available. Complications or acquiring a further condition whilst in hospital, e.g. pneumonia, or sepsis, etc. could also constitute a new (or updated) hospital event. When considering number of hospitalisations and the days spent in-hospital, these

anomalies are allowed for by excluding all days after death and in overlapping periods, only counting each day once. This affected less than three per cent of all hospital 'events'.

5.5 Data analyses methodology

In order to consider claims incurred in different calendar years on a like-for-like basis, an inflation adjustment is applied. All the claim amounts submitted in the years prior to 2017 are adjusted to 2017 ZAR-terms using the weighted average provider tariff increases as published annually by the Council for Medical Schemes. The weights are determined by overall medical scheme spend for the various tariff categories, e.g. the various providers, medicines, equipment, consumables, etc. It is worth bearing in mind that no inflation adjustment methodology is perfect, and that tariff increases are only one component of overall claims cost increases from year to year. Also, the actual weighting of medical scheme expenditure for the sample of decedent beneficiaries are likely to be different to the weightings of expenditure across tariff categories used in determining the overall tariff increase assumptions.

Increase in the utilisation of medical goods and services for the overall scheme population between calendar years is not explicitly allowed for given that the analyses focuses only on a sample of beneficiaries and their individual claims experience. Higher utilisation for individual beneficiaries is reflected in their overall claims experience. Hence only the actual increases in provider tariffs are adjusted for.

The results of the data analyses are presented in Section 6 and the significance and implications thereof are discussed in Section 7. The next subsections outline the methodology followed to perform the data analyses.

5.5.1 Demographic profile and overall claims patterns of decedent beneficiaries

The distribution of deaths in the sample of decedent beneficiaries by calendar month, day of the month and the distribution of age at death by gender were considered earlier in this section. The association of age, sex, geographic location, respectively, with overall claims costs are considered for all decedent beneficiaries. The geographic distribution of deaths (derived from the postal code details contained in the demographic data) are also investigated in some detail.

Further, the geographic analysis considers the claims experience of beneficiaries given that they are classified as having lived in either 'urban' or 'rural' areas, respectively. A report by Statistics South Africa notes the difficulties in defining 'urban' vs 'rural' and highlights various methodologies that may be employed, and the vastly different results using different definitions and approaches (StatsSA 2003). One approach to defining the split is based on population size and population density in particular areas. For purposes of these analyses, the split between 'urban' and 'rural' was done on a pragmatic basis using number of deaths per area as a proxy for population size/density. Any area (by postal code) that experienced 100 or more deaths during 2016 and 2017 (from the sample of decedent beneficiaries) is classified as being an 'urbanised' area and the rest (less than 100 deaths) are classified as being 'rural' areas. Further research is required to classify locations as 'urban' or 'rural' based on a more robust metrics, (e.g. distance to nearest metropole or private hospital, infrastructure in the particular area, etc.), but this is beyond the scope of this research project.

Claim patterns are constructed at various proximities to death (two and four weeks, three, six, twelve and 24 months, respectively) to investigate how claims develop as death for the beneficiaries in the sample draws nearer. In Section 2, the problems with using time-based definitions of dying were considered as well as the usefulness of such definitions, especially when only retrospective data are available (as is the case here).

In a later subsection, these overall claim patterns and characteristics are also considered for the various trajectories of dying as well as for beneficiaries dying in- or out-of-hospital, respectively. Only the experience for lives who were beneficiaries on the scheme for the full 24-month period leading up to their deaths are considered in the analysis of the overall claims patterns. The methodology followed and the results of the analyses for decedent beneficiaries with only partial exposure are given in Sections 5.5.3 and 6.3, respectively.

A brief look is also taken at the distribution of claims excluding the tails of the distribution (the bottom and top ten, twenty, thirty and forty per cent tails of the distribution, respectively) to gauge the effect on average (and median) claim amounts of beneficiaries with higher than average claims. The trimming of the data for this

purpose is done on a pragmatic basis as this sufficiently highlights the effect of these beneficiaries on average claims, and thus the employing of more robust trimming techniques are beyond the scope of this research project.

5.5.2 Place of death

Death in-hospital and the factors associated therewith, and the costs of care in-hospital for the sample of decedent beneficiaries are considered. These are compared to the costs for those who died out-of-hospital. Special consideration is given to the utilisation of hospice care (which is considered to be an indicator of good quality care and an indicator of receiving palliative care near the end of life) and the association between hospice use and overall claims and the likelihood of eventual death in-hospital. Consideration is given to lives having any hospice-related claims in the last 24 months of life, as well as to lives having hospice-related claims during their last four weeks of life – when death is imminent.

The number of hospitalisations and the number of days spent in-hospital for beneficiaries utilising hospice services are also considered and compared to the experience of those who had received no hospice-related care leading up to their deaths.

5.5.3 Analysis of lives with partial exposure

Some decedents in the sample were not scheme beneficiaries for the full 24-month period. They were either new joiners, or had gaps in their coverage – lapsed and subsequently reinstated their cover during their last 24 months of life. Their claims costs are analysed separately to determine whether the profile and the experience of these beneficiaries differed significantly from that of scheme beneficiaries who were on the scheme for longer than the full 24-month period under investigation. This may indicate whether these lives selected against the medical scheme in becoming scheme members/beneficiaries.

5.5.4 Ageing populations, lifestyles and chronic non-communicable diseases

The impact and cost implications of chronic non-communicable conditions and multi-morbidity are important given the increasing incidence and prevalence thereof in

medical scheme risk pools (Govuzela, Thsehla and de Villiers 2018). These are briefly investigated from the information contained in the administrative claims and chronic authorisation data.

The chronic file contains details of the chronic condition authorisations for each decedent beneficiary in the sample. In the analyses these conditions are grouped into main chronic illness groups, predominantly driven by the bodily systems or organs they affect, e.g. the heart, the lungs, the endocrine system, etc. 'Cancer[10]' is a special group that covers all cancer authorisations for all bodily systems and organs. 'Hypertension' and 'hyperlipidaemia', which aren't diseases as such, but conditions that are major risk factors for the development of chronic heart diseases are included in the 'chronic heart disease' category. In South Africa, the legislated CDL includes full payment at the point of service for the treatment and management of hypertension and hyperlipidaemia. It is thus sensible to consider these as chronic conditions/diseases (of the heart) for purposes of this part of the analyses.

Less prevalent diagnosis groups included those for chronic liver illness, chronic skin conditions, haematological conditions (excluding cancer related to the blood or blood-forming organs), immunological conditions (excluding HIV) and chronic prostate conditions. Together these groups affect only six per cent of the total sample and are grouped together in a group called 'OTHER chronic conditions'.

Certain diseases of the central nervous system and musculoskeletal systems provided some difficulty in grouping them into their respective groups since a disease of the nervous system often manifests as a musculoskeletal deficiency, e.g. cerebral palsy or muscle dystrophy. However, the overall prevalence of these two groups of conditions, combined, total only five per cent of the overall prevalence of chronic conditions. The bulk of these conditions being musculoskeletal conditions, i.e. the various forms of arthritis. Given the relatively low prevalence of these conditions, the impact of grouping these as either musculoskeletal disorders or nervous system disorders has no material impact on the results of the investigation. The majority of

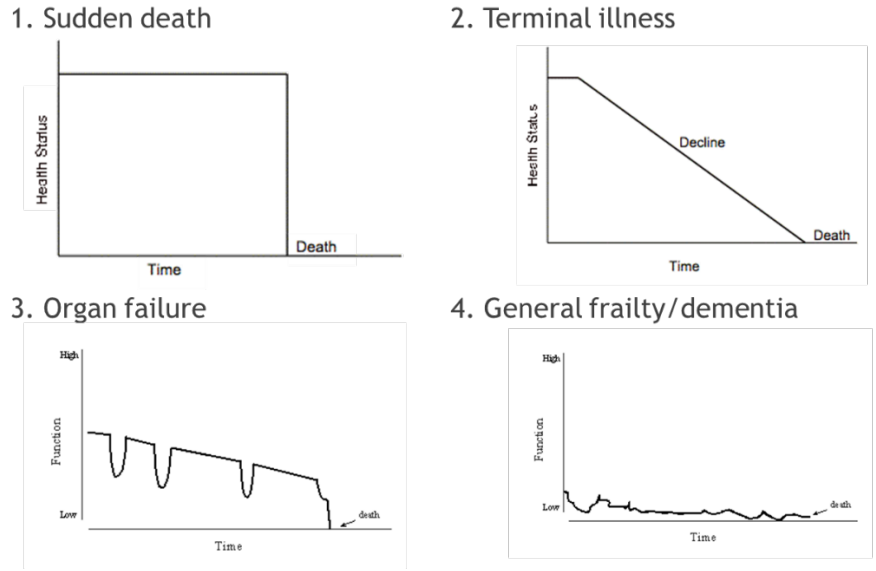
[10] In the data, for the sample of decedent beneficiaries, "Cancer" is recorded as a chronic condition, and is treated as such for the analyses in this subsection. This is despite some cancers being curable/treatable. In the next subsection, where "cancer" is deemed to be the most likely cause of death, it is considered as one of the main trajectories of dying.

these ambiguous conditions are included with musculoskeletal conditions. For a number of other chronic illnesses similar difficulties were experienced and these are pragmatically grouped under a sensible category based on the bodily system or organ they predominantly affect, e.g. dementia is grouped as a condition affecting the brain, and schizophrenia is grouped as a mental health condition, etc.

5.5.5 Trajectories of dying

Following the high-level demographic and claims analyses, above, the decedent beneficiaries are then segmented into the main trajectories of dying to analyse their end-of-life care costs based on their particular trajectory of dying. Differences between the profiles of the lives and claim patterns given each respective trajectory are investigated. The methodology used by Lunney, Lynn and Hogan (2002) which involves a sequential analysis and allocation of a sample of Medicare decedents into the various trajectories of dying, is also broadly followed here. Given the nature of the data used in this research project (retrospective claims data of medical scheme beneficiaries who have died), no information on the beneficiaries' functional status or the decline in functional status over time, their symptom burden or the doctor's prognoses leading up to death are directly available or measurable. However, broad trajectories of dying (e.g. "Sudden death", "Cancer", "Organ failure" and "General frailty") can be analysed based on the observed level of healthcare spending and based on the diagnoses and episodes of care respective beneficiaries experienced during their last year of life. These trajectories are illustrated in Figure 5.5.5.1, below, plotting individuals' health or functional status against time, eventually culminating in death, or a functional status of zero.

Figure 5.5.5.1 – Trajectories of dying



[11] Lunney, Lynn and Hogan (2002)

Lunney, Lynn and Hogan (2002) classifies those decedents having claims of less than $2000USD and being younger than eighty as belonging to the "Sudden death" trajectory. This amount was converted to 2017-ZAR-terms using the methodology described by Turner, Lauer, Tran, Teerawattananon *et al.* (2019), i.e. first converting to ZAR-terms at the 31 December 2002 USD/ZAR-exchange rate and then inflating it to 1 January 2017 using the headline South African inflation index (StatsSA 2019). This came to an amount of approximately R36 000. Medicare only covers persons aged 65 and older, and medical schemes cover lives of all ages (i.e. 35 per cent of all deaths in the sample are beneficiaries younger than 65 years). Given this, and given that medical costs generally increase with age as a result of increasing chronicity (Yu, Ravelo, Wagner and Barnett 2004), the threshold for sudden deaths was set, pragmatically, at R24 000. This amounts to an average of R2 000 per month during the last year of life. A further reason for reducing the threshold is due to frail care and home nursing care being specific medical scheme exclusions, and frail beneficiaries who had died at older ages with relatively low average claims would then erroneously

[11] Lunney, J.R., Lynn, J., and Hogan, C. (2002). Profiles of older medicare decedents. *Journal of the American Geriatrics Society* **50**(6): 1108-1112.

be classified as “Sudden deaths”. ‘Sudden death’ as defined here is intended only for ‘accidental’ and/or ‘unanticipated’ deaths of beneficiaries that had a low level of medical scheme claims during their last year of life.

Given that the exact cause of death for decedent beneficiaries are not available from the claims data, akin to the study on which this methodology is based, a similar approach is followed whereby the assigned episodes of care and ICD-10 codes are analysed to determine the most costly episode/ICD-10 combination for each beneficiary. The most likely cause of death is inferred from this and the beneficiary is allocated to the appropriate trajectory of dying based hereon. Following this methodology (based only on most costly episode/ICD-10 combinations) may result in some beneficiaries being incorrectly classified into the respective trajectories of dying. However, on average, this approach results in a reasonable allocation of beneficiaries to particular trajectories of dying. Appendix 1 contains an extract of the episodes of care and ICD-10 combinations used to classify beneficiaries into the particular trajectories of dying.

After decedent beneficiaries are allocated to the “Sudden death” trajectory as per the above methodology, the “Cancer” trajectory allocation is performed. If the most costly episode of care/ICD-10 combination is cancer-related, then the beneficiary is assigned to the “Cancer” trajectory.

Next, beneficiaries are assigned to the “Organ failure” trajectory. Beneficiaries falling into this trajectory had dominant episodes of care and accompanying ICD-10 coding related to specifically either of heart, respiratory, renal or hepatic (liver) failure.

For the final trajectory, “General frailty”, Lunney, Lynn and Hogan (2002) allocates those with the following diagnoses: stroke, Alzheimer’s disease, dementia, pneumonia, Parkinson’s disease, incontinence, dehydration, delirium, hip fractures, syncope and cellulitis. Similar episodes of care and diagnoses were used for this sample of decedents, including more generalised heart, respiratory, and other organ diseases, i.e. not specific ‘failure’ of these organs, as well as mental health conditions. Furthermore, lives younger than fifty were removed and included in the “Other” group as they are unlikely to be generally ‘frail’.

The remainder of the beneficiaries are grouped into the “Other” group. These are beneficiaries younger than fifty who aren’t grouped into any of the “Sudden death”,

"Cancer" or "Organ failure" groups, those for whom no episode of care/ICD-10 code are assigned or where the dominant episode of care/ICD-10 combinations are unlikely causes of death, e.g. conditions related to ears, eyes, skin, teeth, etc. The "Other" group also contains episodes related to pregnancy and childbirth, claims from trauma-related episodes as well as those related to acute infections. Given the different set of lives considered in the Medicare study, there would not have been any pregnancy and childbirth-related deaths in their dataset (i.e. only lives aged 65 and above are covered by Medicare).

5.5.6 Decedent beneficiaries with high end-of-life care costs

The demographic profile and claims experience of the highest claiming lives (in terms of overall claim amount over the last 24 months of life) are considered. These are the lives that predominantly drive the high overall average claims costs observed near the end of life for medical schemes. Their demographic profile, trajectories of dying, place of death and overall claims profiles are considered in some detail to understand the drivers of their high observed costs when compared to the experience of the overall sample of decedent beneficiaries.

5.5.7 Measuring the quality of care near the end of life

Potential indicators of the quality of care near the end of life that can be measured from the administrative claims data are briefly evaluated and measured. The measurable indicators are: death in-hospital, the number of days spent in-hospital, receiving chemotherapy near the end of life and the utilisation of hospice care services near the end of life.

Details surrounding hospitalisations over the course of the last 24 months of life for the sample of scheme beneficiaries are contained in the 'Events' file. Each event of duration longer than one day (i.e. where the discharge date is at least one day after the admit date) for lives with full exposure is considered as a hospitalisation.

Chemotherapy and/or initialising a new chemotherapy treatment regimen near the end of life are considered to be indicators of poor quality of care near the end of life (Earle *et al.* 2003). The last two weeks and four weeks of life, respectively, are considered here as being 'near' the end of life. The claims data contain the service date

for all claim lines and this date is used to determine the length of time between the last time chemotherapy was administered and the date of death. The claims data contains a field that gives the procedure codes and their descriptions. The dates associated with procedure codes for the administering of infusional or non-infusional chemotherapy (i.e. the daily global fee for the administering of chemotherapy) are compared to the date of death for individual beneficiaries.

Next, hospice utilisation near the end of life is considered. Dates of hospice-related claims are compared to the date of death to determine the proximity of hospice utilisation to death. It is important to note that ad hoc billing processes of hospices may result in billing errors or even non-billing for hospice services utilised by scheme beneficiaries. Potential billing errors made by providers can be seen when considering the number of beneficiaries that have service dates for claims recorded after their date of death (ninety of the 1 219 (or 7.4 per cent) beneficiaries that had utilised some billed hospice services). To be pragmatic, it is assumed that all hospice claims after death occurred on the date of death. Knowing that there may be errors in the hospice claims data impedes on determining exactly how long prior to death these beneficiaries had enrolled for hospice care, and up until which point they received hospice care. However, interesting insights can still be gleaned from the analyses of hospice enrolment and the utilisation of hospice services.

The literature frequently refers to seven days as being an indicator for late hospice enrolment and that three months prior to death is a desirable benchmark for enrolment (Diamond, Russell, Kryza-Lacombe, Bowles *et al.* 2015; Wang, Knight, Evans, Wang *et al.* 2017; Mulville, Widick and Makani 2019). Given the uncertainty about hospice billing and potential errors, looking at the last seven days of life, only, is spurious. However, looking at longer periods, two and four weeks, and three months, respectively, gives a better idea of who *may* have enrolled late for hospice care, or at least who had not enrolled more than three months before death (earlier enrolment is desirable). Also, note that disenrollment from hospice care can also not be measured from the data. Some decedent beneficiaries may have received hospice-related services more than three months before death, but may have opted for hospital-based care at a later stage, potentially stopping hospice care and not benefiting from hospice services

anymore. The results of the analyses into measurable indicators of quality of care near the end of life are discussed in Section 7.7.

The results of all the analyses described above are presented in Section 6, next. The interpretation of the results and a discussion on the practical implications of these results for the medical schemes industry in South Africa follows in Section 7.

6 Data analyses and presentation of the results

The analyses and results that follow are divided into seven main subsections, as set out in the methodology, above.

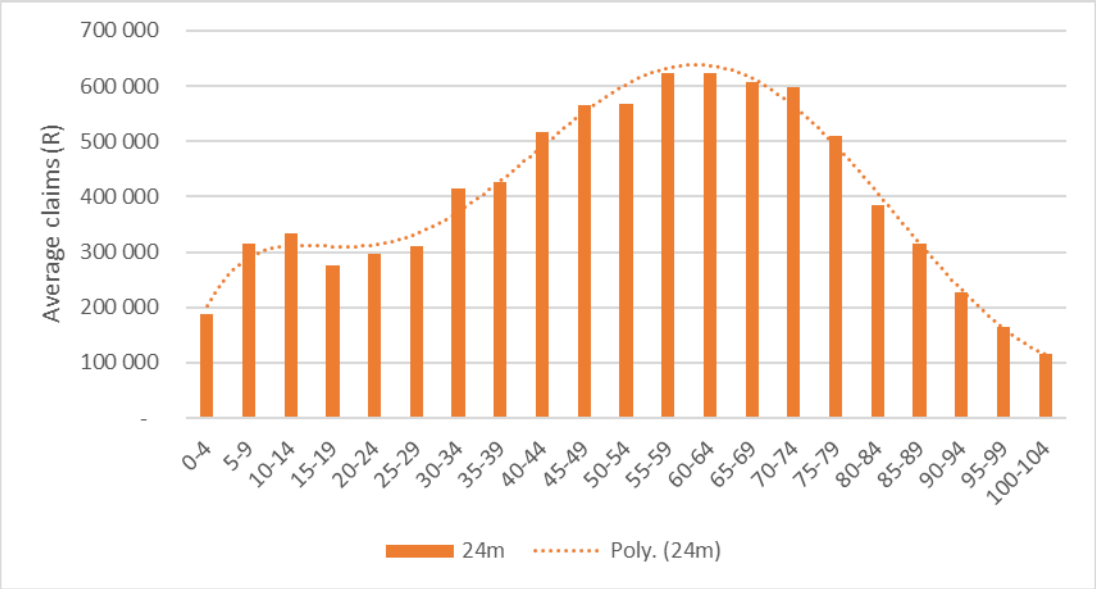
6.1 Demographic profile and overall claims patterns of decedent beneficiaries

High-level summary statistics of the demographic profile of the decedent beneficiaries were given in Section 5.5. Next, the overall claims patterns of the decedent beneficiaries are considered

All claim amounts in this research project are stated in 2017 ZAR-terms having been adjusted by the weighted average medical scheme tariff increases as reported by the Council of Medical Schemes. The overall claims analyses for lives with full exposure are presented in this subsection. Of the 24 980 deaths, 21 457 (or 86 per cent) were scheme beneficiaries for the full 24-month period. However, given that the number of lives with less than full exposure is significant – fourteen per cent of decedents (3 523 lives) – their claims are analysed separately in Section 6.3. The reason for this is to investigate whether there are any apparent signs of anti-selection given that voluntary and open enrolment, and community rating are legislated. Furthermore, medical schemes may only perform limited underwriting on new joiners to their schemes. Neonates (died aged 28 days or younger) accounted for 1.1 per cent (284 lives) of all decedents and child decedents aged younger than two years, excluding neonates, accounted for a further 1.6 per cent (404 lives) of all decedents.

Figure 6.1.1, below, shows the average claim amount over the last 24 months of life for decedent beneficiaries with full exposure in five-year age bands.

Figure 6.1.1 – Average claims over the last 24m of life given age band at death



From Figure 6.1.1, it can be seen that claims costs over the last 24 months of life peak for beneficiaries between the ages of 55 and 75, before rapidly decreasing at more advanced ages. Note that all neonates and children under two years are excluded as they did not contribute full exposure during the period. The overall average claims over the last 24 months of life for those with full exposure is approximately R480 000 (in 2017 ZAR-terms).

The distribution of claims by age band at proximities to death shorter than the full 24-month period (i.e. at two and four weeks, and three, six and twelve months to death, respectively), exhibit a similar pattern to that observed in Figure 6.1.1. The analyses performed in the next subsection (Section 6.1.1) considers the cumulative claims for decedent beneficiaries at these proximities to death.

Table 6.1.1, below, illustrates the overall claims costs for males vs females at the various proximities to death.

Table 6.1.1 – Average cost by proximity to death – split by sex

	Average male cost (R) – per beneficiary	Average female cost (R) – per beneficiary
2w	89 000	80 000
4w	137 000	122 000
3m	232 000	209 000
6m	292 000	272 000
12m	375 000	351 000
24m	494 000	464 000

It can be seen that males, on average, experience higher claims than females at all proximities to death. To confirm this, the null hypotheses that average claims for males are equal to that of females are tested at the various proximities to death. The null hypotheses are rejected unequivocally with all p-values ~0. Z-tests were used given the sample sizes of greater than thirty and ratios of variances between 0.5 and two (i.e. making it reasonable to assume equal sample variances).

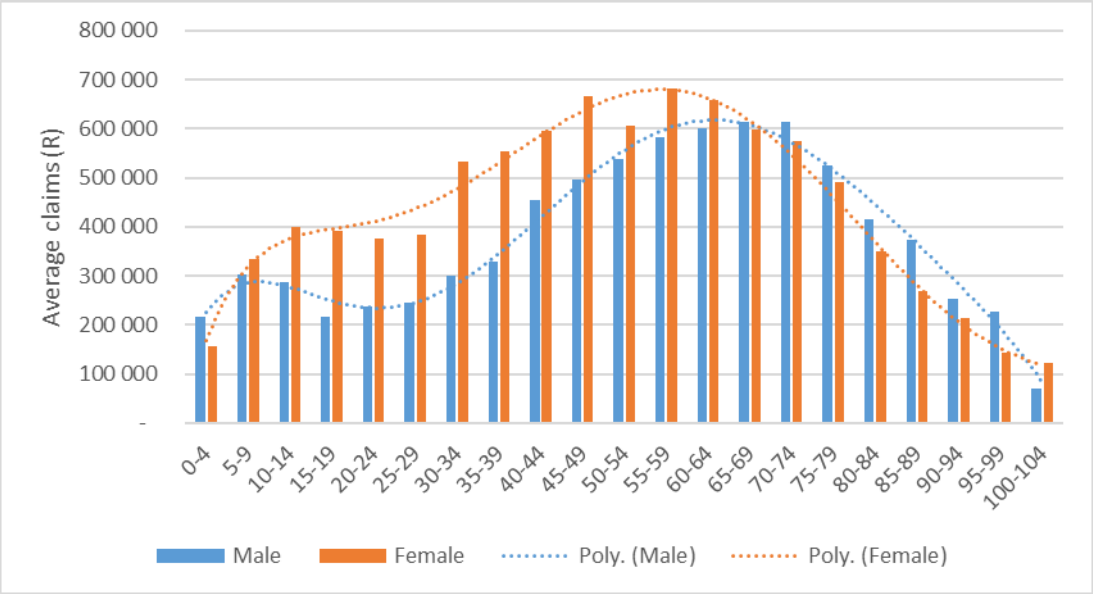
Table 6.1.2, below, shows the standard deviations and lower- and upper bounds of the 95 per cent confidence intervals using a Student's t-distribution at the various proximities to death for males and females, respectively.

Table 6.1.2 – Standard deviation and confidence interval bounds: Males vs Females

	Males – count: 11 486			Females – count: 9 972		
	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
2w	146 000	87 000	92 000	123 000	78 000	83 000
4w	220 000	133 000	141 000	190 000	118 000	126 000
3m	367 000	225 000	239 000	325 000	203 000	216 000
6m	435 000	284 000	300 000	421 000	263 000	280 000
12m	530 000	366 000	385 000	505 000	341 000	360 000
24m	637 000	482 000	505 000	609 000	452 000	476 000

Given the different age profiles of male and female decedent beneficiaries, it is worthwhile to consider the average claims cost for males and females in their respective age bands, depicted in Figure 6.1.2, below.

Figure 6.1.2 – Average claims over the last 24 months given sex and age band at death



It is interesting to observe the overall claim patterns over the last 24 months for males and females in their respective age bands. Except for the age band 0-4 (which had low numbers of deaths for both males and females), females, on average, experience consistently higher claims than males up until age 65. From age 65, onwards, except for the band 100-104 (again, very low numbers of deaths), males experience consistently, albeit less pronounced, higher claims than females. At all proximities to death, a similar pattern is observed. To confirm this, statistically, null hypotheses that claims are equal for males and females younger, and older than 65 years, respectively, are tested at the various proximities to death. Except for lives younger than 65 during their last two weeks of life (rejected at two per cent-level), the null hypotheses are unequivocally rejected at the one per cent level. Thus, females experience higher medical scheme claims than males at the various proximities to death if they are younger than 65 years old and conversely, males experience higher medical scheme claims than females after the age of 65.

Table 6.1.3, below, shows the standard deviations and lower- and upper bounds of the 95 per cent confidence intervals using a Student's t-distribution at the various proximities to death for males and females aged below and above 65, respectively.

Table 6.1.3 - Standard deviation and confidence interval bounds: Males vs Females (younger and older than 65, respectively

	Male (<65) - Count: 4 242			Female (<65) - Count: 3 120		
	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
2w	160 000	87 000	96 000	146 000	94 000	104 000
4w	242 000	130 000	144 000	228 000	142 000	158 000
3m	415 000	219 000	244 000	385 000	243 000	270 000
6m	503 000	282 000	312 000	491 000	319 000	354 000
12m	623 000	360 000	398 000	611 000	425 000	468 000
24m	728 000	463 000	507 000	800 000	567 000	623 000
	Male (>=65) - Count: 7 243			**Female (>=65) - Count: 6 852**		
2w	138 000	85 000	91 000	109 000	69 000	74 000
4w	206 000	132 000	142 000	168 000	105 000	113 000
3m	336 000	225 000	240 000	290 000	181 000	195 000
6m	390 000	280 000	298 000	381 000	233 000	251 000
12m	467 000	363 000	384 000	441 000	297 000	317 000
24m	577 000	485 000	512 000	486 000	393 000	416 000

Next, the geographic distribution of all decedent beneficiaries in the sample are considered (including those with partial exposure). Figure 6.1.3 illustrates the proportion of overall deaths across the nine provinces of South Africa.

Figure 6.1.3 – Number of deaths of deaths by province

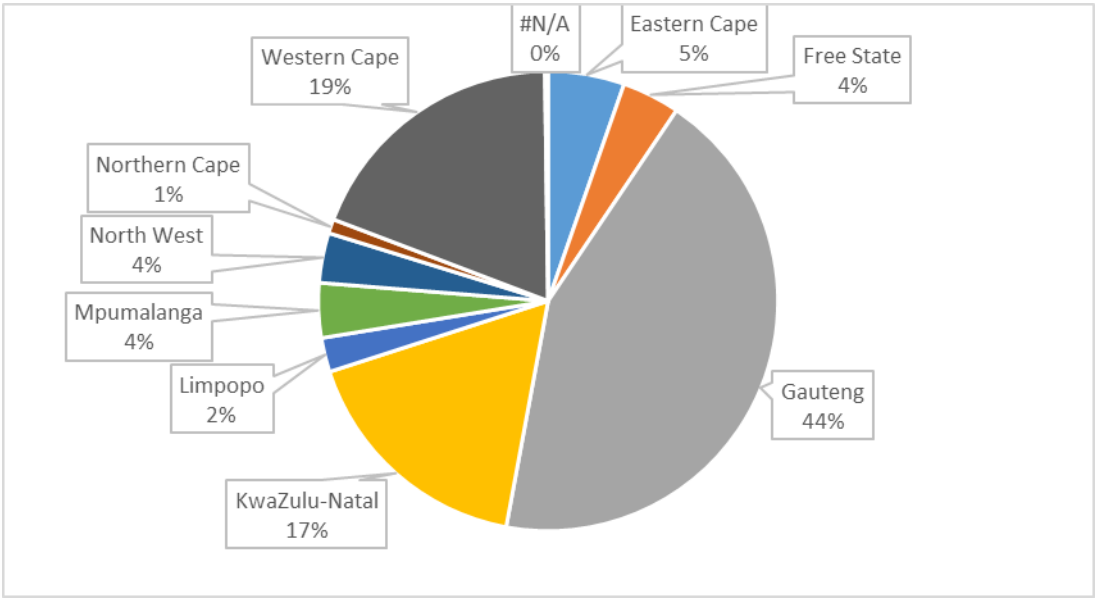
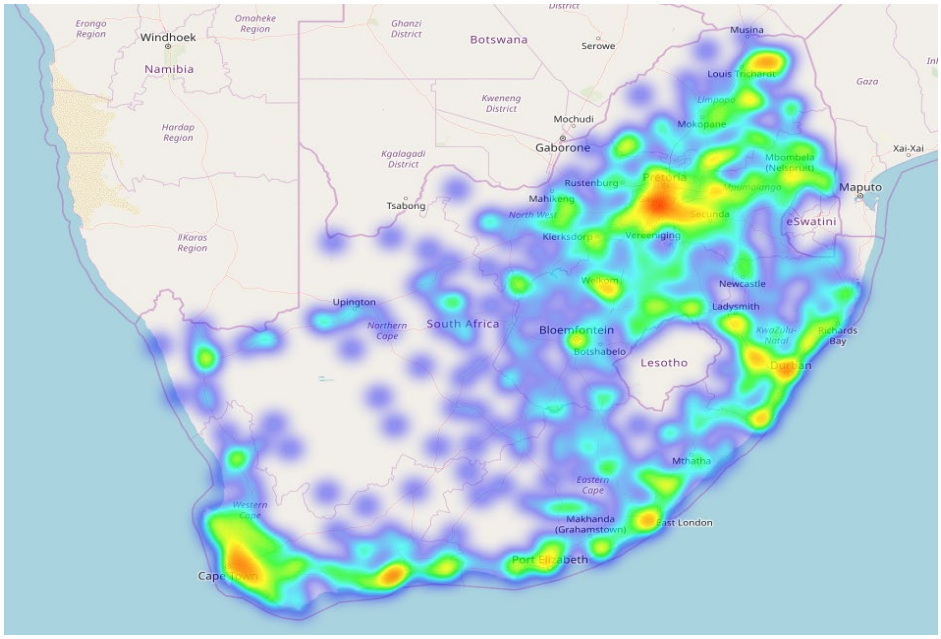


Figure 6.1.3 shows that deaths are concentrated predominantly in provinces with large urban areas, i.e. Gauteng (Johannesburg and Pretoria), Western Cape (Cape Town) and Kwazulu-Natal (Durban).

Almost half of the deaths occurred in Gauteng, and, on average, the Gauteng decedent beneficiaries experienced the highest average claims over the last 24 months of life. The Northern Cape experienced the lowest number of deaths as well as the lowest average claim costs per decedent beneficiary. Figure 6.1.4 illustrates a more granular distribution of deaths across the country in the form of a heat map based on the postal codes recorded for individual decedent beneficiaries in the sample.

Figure 6.1.4 – Location of death heat map



The heat map above clearly shows the concentration of deaths in the more urbanised areas of the provinces with the largest number of deaths (red blotches), e.g. Johannesburg, Cape Town and Durban, and the low concentration of deaths in more rural areas (areas with no blotches or scattered blue spots), particularly in the Northern Cape Province.

Table 6.1.4 highlights a pragmatic split between 'urban' and 'rural' areas and their respective average medical scheme claims costs during the last 24 months if life.

Table 6.1.4 – Urban vs rural split

	Count	Average claims cost (R) – per beneficiary	Standard deviation (R) – per beneficiary
Urban	17 215	489 000	648 000
Rural	7 725	410 000	551 000
Total	**24 980**	**464 000**	**626 000**

An area is considered 'urban' here if it experienced 100 or more deaths. This is a pragmatic distinction between 'urban' and 'rural', used only to illustrate the difference in average claims per decedent beneficiary based on the relative size of the area (measured by the number of deaths in the particular area, where an 'area' is represented by its postal code). Given the high-level split between 'urban and 'rural', approximately 69 per cent of decedent beneficiaries resided in an urbanised area. This split between 'urban' and 'rural' is similar in magnitude to that found in report produced by Statistics South Africa (68.5 per cent) in which urbanity is defined by population size and population density in the particular areas (StatsSA 2003).

The null hypothesis that average claims costs for 'rural' and 'urban' areas are equal is rejected for the alternative hypothesis that 'urban' areas experience higher average claims costs per decedent beneficiary with a p-value of ~0. The null hypothesis was tested using a standard z-test given that the sample sizes are large enough (greater than thirty) and the ratio of the variances lie between 0.5 and two (1.38).

Table 6.1.5, below, shows the lower and upper 95% confidence interval bounds for average claims in urban and rural areas, respectively, using a Student's t-distribution of claim sizes.

Table 6.1.5 – Lower and upper confidence bounds – urban vs rural

	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
Urban	648 000	479 000	499 000
Rural	551 000	397 000	422 000

It can be concluded that the average overall claims are higher in the more urbanised areas (given the high-level distinction between what is classified as 'urban' and what is classified as 'rural'). Beneficiaries residing in more urbanised areas also experienced a greater standard deviation in overall claims over their last 24 months of life. This

could be indicative of those residing in more urbanised areas having a greater number of care options (and more expensive care options) available to them near their end of life as compared to those residing in areas that are more 'rural'.

6.1.1 Claims by proximity to death

Total, average and median claim amounts at various proximities to death (i.e. all the claims in the last x-period before death) for lives with full exposure are given in table 6.1.1.1, below.

Table 6.1.1.1 Claims - proximity to death

	Total claims (Rm)	Total proportion of claims	Average claims (R) – per beneficiary	Median claims (R) - per beneficiary
2w	1 827	18%	85 000	45 000
4w	2 793	27%	130 000	62 000
3m	4 754	46%	222 000	111 000
6m	6 064	59%	283 000	153 000
12m	7 808	76%	364 000	210 000
24m	10 297	100%	480 000	290 000

As can be seen from the Table 6.1.1.1, the total claims during the last 24 months of life for the 21 457 beneficiaries that had full exposure amount to around R10.3bn. 46 per cent of this is spent in the final three months of life and 27 per cent in the last four weeks of life. Another way to consider this is to look at the average cost of medical care per day given the proximity to death. This is given in Table 6.1.1.2, below.

Table 6.1.1.2 Claims cost per day – Proximity to death

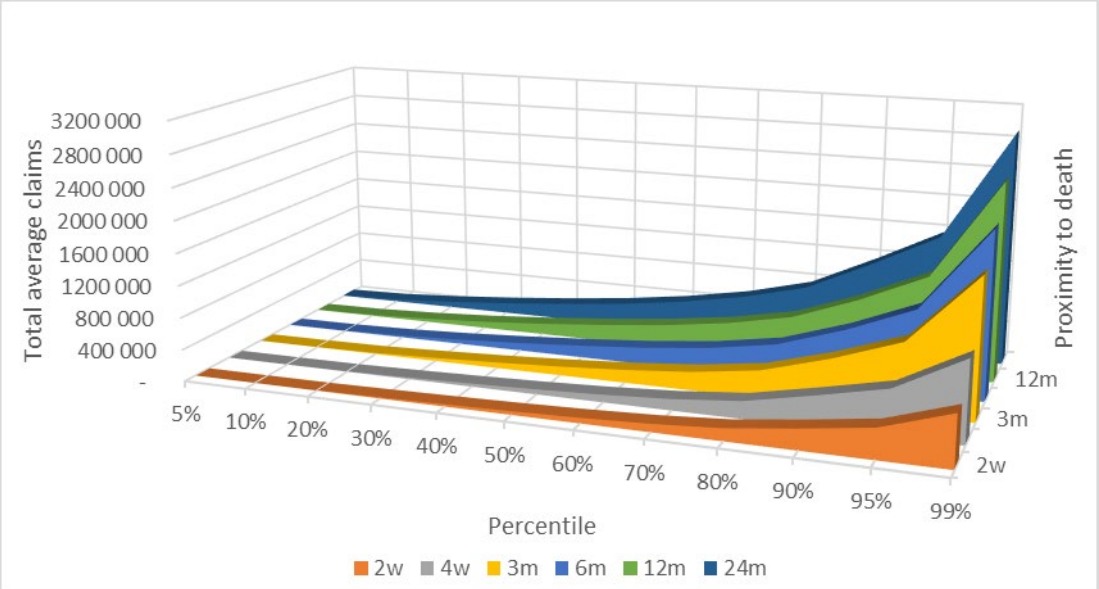
Proximity to death	Average cost per day (R) – per beneficiary	Median cost per day (R) – per beneficiary
2w	6 082	3 204
4w	4 984	2 218
3m	2 435	1 224
6m	1 553	838
12m	996	576
24m	657	397

Average claims cost per day over the last 24 months of life are around R660 per person per day vs during the last two weeks of life, the average cost is nearly ten times higher

at around R6 000 per person per day. This is across all decedent beneficiaries, at all ages and from all causes. At the various proximities to death, it can also be seen that there is a significant discrepancy between the size of the average claim costs and the median claim costs per day. This indicates that there is large variation in total claims around the mean for the decedent beneficiaries.

Figure 6.1.1.1 illustrates the distribution of total claims by proximity to death (two weeks to 24 months) by deciles of the distribution. The 5th, 95th and 99th percentiles are also included to give a more complete picture at the extremes of the distributions.

Figure 6.1.1.1 – Average claims build up by proximity to death - Percentiles of distribution



From Figure 6.1.1.1, it can be seen that, at all proximities to death, the bottom thirty per cent of beneficiaries claim significantly less compared to the total claims of the top thirty per cent of beneficiaries. The 100th percentile of the distribution has been excluded from the figure as the maximum claims at each proximity is very high (relative to even the 99th percentile) and distorts the graph significantly. The top one per cent of claimants claimed almost ten per cent of the overall claims for all the decedent beneficiaries over the last 24 months of life. The top ten per cent claimed 39 per cent of overall claims and the top thirty per cent claimed 71 per cent of overall claims. The bottom fifty per cent of claimants only claimed twelve per cent of the

overall claims in the last 24 months of life, and the bottom ten per cent almost none compared to the top claimants.

Table 6.1.1.3, below, illustrates the cumulative proportion of overall claims at various proximities to death, highlighting the skewed distribution of claims towards the high claimants at the end of life.

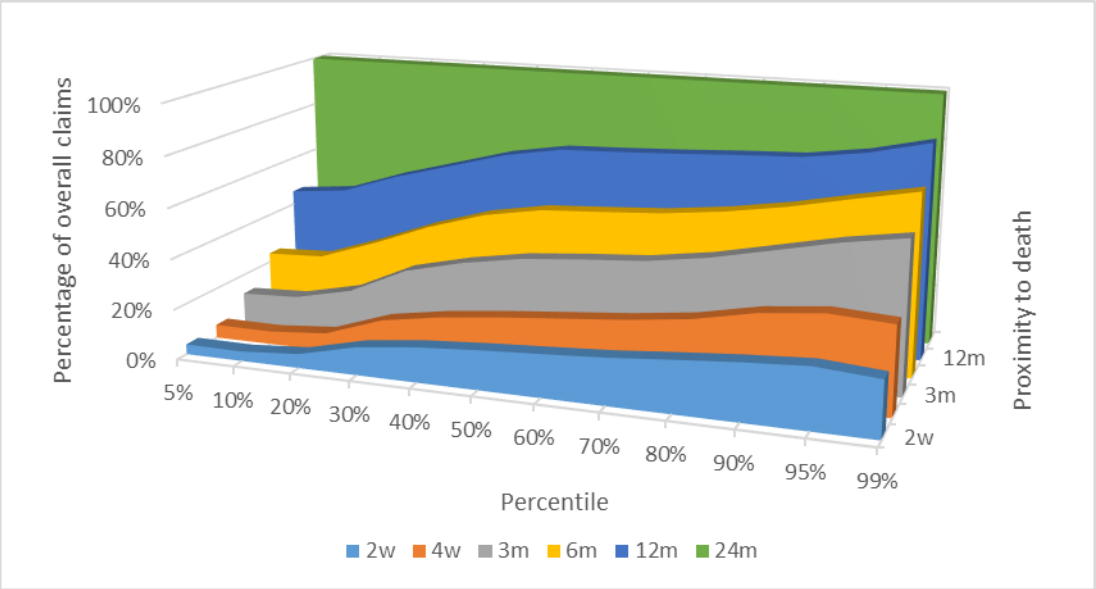
Table 6.1.1.3 – Distribution of high and low claimers

	Proportion of overall claims by proximity to death: Top and bottom ends of distribution					
Percentile	**2w**	**4w**	**3m**	**6m**	**12m**	**24m**
Top 1%	9%	9%	10%	10%	10%	9%
Top 5%	29%	30%	31%	29%	27%	25%
Top 10%	45%	46%	46%	44%	42%	39%
Top 20%	65%	67%	65%	63%	61%	58%
Top 30%	78%	79%	78%	76%	74%	71%
Top 40%	87%	88%	86%	85%	83%	81%
Top 50%	93%	93%	92%	91%	90%	88%
Bottom 5%	0%	0%	0%	0%	0%	0%
Bottom 10%	0%	0%	0%	0%	0%	0%
Bottom 20%	0%	0%	0%	1%	1%	1%
Bottom 30%	1%	1%	2%	2%	3%	3%
Bottom 40%	3%	3%	4%	5%	6%	7%
Bottom 50%	7%	7%	8%	9%	10%	12%

From this distribution it can be seen that end-of-life medical care, on average, is very expensive, but that it is a reasonably small number of very high claiming decedent beneficiaries that drive the majority of these costs.

Figure 6.1.1.2, below, shows the cumulative distribution of claims by decile (including the 5th and 99th percentiles) at the various proximities to death.

Figure 6.1.1.2 – Percentage of overall claims by proximity to death – Percentiles of distribution



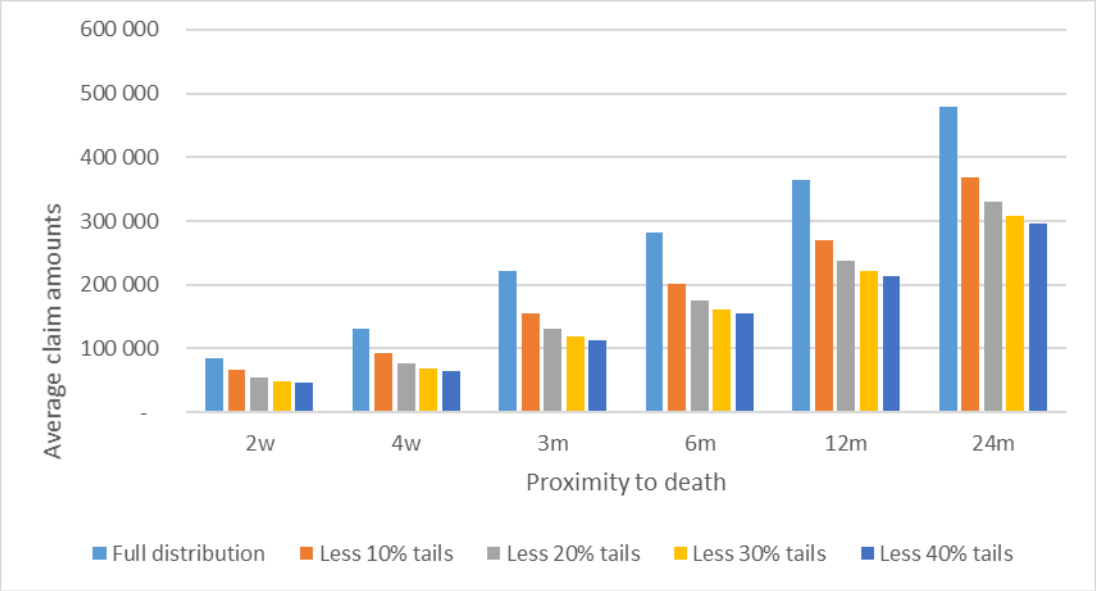
From figure 6.1.1.2 it can be seen that the low claimants (bottom thirty per cent) have relatively low levels of claims near their date of death (two weeks up to even twelve months) with 40-55 per cent (depending on relative claim level – i.e. percentile of the distribution) of claims occurring between twelve and 24 months prior to death. For high claimants (top thirty per cent), almost twenty per cent of claims occur in the last two weeks of life and roughly fifty per cent in the last three months of life, with only fifteen to 25 per cent of their claims being between twelve and 24 months prior to death.

A relatively small proportion of decedent beneficiaries drive the observed high level of average medical scheme claim costs near the end of life. The majority of decedent beneficiaries (bottom fifty per cent) claim only slightly more (twelve per cent of overall claims) than the top one per cent (nine per cent of overall claims) of claimers. The top thirty per cent of claimers are considered in further detail in this Section 6.6 to identify the main factors associated with their claims experience, e.g. age, sex, trajectory of dying, number and length of hospitalisations, place of death and the impact of co-morbidities on their medical scheme claims.

6.1.2 Truncated distributions

The analysis, so far, has been performed looking at the full distribution of lives with full exposure, thus including all outliers. Figure 6.1.2.1, below, details the average claims per decedent beneficiary (at the various proximities to death) for the overall and truncated distributions.

Figure 6.1.2.1 –Distribution of average claims by proximity to death – truncated distributions



As can be seen from Figure 6.1.2.1, excluding a step-wise increasing tail, decreases the average claim amount at all proximities to death. The average claim costs seem to stabilise at around the thirty per cent level, emphasising the importance of investigating and better understanding the claims experience of the top thirty per cent of claimers – explored in Section 6.6. The trimming is done pragmatically as this sufficiently highlights the impact of outliers on average claim amounts at all proximities to death.

6.1.3 Claims by provider type

Table 6.1.3.1 highlights the total proportion of claims for the top ten provider types at the various proximities to death.

Table 6.1.3.1 – Claims by practice type

Practice type (Top 10)	2w	4w	3m	6m	12m	24m
Private hospitals	56%	57%	57%	54%	51%	48%
Pharmacy	1%	2%	3%	5%	7%	9%
Radiologist	5%	5%	5%	5%	5%	6%
Clinical Pathologist	6%	6%	5%	5%	5%	5%
Physicians	5%	5%	5%	4%	4%	4%
Blood transfusion	6%	6%	5%	4%	4%	4%
Clinical or Medical technology	4%	3%	3%	3%	3%	3%
Radiotherapist	1%	1%	1%	2%	2%	3%
Anaesthetist	3%	2%	2%	2%	2%	2%
Surgeon	2%	2%	2%	2%	2%	2%
Total	**88%**	**88%**	**87%**	**87%**	**86%**	**85%**

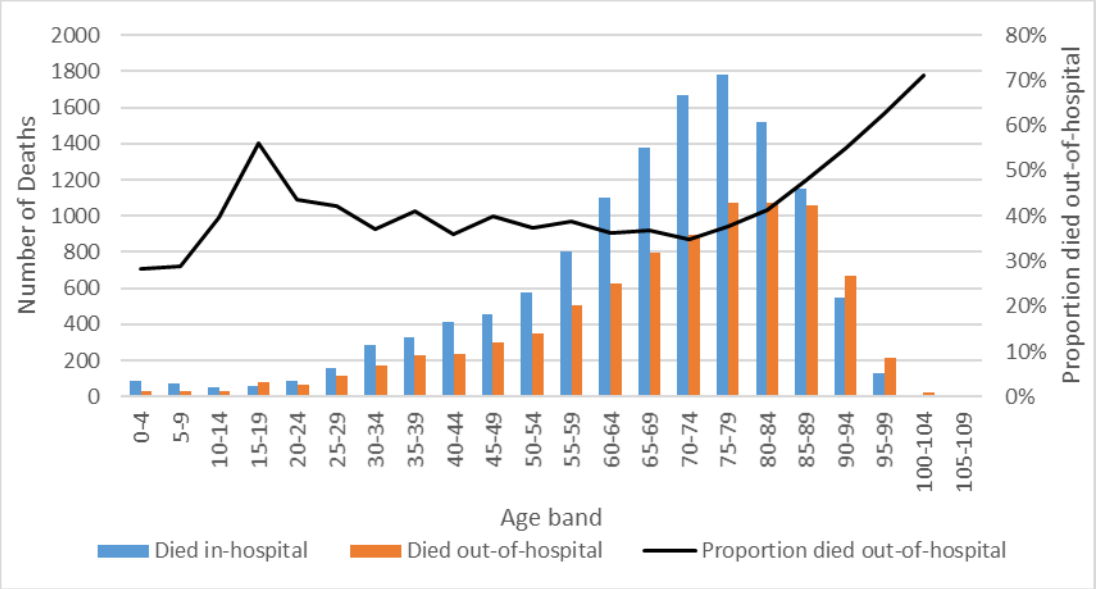
The majority of claims costs (48-56 per cent of overall claims) over the last 24 months of life are the costs of private hospital care (including one per cent of overall claims in sub-acute facilities). Note that the claims for specifically hospital providers do not represent the full quantum of claims incurred by beneficiaries in-hospital. Other providers, e.g. specialists, bill separately for services they render to hospitalised beneficiaries.

The proportion of overall claims billed by private hospitals, specifically, increases as death draws nearer. At 24 months, pharmacies are the next most utilised providers (in terms of cost) – nine per cent of total claims. The proportion of claims from pharmacies (relative to other practice types) decrease as death becomes imminent (down to one per cent during the last two weeks of life). Blood transfusion and medical technology (e.g. dialysis) account for around ten per cent of total claims and there is an increasing utilisation (in terms of cost) as death draws nearer. Pathology accounts for around five to six per cent of claims, slightly increasing with increasing imminence of death. The bulk of the remaining expenditure (around twenty per cent) are for various specialists, mainly radiologists, physicians, radiotherapists and anaesthetists. The remaining five per cent of overall claims are spread between auxiliary healthcare professionals and all the other provider types.

6.2 Place of death

For beneficiaries in the sample with full exposure, sixty per cent died in-hospital. Figure 6.2.1, below, illustrates the place of death for lives with full exposure given their age band at death in five-year intervals.

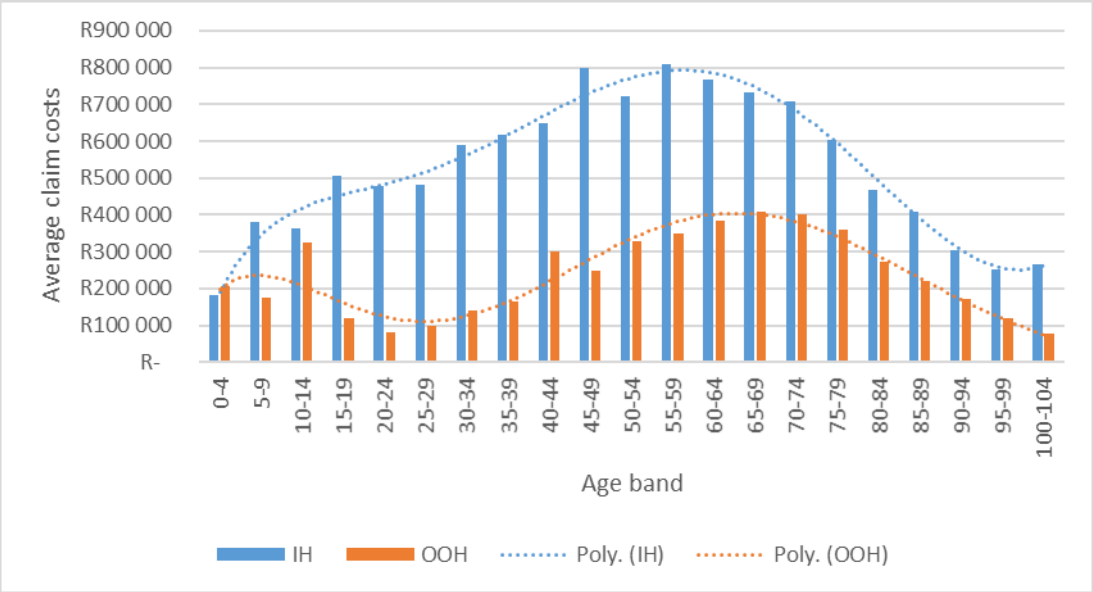
Figure 6.2.1 – Number of deaths by age band and place of death



It can be seen from Figure 6.2.1 that as age increases (at the advanced ages), the proportion of deaths out-of-hospital increases – at ages 70-74 the proportion is 35 per cent and this steadily increases to around seventy per cent at ages 100-104 (bearing in mind the low exposure at these advanced ages).

Figure 6.2.2, below, illustrates the average claims for decedent beneficiaries over the last 24 months of life by death in- or out-of-hospital, respectively.

Figure 6.2.2 – Average claims by place of death and age band



From Figure 6.2.2 it can be seen that dying in-hospital is consistently more expensive than dying out-of-hospital, and that for both in- and out-of-hospital deaths, average claims costs increase with increasing age, and eventually decreases at more extreme ages (75 and above).

Average costs over the last 24 months of life for those who died in-hospital amounted to around R613 000 per beneficiary whereas the costs for those that died out-of-hospital amounted to around R295 000 per beneficiary. This means, all else being equal, that beneficiaries dying in-hospital experience claims that are at least two times higher, on average, than the claims for beneficiaries dying out-of-hospital. Table 6.2.1, below, shows the average cost per beneficiary dying in- and out-of-hospital, respectively, at the various proximities to death.

Table 6.2.1– Average claims by place of death

Proximity to death	Average cost (R) – per beneficiary (died in-hospital)	Average cost (R) – per beneficiary (Died out-of-hospital)	Multiple	Proportion died in-hospital
2w	136 000	18 000	7.38	66%
4w	202 000	33 000	6.06	63%
3m	321 000	86 000	3.73	61%
6m	392 000	133 000	2.96	60%
12m	485 000	197 000	2.46	60%
24m	613 000	295 000	2.08	60%

From Table 6.2.1 it is interesting to note the relative costs in the last two weeks, four weeks and three months of life, respectively. First, those who had claims during their last two weeks of life experienced a greater likelihood of eventual death in hospital (66 per cent) as compared to someone claiming three months from death (61 per cent).

Second, the average claims for those dying in-hospital increase significantly relative to the costs for the average beneficiary that died out-of-hospital as death draws nearer. From a multiple of two times during the last 24 months of life to a multiple of more than seven times during the last two weeks of life. This may mean that a significant number of those beneficiaries who died out-of-hospital also experienced relatively high claims due to intensive and/or curative interventions in-hospital at such a time before death was clearly imminent, i.e. when their death was three or more months away. Note that this effect will be somewhat muted if beneficiaries who had died suddenly/unexpectedly are excluded from the above.

For the various proximities to death considered, testing the null hypotheses that claims costs for beneficiaries who had died in-hospital are equal to that of beneficiaries who had died out-of-hospital results in them being rejected for the alternative hypotheses that those who died out-of-hospital experienced lower overall claims. The p-values are ~0 at each of the proximities to death. Welch's t-tests are used to test these hypotheses given the large ratios between the variances (greater than two) for those who died in- and out-of-hospital, respectively, at each proximity to death.

Table 6.2.2, below, shows the standard deviation and lower- and upper bounds (at 95 per cent confidence) of the average claims costs given place of death at the various proximities to death (using a Student's t-distribution).

Table 6.2.2 – Standard deviation and confidence intervals – Place of death

	Death in-hospital			Death out-of-hospital		
	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
2w	156 000	133 000	138 000	45 000	17 000	19 000
4w	239 000	197 000	206 000	71 000	32 000	35 000
3m	404 000	314 000	328 000	167 000	82 000	90 000
6m	494 000	384 000	401 000	239 000	127 000	138 000
12m	593 000	475 000	496 000	315 000	190 000	204 000
24m	708 000	601 000	626 000	411 000	286 000	304 000

Irrespective of whether a beneficiary died in- or out-of-hospital, table 6.2.3 highlights the total claims for procedures/treatments that were performed in-hospital by proximity to death. Only lives with full 24 months exposure are considered here.

Table 6.2.3 – Total claims by proximity to death

Proximity to death	Total claims (Rm)	Proportion of claims in-hospital
2w	1 827	94%
4w	2 793	93%
3m	4 754	89%
6m	6 064	85%
12m	7 808	80%
24m	10 297	75%

As can be seen from Table 6.2.3, a significant proportion of claims result from treatments/procedures performed in-hospital – upwards of 75 per cent of all claims in the last 24 months of life. As death draws nears, the claims in-hospital as a proportion of total claims increase to 94 per cent of total claims in the last two weeks of life, irrespective of whether death occurred in- or out-of-hospital. When considering deaths that occurred in-hospital, 96 per cent of claims in the last two weeks of life were for procedures or treatments in-hospital (compared to 68 per cent for lives that died out-of-hospital). Over the last 24 months of life, 79 per cent of total claims for lives that died in-hospital were for treatments and procedures in-hospital (compared to 63 per cent for lives that died out-of-hospital).

6.2.1 Hospice utilisation

Hospice utilisation (in terms of overall claims cost of the sample of decedents) is 0.19 per cent (during the last 24 months of life) and increases to 0.37 per cent of overall cost (during the last two weeks of life). Below the utilisation of hospice services by the sample of decedents are explored in further detail.

Of the 24 980 decedent beneficiaries in the sample, a total of 1 219 (or 4.9 per cent) had utilised some hospice services during their last 24 months of life. Looking at lives with full exposure only, 1 176 (or 5.5 per cent) of the 21 457 decedent beneficiaries utilised hospice services. The average age at death of these beneficiaries is 69 years (higher than the overall average age of all decedents – 64 years), with a median age at death of 70 years (the same as the overall median age). Half of the hospice users were male. Of the beneficiaries utilising hospice services, 94 per cent had a registered chronic condition. Hospice utilisation for deaths occurring in 2017 was around twenty per cent greater than for deaths occurring in 2016, but given the small number of beneficiaries utilising hospice services, this may just be due to random variation between the two calendar years, or may be due to changes in hospice billing practices. This may also be as a result of a trend towards more hospice utilisation by medical scheme beneficiaries, but a two-year period is too short to confirm this. The below analyses focus only on lives with full exposure over the 24-month period prior to death. It is important to note that the following analyses may be skewed due to non-billing or non-submission of hospice-related claims and should be interpreted with caution.

Beneficiaries that had used some hospice services in their last 24 months of life were less likely, overall, to die in-hospital – thirty per cent vs sixty per cent of deaths occurred in hospital, respectively. Furthermore, beneficiaries that had utilised some hospice services during their last four weeks of life were even less likely to die in hospital – only 25 per cent of these beneficiaries died in hospital.

The claims experience for beneficiaries that had utilised some hospice services (during the last 24 months of life) are compared to those who had utilised none at all. The analysis focuses on the average claims experience in the last four weeks of life as this is where the majority of hospice claims costs are concentrated (around 52 per cent of all hospice-related claims). Beneficiaries who had no hospice-related claims had

overall average claims amounting to around R143 000 during the last four weeks of life. This is significantly higher (p-value of ~0; tested using a Welch's t-test) than the average claims during the last four weeks of life for those beneficiaries who had utilised at least some hospice services in the last 24 months of life (around R80 000). A Welch's t-test allows for differences in sample sizes as well as differences in sample variances (in this case it cannot be reasonably concluded that the sample variances are equal since the variance ratio between the samples is greater than two).

Table 6.2.1.1, below, shows the standard deviation of claims during the last four weeks of life and the 95 per cent confidence interval for these claims using a Student's t-distribution.

Table 6.2.1.1 – Standard deviation and confidence interval in last 4 weeks – Hospice use vs no hospice during last 24 months

	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
Hospice (n= 1 176)	115 000	74 000	87 000
No hospice (n= 18 838)	215 000	140 000	146 000

Next, the claims experience for those beneficiaries that had utilised some hospice services during the last four weeks of life are compared to those who had utilised none in the last four weeks of life (but had utilised some in the last 24 months of life). The average claim costs amounted to around R76 000 and R102 000, respectively. The null hypothesis that the average claims during the last four weeks of life are equal for those dying whilst receiving hospice care and for those dying without receiving hospice care is tested against the alternative hypothesis that those receiving hospice care have lower average claims during the last four weeks of life using a Welch's t-test. There is a significant difference between sample variances (ratio greater than four). The sample variance for those that died without receiving hospice care during their last four weeks of life (but had some hospice care earlier on) is particularly large (and the sample size is relatively small – 192 beneficiaries) which may distort the results. However, the null hypothesis is still rejected in favour of the alternative hypothesis at the five per cent-level with a p-value of 0.035.

Table 6.2.1.2, below, shows the standard deviation of claims during the last four weeks of life for those who had hospice claims during the last four weeks and those who had not (but had utilised some hospice in the last 24 months of life), and the 95 per cent confidence interval for these claims using a Student's t-distribution.

Table 6.2.1.2 - Standard deviation and confidence interval – Hospice use vs no hospice use in the last four weeks of life

Last 4w	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
Hospice (n = 984)	92 000	70 000	82 000
No hospice (n = 192)	191 000	74 000	129 000

We can thus conclude that, with all else being equal, hospice utilisation near the end of life is associated with lower overall claims costs and a significantly reduced probability of death in-hospital.

A further interesting observation comes from comparing the overall average costs in the last four weeks of life for those that died *out-of-hospital*, grouped based on whether or not there had been any billed hospice services during this time. A total of 735 beneficiaries died out-of-hospital having billed hospice care in the last four weeks of life, compared to 6 638 beneficiaries that died out-of-hospital with no billed hospice care in the last four weeks of life. The average cost for these beneficiaries amounted to around R60 000 and R30 000, respectively. The null hypothesis that these amounts are equal is rejected (with a p-value of ~0. using a Z-test given the sufficiently large sample sizes and almost identical variances – ratio of 0.985). The hypothesis is rejected in favour of the alternative hypothesis that those receiving hospice care, who died out-of-hospital, experience higher claims, on average, during their last four weeks of life when compared to those dying out-of-hospital that have no billed hospice services during their last four weeks of life.

Table 6.2.1.3, below, shows the standard deviation of claims during the last four weeks of life for those who died out-of-hospital either having utilised hospice care, or not, and the 95 per cent confidence interval for these claims using a Student's t-distribution.

Table 6.2.1.3 – Standard deviation and confidence interval – Death out-of-hospital

Died-out-of-hospital	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
Hospice (n = 735)	71 000	55 000	65 000
No hospice (n = 6638)	70 565	29 000	32 000

Note that even though the average claims costs for beneficiaries utilising hospice services and dying *out-of-hospital* is significantly higher than the costs for the corresponding beneficiaries who had not utilised hospice services, the converse is true for deaths occurring *in-hospital* (and exceeds the relative difference in cost for out-of-hospital deaths), i.e. around R203 000 vs R124 000, respectively. Using a Welch's t-test, the hypothesis that these amounts are equal is rejected with a p-value of ~0.

Table 6.2.1.4, below, shows the standard deviation and 95 per cent confidence interval (using a Student's t-distribution) of the average claim costs for those dying in-hospital utilising hospice services, or not, respectively.

Table 6.2.1.4 - Standard deviation and confidence interval – Death in-hospital

Died in-hospital	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
Hospice (n = 249)	124 000	108 000	140 000
No hospice (n = 12 389)	240 000	199 000	207 000

Table 6.2.1.5, below, summarises the average claims during the last four weeks of life according to whether the beneficiary died in- or out-of-hospital, and whether or not they had any billed hospice services during their last four weeks of life.

Table 6.2.1.5 – Average claims last four weeks – Hospice vs no hospice in the last four weeks of life

Average claims - Last 4w (Number of beneficiaries)	Died receiving hospice care – per beneficiary	Died not receiving hospice care – per beneficiary	Overall average during the last 4w
Died in-hospital	R124 000 (249)	R203 000 (12 389)	**R202 000 (12 638)**
Died out-of-hospital	R60 000 (735)	R30 000 (6 638)	**R33 000 (7 373)**
Overall average (Number of beneficiaries)	**R76 000 (984)**	**R143 000 (19 027)**	**R140 000 (20 011)***

*20 011 is the total number of beneficiaries that had full exposure and claims >0 during the last four weeks of life

The number of beneficiaries not utilising hospice services in their last four weeks of life and dying in-hospital are much greater than the corresponding number of beneficiaries dying out-of-hospital, 12 389 vs 6 638 beneficiaries, respectively, and significantly greater than the number dying in-hospital whilst utilising hospice services, i.e. 249.

The relatively high observed cost for beneficiaries who died out-of-hospital whilst receiving hospice care is partly explained by the cost of hospice care services – average cost of R12 000 per beneficiary during their last four weeks of life. A further part of the result may be explained by the profile of the beneficiaries utilising hospice services. Scheme beneficiaries utilising hospice services are predominantly those with cancer. More than 90 per cent of beneficiaries that had utilised hospice services over their last 24 months of life and had died out-of-hospital had cancer-related claims. Comparing the claims experience in the last four weeks of life of beneficiaries who died out-of-hospital that had claimed for cancer-related benefits to those that died out-of-hospital and had no cancer-related claims yielded the following results. Average claim amounts amounted to around R49 000 and R24 000, respectively, with a variance ratio of less than two. Performing a Z-test indicates that the average claim costs for those diagnosed with cancer (who died out-of-hospital) is significantly higher during the last four weeks of life than for those without cancer – p-value ~0.

Table 6.2.1.6, below, shows the standard deviation and 95 per cent confidence interval for claims during the last four weeks of life for those who died out-of-hospital who had cancer-related claims and for those who died out-of-hospital who did not have cancer-related claims during this time, respectively.

Table 6.2.1.6 – Standard deviation and confidence interval – Last four weeks; Cancer-related claims vs no cancer-related claims

Died out-of-hospital	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
Cancer claims (n = 2 752)	77 000	46 000	52 000
No cancer claims (n = 4 621)	66 000	22 000	26 000

The result of this hypothesis test means that average claims costs for those receiving hospice care and dying out-of-hospital is expected to be greater than the costs for those

dying out-of-hospital and not receiving hospice care due to these beneficiaries likely having been diagnosed with cancer. The claims experience of beneficiaries that had been diagnosed with and who are likely to have died of cancer is briefly considered in Section 6.5 that covers the main trajectories of dying.

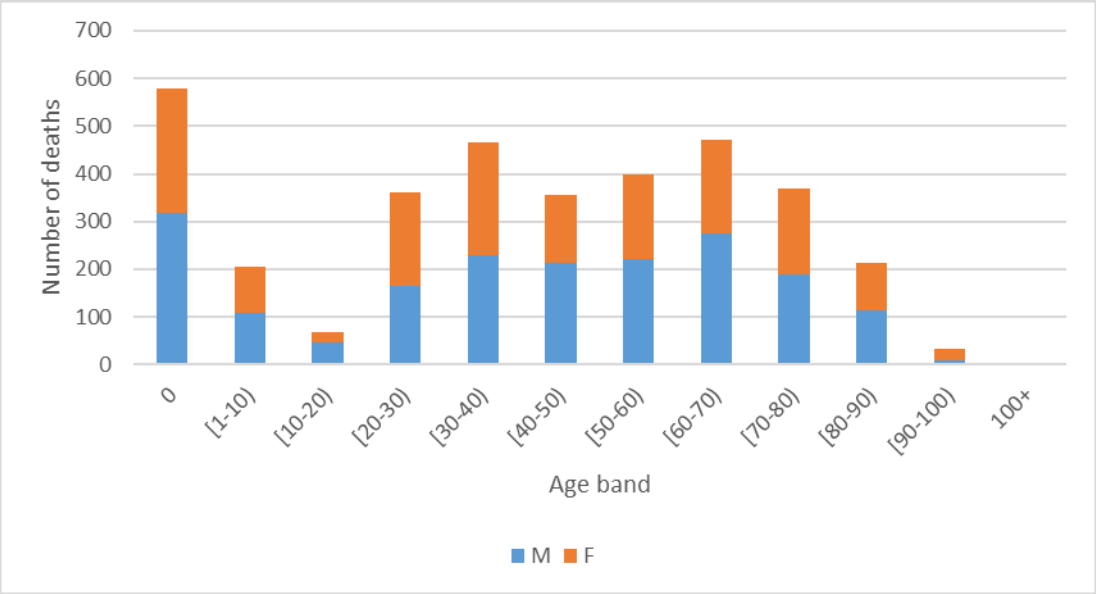
6.3 Analysis of lives with partial exposure

An interesting hypothesis to test is whether, based on the profile of the lives and their total claims, there exists any evidence to suggest that lives that joined the scheme within the last 24 months of life did so with the aim of selecting against the scheme.

Of the total 24 980 deaths recorded 3 523, or fourteen per cent, only had partial exposure. Of these beneficiaries, 61 per cent died in-hospital – this is similar to the experience of those with full exposure over the 24-month period – 60 per cent died in hospital. 283 decedents were neonates (younger than 28 days) and a further 404 child decedents died before being aged two years (and will thus necessarily have exposure of less than two years). Neonates and children younger than two total approximately twenty per cent of beneficiaries with partial exposure. Of the lives with partial exposure, a total of 343 decedent beneficiaries (approximately ten per cent) had no claims during their period of cover (compared to only 202 decedent beneficiaries (approximately one per cent) that were exposed for the full 24-month period having no claims).

Figure 6.3.1, below, illustrates the distribution of male and females deaths by age band for those that only had partial exposure.

Figure 6.3.1 – Distribution of deaths by age band – partial exposure



As expected, there is a relatively large number of neonatal and infant deaths. However, within the adult age bands there is no observable trend towards more deaths at older ages (as seen in the distribution of deaths of the lives with full exposure).

This part of the analysis is performed to determine whether schemes experience higher claims due to the anti-selective behaviour of new joiners. Average claims are considered at the various proximities to death as with the analysis for lives with full exposure above. Table 6.3.1, below, compares the average costs for those decedent beneficiaries with partial exposure to the average cost for those decedent beneficiaries with full exposure (in both cases the lives with zero claims are also included in the denominator to give a more accurate average).

Table 6.3.1 – Average cost comparison – full vs partial exposure

All incl. zero claims	Partial exposure			Full exposure
Exposure period	#Lives	Cumulative number partially exposed (given period)	Average costs (R) – per beneficiary	Average costs (R) – per beneficiary
0m	270	3 523	106 000	-
2w	144	3 253	85 000	85 000
4w	409	3 109	126 000	130 000
3m	489	2 700	190 000	222 000
6m	836	2 211	241 000	283 000
12m	1 375	1 375	316 000	364 000
24m	0		-	480 000

Table 6.3.1 reads as follows: an exposure period of '2w' means having at least two weeks' exposure; '4w' means having at least four weeks' exposure, and so on. None of these lives were exposed for the full period and all were exposed at least for one day (the '0m' exposure period). The average costs of the '0m' exposure period is higher than that of the '2w' period mainly due to the effect of neonatal deaths and the high costs associated with neonatal ICU (Richardson, Zupancic, Escobar, Ogino *et al.* 2001).

It can be seen from Table 6.3.1 that claims for decedent beneficiaries who only had cover for part of the period under consideration, consistently had lower claims, on average than beneficiaries who enjoyed cover for the full period. The null hypotheses that the overall average claims for decedent beneficiaries with partial exposure are equal to the overall average claims of those with full exposure are tested against the alternative hypotheses that beneficiaries with partial exposure have lower average claims. At two weeks and four weeks proximity to death, there is no evidence to suggest that average claims for lives with partial exposure is any different to that of lives with full exposure – p-value >0.1. At greater proximities to death, three months or more, statistically, claims for decedent beneficiaries with full exposure are greater than for lives with partial exposure who had been on the scheme for at least the corresponding period – p-value ~0. For these hypotheses, z-tests were used given sample sizes of greater than thirty and ratios of sample variances being between 0.5 and two in all cases (i.e. it is not unreasonable to assume equal sample variances).

Table 6.3.2, below, shows the standard deviation and 95 per cent confidence intervals for those with full and partial exposure, respectively, at the various proximities to death.

Table 6.3.2 – Standard deviation and confidence intervals – lives with partial exposure

	Full exposure		
n = 21 457	Standard Deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
2w	136 000	83 000	87 000
4w	206 000	127 000	133 000
3m	348 000	217 000	226 000
6m	429 000	277 000	288 000
12m	518 000	357 000	371 000
	Partial exposure		
	Standard Deviation (R)	**Lower 95% CI bound (R)**	**Upper 95% CI bound (R)**
2w (n = 3 253)	161 000	79 000	90 000
4w (n = 3 109)	236 000	117 000	134 000
3m (n = 2 700)	345 000	177 000	204 000
6m (n = 2 211)	421 000	223 000	258 000
12m (n = 1 375)	579 000	286 000	347 000

Since ten per cent of the decedent beneficiaries with partial exposure had no claims (possibly due to the enforcing of waiting periods), compared to only one per cent of decedent beneficiaries with full exposure, average costs for only those that had claims are also considered in Table 6.3.3, below.

Table 6.3.3 - Average cost comparison – full vs partial exposure (non-zero claimers)

Beneficiaries with claims	Partial exposure			Full exposure
Exposure period	#Lives	Cumulative number partially exposed (given period)	Average costs (R) – per beneficiary	Average costs (R) – per beneficiary
0m	239	3 143	120 000	-
2w	88	2 904	95 000	96 000
4w	297	2 816	139 000	140 000
3m	424	2 519	204 000	230 000
6m	765	2 095	254 000	290 000
12m	1330	1 330	327 000	370 000
24m	0			485 000

As can be seen from Table 6.3.3, excluding those with zero claims increases the average claim amounts (at each proximity to death) for both those with full and those with partial exposure. This is as expected – smaller denominator with the same numerator. However, claims for those with partial exposure remains consistently below that for lives with full exposure, on average. Similar to the above, claims in the last month of life for decedent beneficiaries, both those with full and those with partial exposure during the period, are statistically similar.

6.4 Ageing populations, lifestyles and chronic non-communicable diseases

This section considers the effect on care costs near the end of life of having one or more chronic conditions. The chronic registration/authorisation for the decedent beneficiaries under consideration show that 18 173 (or about 73 per cent) of the decedent beneficiaries had at least one chronic condition. This information is contained in the data in the form of a "chronic indicator" per decedent beneficiary. In fact, 55 per cent of decedent beneficiaries had more than one chronic authorisation/condition at the time of their death.

Of the sample of 24 980 deaths, irrespective of the number of co-morbidities, 49 per cent of the decedents had been diagnosed with hypertension and 31 per cent had a hyperlipidaemia diagnosis before death. 57 per cent decedent beneficiaries had one or more chronic conditions of the heart (including hypertension and hyperlipidaemia) – making this the most prevalent chronic condition group for the sample of decedent beneficiaries. 24 per cent of the sample of decedent beneficiaries suffered from a form

of cancer during their last 24 months of life. 21 per cent of decedent beneficiaries suffered from a chronic endocrine-related illness (including sixteen per cent suffering from diabetes), twelve per cent had a chronic respiratory illness and eight per cent experienced chronic mental illness.

Table 6.4.1, below, summarises the various chronic condition groupings together with the prevalence of each, ordered from most prevalent to the least prevalent. These include lives with both full and partial exposure.

Table 6.4.1 – Prevalence of chronic conditions

Condition group	Count of decedents	Prevalence
Chronic heart condition	14 130	57%
Cancer	6 091	24%
Chronic endocrine condition	5 288	21%
Chronic respiratory disorder	3 051	12%
Chronic mental condition	1 879	8%
OTHER chronic condition	1 449	6%
Chronic brain condition	1 403	6%
Chronic musculoskeletal condition	1 217	5%
Chronic renal condition	798	3%
HIV	714	3%

Figure 6.4.1, below, benchmarks the relative cost of having a single condition in one of these groups relative to having no chronic conditions. This figure only contains the data for lives with full 24-month exposure who only had one authorised chronic condition in any one of the groups above. Having no chronic conditions, i.e. 'NONE' is taken as the benchmark with a weight of one.

Figure 6.4.1 – Chronic condition cost relative to the benchmark

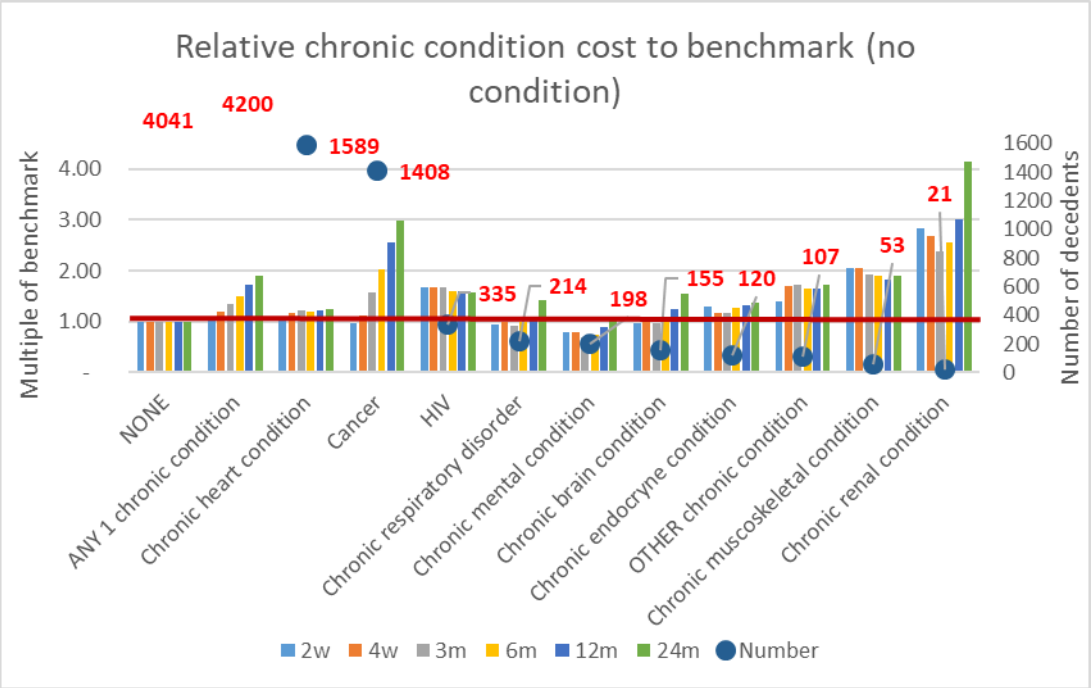


Figure 6.4.1 highlights the relative cost as a multiple of the average claims cost of having no registered chronic conditions. Note that the numbers of lives having only one chronic condition in each respective category is relatively low – shown in Figure 6.4.1. The results may thus be prone to statistical variation over the 24-month period and multiple unobserved interactions or confounding factors influencing overall claims may be present. Hence, these results should be interpreted with caution. Note that Figure 6.4.1 ignores all lives that have multiple chronic conditions.

Note the very small numbers exposed to (only) renal and musculoskeletal conditions, respectively. This may result in statistical variation in the results and the results are thus prone to being skewed by outliers. Cancer and chronic renal conditions exhibit interesting patterns and levels of claims relative to the benchmark, on average. HIV, musculoskeletal and 'other' conditions exhibit a high level of claims relative to the benchmark and conditions related to mental health exhibit a relatively low overall level when compared to the benchmark.

The following analysis considers the impact of having multiple chronic conditions on overall claims costs. Table 6.4.2, below, illustrates the prevalence of

chronic conditions and the high rate of co-morbidity experienced by the decedent beneficiaries in the sample leading up to death.

Table 6.4.2 – Comorbidity (all decedent beneficiaries)

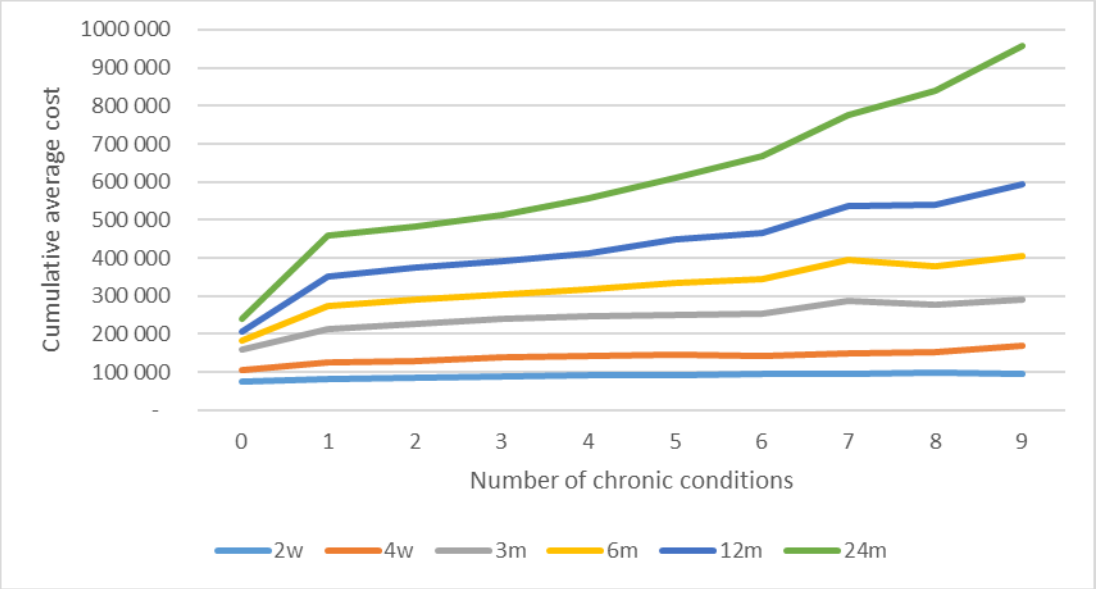
#Conditions	Total	Total proportion
0	**6 443**	26%
1	**4 722**	19%
2	**3 875**	16%
3	**3 462**	14%
4	**2 708**	11%
5	**1 790**	7%
6	**1 051**	4%
7	**528**	2%
8	**241**	1%
9	**110**	0%
10	**35**	0%
11	**12**	0%
12	**3**	0%

Table 6.4.2 includes both those the decedents with full and partial exposure over the period (i.e. all 24 980 deaths). Conditions are counted individually, irrespective of how they are grouped. For example, if a beneficiary had multiple heart conditions, e.g. hypertension and ischaemic heart disease, these are counted separately, i.e. this particular beneficiary is considered to have had two chronic heart conditions.

From Table 6.4.2, above, it can be seen that 55 per cent of all decedent beneficiaries experience multi-morbidity, i.e. suffering from more than one chronic condition, at the time of death. The proportion is reasonable given the age structure of the sample of decedent beneficiaries (average age of 64, median age of 70) with 35 per cent of lives being younger than age 65. In a US study of individuals ages 65 and older (average age 73), it was found that 67 per cent of individuals experienced multi-morbidity (Jindai, Nielson, Vorderstrasse and Quiñones 2016).

Figure 6.4.2, below, highlights the cumulative average costs for all beneficiaries with full 24-month exposure given the number of chronic illnesses and authorisations they had.

Figure 6.4.2 – Cumulative average cost given the number of chronic conditions at the various proximities to death



From Figure 6.4.2, above, it can be seen that there is an upward trend in end-of-life medical care claims costs at all proximities to death with an increasing number of chronic diseases. There were very few beneficiaries that had ten or more conditions (fifty in total), and the impact of their total (high) average claim costs distort the graph and masks the upward trend (given an increasing number of chronic conditions) for beneficiaries with fewer chronic conditions. As such, these are not shown in Figure 6.4.2.

Hypotheses testing are performed to confirm, statistically, that having one (or more) chronic conditions results in higher claim costs than having no chronic conditions. Lives with full exposure are grouped as either having '0', '1 or 2', or '3+' chronic conditions. This grouping results in groups of comparable size with sufficient statistical credibility. At the various proximities to death, the impact on claims of having one (or more) chronic conditions as compared to having none, resulted in significantly higher overall claims, on average (p-value ~0.). Z-tests were used given large enough sample sizes and ratios of variances between 0.5 and 2.

Table 6.4.3, below, sets out the decedent beneficiaries' average claims (at the various proximities to death), given their number of registered chronic conditions.

Table 6.4.3 – Average claims cost given chronic conditions at each proximity to death

		Average claim costs (R) – per beneficiary					
	Count (n)	2w	4w	3m	6m	12m	24m
0 conditions	4 041	74 000	105 000	158 000	182 000	206 000	240 000
1 or 2 conditions	7 849	83 000	128 000	220 000	281 000	363 000	470 000
3+ conditions	9 567	92 000	143 000	250 000	326 000	431 000	589 000

Table 6.4.4, below, shows the standard deviation and 95 per cent confidence intervals (using a Student's t-distribution) of the average claims cost at the various proximities to death, given the number of chronic conditions per decedent beneficiary.

Table 6.4.4 – Standard deviation and confidence intervals – chronic condition groupings

	0 conditions (n = 4 041)		
	Standard Deviation (R)	Lower 95% CI band (R)	Upper 95% CI band (R)
2w	149 000	69 000	78 000
4w	220 000	98 000	112 000
3m	358 000	147 000	169 000
6m	434 000	169 000	195 000
12m	488 000	191 000	221 000
24m	526 000	224 000	256 000
	1 or 2 conditions (n = 7 849)		
	Standard Deviation (R)	Lower 95% CI band (R)	Upper 95% CI band (R)
2w	132 000	80 000	86 000
4w	206 000	123 000	132 000
3m	336 000	212 000	227 000
6m	424 000	272 000	291 000
12m	500 000	352 000	374 000
24m	579 000	457 000	483 000
	3 or more conditions (n = 9 567)		
	Standard Deviation (R)	Lower 95% CI band (R)	Upper 95% CI band (R)
2w	134 000	89 000	94 000
4w	205 000	139 000	147 000
3m	357 000	243 000	257 000
6m	445 000	317 000	335 000
12m	543 000	420 000	442 000
24m	668 000	576 000	603 000

The Pearson correlation coefficients between total claims and the number of chronic conditions, and between the number of days spent-in-hospital (during the specific period preceding death) and the number of chronic conditions, respectively, are set out in Table 6.4.5 and Table 6.4.6, below.

Table 6.4.5 - Correlation coefficients – Total claims and number of chronic conditions

	2w	4w	3m	6m	12m	24m
Pearson correlation	0.05	0.06	0.09	0.12	0.15	0.21

Table 6.4.6– Correlation coefficients – Number of days spent in-hospital and number of chronic conditions

	2w	4w	3m	6m	12m	24m
Pearson's correlation	0.12	0.12	0.13	0.16	0.18	0.22

By computing the Pearson correlation coefficients between total claims and the number of chronic conditions at the various durations from death, we can see that a positive correlation exists. Similarly, the Pearson correlation coefficients between the number of days spent in-hospital and the number of chronic conditions shows a positive relationship (correlation coefficient greater than zero).

Additionally, the Pearson's correlation coefficient between the number of chronic conditions and the number of hospitalisations the decedent beneficiary experiences in their last 24 months of life is 0.3, showing that these are also positively correlated.

6.5 Trajectories of dying

A broadly similar methodology to that followed by Lunney, Lynn and Hogan (2002) to study the profiles (or trajectories of dying) of decedent Medicare beneficiaries is used here. The coding methodologies and/or conventions used between different territories, insurers, providers, etc. may mean that there are significant differences between the two sets of data, and hence the results are likely not directly comparable. The four main trajectories of dying considered are: 1) "Sudden death", 2) "Cancer", 3) "Organ failure" and 4) "General frailty". A 5th group, "Other", is used to capture lives that cannot be sensibly or easily grouped into one of the other four trajectories. Only

lives with full exposure who had medical scheme claims in the last twelve months of life are considered here. This yielded a total of 21 105 beneficiaries.

Beneficiaries are allocated to the "Sudden death" trajectory if their total claims are below R24 000 in their last year of life and if they are younger than eighty years old. This yielded a total of 2 125 (or ten per cent) of beneficiaries that had died suddenly. Given the lower claim amount threshold and greater age spread in the data used for purposes of this study, this appears reasonable when compared to the seven per cent found by Lunney, Lynn and Hogan (2002). Trauma-related deaths with relatively high claims (relative to the R24 000 threshold) which may have included emergency transport and/or care will not be reflected in the "Sudden death" trajectory.

Next, beneficiaries in the "Cancer" trajectory are identified by looking at the most costly episode of care/ICD-10 combinations for each beneficiary in their claims data. This yielded a total of 4 112 (or nineteen per cent) of beneficiaries, which is comparable to the 22 per cent found by Lunney, Lynn and Hogan (2002) in the corresponding Medicare study. In the previous section, it was found that 24 per cent of decedent beneficiaries had been diagnosed with a form of cancer. It is worth noting that not every beneficiary diagnosed with cancer dies of cancer and that the trajectories of dying are based on the most costly episode of care/ICD-10 code combination for each beneficiary, which may not necessarily coincide with the chronic disease registration.

If beneficiaries experienced heart, respiratory, hepatic (liver) or renal failure as their most costly episode of care/ICD-10 combination, they are allocated to the "Organ failure" trajectory. This yielded 3 002 (or fourteen per cent) of beneficiaries, comparable to the sixteen per cent found in the corresponding Medicare study.

Next, the remaining beneficiaries meeting the clinical requirements for the "General frailty" trajectory are assigned to this trajectory. This included chronic conditions related to the above-mentioned organs (not specifically failure of these organs) and other conditions associated with frailty at older ages. This yielded 8 306 (or 39 per cent) of beneficiaries, compared to the 47 per cent in the Medicare study. Note that the Medicare study only contained lives older than 65 years, so a reduced proportion of frail individuals is expected in the overall medical schemes sample of decedent beneficiaries.

The remainder of the beneficiaries are assigned to the "Other" trajectory. A total of 3 556 (or seventeen per cent of) beneficiaries formed this group – comparable to eight per cent found in the Medicare study. Given the greater age spread, the number of anomalous episodes of care/ICD-10 codes, and the inclusion of those younger than fifty within this group, this appears reasonable.

Table 6.5.1, below, summarises the results of the analyses of the various trajectories of dying, including the average age, average and median claim amounts, sex split and the proportion that died in-hospital (captured in the data by an indicator of whether death occurred in- or out-of-hospital).

Table 6.5.1 – Trajectories of dying

Trajectory of dying	Number of beneficiaries/ (%)	Average age	Average cost (R) – per beneficiary	Median cost (R) – per beneficiary	% Male	% died in-hospital
Sudden death	2 125 (10%)	49	9 000	8 000	69%	16%
Cancer	4 114 (19%)	66	515 000	399 000	53%	62%
Organ failure	3 004 (14%)	70	529 000	338 000	54%	79%
General frailty	8 306 (39%)	77	368 000	211 000	51%	65%
Other	3 556 (17%)	62	288 000	110 000	49%	57%
Total	**21 105**	**68**	**370 000**	**210 000**	**53%**	**60%**

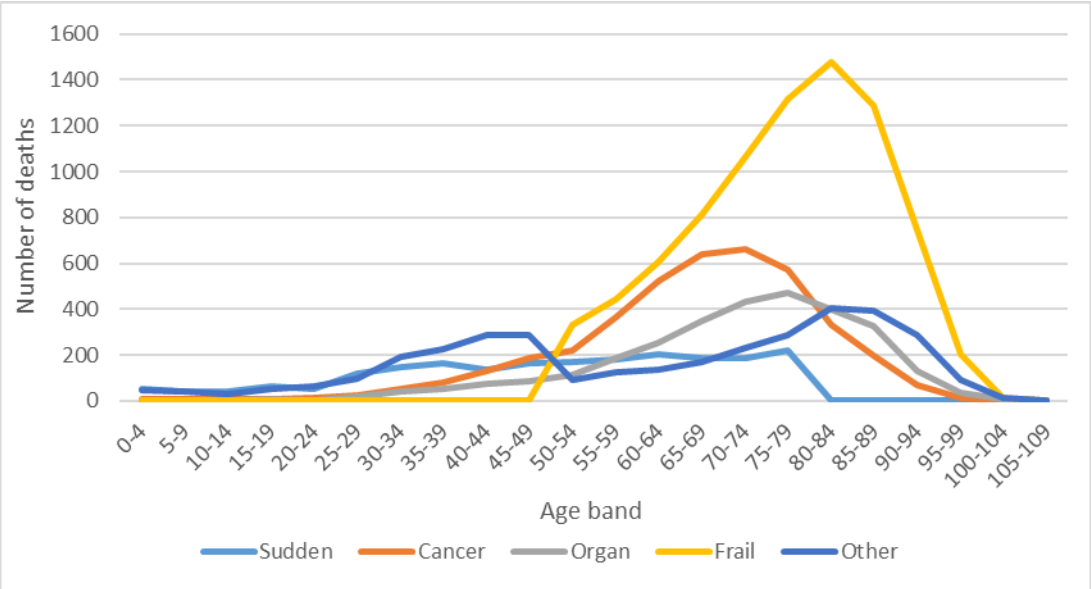
As can be seen from Table 6.5.1, the "Sudden death" trajectory has the lowest average age due to the exclusion of beneficiaries eighty years and older, and due to the low annual claims threshold to be included in the trajectory. Only sixteen per cent of these beneficiaries died in-hospital, which is not unexpected given the low overall costs and the predominantly accidental nature of the deaths in this trajectory. 65 per cent of beneficiaries assigned to the "General frailty" trajectory died in-hospital and this trajectory had a higher than average age profile. The "Organ failure" trajectory has a higher than average age profile and 79 per cent of the beneficiaries in this trajectory died in-hospital, relatively more than in the other trajectories.

The "Organ failure" trajectory has the highest average costs in the last year of life, followed by the "Cancer" trajectory. When looking at the median costs in the last year of life, the "Cancer" trajectory has the highest median claim amount. As expected,

the “Sudden death” trajectory has very low average claims, and the “Other” trajectory has relatively low average and median claims as compared with the other trajectories of dying.

Figure 6.5.1, below, illustrates the number of deaths for the various trajectories given the decedents’ age at death, in five-year intervals.

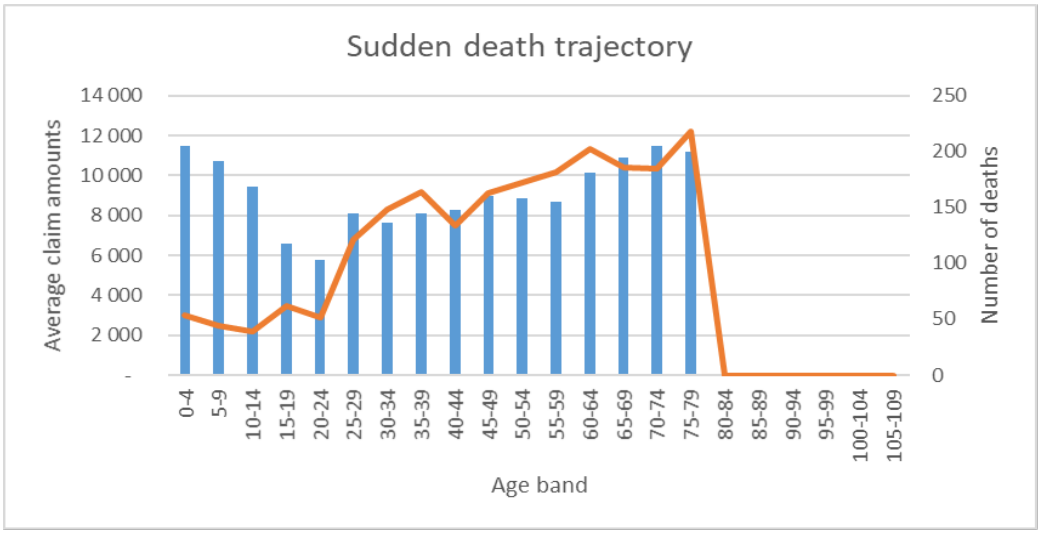
Figure 6.5.1 – Number of deaths per trajectory given age band at death

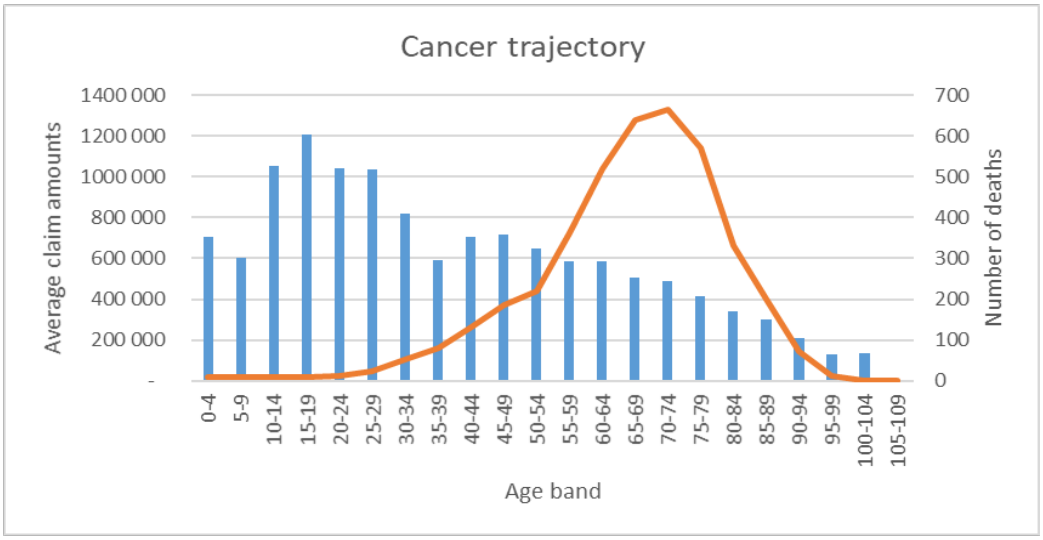


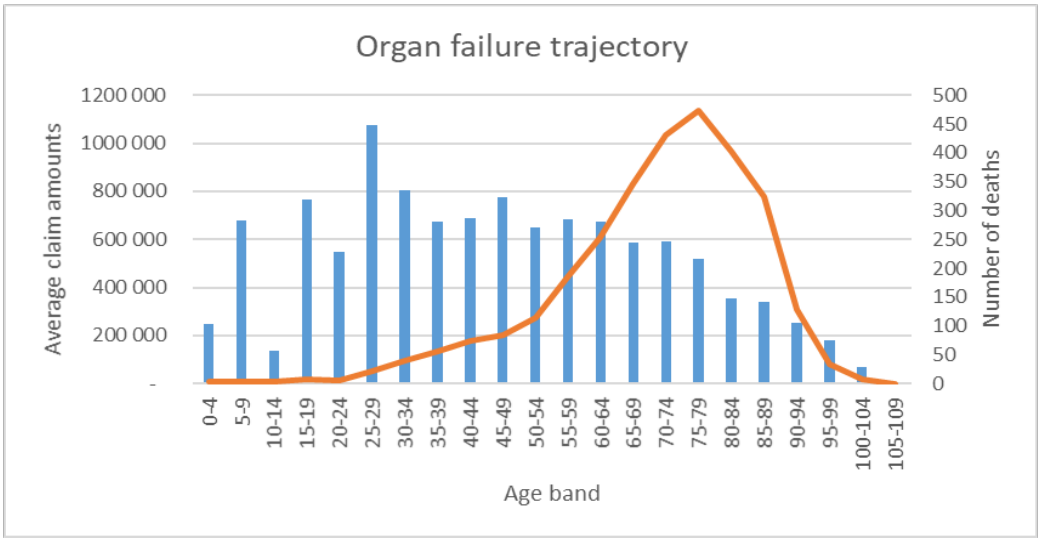
As can be seen from Figure 6.5.1, “General frailty” is the dominant trajectory of dying (similar to the results of the Medicare study). The number of deaths peak at 80-84 for the “General frailty” and “Other” trajectories. “Organ failure” peaks at 75-79 and “Cancer” peaks at ages 70-74. The “Sudden death” trajectory has reasonably constant number of deaths at all ages (slightly lower at younger ages, given the lower number of deaths (and exposure to the risk of death) at these ages). The number of decedent beneficiaries in the “Other” trajectory exhibits an odd pattern due to the inclusion of all lives younger than fifty who have not been assigned to any of the other main trajectories of dying.

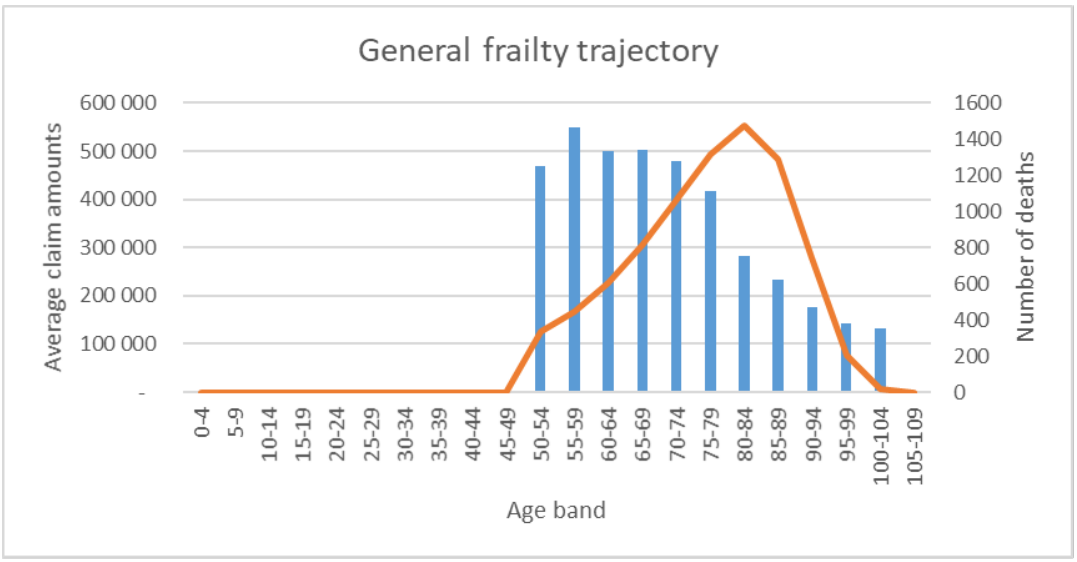
Figure 6.5.2, below, illustrates the average claim costs (for the last twelve months of life) and the number of decedent beneficiaries in five-year age bands for the various trajectories of dying.

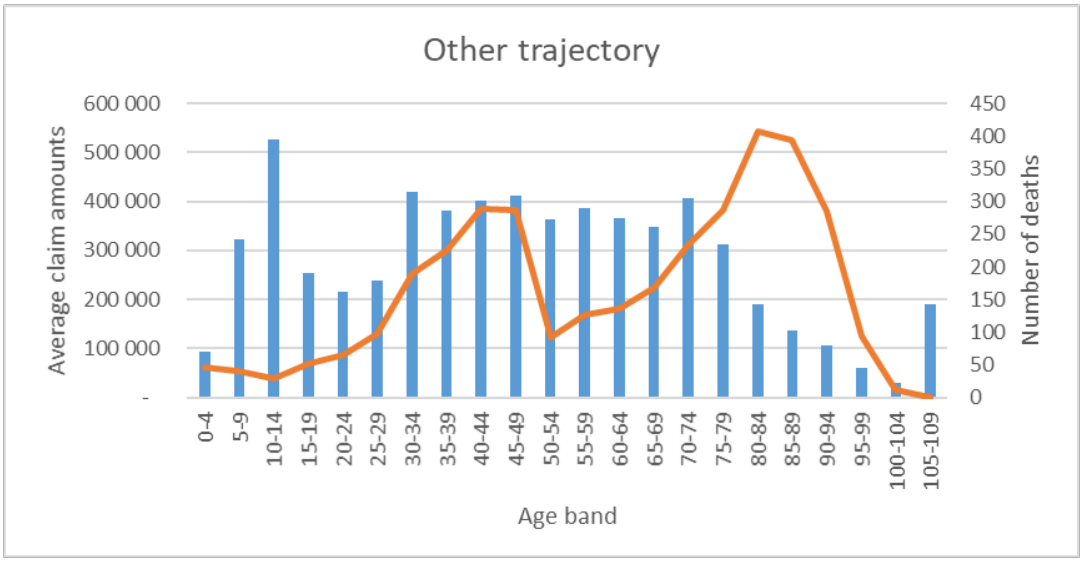
Figure 6.5.2 – Average claims costs and distribution of deaths by trajectory and age band

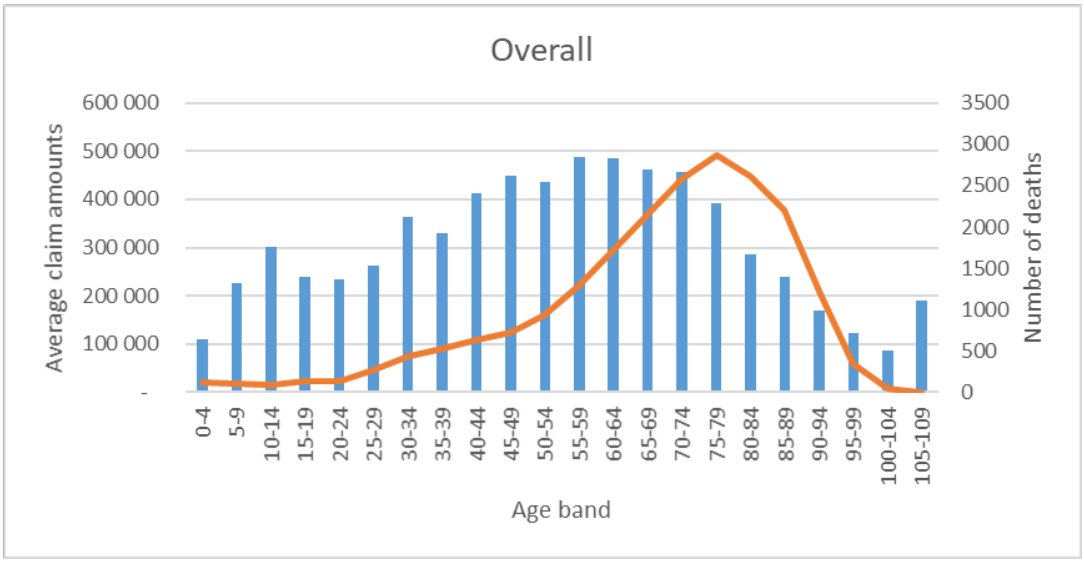







General frailty trajectory
Average claim amounts
600 000
500 000
400 000
300 000
200 000
100 000
-
Number of deaths
1600
1400
1200
1000
800
600
400
200
0
0-4
5-9
10-14
15-19
20-24
25-29
30-34
35-39
40-44
45-49
50-54
55-59
60-64
65-69
70-74
75-79
80-84
85-89
90-94
95-99
100-104
105-109
Age band


Other trajectory
Average claim amounts
600 000
500 000
400 000
300 000
200 000
100 000
-
Number of deaths
450
400
350
300
250
200
150
100
50
0
0-4
5-9
10-14
15-19
20-24
25-29
30-34
35-39
40-44
45-49
50-54
55-59
60-64
65-69
70-74
75-79
80-84
85-89
90-94
95-99
100-104
105-109
Age band


Overall
Average claim amounts
600 000
500 000
400 000
300 000
200 000
100 000
-
Number of deaths
3500
3000
2500
2000
1500
1000
500
0
0-4
5-9
10-14
15-19
20-24
25-29
30-34
35-39
40-44
45-49
50-54
55-59
60-64
65-69
70-74
75-79
80-84
85-89
90-94
95-99
100-104
105-109
Age band

Across all trajectories, except for the "Sudden death" trajectory, the phenomenon of overall average claims costs decreasing at advanced ages (aged seventy and above) is again evident.

There are a relatively low number of child decedents, which may result in a single outlier per age group distorting the overall average claims costs for children. Children and young adults (younger than thirty) had relatively high "Cancer" and "Organ failure" claims costs as compared to the experience of older decedent beneficiaries in these trajectories. The double-hump in the "Other" trajectory can clearly be seen from Figure 6.5.2. This is due to all decedent beneficiaries younger than fifty not grouped as "Sudden death", "Cancer", "Organ failure" being included in this trajectory. These likely include most deaths due to traumatic events/accidents that resulted in claims above R24 000. After age fifty, the "Other" trajectory yields a similar distribution of deaths by age as the "Cancer", "Organ failure" and "General frailty" trajectories.

Table 6.5.2, below, sets out the average claims by proximity to death for the various trajectories of dying, as well as the cumulative proportion of claims over the 24-month period.

Table 6.5.2 – Average claims cost (per beneficiary) – by proximity to death and trajectory of dying

Proximity to death (Proportion of claims)	2w (%)	4w (%)	3m (%)	6m (%)	12m (%)	24m (%)
Sudden death	2 000 (7%)	3 000 (8%)	4 000 (11%)	6 000 (17%)	9 000 (27%)	34 000 (100%)
Cancer	73 000 (10%)	119 000 (17%)	247 000 (35%)	358 000 (51%)	515 000 (73%)	705 000 (100%)
Organ failure	139 000 (20%)	213 000 (31%)	348 000 (50%)	426 000 (61%)	529 000 (76%)	696 000 (100%)
Frail	100 000 (21%)	150 000 (32%)	243 000 (52%)	300 000 (64%)	368 000 (79%)	466 000 (100%)
Other	80 000 (21%)	119 000 (31%)	188 000 (50%)	229 000 (61%)	288 000 (76%)	379 000 (100%)
Overall	**85 000 (18%)**	**130 000 (27%)**	**222 000 (46%)**	**283 000 (59%)**	**370 000 (77%)**	**480 000 (100%)**

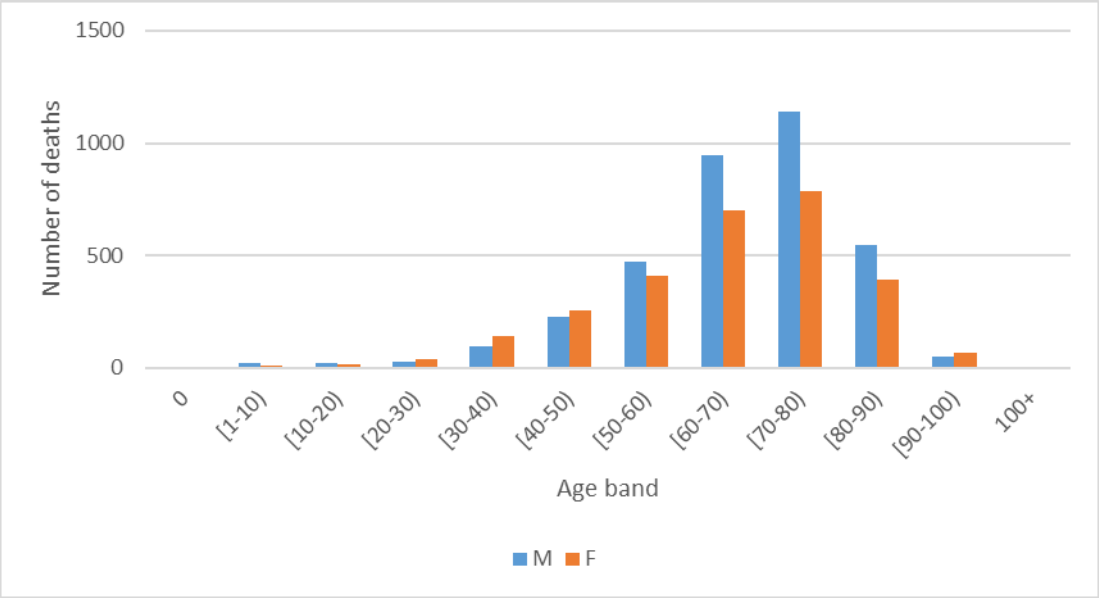
As can be seen from Table 6.5.2, other than for the "Sudden death" beneficiaries, the beneficiaries in the "Cancer" trajectory have relatively lower claim amounts during

their last two weeks of life when compared to beneficiaries in the other trajectories of dying. Considering the proportion of overall claims, the “Cancer” trajectory has a notably lower proportion of claims, relative to the other trajectories, excluding “Sudden deaths”, at all proximities to death less than twelve months. This means that significantly more cancer claims are incurred twelve to 24 months prior to death as compared with the other trajectories of dying, which experience more claims at shorter proximities to death. On average, the “Organ failure” trajectory is the most costly during the last two weeks, four weeks, and three, six and twelve months of life. The last two weeks of life are particularly costly for the “Organ failure” trajectory when compared to the other trajectories.

6.6 Decedent beneficiaries with high end-of-life care costs

As outlined in the methodology, the profile of high cost decedent beneficiaries are analysed separately as it is these lives that predominantly drive the high overall claims costs near the end of life. In Section 6.1.1, it was determined that the top thirty per cent of claimers are responsible for just over seventy per cent of all decedent beneficiary claim costs over the last 24 months of life and nearly eighty per cent of all claims over the last three months of life. This section considers the claims experience and profile of the thirty per cent of beneficiaries (with full exposure) who experienced the highest average claim costs over the last 24 months of life. Figure 6.6.1, below, highlights the age and sex split of the top thirty per cent of claimers.

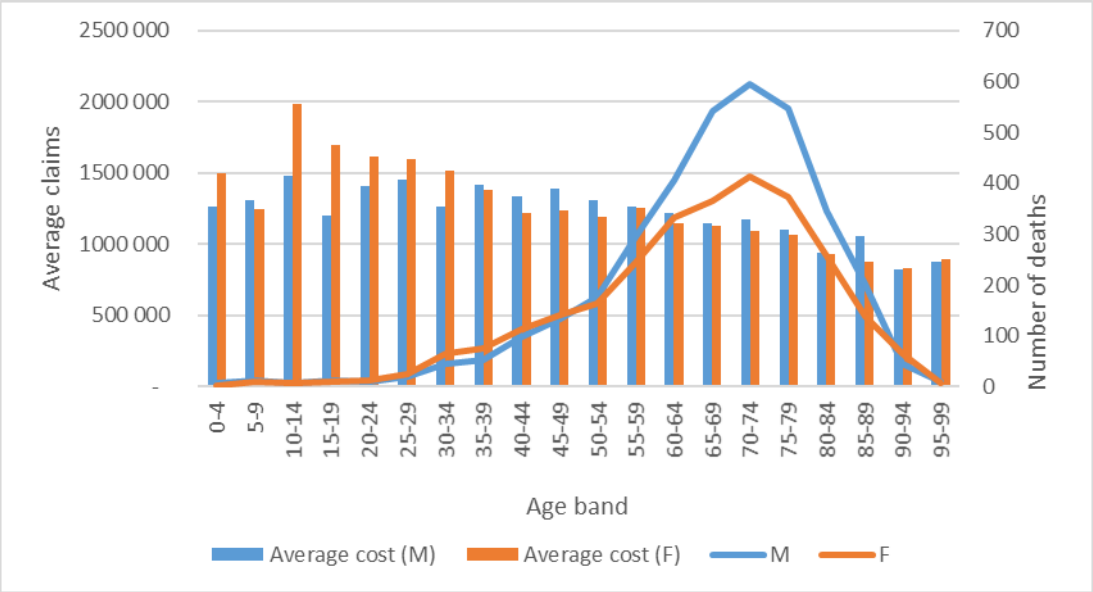
Figure 6.6.1 – Age and sex split – top 30 per cent of claimers



The distribution follows a similar pattern to the overall distribution of all deaths, except for a relatively lower number of child and young adult deaths. During the childbearing years, there are more female than male deaths, and at more advanced ages, there are more male deaths among the top thirty per cent of claimers. 91 per cent of these beneficiaries had at least one registered chronic condition (compared to 73 per cent of all beneficiaries in the overall sample) and 77 per cent died in-hospital (compared to 60 per cent of all beneficiaries in the overall sample). This is in-line with expectations that higher chronicity and death in-hospital are associated with higher claims costs, on average, near the end of life.

Figure 6.6.2, below, illustrates the average claims costs per beneficiary given their sex and age in five-year bands.

Figure 6.6.2 – Average costs – by age band and sex – top thirty per cent of claimers



For the highest claiming thirty per cent of beneficiaries, the overall average claims costs do not differ significantly between males and females (at the one or five per cent-level – p-value of 0.06) – tested using a two-tailed (i.e. sample means are unequal) z-test (since the variance of the claims between males and females, respectively, are roughly equal (ratio of 0.94) and their sample sizes are sufficiently large). From Figure 6.6.2, above, it can be seen that young females have slightly higher claims costs, on average, than young males and from age forty onwards, males have slightly higher claims costs than females, balancing out overall. Using a one-tailed z-test, at the five per cent-level, males are, on average, more costly than females (p-value of 0.03).

There is a slight downward trend in average costs with increasing age, but for the high claimers this is not as pronounced as with the entire sample of decedent beneficiaries where average costs are significantly lower at extreme ages relative to the other 'elderly' ages (ages sixty to 75). Children and young adults have the highest average claim costs among the high claimers. The higher number of males in the top thirty per cent of claimers between ages 55 and 89 can also be seen from Figure 6.6.2.

Table 6.6.1, below, shows the standard deviation and 95 per cent confidence intervals (using a Student's t-distribution) of the average claims costs for the top thirty per cent of claimers by sex.

Table 6.6.1 – Standard deviation and confidence intervals by sex – Top thirty per cent of claimers

	Standard deviation (R)	Lower 95% CI bound (R)	Upper 95% CI bound (R)
Males (n = 3 555)	774 000	1 141 000	1 192 000
Females (n = 2 817)	796 000	1 100 000	1 159 000

Table 6.6.2, below, shows the average claims cost by proximity to death for those high claimers dying in- and out-of-hospital, respectively.

Table 6.6.2 – Average claims by proximity to death – top 30 per cent of claimers

Proximity to death	Overall (R)	Average cost per day (R) – per beneficiary	Died in-hospital (R) – per beneficiary	Died out-of-hospital (R) – per beneficiary	Multiple
2w	167 000	11 908	206 000	36 000	5.70
4w	281 000	10 034	342 000	79 000	4.32
3m	521 000	5 664	602 000	257 000	2.34
6m	676 000	3 696	752 000	429 000	1.75
12m	878 000	2 402	943 000	663 000	1.42
24m	1 150 000	1 574	1 198 000	994 000	1.20

As with the full sample of lives, it can be seen that as death draws nearer, the average medical scheme claims cost per day increases rapidly. Average claims cost per day during the last two weeks of life is more than 7.5 times greater than average claims cost per day during the entire 24-month period preceding death. When death is not yet imminent (more than six months away), the difference in overall average claims between those dying in- and out-of-hospital, respectively is not as pronounced (a multiple of less than two). As death draws near, the costs for those dying in-hospital become significantly higher than for those dying out-of-hospital.

Next, the number of hospitalisations and the number of days spent in-hospital by the high claimers are considered. The average number of hospitalisations for the top thirty per cent of claimers during their last 24 months of life was six (compared to the four hospitalisation experienced by all the decedent beneficiaries, on average, in the sample). The average length of these hospitalisations were ten days (compared to the nine-day average length of stay for all hospitalised decedent beneficiaries in the sample).

Table 6.6.3, below, shows the average number of days spent in-hospital by these beneficiaries given their proximity to death.

Table 6.6.3 – Number of days (proportion of time, of the given proximity to death) spent in hospital by the top thirty per cent of claimers

Days in-hospital	2w (%)	4w (%)	3m (%)	6m (%)	12m (%)	24m (%)
Overall	8 (60%)	14 (51%)	28 (30%)	37 (20%)	47 (13%)	62 (8%)
Died IH	10 (73%)	17 (60%)	31 (33%)	39 (21%)	50 (14%)	63 (9%)
Died OOH	2 (17%)	6 (21%)	18 (19%)	28 (15%)	40 (11%)	56 (8%)
Multiple (IH/OOH)	4.24	2.85	1.72	1.41	1.25	1.13

For the top thirty per cent of claimers, an average of 62 days was spent in-hospital during the last 24 months of life. Those that died in-hospital, spent more days in-hospital than those that died out-of-hospital, on average, at each proximity to death. As a proportion of the duration and as a relative multiple of days spent in-hospital, this becomes more pronounced as death draws nearer. Hospitalisations and the number of days spent in hospital are considered in further detail in Section 6.7, below.

Given the methodology for classifying lives by trajectory of dying, very few (ten beneficiaries in total) of the top thirty per cent of claimers were allocated to the sudden death trajectory. These are beneficiaries who experienced high claims in the year prior to the year of death, and low claims during their last year of life (less than R24 000).

Table 6.6.4, below, shows the split of the top claimers by trajectory of dying.

Table 6.6.4 – Trajectories of dying – Top 30 per cent

Trajectory	# beneficiaries	Proportion
Sudden Death	10	0%
Cancer	2 142	34%
Organ Failure	1 292	20%
General Frailty	2 251	35%
Other	677	11%
Total	**6 372**	**100%**

Approximately one third of the top thirty per cent of claimers were categorised into each of the “Cancer” and “General frailty” trajectories; twenty per cent of the top

claimers are categorised into the "Organ failure" trajectory and eleven per cent are classified as the "Other" trajectory. Relatively more of the top claimers belong to the "Cancer" and "Organ failure" trajectories, respectively, when compared to the distribution of the full sample of decedent beneficiaries by trajectory of dying (i.e. nineteen per cent "Cancer" and fourteen per cent "Organ failure").

The following section considers indicators of quality care near the end of life that can be measured from the administrative claims data.

6.7 Measuring the quality of care near the end of life

In addition to cost, it is important also to consider the quality component of value in order to achieve the aim of maximising the value of end-of-life care for the key stakeholders. Quality considerations were explored in Section 2, and below a number of quality indicators/metrics observable from the administrative data are investigated. These include: 1) Death in-hospital, 2) Days spent in-hospital, 3) Chemotherapy in the last weeks of life, and 4) Hospice utilisation near the end of life.

These indicators/metrics can be used to develop robust, reportable measures of quality care near the end of life, e.g. documenting end-of-life care discussions with individuals (and the frequency of these discussions as circumstances change) and the drawing up of advance directives, recommendations for palliative care consultations, patient/family surveys, etc. These metrics also provide a useful baseline for assessing the impact of interventions on quality of care and on care outcomes.

6.7.1 Quality indicators observable from the claims data

Death in hospital

In Section 6.2, it was seen that sixty per cent of all decedent beneficiaries in the sample died in-hospital and that 75 per cent of all claims over the last 24 months of life for the decedent beneficiaries were incurred in a hospital setting. During the last two weeks of life, for those decedent beneficiaries that had non-zero claims, 94 per cent of these claims were for treatments or procedures performed in-hospital and 66 per cent of these beneficiaries eventually died in-hospital. Hospital utilisation near the end of life was considered in Section 6.2. Furthermore, in Section 6.5, it was established that the

"Organ failure" trajectory had the highest likelihood of death in hospital at 79 per cent, followed by "General frailty" (65 per cent) and "Cancer" (62 per cent).

Days spent in hospital

Of the 21 457 beneficiaries with full exposure, 18 098 (or 84 per cent) had at least one hospitalisation with at least one night spent in-hospital. Beneficiaries that had a hospitalisation in the last 24 months of life, on average had four hospitalisations during this time. The average length of stay per hospitalisation was nine days. Table 6.7.1.1, below, shows the average number of days spent in hospital, given the proximity to death for those lives who spent at least one day in hospital during that time. The average proportion of time, given the time to death is also shown for those that had a hospitalisation within that particular proximity to death.

Table 6.7.1.1 – Average number of days in hospital

Proximity to death	24m	12m	6m	3m	4w	2w
Average # days	35	29	24	19	12	8
% of time	5%	8%	13%	21%	44%	59%

On average, the sample of decedent beneficiaries spent 35 days in hospital during their last 24 months of life, or five percent of the last 24 months of life. In the last year of life, this was, on average, 29 days (or eight per cent). As death draws nearer, the number of days spent in hospital as a proportion of the time until death for those that have a hospitalisation increase significantly. 44 per cent and 59 per cent of the last four weeks and two weeks of life, respectively, are spent in-hospital, on average. There is no significant difference between the number of days spent in hospital by males and females, respectively, near their end of life.

Table 6.7.1.2, below, shows the average days by proximity to death, for lives that died in- and out-of-hospital, respectively.

Table 6.7.1.2 – Place of death and average number of days in hospital

Proximity to death	24m	12m	6m	3m	4w	2w
Died in-hospital						
Average number of days	38	30	25	20	13	9
% of time	5%	8%	14%	22%	45%	61%
Died out-of-hospital						
Average number of days	29	24	20	16	10	6
% of time	4%	7%	11%	18%	34%	45%

Those who died in-hospital spent more days, on average, in hospital at all proximities to death. On average, those who died in-hospital had nineteen per cent more hospitalisations than those who died out-of-hospital, which may partly explain the greater number of days spent in-hospital by those who eventually died in-hospital. 22 per cent of decedent beneficiaries that had at least one hospitalisation of more than one day spent all of their last two weeks of life in-hospital. Ten per cent of decedent beneficiaries that had at least one hospitalisation spent all of their last four weeks of life in-hospital.

Table 6.7.1.3, below, shows the number of days spent in hospital by those that had utilised some billed hospice services leading up to death.

Table 6.7.1.3 – Average number of days spent in-hospital

Hospice users	24m	12m	6m	3m	4w	2w
Utilised hospice	34	27	21	16	10	7
% time	5%	7%	12%	18%	36%	51%

Decedent beneficiaries that had utilised some hospice services near their end of life were shown in Section 6.2.1 to have a significantly lower probability of dying in-hospital (and lower average claims costs) as compared to those who had not utilised any hospice services. From Table 6.7.1.3, it can also be seen that those beneficiaries who utilised some billed hospice services (and had at least one hospitalisation) also spent fewer days in-hospital near their end of life, on average, when compared to the overall sample of beneficiaries that had at least one hospitalisation during their last 24 months of life. The average number of days spent in-hospital will be slightly lower if including those hospice users that had no hospitalisations at all.

Chemotherapy in the last weeks of life

Table 6.7.1.4, below, shows the number of beneficiaries that had chemotherapy claims in their last two weeks, four weeks and three months of life, respectively.

Table 6.7.1.4 – Chemotherapy claims near the end of life

Proximity to death	# beneficiaries	Proportion receiving chemo at the given proximity to death
2w	615	17%
4w	1 181	32%
3m	2 409	65%
3m+	1 313	35%

It can be seen from Table 6.7.1.4 that seventeen per cent of beneficiaries that had claims for the administering of chemotherapy, had chemotherapy administered in their last two weeks of life. Approximately one third of beneficiaries had chemotherapy-related claims in their last four weeks of life and two thirds had chemotherapy-related claims during their last three months of life.

There were more males than females receiving chemotherapy over the last 24 months of life (52 per cent vs 48 per cent of those receiving chemotherapy). Males were also more likely, on average, to receive chemotherapy during their last three months of life than females (67 percent vs 62 per cent). 66 per cent of those that had received chemotherapy at some point during the last 24 months of life died in-hospital.

Table 6.7.1.5, below, shows the administering of chemotherapy to those beneficiaries dying in- and out-of-hospital, respectively, given their proximity to death.

Table 6.7.1.5 – Chemotherapy near the end-of-life and place of death

Death in-hospital	2440	66%
Proximity to death	# beneficiaries	Proportion of beneficiaries
2w	516	21%
4w	933	38%
3m	1 698	70%
3m+	742	30%
Death out-of-hospital	1 282	34%
Proximity to death	# beneficiaries	Proportion of beneficiaries
2w	99	8%
4w	248	19%
3m	711	55%
3m+	571	45%

It can be seen that those beneficiaries receiving chemotherapy that died in-hospital were more likely to receive chemotherapy during their last two weeks and four weeks of life, respectively. 21 per cent of those dying in-hospital (vs eight per cent of those who died out-of-hospital) were receiving chemotherapy during their last two weeks of life. Similarly, during the last four weeks of life, 38 per cent of those who died in-hospital (vs nineteen per cent of those who died out-of-hospital) received chemotherapy.

Table 6.7.1.6, below, details the average age at death of lives who received some chemotherapy during the last 24 months of life.

Table 6.7.1.6 – Average age at death – chemotherapy users

	Average age	#Beneficiaries
Males	65	1 937
Females	62	1 785
Died in-hospital	62	2 440
Died out-of-hospital	66	1 282
Overall	64	3 722

Males receiving chemotherapy are, on average, older than females receiving chemotherapy. Those who received chemotherapy that died in-hospital tended to be younger than those who received chemotherapy and had died out-of-hospital.

No/late hospice enrolment

In a Section 6.2.1 it was found that less than five per cent of decedent beneficiaries had utilised any hospice services prior to them dying. Hospice users were mainly beneficiaries suffering from cancer and they experienced a reduced likelihood of death in-hospital – thirty per cent vs sixty per cent, overall. Further details on the analyses performed and the results of these analysis can be found in Section 6.2.1. Below, the timing of hospice enrolment is considered by looking at the first recorded date for hospice-related claims in the claims data. This results in an average hospice enrolment of 3.5 months (or 106 days) before death.

Table 6.7.1.7, below, shows the number of hospice enrolees given their proximity to death.

Table 6.7.1.7 – Hospice enrolment by proximity to death

Enrolled in hospice	Count	Proportion
Last 7 days of life	269	22%
Last 2w of life	391	32%
Last 4w of life	547	45%
More than 4w from death	681	56%
More than 3m from death	363	30%

56 per cent of decedent beneficiaries that had utilised hospice-related services started utilising these services more than four weeks before death and thirty per cent of these beneficiaries started utilising hospice services more than three months before death. 22 per cent of beneficiaries utilising hospice services had less than seven days of hospice care before death. 32 per cent of those utilising hospice enrolled during their last two weeks of life.

7 Discussion of results

The end of life and end-of-life care are complex, multi-dimensional and, surprisingly, poorly understood concepts. In the dynamic world of technological advances, drug and treatment innovation and an increasing capacity to deliver care, the ability of medicine, as well as the perceptions regarding this ability, are continually changing. With this, end-of-life care is also constantly evolving and continually being adapted to the changing medical landscape. This research project aimed to identify the multitude of contributory factors that are associated with end-of-life care in the South African medical schemes environment, and theorises the interaction between these factors and their effect on the observed claims cost near the end of life. The results of the data analyses performed in the previous section are interpreted and their implications discussed, below.

7.1 Demographic profile and overall claims patterns of decedent beneficiaries

For the sample of decedent beneficiaries, the majority of deaths occur between the ages of sixty and ninety years with a median age at death of seventy years. This is consistent with expectations given that medical scheme membership is concentrated in top income quintile of South Africa (McIntyre 2010). This subset of the population have health outcomes, life expectancies and a disease burdens comparable to that of economically developed nations. The sample contained more male deaths than female deaths and, on average, males experienced greater medical scheme claims near their end of life, overall. At advanced ages (eighty years and older) there are more female deaths. This may be due to the longer life expectancy of females (and hence number of females alive at these advanced ages compared to the number of males alive at these ages) (Barford, Dorling, Smith and Shaw 2006). However, this cannot be said with certainty as distribution of the overall population of beneficiaries exposed to the risk of dying at advanced ages is unknown.

More deaths are recorded in the winter months – July and August. The most at-risk members of the exposed population (the very old and/or the very sick) tend to be more vulnerable during the colder winter months (influenza season) as opposed to during the summer months (Wilkinson, Pattenden, Armstrong, Fletcher *et al.* 2004).

Similarly, January and February (summer) have lower numbers of deaths, on average, bearing in mind that February is also the shortest month of the year.

The claims costs analyses performed only considers the actual medical scheme claims submitted for the decedent beneficiaries. It should be borne in mind that there may be other costs not reflected in these amounts – both financial, quantifiable costs and other non-financial or indirect costs (Tseng and Hicks 2016). Financial costs include, for example, direct out-of-pocket healthcare expenditure, the cost of home modifications, loss of employment and income, etc. Non-financial costs include, for example, productive time lost due to illness/injury, healthy life years lost, family members needing to provide care and having a reduced capacity to work, the emotional impact of anxiety and depression caused by ill health, both for the patient and their families, etc.

86 per cent of decedent beneficiaries in the sample had been on the scheme for the full 24-month period preceding their deaths, and experienced average medical scheme claims of R480 000 (in 2017 ZAR-terms) per beneficiary during this period.

The results show that average medical care costs over the last 24 months of life increase with increasing age, up until around age 75, and then decreases sharply, on average, at more advanced ages. This is consistent with findings in the literature (Levinsky, Yu, Ash, Moskowitz *et al.* 2001; Hoover, Crystal, Kumar, Sambamoorthi *et al.* 2002; Ranchod, Abraham and Bloch 2015). Decedent beneficiaries at more advanced ages may have been healthier throughout their lives, i.e. not having had chronic conditions, resulting in them being healthier at more advanced ages, requiring less medical care and experiencing fewer hospitalisations, overall (Yang, Norton and Stearns 2003). Also, at more advanced ages, there may be greater rationing of medical goods and services, either by providers, the medical schemes, or both (Levinsky *et al.* 2001). Beneficiaries may themselves also choose to forego invasive and aggressive care at more advanced ages, resulting in a lower level of average cumulative claims observed for these decedent beneficiaries.

For middle-aged to elderly decedent beneficiaries (ages forty to eighty), the high prevalence of and ongoing management of chronic conditions, together with frequent hospitalisation, especially towards the very end of life, may explain the high level of cumulative claims (on average) that these beneficiaries experience during their last 24

months of life. Advances in medical care have resulted in seriously ill persons being able to live longer, albeit with significantly higher levels of disability and higher medical care costs before their eventual deaths (Cutler 2007).

The overall claims experience between males and females at different ages yielded some interesting results. At ages younger than 65 years, females experienced higher average claims than males with the relationship switching at ages greater than 65 years. This may be due to the high cost of pregnancy-related complications that result in death and the higher incidence of terminal breast and cervical cancers at relatively young ages for females compared to the relative incidence rates of terminal cancers for males at young ages (Mustard, Kaufert, Kozyrskyj and Mayer 1998; Cook, Dawsey, Freedman, Inskip *et al.* 2009). Also, young males are more at risk of unexpected or accidental deaths than young females (Stiglets 2001; Patton, Coffey, Sawyer, Viner *et al.* 2009). Furthermore, at middle ages, males may experience more sudden deaths, e.g. death from myocardial infarction (heart attacks) and cerebrovascular accidents (strokes) due to undiagnosed cardiovascular conditions (Regitz-Zagrosek 2012). Where accidents result in sudden death or where an underlying cardiovascular condition has gone undiagnosed and untreated, these would typically not be associated with high medical care costs, and hence lower claims, on average. It should be noted that most deaths (males and females) are concentrated between the ages of 65 and ninety. The higher concentration of lives at the older ages, with males experiencing higher average claims costs at these ages result in the higher overall average claims costs for males, at all proximities to death.

The geographic distribution of decedent beneficiaries shows that there are more deaths in urbanised areas. The more rural areas, e.g. the Northern Cape, have a much lower concentration of deaths. This is not unexpected as the geographic distribution of the underlying population from which the decedents are drawn is more concentrated in urbanised areas (Council for Medical Schemes 2019). Interestingly, the more rural areas, e.g. the Northern Cape, experience significantly lower average claims costs near the end of life than the more urbanised areas, e.g. Gauteng. This may be due to the rural areas having a lower concentration of private hospitals than the more urbanised areas. This may result in hospitals in more rural provinces being less easily accessible and reduces utilisation of hospital and other expensive medical services near the end

of life for beneficiaries residing in these areas. The Gauteng province is the most urbanised and has the highest average claims costs per decedent beneficiary, possibly due to beneficiaries having easier access to more expensive care in private hospitals.

7.1.1 Claims by proximity to death

Medical scheme claims costs near the end of life increase significantly as death draws nearer. Average medical scheme claims for these beneficiaries during their last year of life amounted to R364 000 (in 2017 ZAR-terms) per beneficiary, i.e. three times higher than in the year preceding their year of death. Almost fifty per cent of the claims costs incurred by beneficiaries during their last 24 months of life are incurred during their last three months of life, and 25 per cent of overall claims are incurred in the last month of life. Similar results have been found in international literature (Yang, Norton and Stearns 2003).

There is a large difference between the mean and median claims for the decedent beneficiaries at all proximities to death. This is expected as on the one hand, some would have died suddenly, or unexpectedly, with little or no interaction with the healthcare system and hence no (or very few) claims. Others would have died following a relatively brief illness whilst some would have foregone intensive medical interventions or hospitalisations in the period preceding their death, all resulting in relatively low claims for these particular beneficiaries. On the other hand, some may have died following long or multiple hospitalisations with bouts of intensive care and/or other expensive treatments potentially with a number of complications during these hospitalisations requiring further expensive/intensive intervention. The relatively low number of very costly cases pushes the overall average claims cost upward and the large number of relatively low cost cases pulls the median claims cost downward.

Considering the claims cost during the last year of life compared to the claims cost during the twelve months preceding the last year of life shows similar results to the study performed by Ranchod, Abraham and Bloch (2015) which was based on an independent set of lives, covering a different time period as well as the experience of different medical schemes. In their research they found that the costs in the last year of life was 3.3 times higher than in the year preceding the year of death. Having

excluded neonate deaths and all lives with partial exposure, the experience of the lives under consideration in this research project shows threefold increase in costs in the last year of life as compared to the year prior to the year of death. Not excluding neonates or lives with partial exposure without any claim/exposure adjustments, this multiple increases to 3.4 times. However, this incorrectly places too much weight on the costs incurred in the last year due to neonates and other lives with partial exposure having no (or significantly less) claims in the year prior to the year of death.

Claims acceleration with death drawing nearer is not unexpected given that beneficiaries are likely to be seriously ill near their end of life and require heroic efforts (costly and resource-intensive) to prevent them from dying.

This acceleration can clearly be seen when looking at the daily average claims amount for decedent beneficiaries. This increases from about R660 per beneficiary per day during the last 24 months of life to around R6 000 per beneficiary per day during the last two weeks of life.

7.1.2 Truncated distributions

In Section 6.1.2, it is shown that the average claim amounts are significantly higher than the median claim amounts. This indicates that the distribution of end-of-life care costs are skewed towards the decedent beneficiaries having higher than average claims costs at the end of life, which prompted an investigation into the distribution of claims excluding the tail ends of the distribution – i.e. both the top and bottom claimers.

The effect of excluding the tails is most notable at the ten per cent level (excluding the highest and lowest claiming ten per cent of beneficiaries) further highlighting the effect of the relatively small number of decedent beneficiaries with very high claims near their end of life on the overall end-of-life claim costs for medical schemes.

The experience stabilises at around the thirty per cent level, which prompted the analyses into the profile and experience of the top thirty per cent of claimers. These beneficiaries mainly drive the high average claim costs experienced by medical schemes for beneficiaries near their end of life. For these high cost cases the majority of medical claim costs are concentrated in the last three months of life (around fifty per cent). These beneficiaries may be receiving intensive, aggressive, yet ineffective

curative interventions near their end of life and they may have palliative and other needs that are not being met. This should be interpreted with caution as no data are available on beneficiaries with similar clinical profiles who survive because of these curative interventions, i.e. who would have died without them.

The bottom fifty per cent of the sample of decedent beneficiaries claim only twelve per cent of the overall claim costs of the sample. The top one per cent of claimers claim nearly ten per cent of overall claims and the top ten per cent claims nearly forty per cent of the overall claims of the entire sample of decedent beneficiaries.

7.1.3 Claims by provider type

The bulk of medical scheme claims costs for decedent beneficiaries near their end of life are the costs of private hospital care (around fifty per cent of overall claims in the last 24 months of life are billed by private hospitals themselves). Around 75 per cent of total claims for the decedent beneficiaries in the last 24 months of life result from procedures performed or care received in a hospital setting. This means around 25 per cent of overall claims are billed by specialists, auxiliary healthcare providers and pharmacies for beneficiaries who are receiving treatment and care in-hospital, over and above the fifty per cent of overall claims billed by the hospitals themselves. The total proportion of costs incurred by beneficiaries for and in private hospitals increase as death draws nearer indicating an increased likelihood of hospitalisation as death draws nearer. The other main provider types driving claims near the end of life are pharmacies and specialists.

7.2 Place of death

60 per cent of the sample of decedent beneficiaries died in-hospital. Comparing the overall claims experience of those dying in- vs out-of-hospital, it is seen that those dying in-hospital, irrespective of the number and length of hospitalisations during their last 24 months of life, experience consistently higher claim costs over their last 24 months of life. These analyses do not aim to attribute causality – the beneficiaries dying in-hospital may have been much sicker than those dying out-of-hospital, requiring significantly more, and more specialised medical care, driving their observed

higher claims costs. The ratio of claims cost for those dying in-hospital compared to those dying out-of-hospital increases from two during the last 24 months of life, to seven during the last two weeks of life.

In addition, irrespective of death occurring in- or out-of-hospital, the overall average claim costs for beneficiaries aged 75 years and older, still decrease with increasing age – a reversal of the trend seen with increasing ages below the age of 75 years. This may further suggest that there is either conscious choice by the beneficiaries, their families or the medical care providers to ration the use of intensive, aggressive care at advanced ages. At the teenage/young adult ages, the difference between average costs for those that died in-hospital vs those that died out-of-hospital is the greatest. This is likely due to the sudden or accidental nature of out-of-hospital deaths at young ages and hence, a low level of medical care utilisation and cost.

Irrespective of whether a beneficiary dies in- or out-of-hospital, the majority of treatments/procedures near the end of life are performed in a hospital setting (75 per cent of overall claims costs). This means that as death nears, it becomes almost inevitable for beneficiaries to become hospitalised at some point leading up to their death. For those dying in-hospital, the overall proportion of claims at all proximities to death for treatments/procedures performed in a hospital setting is significantly higher than for those dying out-of-hospital (79 vs 63 per cent during the last 24 months of life, and 96 vs 68 per cent during the last two weeks of life). It is expected that the claims cost for those beneficiaries that die in-hospital will be greater than for those beneficiaries that died out-of-hospital due to the nature of hospital-based care being more resource-intensive and more specialised. With increasing age after age 75, the proportion of deaths occurring out-of-hospital increases.

By comparing the age profiles, the total proportion and the acceleration of claims in-hospital between those dying in- and out-of-hospital, respectively, it appears that dying out-of-hospital (or foregoing further curative interventions or hospitalisation) may have been a conscious choice for some beneficiaries. This does not mean that they had foregone all forms of care, but these beneficiaries may have obtained alternative care, e.g. home nursing or hospice care that is not covered by their medical scheme (and hence are not claimed for).

Dying in-hospital may be contrary to the wishes of the dying beneficiary, potentially resulting from the beneficiary not having any alternative funded care options, e.g. nursing or hospice care, at such a time when their condition deteriorates and they are in need of care. The result potentially being that people die in-hospital receiving more intensive and more expensive care than may be warranted or effective given their condition, as well as potentially being contrary to their preferences. This is based on conjecture and on the research surrounding patients' expressed preferences for not dying in a hospital setting contained in the literature. From the data analysed, beneficiaries' preferences for setting(s) of care near the end of life and preferences for place of death, cannot be confirmed.

7.2.1 Hospice utilisation

Hospices in South Africa operate on a charitable basis serving indigent individuals[12] and as a result, the billing for hospice services utilised by medical scheme beneficiaries has often been on an ad hoc rather than on a structured basis. This may also result in billing errors and inconsistencies between different hospices. Hospice billing of medical schemes for the services utilised by their beneficiaries have improved over time and this may partly explain why utilisation in 2017 is greater than in 2016 (an increase in utilisation of twenty per cent is observed). Furthermore, in 2017, significantly fewer beneficiaries had hospice-related claims recorded after their date of death as compared to 2016. This may potentially indicate improved and more established billing processes followed by hospices with fewer errors. It should be noted that actual hospice utilisation by decedent beneficiaries may be higher than indicated by the claims data due to direct out-of-pocket payment and/or due to non-billing of these services rendered by individual hospices to medical scheme beneficiaries. 'Utilisation', below, refers only to the utilisation of billed hospice services.

Hospice service utilisation (that were specifically billed for by the hospices) for the sample of decedent beneficiaries is low (less than five per cent of decedent beneficiaries). 94 per cent of beneficiaries utilising hospice services had been

[12] HPCA. (2019). HPCA. Available: https://hpca.co.za/palliative-care/who-qualifies/ (accessed: 14 November, 2019).

diagnosed with a chronic condition (compared to 73 per cent in the overall sample of decedent beneficiaries). More than ninety per cent of beneficiaries that had utilised some hospice services had previously been diagnosed with a form of cancer. The average age of hospice users is 69 years and the sex split is roughly equal.

Beneficiaries that had utilised some hospice services had a significantly lower probability of death in-hospital – only thirty per cent of beneficiaries that had utilised hospice services eventually died in-hospital (compared to sixty per cent of the overall sample of decedent beneficiaries). Those who had utilised hospice services also experienced significantly reduced overall medical scheme claims near their end of life, on average (R76 000 vs R143 000 during the last four weeks of life, in 2017 ZAR-terms). The lower overall claims cost for beneficiaries who died whilst actively receiving hospice care services may be due to lower rates of hospitalisation as found in a study by Obermeyer, Makar, Abujaber, Dominici *et al.* (2014) on Medicare beneficiaries with poor-prognosis cancer utilising hospice services. These results are similar to the findings of Emanuel, Ash, Yu, Gazelle *et al.* (2002) who studied the effects of hospice utilisation on end-of-life care costs and the place of death for a sample of decedent Medicare beneficiaries.

Beneficiaries that had utilised some hospice services and died out-of-hospital experienced significantly higher costs than the beneficiaries dying out-of-hospital and utilising no hospice care during their last four weeks of life (R60 000 vs R30 000 during the last four weeks of life) . This is partly because of the cost of hospice care and because of hospice care mainly being utilised by beneficiaries with cancer. Beneficiaries with cancer experience significantly higher medical scheme claims, on average, during the last four weeks of life when compared to beneficiaries that do not have cancer (R49 000 vs R24 000 for deaths occurring out-of-hospital; having cancer vs not having cancer, respectively). The reason for observing such a high number of beneficiaries with cancer utilising hospice services may be due to scheme benefits, such as ‘alternatives to hospitalisation’ or ‘compassionate care’ benefits, that predominantly targets beneficiaries with cancer near their end of life.

7.3 Analysis of lives with partial exposure

Given the stringent regulations surrounding voluntary and open enrolment (schemes are not allowed to decline membership based on age, state of health, etc.) and community rating (no differential pricing based on age, state of health, etc.), an environment is created in which individuals can select against medical schemes (McLeod and Ramjee 2007). The problem is two-fold – young, healthy individuals opt out of purchasing cover (these lives would have served to improve the overall risk profile of the scheme). On the other hand, older, sicker individuals take up medical scheme cover at a point where they either require care or believe their risk of requiring care in the near future is significant enough to justify paying for cover (these lives serve to worsen the overall risk profile of the scheme). Medical schemes have a limited range of underwriting tools available with which to protect themselves against such anti-selection. A three-month general waiting period and a twelve-month condition-specific waiting period may be applied, subject to certain rules depending on whether the beneficiary had prior, recent and uninterrupted medical scheme coverage (Department of Health 1998). The three-month period may be applied to any claims submitted and the twelve-month period may be applied to specific conditions for which medical advice was sought over the preceding twelve-month period.

Fourteen per cent of beneficiaries were new joiners (or members that had cover, lapsed and subsequently re-joined) to the scheme within the 24-month period preceding their death. Compared to the overall sample of beneficiaries, a similar proportion of beneficiaries with partial exposure died in-hospital, i.e. around 60 per cent. The age distribution of the decedent beneficiaries with partial exposure is, however, different to that of beneficiaries that had been exposed for the full 24-month period preceding their deaths. This may be indicative of anti-selective behaviour, i.e. persons only opting for cover once becoming ill and requiring (expensive) care, irrespective of their age. This should be interpreted with caution given the low numbers of deaths in each age band with partial exposure (around 400 per age band). This may simply be due to statistical variation and is merely suggestive of the existence of anti-selection by new joiners near their end of life.

Ten per cent of beneficiaries with partial exposure had zero claims whereas only one per cent of beneficiaries with full exposure had zero claims. This may be due to

the effect of the waiting periods being enforced on new joiners. Considering the claim amounts for the lives with partial exposure, there is no conclusive evidence of any anti-selection near their end of life. However, this does not mean that no such anti-selection exists. The application of the general three-month and twelve-month condition-specific waiting periods may mask the effect of any anti-selective behaviour that may exist, i.e. new joiners may not be submitting claims, knowing that these won't be paid for by the scheme.

In the last month of life, claims for partially exposed decedent beneficiaries are not statistically different to those of the fully exposed beneficiaries (R126 000 vs R130 000). A possible reason for this may be that by this time most waiting periods may have elapsed, or that the scheme may be waiving the waiting periods in cases of emergencies at the end of life (ex-gratia payments).

7.4 Ageing populations, lifestyles and chronic non-communicable diseases

Research has shown that the burden of chronic non-communicable diseases are on the rise, but that the risk of becoming chronically ill can be significantly reduced by lifestyle and behavioural changes, e.g. increased physical activity, healthy diets, mental wellbeing, stopping smoking and responsible alcohol consumption (Habib and Saha 2010; World Health Organization 2011). Chronic non-communicable diseases significantly impacts medical scheme claim costs over the lifetime of their beneficiaries diagnosed with these conditions. This is especially true for the PMB chronic disease list (CDL) conditions that require full payment for the diagnosis, treatment and ongoing management of the conditions without any limits or co-payments (Department of Health 1998).

Given the average age of death of greater than sixty years (and median age at death of seventy years), the incidence of chronic conditions is not surprising. Around 73 per cent of decedent beneficiaries have at least one chronic condition). This is in line with findings by Joubert and Bradshaw (2006) on the incidence of chronic conditions, and the high proportion of deaths as a result of chronic conditions for lives aged sixty years and older in South Africa. Increasing chronic prevalence at older ages is well-documented in the literature (Hung, Ross, Boockvar and Siu 2011). A total of 55 per cent of decedent beneficiaries in the sample experienced multi-morbidity, i.e.

having two or more chronic conditions simultaneously. The most prevalent chronic conditions were heart conditions (57 per cent of decedent beneficiaries), cancer (24 per cent of decedent beneficiaries), diabetes (sixteen per cent of decedent beneficiaries), chronic respiratory conditions (twelve per cent of decedent beneficiaries) and mental health conditions (eight per cent of beneficiaries).

When considering beneficiaries with only one chronic condition, it is interesting to note the high cancer costs at the various proximities to death relative to the benchmark cost (i.e. relative to the cost for those who have no registered/authorised chronic conditions) three months or more from their date of death. This may be explained by the high cost of cancer treatment and anti-cancer drugs and the relatively long period preceding death over which the cancer treatment is given. Similarly for those suffering from a chronic renal condition (possibly requiring regular and costly dialysis), the average costs are significantly higher than the benchmark at all durations, and especially high in the year preceding the year of death. HIV, musculoskeletal and 'OTHER' conditions also have relatively high costs compared to the benchmark cost, whereas the remaining groups do not demonstrate quite such a pronounced deviation from the benchmark.

It is further shown that having more chronic conditions is associated with higher claims costs near the end of life at all proximities to death, increasing, on average, with each additional chronic condition. When death is imminent, i.e. during the final month, the trend is less pronounced than with durations further from death. This is not surprising given the knowledge that these beneficiaries are very close to death, i.e. the costs in the acute dying phase drown out the effect of multi-morbidity on costs during this phase.

For decedent beneficiaries with a large number of chronic conditions, the trend of higher claim costs is more pronounced when death is further away (twelve to 24 months) indicating that they had relatively high medical scheme claims costs in the year preceding their year of death. This is not surprising given that these beneficiaries would have required more frequent care interventions and ongoing management of their (multiple) conditions, and may have had more hospitalisations in the year preceding their year of death than beneficiaries with fewer or no chronic conditions. These beneficiaries are also less likely to have died suddenly given their significant

level of interaction with the healthcare system and the (often) progressive nature of chronic illnesses.

A positive correlation exists between the number of chronic conditions and the overall medical scheme claims costs near the end of life as well as with the number of hospitalisations and number of days spent in-hospital, respectively. So, in addition to having higher costs, on average, this means that beneficiaries with more registered chronic conditions also have a relatively higher number of hospitalisations and spend relatively more days in-hospital, on average, than those with fewer chronic conditions.

A myriad of other factors, e.g. lifestyle factors, accidents, severity of chronic condition(s), chronic medication adherence, personal care preferences, etc. influences the ultimate medical claims costs and hospitalisations experienced by each individual decedent beneficiary. The analyses into the association of chronic conditions with overall claims costs considered only the number of chronic conditions and not at the relative severity of specific conditions between and within groups of conditions. For example, a chronic condition of the eye is expected to result in fewer hospital admissions and in lower claims on an ongoing basis to manage than an invasive cancer that affects multiple bodily systems and organs, requiring expensive medication, ongoing treatment and frequent hospital admissions. Furthermore, the actual effect of the chronic condition on the overall claims cost may be further masked by varying degrees of severity within chronic disease groupings. As an example consider the cancer grouping – within this group there will be 'stage IV[13]' cancers and 'stage I' cancers. The expectation is that for a 'stage IV' cancer, the beneficiary is likely to be sicker, require more medication, be hospitalised more frequently and more aggressive treatment for the cancer will be administered as opposed to a beneficiary with a 'stage I' cancer in relatively good health requiring mainly outpatient treatment. The low level of correlation between overall claim costs and having an additional chronic condition (as observed) may simply be because of the way in which the chronic conditions are grouped and their relative severity within these groups.

[13] Cancer 'staging' is a standard method of categorising cancers by their relative severity and their extent and location of spreading throughout the body.

However, as shown earlier, there is significant evidence to conclude that having one or more chronic conditions results in increased costs and more hospitalisations near the end of life. This makes chronicity an important factor associated with medical care costs near the end of life.

7.5 Trajectories of dying

The sample of decedent beneficiaries are sequentially grouped into the main trajectories of dying. This analysis yielded the following results: ten per cent of decedent beneficiaries are classified as "Sudden deaths"; nineteen per cent as "Cancer" deaths; fourteen per cent as "Organ failure" deaths, and 39 per cent of decedent beneficiaries are classified as deaths due to "General frailty". Seventeen per cent of decedent beneficiaries could not be grouped into one of the main trajectories of dying, and are classified as the "Other" trajectory. The "Cancer" and "Organ failure" trajectories are the most costly and warrant further investigation into the effective management and treatment of beneficiaries falling into these trajectories.

As expected, the "Sudden death" trajectory has a very low average cost (R9 000) during the last year of life and a very low proportion of deaths occurring in hospital (sixteen per cent), as well as a relatively low average age of decedent beneficiaries (49 years). It also has relatively more male deaths (69 per cent) than the other trajectories (around fifty per cent) which may be due to younger males tending to be more risk-seeking (Stiglets 2001). The "General frailty" and "Other" trajectories have relatively more females than average (51 and 49 per cent, respectively, vs 47 per cent). This may be due to the higher average age for the "General frailty" trajectory and the higher number of females at advanced ages in the sample of decedents, and the inclusion of childbirth and pregnancy-related deaths in the "Other" trajectory. The "General frailty" trajectory has the highest average age (77 years) since all beneficiaries younger than fifty are excluded from this trajectory, and the conditions that make up this trajectory are predominantly those that manifest at older ages. The "Organ failure" trajectory has a higher than average age (seventy years) which is not unexpected given the long-term, progressive nature of "Organ failure". The relatively high proportion of hospital deaths (79 per cent) for this trajectory is also not surprising given the intensive hospital treatment required in the event of an organ failure event, e.g. mechanical

ventilation, dialysis, resuscitation, intensive care unit stays, etc. (Groeger and Aurora 2001; Murray *et al.* 2005). The "Organ failure" trajectory has the highest average costs during the last year of life (R529 000), followed by the "Cancer" trajectory (R515 000), whereas the "Cancer" trajectory has the highest median claims cost during the last year of life (R399 000). This means that there are a larger number of relatively high cost beneficiaries in the "Organ failure" group, as compared to the "Cancer" group, i.e. removing the outliers, results in the "Cancer" trajectory being the most expensive trajectory, on average, during the last year of life. Given the highly uncertain nature of the health exacerbations and care requirements for beneficiaries in the "Organ failure" trajectory, this result is not surprising. During the last year of life the "Other" trajectory has relatively low average claims (R288 000), average age (62 years) and proportion of deaths in-hospital (57 per cent) as compared to the "Cancer" (R515 000, 66 years, 62 per cent), "Organ failure" (R529 000, 70 years, 79 per cent) and "General frailty" (R368 000, 77 years, 65 per cent) trajectories.

When considering proximities nearer to death (i.e. periods shorter than the last twelve months of life), the "Organ failure" trajectory still has the highest average claim costs, especially pronounced in the last two weeks of life. This is likely because of the intensive interventions used to try reverse episodes of organ failure. This may explain the high proportion of hospital deaths observed for beneficiaries in the "Organ failure" trajectory. On the other hand, beneficiaries in the "Cancer" trajectory experience a relatively low proportion of their overall claims during their last two weeks of life (ten per cent), when compared to the "Organ failure" (twenty per cent), "General frailty" (21 per cent) and "Other" (21 per cent) trajectories. This may be due to the relatively higher use (and lower relative cost) of hospice care near the end of life for beneficiaries with terminal cancer and the foregoing of intensive anti-cancer therapies as the end of life becomes imminent.

7.6 Decedent beneficiaries with high end-of-life care costs

The top thirty per cent of claimers are identified in Section 6.6 to be the beneficiaries mainly driving the high average claims costs observed near the end of life and their profile and experience are analysed separately. These top claimers skew the overall claims experience – observed when comparing mean and median claims of the sample

of decedent beneficiaries. The high claimers have a significantly higher chronic prevalence (91 per cent vs 73 per cent) and a significantly greater proportion of these beneficiaries died in-hospital (77 per cent vs sixty per cent) as compared to overall sample of decedent beneficiaries. The top claimers spent significantly more time in-hospital than the overall sample of decedent beneficiaries during their last 24 months of life (62 days vs 35 days, on average) and experienced a higher number of hospitalisations, on average (six vs four hospitalisations). The overall claims for males and females were not significantly different for the top claiming decedent beneficiaries. The sex split of the high claimers is 56 per cent male and 44 per cent female, having a slightly higher proportion of males than the overall sample of decedent beneficiaries (54 per cent). A slight downward trend is observed in average claims costs with increasing age at the more advanced ages, but this is not as marked as with the overall sample of decedent beneficiaries.

Comparing the experience of the high claimers (the top thirty per cent of claimers) who died in-hospital to those high claimers that died out of hospital, we see that costs are, again, consistently higher, on average, for those that died in-hospital, at all proximities to death. The difference between overall claims for those dying in- and out-of-hospital, respectively, is less pronounced at further durations from death (multiple of 1.2 times for in-hospital at 24 months), growing more pronounced as death draws nearer (multiple of 5.7 times for in-hospital at two weeks). This may be an indication that those who died out-of-hospital (but are still high claimers – top thirty per cent) may have foregone further life-sustaining/curative treatments or interventions near their end of life following a period or periods of intensive treatment before death was imminent or was known to be imminent.

Around one third of the top thirty per cent of claimers are grouped into each of the "Cancer" and "General frailty" trajectories and a further twenty per cent are grouped in each of the "Organ failure" and "Other" trajectories. A greater proportion of the top claiming decedent beneficiaries belong to the "Cancer" and "Organ failure" trajectories as compared with the overall investigation in Sections 6.6 and 6.7, considering all decedent beneficiaries with full exposure. This is due to the relatively higher treatment cost of cancer and the intensive in-hospital nature of care for the various types of organ failure. Together, these two trajectories comprise more than half

of the high-cost cases and thus provides the greatest opportunity for interventions focused on improving the quality of care provided and reducing any unnecessary spending and hospitalisations near the end of life.

7.7 Measuring the quality of care near the end of life

A number of indicators of the quality of care near the end of life are measured from the data. These are: 1) Death in-hospital, 2) Days spent in-hospital, 3) Chemotherapy in the last weeks of life, and 4) Hospice utilisation near the end of life. This list is not an exhaustive list of quality of care indicators that can be measured. Emergency room visits are an important metric for measuring the quality of care a beneficiary receives as it indicates how well the beneficiary's condition is managed outside of a hospital setting. Repeat visits may indicate poor quality of care (Pines, Mullins, Cooper, Feng *et al.* 2013). The data, however, does not allow for the accurate identification of emergency room visits.

The results of the analyses show that a significant number of medical scheme beneficiaries die in-hospital (sixty per cent overall) and that these beneficiaries spend significant amounts of time in-hospital (an average of 35 days during the last 24 months of life, on average). Trajectories of dying, i.e. "Organ failure" and "General frailty" have a significantly higher rate of deaths in-hospital (79 per cent and 65 per cent, respectively). Significant time spent in hospital near the end of life may be an indicator of poor quality care near the end of life and is also associated with a higher probability of eventual death in-hospital (Iezzoni 1997). The top five 'episodes of care' by days spent in-hospital are, unsurprisingly, those related to critical care for mechanically ventilated beneficiaries, pneumonia, septicaemia (likely acquired in-hospital following surgery), heart failure and shock, and cerebrovascular accidents (strokes). Renal failure, respiratory failure and chronic obstructive pulmonary disease (COPD) episodes of care follow thereafter. These are complicated conditions, requiring intensive care and treatment, and are thus associated with more hospital admissions and longer (more costly) hospital stays and are more prone to the development of complications.

Almost a third of decedent beneficiaries diagnosed with cancer had received chemotherapy during their last month of life, and almost two-thirds received

chemotherapy during their last three months of life. This means that almost one third of beneficiaries receiving chemotherapy may be receiving ineffective treatment close to their end of life and may be experiencing sub-optimal care during this period.

Overall, the utilisation of hospice services are very low (less than five per cent of decedent beneficiaries) and are predominantly accessed by beneficiaries diagnosed with cancer. The use of hospice-related services is associated with improved quality of life near the end of life and reduced end-of-life care costs (Wang *et al.* 2017). The improved quality of life is in the form of better symptom and pain management, management of psychological distress, care that is better aligned with patient preferences, a lower likelihood of dying in hospital and less use of intensive/aggressive, yet ineffective interventions near the end of life (Wang *et al.* 2017).

For the low proportion of beneficiaries (less than five per cent overall) that do enrol for hospice care, it is concerning that 22 per cent only enrol in the last week of life and that 45 per cent only enrol during the last four weeks of life. Thirty per cent of these beneficiaries enrol three or more months before death, which may indicate good quality care for these beneficiaries. It is encouraging to see a greater uptake for those dying in 2017 as compared to those dying in 2016, but a longer time period needs to be investigated to establish whether this represents a true trend towards greater hospice utilisation (and/or better billing of hospice services to medical schemes). It is also important to bear in mind that only hospice services that have been billed to the medical scheme are included here. Any out-of-pocket or non-billing of services cannot be estimated, and hence the results need to be interpreted with some caution.

In order to optimise care near the end of life for individual beneficiaries, early initiation of palliative care and determining care preferences and goals of care, and subsequently refining these as individual circumstances evolve are paramount (Dalgaard *et al.* 2014; Foglia, Lowery, Sharpe, Tompkins *et al.* 2019).

7.8 Research project limitations

As noted in Section 5, the data used for purposes of this project are limited to retrospective administrative claims data for beneficiaries that have died. Limited clinical information are available from these data. Data on claims for survivors with

similar clinical profiles are not available for direct comparison, making it impossible to gauge the effectiveness of certain care interventions near the end of life. This problem is exacerbated by not having any information on beneficiaries' prognoses (prospective information) at that time the specific care interventions are administered.

The exact cause of death for individual beneficiaries are not known and are inferred from the claims data based on their episodes of care and the accompanying ICD-10 coding. This presents the opportunity for the incorrect classification of deaths by trajectory of dying.

Demand- and supply-side drivers of healthcare costs are considered in this research, but it should be noted that the distinction between these are often not clear. Demand for healthcare may shape and inform supply and equally, supply can directly influence the demand for healthcare, e.g. the behaviour of providers, the effects of medical scheme benefit design, etc. It should be borne in mind that where distinction is drawn, it remains open to alternative interpretation, given the nuances and intricate interwoven nature of the supply and demand for private healthcare in South Africa.

The distinction between 'urban' and 'rural' areas in the analyses is pragmatic and it is noted that more robust definitions and methodologies exist for making such a distinction between 'urban' and 'rural', but this is beyond the scope of this research project.

No research exists in the South African medical schemes environment surrounding the care preferences, the intricate interaction between the key stakeholders and the eventual decisions of stakeholders regarding medical care at the end of life. International research overlaid on the South African medical schemes environment is used as a basis for conjecture as to how these might play out in this environment.

This research focuses only on South African medical schemes, and the experience and characteristics of this sub-population may not be directly relatable to the overall South African population and the bigger picture surrounding end-of-life care and the delivery thereof in the broader South African context.

8 Conclusion

This research project considers the various factors that are associated with end-of-life care claim costs for South African medical schemes. At the macro-, or structural level, it is evident that the fee-for-service reimbursement mechanism, the hospi-centric PMB legislation and the resultant medical scheme benefit designs, and the existence of a 3rd party payer creates incentives for care and treatment in-hospital and potentially for over-servicing beneficiaries. This may partly explain the high proportion of beneficiaries observed to die in-hospital. For decedent beneficiaries, hospital-based costs account for almost 75 per cent of overall medical scheme claims costs over the last 24 months of life, and eighty per cent over the last twelve months of life. At the micro-level, individual care and treatment preferences, religious beliefs, cultural traditions, expectations of society and those of close relations, the awareness of and the costs of alternative care options, etc. influence end-of-life care decision-making and directly impacts on whether a beneficiary gets admitted to and is likely to die in-hospital.

Illness, disability, frailty, medical care, hospitals, hospices and eventual death are anxiety-provoking concepts (Grumann and Spiegel 2003; Lehto and Stein 2009). This may result in a general avoidance of these topics, a lack of advance care planning and ignorance about what to expect, what care options exist, and what cover is available. This ignorance, together with fragmented care delivery and misaligned stakeholder incentives, may result in costly, aggressive, sub-optimal care for scheme beneficiaries near their end of life (Connors *et al.* 1995; Emanuel and Ferris 2000).

None of these macro- or micro-level factors, directly observable or otherwise, are independent of each other. The confluence of these factors are complex and multi-faceted given the dynamic, uncertain and unique end-of-life experience of each individual scheme beneficiary. There is no one-size-fits-all solution for deciding on the most appropriate care pathway near the end of life, and even for a particular beneficiary, the optimal care pathway is likely to change over time. What is optimal and appropriate changes depending on beneficiaries' specific needs, care requirements and the complex progression of their illness, or their combination of illnesses.

Additionally, the impact of a multitude of external or indirect factors may also influence what is deemed optimal or appropriate at a particular point in time.

The analyses of the demographic characteristics and medical scheme claims data for a sample of decedent scheme beneficiaries, show that factors such as age, sex, place of residence, number of chronic conditions, hospice use, etc. are associated with claims costs near the end of life. Claims during the last four weeks of life for beneficiaries that had utilised some hospice care services were nearly half that of beneficiaries who had not utilised any hospice services. The number of days spent in-hospital, and dying in-hospital show a positive association with the overall claims cost for decedent beneficiaries. Beneficiaries that died in-hospital, on average, experienced claims more than double that of beneficiaries who died out-of-hospital, all else being equal. This may be due to private hospitals being relatively more expensive care settings, but there may be a secondary consequence of being in hospital increasing the likelihood of more aggressive care interventions at the end of life (i.e. there may be a greater inclination towards heroic lifesaving interventions for beneficiaries who are in-hospital).

Given the high proportion of deaths in-hospital and the number of days spent in-hospital, the low utilisation of hospice services and the (international) literature indicating an overall preference for death either at home or in a hospice environment, it would appear that a significant number of medical scheme beneficiaries are likely receiving sub-optimal end-of-life care.

On the cost front, medical schemes are experiencing ageing memberships and an observed increase in the incidence and cost of treating and managing chronic non-communicable diseases with a significant proportion of beneficiaries eventually dying because of such chronic conditions. Medical schemes have also been facing cost pressures due to new technology, high demand for experimental/new treatments and therapies and a year-on-year increase in utilisation of healthcare services by scheme beneficiaries. These point to an expectation of further significant cost increases in future.

A key takeaway from this research project is that in order to manage end-of-life care costs, and to optimise stakeholder value in end-of-life care, it is required to enable beneficiaries to make optimal care decisions, all else being equal. In order to achieve this, appropriate care options should be made available through the medical scheme

and beneficiaries should be fully informed about their care options. Beneficiaries should have an appreciation for how their illness(es) are likely to progress and how their physical condition may deteriorate over time, and focus should be placed on continually discussing care goals and preferences with their providers of medical care. This implies significant end-of-life care benefit reform within the current legislative framework to ensure seamless, cost-effective and appropriate care delivery all along each end-of-life pathway.

The success of such benefit reform is highly dependent on multi-disciplinary stakeholder buy-in and cooperation (to ensure seamless delivery), early, effective and ongoing communication (to enable optimal decision-making) and innovative managed care solutions (to manage risk and to ensure quality outcomes are achieved). Ongoing monitoring, feedback and quality measurement together with incentivised alternative reimbursement mechanisms are vital to ensuring that the desired optimal outcomes are consistently achieved for beneficiaries nearing their end of life.

This research project has evaluated end-of-life care in the South African medical schemes environment and has identified factors associated with the claims costs observed for beneficiaries near their end of life. The research aimed to illustrate the complexities surrounding communication, decision-making and care delivery near the end of life and the factors that contribute to this uncertainty. It also considered the profile and claims cost of medical scheme beneficiaries near their end of life to gain an understanding of the factors influencing the care costs near the end of life for these beneficiaries. Significant areas for further research, beyond the scope of this project, are also identified in performing this research. These are summarised below.

Opportunities for further research

Further research is required on how to elicit care goals and preferences and to facilitate death in the beneficiaries' preferred setting of care, bearing in mind the scheme benefit design, the beneficiaries' personal circumstances (e.g. their functional status, their home and family environment, their care needs, etc.) and the financial implications to both the schemes and their beneficiaries. This research is needed in the South African context in order to be relevant. This may assist in preventing unnecessary hospitalisations, shortening length of stay and facilitating the transfer of the

beneficiary to the appropriate or optimal care setting(s) near their end of life. Research is also required to determine the extent to which a stigma towards death exists within the medical scheme membership base and how the stigma affects advanced care discussions and planning for care near the end of life. An understanding of these preferences and an appreciation for the discomfort caused by confronting the idea of mortality can highlight the best strategies to educate scheme beneficiaries and healthcare providers about important care considerations near the end of life. Such an understanding will assist in optimising decision-making by both the beneficiaries and the providers in the face of serious illness. Further research into the design and delivery of appropriate palliative care benefits are required to ensure that beneficiaries have access to and are aware of such care to facilitate the early integration of palliative care with curative care and ensuring a smooth transition to more palliative-orientated care as the end of life draws near.

Longitudinal studies on the claims experience of beneficiaries living with chronic non-communicable diseases will highlight the impact on claims of these conditions over time as opposed to only the association of these conditions with claims cost near the end of life. Specific attention needs to be given to the most prevalent and the most costly chronic conditions. Studies of this nature will also be useful in understanding the relative costs of different conditions and the impact of multi-morbidity on overall costs, both at the end of life as well as over longer periods of time. Additional research is required to determine the impact on medical scheme claim costs near the end of life for the most prevalent and most severe chronic conditions, e.g. heart disease, cancer, chronic endocrine disorders (e.g. diabetes) and chronic respiratory diseases. Further research is also required to develop more effective strategies to lower the incidence and prevalence of chronic, non-communicable diseases in medical schemes' risk pools. This is particularly true for preventable, lifestyle-related chronic conditions.

More in-depth analyses of the various trajectories of dying, adapted to the South African medical schemes environment (as opposed to the Medicare environment which predominantly covers lives older than 65 years and based on an entirely different set of insurance and benefit rules) with a more robust identification and attribution of cause of death are required. These studies may prove useful in

determining which care pathways are optimal for beneficiaries given their trajectory of dying. The type and timing of optimal care interventions may well differ between the various trajectories of dying. Significant research and development of guidelines and care interventions have been undertaken for the "Cancer" trajectory, globally (as well as in South Africa), but not for the other trajectories of dying where beneficiaries may also have significant unmet palliative and other care needs near the end of life. There is significant scope for further research in this area.

Research in South Africa around the drivers of the sustained utilisation and cost increases are sparse – especially at the end of life. This project aimed to untangle components of the complex private healthcare funding system in South Africa to identify both demand-side and supply-side cost drivers with a focus on the cost drivers that are observable from historic claims data. Some supply-side drivers, e.g. supplier-induced demand, structural and system inefficiencies, e.g. 3rd-party payer dynamics, fee-for-service reimbursement arrangements, full payment for PMB's, etc. were considered on a theoretical basis. The interaction between these factors and the various stakeholders were also considered on a theoretical basis. Further research is required to quantify the impact of and to measure the multi-dimensional link between the supply and demand for healthcare and between the factors identified in this research, and their effect on medical scheme claims cost and the increases in these costs over time. A strong evidence base is required to enact policy and regulatory change towards a more efficient, more sustainable private healthcare funding system in South Africa.

Community- or home-based care and the development of such care initiatives in communities (both urban and rural) have shown to improve end-of-life care outcomes for patients and their families and to build social capital (Horsfall, Noonan and Leonard 2012). The existence of such informal community-based care and the social structures through which such care are delivered in South Africa needs further research. There is some evidence from the data that the care received by beneficiaries in 'rural' areas and smaller towns are different to the care received by those in more urbanised areas – evidenced by significantly different medical scheme claims cost near the end of life between these areas. It may be that the lack of specialist care and limited quaternary care in more rural areas have necessitated the development of more informal care networks and alternative care pathways for the dying. The composition

of these community- or home-based care networks (where they exist), their efficacy in delivering end-of-life care and the quality of care provided needs further investigation.

Hospice service utilisation near the end of life is associated with better quality care and lower costs of care. More research is required on the hospice utilisation patterns of medical scheme beneficiaries and the billing practices of hospices to get an accurate picture of the use of hospice care by medical scheme beneficiaries and the impact thereof on medical scheme claim costs near the end of life. Where a trade-off between hospice and hospital care exist, further research is required to identify the factors that impact on decision-making surrounding this trade-off and to understand which beneficiaries opt for hospice care and why. This may assist with facilitating a transition from hospital- to hospice- or home-based care for a greater proportion of beneficiaries, potentially more in line with their care preferences and resulting in an improved quality of life and of care, and a reduction in end-of-life care costs for a greater number of medical scheme beneficiaries.

Brief consideration is also given to the importance of measuring (and rewarding) quality care to optimise care outcomes. Evidence of poor quality care near the end of life are investigated by considering a number of measurable quality indicators that can be gleaned from the claims data. Further research is required to identify more indicators and to develop fair, objective measures of quality end-of-life care that are applicable to the South African medical scheme environment. The measures developed should be simple, pragmatic and used consistently across providers, settings and levels of care, as is appropriate. They should encourage both the providers and the beneficiaries to engage in an iterative approach of analysing and eliciting goals of care, treatment preferences, care settings of choice, etc. The quality measures should not be static and should be linked to appropriate provider incentives to help achieve optimised care outcomes for beneficiaries near their end of life.

The retrospective analysis of indicators (both of good and poor quality end-of-life care) can be used in engagement with providers to highlight gaps and areas for improvement in the delivery of end-of-life care. It is important to note that there is no one-size-fits-all approach to measuring the quality of care near the end of life, and different illness trajectories or stages within trajectories will call for different modes of care and hence different metrics for measuring the quality of care and the care

outcomes. These need to be developed, tested and refined over time to ensure optimal outcomes given differing stakeholder needs and preferences and constrained financial-, human- and infrastructural resources for healthcare.

Looking ahead, the role of medical schemes (and the private healthcare sector as a whole) is unclear in South Africa. The country is moving towards universal healthcare coverage for its population, and there are currently significant debate, policy reform and development around introducing the National Health Insurance (NHI) framework in South Africa. Questions still exist as to what exactly the NHI will cover, how it will be implemented and governed, and whether it will be successful in achieving the aims of universal health coverage in South Africa (Passchier 2017). Valuable lessons can be learnt from the experience of South Africa's private healthcare sector, i.e. medical schemes, in the design and delivery of the optimal benefits, including end-of-life care benefits. As more clarity around NHI unfolds, research into delivering high quality, cost-effective end-of-life care at the population level will be required. The characteristics of the overall population is different to the profile of the lives that currently have medical scheme cover and the factors affecting their medical costs and/or care preferences and decisions near the end of life may well also be different.

9 Ethical considerations and declaration of interests

The analytical component of this research project involves analysing actual past medical scheme claims submitted on behalf of individual medical scheme beneficiaries that had died in the calendar years 2016 and 2017. Permission was obtained to analyse the data and the use and dissemination of the data are protected by means of a non-disclosure agreement. In accordance with the internal processes of the owner of the data and in compliance with applicable legislation, all data have been fully de-identified prior to it being used for the purposes of this research project. A unique, random string is assigned to each individual's demographic and claims data to ensure that the data can in no way be identified to any individual person or persons. As such, the data used in this research project poses no ethical or physical risks to the persons involved, and their privacy and that of their relatives are fully protected.

Ethical clearance for this research project was obtained from the University of Cape Town's Commerce Faculty Ethics Committee.

I have no conflicts of interest to declare and there was no external funding obtained for the purposes of this research project.

I declare that this is my own, unique work, and where applicable the work of other authors are appropriately attributed.

Pieter Botha
July 2020

References

Adams, J.R. and Drake, R.E. (2006). Shared decision-making and evidence-based practice. *Community mental health journal* **42**(1): 87-105.

Al-Qurainy, R., Collis, E., and Feuer, D. (2009). Dying in an acute hospital setting: the challenges and solutions. *International journal of clinical practice* **63**(3): 508-515.

Aldridge, M.D., Hasselaar, J., Garralda, E., van der Eerden, M., Stevenson, D., McKendrick, K.*, et al.* (2016). Education, implementation, and policy barriers to greater integration of palliative care: a literature review. *Palliative Medicine* **30**(3): 224-239.

Angus, D.C., Barnato, A.E., Linde-Zwirble, W.T., Weissfeld, L.A., Watson, R.S., Rickert, T.*, et al.* (2004). Use of intensive care at the end of life in the United States: An epidemiologic study*. *Critical care medicine* **32**(3): 638-643.

Ataguba, J.E. and McIntyre, D. (2012). Paying for and receiving benefits from health services in South Africa: is the health system equitable? *Health policy and planning* **27**(suppl_1): i35-i45.

Bach, P.B., Schrag, D., and Begg, C.B. (2004). Resurrecting treatment histories of dead patients: a study design that should be laid to rest. *Jama* **292**(22): 2765-2770.

Barber, S.L., Kumar, A., Roubal, T., Colombo, F., and Lorenzoni, L. (2018). Harnessing the private health sector by using prices as a policy instrument: Lessons learned from South Africa. *Health Policy* **122**(5): 558-564.

Barford, A., Dorling, D., Smith, G.D., and Shaw, M. (2006). Life expectancy: women now on top everywhere. British Medical Journal Publishing Group.

Bennett, M.I., Davies, E.A., and Higginson, I.J. (2010). Delivering research in end-of-life care: problems, pitfalls and future priorities. *Palliative Medicine* **24**(5): 456-461.

Bern-Klug, M., Gessert, C., and Forbes, S. (2001). The need to revise assumptions about the end of life: Implications for social work practice. *Health & Social Work* **26**(1): 38-48.

Billings, J.A. (1998). What is palliative care? *Journal of palliative medicine* **1**(1): 73-81.

Blagden, S., Charman, S.C., Sharples, L., Magee, L., and Gilligan, D. (2003). Performance status score: do patients and their oncologists agree? *British journal of cancer* **89**(6): 1022-1027.

Bradshaw, D., Pillay-Van Wyk, V., Laubscher, R., Nojilana, B., Groenewald, P., Nannan, N.*, et al.* (2010). Cause of death statistics for South Africa: Challenges and possibilities for improvement. *South African MRC Burden of Disease Research Unit*.

Braun, U.K., Beyth, R.J., Ford, M.E., and McCullough, L.B. (2008). Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of general internal medicine* **23**(3): 267-274.

Broad, J.B., Gott, M., Kim, H., Boyd, M., Chen, H., and Connolly, M.J. (2013). Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health* **58**(2): 257-267.

Byock, I., Norris, K., Curtis, J.R., and Patrick, D.L. (2001). Improving end-of-life experience and care in the community: a conceptual framework. *Journal of pain and symptom management* **22**(3): 759-772.

Caldis, K., McLeod, H., and Smith, P. (2001). The fall of the bamboo curtain: a review of complementary medicine in South Africa. *South African Actuarial Journal* **1**(1): 63-95.

Campion, E.W., Kelley, A.S., and Morrison, R.S. (2015). Palliative care for the seriously ill. *N Engl J Med* **373**(8): 747-755.

Cheung, M.C., Earle, C.C., Rangrej, J., Ho, T.H., Liu, N., Barbera, L.*, et al.* (2015). Impact of aggressive management and palliative care on cancer costs in the final month of life. *Cancer* **121**(18): 3307-3315.

Chochinov, H.M. and Janson, K. (1998). Dying to pay: the cost of end-of-life care. *Journal of Palliative Care* **14**(4): 5.

Chow, E., Harth, T., Hruby, G., Finkelstein, J., Wu, J., and Danjoux, C. (2001). How accurate are physicians' clinical predictions of survival and the available

prognostic tools in estimating survival times in terminally iII cancer patients? A systematic review. *Clinical Oncology* **13**(3): 209-218.

Clark, D. (2007). From margins to centre: a review of the history of palliative care in cancer. *The lancet oncology* **8**(5): 430-438.

Cohen, M.L. (2000). Changing patterns of infectious disease. *Nature* **406**(6797): 762.

Competition Commission South Africa. (2019). Health Market Enquiry - Final findings and recommendations report. Available: http://www.compcom.co.za/wp-content/uploads/2014/09/Health-Market-Inquiry-Report.pdf (accessed: 1 November 2019,

Connor, S.R. and Sepulveda Bermedo, M.C. (2018). Global atlas of palliative care at the end of life.

Connors, A.F., Dawson, N.V., Desbiens, N.A., Fulkerson, W.J., Goldman, L., Knaus, W.A., *et al.* (1995). A controlled trial to improve care for seriously iII hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Jama* **274**(20): 1591-1598.

Cook, M.B., Dawsey, S.M., Freedman, N.D., Inskip, P.D., Wichner, S.M., Quraishi, S.M., *et al.* (2009). Sex disparities in cancer incidence by period and age. *Cancer Epidemiology and Prevention Biomarkers* **18**(4): 1174-1182.

Council for Medical Schemes. (2016). Prescribed Minimum Benefits

Review. Available: https://www.medicalschemes.com/files/PMB%20Review/PMB%20Review%20consultative%20doc.pdf (accessed: 31 October 2019,

Council for Medical Schemes. (2019). CMS Annual Report 2018/19. Available: https://www.medicalschemes.com/files/Annual%20Reports/CMSAR2018_19.pdf (accessed:

Curtis, J.R., Treece, P.D., Nielsen, E.L., Gold, J., Ciechanowski, P.S., Shannon, S.E., *et al.* (2016). Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *American journal of respiratory and critical care medicine* **193**(2): 154-162.

Cutler, D.M. (2007). The lifetime costs and benefits of medical technology. *Journal of health economics* **26**(6): 1081-1100.

Dalal, S., Palla, S., Hui, D., Nguyen, L., Chacko, R., Li, Z.*, et al.* (2011). Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *The Oncologist* **16**(1): 105-111.

Dalgaard, K.M., Bergenholtz, H., Nielsen, M.E., and Timm, H. (2014). Early integration of palliative care in hospitals: a systematic review on methods, barriers, and outcome. *Palliative & supportive care* **12**(6): 495-513.

Ddungu, H. (2011). Palliative care: what approaches are suitable in developing countries? *British journal of haematology* **154**(6): 728-735.

Delobelle, P., Sanders, D., Puoane, T., and Freudenberg, N. (2016). Reducing the role of the food, tobacco, and alcohol industries in noncommunicable disease risk in South Africa. *Health Education & Behavior* **43**(1_suppl): 70S-81S.

Department of Health. (1998). Medical Schemes Act No. 131 of 1998. Department of Health. South Africa.

Detering, K.M., Hancock, A.D., Reade, M.C., and Silvester, W. (2010). The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *Bmj* **340**: c1345.

Diamond, E.L., Russell, D., Kryza-Lacombe, M., Bowles, K.H., Applebaum, A.J., Dennis, J.*, et al.* (2015). Rates and risks for late referral to hospice in patients with primary malignant brain tumors. *Neuro-oncology* **18**(1): 78-86.

Earle, C.C. and Ayanian, J.Z. (2006). Looking back from death: the value of retrospective studies of end-of-life care. *Journal of clinical oncology* **24**(6): 838-840.

Earle, C.C., Park, E.R., Lai, B., Weeks, J.C., Ayanian, J.Z., and Block, S. (2003). Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *Journal of clinical oncology* **21**(6): 1133-1138.

Edmeston, M. and Francis, K. (2012). Beyond Band-Aids: Reflections on public and private health care in South Africa. *The Journal of the Helen Suzman Foundation* **67**: 41-46.

Ellershaw, J., Neuberger, R.J., and Ward, C. (2003). Care of the dying patient: the last hours or days of lifeCommentary: a “good death” is possible in the NHS. *Bmj* **326**(7379): 30-34.

Emanuel, E.J., Ash, A., Yu, W., Gazelle, G., Levinsky, N.G., Saynina, O.*, et al.* (2002). Managed care, hospice use, site of death, and medical expenditures in the last year of life. *Archives of internal medicine* **162**(15): 1722-1728.

Emanuel, E.J. and Emanuel, L.L. (1998). The promise of a good death. *The lancet* **351**: SII21-SII29.

Emanuel, L.L. and Ferris, F. (2000). Gaps in end-of-life care. *Archives of Family Medicine* **9**(10): 1176-1180.

Emanuel, L.L., von Gunten, C.F., and Ferris, F.D. (2000). Advance care planning. *Archives of Family Medicine* **9**(10): 1181.

Erasmus, D., Ranchod, S., Abraham, M., Carvounes, A., and Dreyer, K. (2016). Challenges and opportunities for health finance in South Africa.

Erasmus, M. and Kean, H. (2018). Private hospital expenditure and relation to utilisation: Observations from the data. *South African Journal of Economic and Management Sciences* **21**(1): 1-14.

Ersek, M. and Wilson, S.A. (2003). The challenges and opportunities in providing end-of-life care in nursing homes. *Journal of palliative medicine* **6**(1): 45-57.

Fagerlin, A., Ditto, P.H., Hawkins, N.A., Schneider, C.E., and Smucker, W.D. (2002). The use of advance directives in end-of-life decision making: Problems and possibilities. *American Behavioral Scientist* **46**(2): 268-283.

Fallon, M. and Smyth, J. (2008). Terminology: the historical perspective, evolution and current usage–room for confusion? *European Journal of Cancer* **44**(8): 1069-1071.

Fassbender, K., Fainsinger, R.L., Carson, M., and Finegan, B.A. (2009). Cost trajectories at the end of life: the Canadian experience. *Journal of pain and symptom management* **38**(1): 75-80.

Feigin, V. (2016). Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980-2015: a systematic analysis for the Global Burden of Disease Study 2015. *The lancet* **388**(10053): 1459-1544.

Felder, S., Meier, M., and Schmitt, H. (2000). Health care expenditure in the last months of life. *Journal of health economics* **19**(5): 679-695.

Fendler, T.J., Swetz, K.M., and Allen, L.A. (2015). Team-based palliative and end-of-life care for heart failure. *Heart failure clinics* **11**(3): 479-498.

Fennell, M.L., Prabhu Das, I., Clauser, S., Petrelli, N., and Salner, A. (2010). The organization of multidisciplinary care teams: modeling internal and external influences on cancer care quality. *Journal of the National Cancer Institute Monographs* **2010**(40): 72-80.

Fisher, E.S., Wennberg, D.E., Stukel, T.A., Gottlieb, D.J., Lucas, F.L., and Pinder, E.L. (2003). The implications of regional variations in Medicare spending. Part 2: health outcomes and satisfaction with care. *Annals of internal medicine* **138**(4): 288-298.

Flory, J., Young-Xu, Y., Gurol, I., Levinsky, N., Ash, A., and Emanuel, E. (2004). Place of death: US trends since 1980. *Health Affairs* **23**(3): 194-200.

Foglia, M.B., Lowery, J., Sharpe, V.A., Tompkins, P., and Fox, E. (2019). A comprehensive approach to eliciting, documenting, and honoring patient wishes for care near the end of life: The veterans health administration's life-sustaining treatment decisions initiative. *The Joint Commission Journal on Quality and Patient Safety* **45**(1): 47-56.

Fontalis, A., Prousali, E., and Kulkarni, K. (2018). Euthanasia and assisted dying: what is the current position and what are the key arguments informing the debate? *Journal of the Royal Society of Medicine* **111**(11): 407-413.

Frost, D.W., Cook, D.J., Heyland, D.K., and Fowler, R.A. (2011). Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: A systematic review*. *Critical care medicine* **39**(5): 1174-1189.

Gardiner, C., Cobb, M., Gott, M., and Ingleton, C. (2011). Barriers to providing palliative care for older people in acute hospitals. *Age and Ageing* **40**(2): 233-238.

Gawande, A. (2014). *Being mortal: medicine and what matters in the end* Macmillan.

George, L.K. (2002). Research Design in End-of-Life Research State of Science. *The Gerontologist* **42**(suppl 3): 86-98.

Gibbins, J., McCoubrie, R., and Forbes, K. (2011). Why are newly qualified doctors unprepared to care for patients at the end of life? *Medical education* **45**(4): 389-399.

Glare, P., Virik, K., Jones, M., Hudson, M., Eychmuller, S., Simes, J.*, et al.* (2003). A systematic review of physicians' survival predictions in terminally ill cancer patients. *Bmj* **327**(7408): 195.

Gomes, B., Calanzani, N., and Higginson, I.J. (2012). Reversal of the British trends in place of death: time series analysis 2004–2010. *Palliative Medicine* **26**(2): 102-107.

Gomes, B. and Higginson, I.J. (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *Bmj* **332**(7540): 515-521.

Gomes, B. and Higginson, I.J. (2008). Where people die (1974—2030): past trends, future projections and implications for care. *Palliative Medicine* **22**(1): 33-41.

Gott, M. and Ingleton, C. (2011). How can we improve palliative care provision for older people? Global perspectives. British Medical Journal Publishing Group.

Gott, M., Ingleton, C., Bennett, M.I., and Gardiner, C. (2011). Transitions to palliative care in acute hospitals in England: qualitative study. *Bmj* **342**: d1773.

Gott, M., Seymour, J., Ingleton, C., Gardiner, C., and Bellamy, G. (2012). 'That's part of everybody's job': the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care. *Palliative Medicine* **26**(3): 232-241.

Govuzela, M., Thsehla, E., and de Villiers, A. (2018). Prevalence of chronic diseases in the population covered by medical schemes in South Africa.

Gray, B.H. (1997). Trust and trustworthy care in the managed care era. *Health Affairs* **16**(1): 34-49.

Greene, J. and Baron, J. (2001). Intuitions about declining marginal utility. *Journal of Behavioral Decision Making* **14**(3): 243-255.

Groeger, J.S. and Aurora, R.N. (2001). Intensive care, mechanical ventilation, dialysis, and cardiopulmonary resuscitation: implications for the patient with cancer. *Critical care clinics* **17**(3): 791-803.

Grumann, M.M. and Spiegel, D. (2003). Living in the face of death: interviews with 12 terminally ill women on home hospice care. *Palliative & supportive care* **1**(1): 23-32.

Gwyther, L., Krause, R., Cupido, C., Stanford, J., Grey, H., Credé, T.*, et al.* (2018). The development of hospital-based palliative care services in public hospitals

in the Western Cape, South Africa. *South African Medical Journal* **108**(2): 86-89.

Habib, S.H. and Saha, S. (2010). Burden of non-communicable disease: global overview. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews* **4**(1): 41-47.

Harding, R., Bristowe, K., Downing, J., Gwyther, L., Luyirika, E., Meiring, M.*, et al.* (2019). Policies on Palliative Care in Different Parts of the World. *Textbook of Palliative Care*: 89-104.

Harding, R. and Higginson, I.J. (2005). Palliative care in sub-Saharan Africa. *The lancet* **365**(9475): 1971-1977.

Head, B., Ritchie, C.S., and Smoot, T.M. (2005). Prognostication in hospice care: can the palliative performance scale help? *Journal of palliative medicine* **8**(3): 492-502.

Heyland, D.K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D.*, et al.* (2006). What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal* **174**(5): 627-633.

Hibbard, J.H., Greene, J., Sofaer, S., Firminger, K., and Hirsh, J. (2012). An experiment shows that a well-designed report on costs and quality can help consumers choose high-value health care. *Health Affairs* **31**(3): 560-568.

Highet, G., Crawford, D., Murray, S.A., and Boyd, K. (2014). Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. *BMJ supportive & palliative care* **4**(3): 285-290.

Hogan, C., Lunney, J., Gabel, J., and Lynn, J. (2001). Medicare beneficiaries' costs of care in the last year of life. *Health Affairs* **20**(4): 188-195.

Hoover, D.R., Crystal, S., Kumar, R., Sambamoorthi, U., and Cantor, J.C. (2002). Medical expenditures during the last year of life: findings from the 1992–1996 Medicare current beneficiary survey. *Health services research* **37**(6): 1625-1642.

Horowitz, R., Gramling, R., and Quill, T. (2014). Palliative care education in US medical schools. *Medical education* **48**(1): 59-66.

Horsfall, D., Noonan, K., and Leonard, R. (2012). Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities. *Health Sociology Review* **21**(4): 373-382.

HPCA. (2017). National Policy Framework and Strategy on Palliative Care. https://hpca.co.za/download/national-policy-framework-and-strategy-on-palliative-care-2017-2022/

HPCA. (2019). HPCA. Available: https://hpca.co.za/palliative-care/who-qualifies/ (accessed: 14 November, 2019).

Hui, D., De La Cruz, M., Mori, M., Parsons, H.A., Kwon, J.H., Torres-Vigil, I.*, et al.* (2013). Concepts and definitions for "supportive care,""best supportive care,""palliative care," and "hospice care" in the published literature, dictionaries, and textbooks. *Supportive Care in Cancer* **21**(3): 659-685.

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., De La Cruz, M., Kim, S.H.*, et al.* (2014). Concepts and definitions for "actively dying,""end of life,""terminally ill,""terminal care," and "transition of care": a systematic review. *Journal of pain and symptom management* **47**(1): 77-89.

Hung, W.W., Ross, J.S., Boockvar, K.S., and Siu, A.L. (2011). Recent trends in chronic disease, impairment and disability among older adults in the United States. *BMC geriatrics* **11**(1): 47.

Hutcheson, H.-D. (2011). *A regulatory capture explanation of South Africa's private health insurance legislation*.

Iezzoni, L.I. (1997). Assessing quality using administrative data. *Annals of internal medicine* **127**(8_Part_2): 666-674.

Jackson, H.A., Walsh, B., and Abecassis, M. (2016). A surgeon's guide to bundled payment models for episodes of care. *JAMA surgery* **151**(1): 3-4.

Jakovljevic, M.B. and Milovanovic, O. (2015). Growing burden of non-communicable diseases in the emerging health markets: the case of BRICS. *Frontiers in public health* **3**: 65.

Jindai, K., Nielson, C.M., Vorderstrasse, B.A., and Quiñones, A.R. (2016). Peer Reviewed: Multimorbidity and Functional Limitations Among Adults 65 or Older, NHANES 2005–2012. *Preventing chronic disease* **13**.

Joubert, J. and Bradshaw, D. (2006). Population Ageing and Health Challenges. *View a breakdown of smaller files at http://www. mrc. ac. za/chronic/cdl1995-2005. htm* **204**.

Kaplan, J. and Ranchod, S. (2014). Analysing the structure and nature of medical scheme benefit design in South Africa. *South African health review* **2014**(1): 165-179.

Kaplan, J. and Ranchod, S. (2015). An actuarial perspective on medical scheme benefit design. *Actuarial Society of South Africa's*.

Kaplan, R.M., Spittel, M.L., and David, D.H. (2015). *Population health: behavioral and social science insights* Government Printing Office.

Kavalieratos, D., Corbelli, J., Zhang, D., Dionne-Odom, J.N., Ernecoff, N.C., Hanmer, J.*, et al.* (2016). Association between palliative care and patient and caregiver outcomes: a systematic review and meta-analysis. *Jama* **316**(20): 2104-2114.

Keeley, M. (2017). Family communication at the end of life. Multidisciplinary Digital Publishing Institute.

Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine* **106**(12): 1071-1075.

Kelley, A.S. and Meier, D.E. (2010). Palliative care—a shifting paradigm. Mass Medical Soc.

Kelley, A.S. and Morrison, R.S. (2015). Palliative care for the seriously ill. *New England Journal of Medicine* **373**(8): 747-755.

Kirshbaum, M.N., Purcell, B., and Nash, S. (2011). Talking about dying and death: a focus group study to explore a local community perspective. *Nursing Reports* **1**(1): e8-e8.

Kompanje, E.J., Piers, R.D., and Benoit, D.D. (2013). Causes and consequences of disproportionate care in intensive care medicine. *Current opinion in critical care* **19**(6): 630-635.

Kongstvedt, P.R. (2013). *Essentials of managed health care* Jones & Bartlett Publishers.

Lamont, E.B. (2005). A demographic and prognostic approach to defining the end of life. *Journal of palliative medicine* **8**(supplement 1): s-12-s-21.

Lamont, E.B. and Christakis, N.A. (1999). Some elements of prognosis in terminal cancer. *Oncology-Huntington* **13**(8): 1165-1170.

Lau, F., Cloutier-Fisher, D., Kuziemsky, C., and Black, F. (2007). A systematic review of prognostic tools for estimating survival time in palliative care. *Journal of palliative care* **23**(2): 93.

Legotlo, T. and Mutezo, A. (2018). Understanding the types of fraud in claims to South African medical schemes. *South African Medical Journal* **108**(4): 299-303.

Lehto, R. and Stein, K. (2009). Death anxiety: an analysis of an evolving concept.

Levinsky, N.G., Yu, W., Ash, A., Moskowitz, M., Gazelle, G., Saynina, O., *et al.* (2001). Influence of age on Medicare expenditures and medical care in the last year of life. *Jama* **286**(11): 1349-1355.

Lizza, J.P. (2006). *Persons, humanity, and the definition of death* The Johns Hopkins University Press.

Longtin, Y., Sax, H., Leape, L.L., Sheridan, S.E., Donaldson, L., and Pittet, D. 2010. Patient participation: current knowledge and applicability to patient safety, in *Mayo Clinic Proceedings,* Volume 85 Elsevier, pp. 53-62. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2800278/pdf/mayoclinproc_85_1_009.pdf

Lopez, A., Mathers, C., Ezzati, M., Jamison, D., and Murray, C. (2014). Global burden of disease and risk factors. Washington, DC: World Bank; 2006.

Luckett, T., Phillips, J., Agar, M., Virdun, C., Green, A., and Davidson, P.M. (2014). Elements of effective palliative care models: a rapid review. *BMC health services research* **14**(1): 136.

Lunney, J.R., Lynn, J., Foley, D.J., Lipson, S., and Guralnik, J.M. (2003). Patterns of functional decline at the end of life. *Jama* **289**(18): 2387-2392.

Lunney, J.R., Lynn, J., and Hogan, C. (2002). Profiles of older medicare decedents. *Journal of the American Geriatrics Society* **50**(6): 1108-1112.

Lynch, T., Connor, S., and Clark, D. (2013). Mapping levels of palliative care development: a global update. *Journal of pain and symptom management* **45**(6): 1094-1106.

Lynn, J. and Adamson, D.M. (2003). *Living well at the end of life. Adapting health care to serious chronic illness in old age*. DTIC Document.

Mack, J.W., Weeks, J.C., Wright, A.A., Block, S.D., and Prigerson, H.G. (2010). End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *Journal of clinical oncology* **28**(7): 1203.

Materstvedt, L.J., Clark, D., Ellershaw, J., Førde, R., Gravgaard, A.-M.B., Müller-Busch, H.C.*, et al.* (2003). Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force. *Palliative Medicine* **17**(2): 97-101.

Mayosi, B.M. and Benatar, S.R. (2014). Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine* **371**(14): 1344-1353.

McConnell, S., Moules, N.J., McCaffrey, G., and Bouchal, S.R. (2012). The hidden nature of death and grief. *Journal of Applied Hermeneutics*.

McIntyre, D. (2010). Private sector involvement in funding and providing health services in South Africa: implications for equity and access to health care. *EQUINET, Harare: Health Economics Unit*.

McLeod, H. and Ramjee, S. (2007). Medical schemes: pooling of resources and purchasing of health care. *South African health review* **2007**(1): 47-70.

Meier, D.E., Lim, B., and Carlson, M.D. (2010). Raising the standard: palliative care in nursing homes. *Health Affairs* **29**(1): 136-140.

Meisel, A., Snyder, L., Quill, T., and Panel, A.C.o.P.-A.S.o.I.M.E.-o.-L.C.C. (2000). Seven legal barriers to end-of-life care: myths, realities, and grains of truth. *Jama* **284**(19): 2495-2501.

Mobley, M.J., Rady, M.Y., Verheijde, J.L., Patel, B., and Larson, J.S. (2007). The relationship between moral distress and perception of futile care in the critical care unit. *Intensive and Critical care nursing* **23**(5): 256-263.

Moraga, P. (2017). Global, regional, and national age-sex specific mortality for 264 causes of death, 1980-2016: a systematic analysis for the Global Burden of Disease Study 2016. *The lancet* **390**(10100): 1151-1210.

Mulville, A.K., Widick, N.N., and Makani, N.S. (2019). Timely referral to hospice care for oncology patients: a retrospective review. *American Journal of Hospice and Palliative Medicine®* **36**(6): 466-471.

Murray, S.A., Kendall, M., Boyd, K., and Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ: British Medical Journal* **330**(7498): 1007.

Mustard, C.A., Kaufert, P., Kozyrskyj, A., and Mayer, T. (1998). Sex differences in the use of health care services. *New England Journal of Medicine* **338**(23): 1678-1683.

Obermeyer, Z., Makar, M., Abujaber, S., Dominici, F., Block, S., and Cutler, D.M. (2014). Association between the Medicare hospice benefit and health care utilization and costs for patients with poor-prognosis cancer. *Jama* **312**(18): 1888-1896.

Odejide, O.O. (2016). A policy prescription for hospice care. *Jama* **315**(3): 257-258.

Oshima Lee, E. and Emanuel, E.J. (2013). Shared decision making to improve care and reduce costs. *New England Journal of Medicine* **368**(1): 6-8.

Ostgathe, C. and Voltz, R. (2010). Quality indicators in end-of-life care. *Current opinion in supportive and palliative care* **4**(3): 170-173.

Palladino, R., Tayu Lee, J., Ashworth, M., Triassi, M., and Millett, C. (2016). Associations between multimorbidity, healthcare utilisation and health status: evidence from 16 European countries. *Age and Ageing* **45**(3): 431-435.

Parks, S.M., Winter, L., Santana, A.J., Parker, B., Diamond, J.J., Rose, M.*, et al.* (2011). Family factors in end-of-life decision-making: Family conflict and proxy relationship. *Journal of palliative medicine* **14**(2): 179-184.

Passchier, R. (2017). Exploring the barriers to implementing National Health Insurance in South Africa: the people's perspective. *South African Medical Journal* **107**(10).

Patton, G.C., Coffey, C., Sawyer, S.M., Viner, R.M., Haller, D.M., Bose, K.*, et al.* (2009). Global patterns of mortality in young people: a systematic analysis of population health data. *The lancet* **374**(9693): 881-892.

Perkins, H.S. (2007). Controlling death: the false promise of advance directives. *Annals of internal medicine* **147**(1): 51-57.

Peterson, C., Grosse, S.D., and Dunn, A. (2019). A practical guide to episode groupers for cost-of-illness analysis in health services research. *SAGE open medicine* **7**: 2050312119840200.

Pillay-van Wyk, V., Msemburi, W., Laubscher, R., Dorrington, R.E., Groenewald, P., Glass, T.*, et al.* (2016). Mortality trends and differentials in South Africa from

1997 to 2012: second National Burden of Disease Study. *The Lancet Global Health* **4**(9): e642-e653.

Pines, J.M., Mullins, P.M., Cooper, J.K., Feng, L.B., and Roth, K.E. (2013). National trends in emergency department use, care patterns, and quality of care of older adults in the United States. *Journal of the American Geriatrics Society* **61**(1): 12-17.

Polder, J.J., Barendregt, J.J., and van Oers, H. (2006). Health care costs in the last year of life—the Dutch experience. *Social science & medicine* **63**(7): 1720-1731.

Porter, M.E. (2010). What is value in health care. *N Engl J Med* **363**(26): 2477-2481.

Prendergast, T.J. (2001). Advance care planning: pitfalls, progress, promise. *Critical care medicine* **29**(2): N34-N39.

Preston, S.H. (2015). Identifying the Principal Factors Responsible for Improvements in the Health of Populations. *Population Health: Behavioral and Social Science Insights*: 89.

Quill, T.E. and Abernethy, A.P. (2013). Generalist plus specialist palliative care—creating a more sustainable model. *New England Journal of Medicine* **368**(13): 1173-1175.

Quill, T.E. and Battin, M.P. (2004). *Physician-assisted dying: The case for palliative care and patient choice* JHU Press.

Quora. (2017). What is the most common cause of human death in history. Available: https://www.quora.com/What-is-the-most-common-cause-of-human-death-in-history (accessed: 26 January, 2018).

Radbruch, L., Leget, C., Bahr, P., Müller-Busch, C., Ellershaw, J., De Conno, F.*, et al.* (2016). Euthanasia and physician-assisted suicide: a white paper from the European Association for Palliative Care. *Palliative Medicine* **30**(2): 104-116.

Ramjee, S., Abraham, M., Kaplan, J., Taylor, R., and Vieyra, T. (2013). National Health Insurance and South Africa's private sector. *South African health review* **2013**(1): 93-103.

Ramjee, S. and Vieyra, T. 2014. Neither here nor there: the South African medical scheme industry in limbo, in *Actuarial Society of South Africa Convention, Cape Town*.

Ranchod, S., Abraham, M., and Bloch, J. (2015). An actuarial perspective on healthcare expenditure in the last year of life. *South African Actuarial Journal* **15**: 31-49.

Regitz-Zagrosek, V. (2012). Sex and gender differences in health. *EMBO reports* **13**(7): 596-603.

Richardson, D.K., Zupancic, J.A., Escobar, G.J., Ogino, M., Pursley, D.M., and Mugford, M. (2001). A critical review of cost reduction in neonatal intensive care I. The structure of costs. *Journal of Perinatology* **21**(2): 107.

Riley, J.C. (2001). *Rising life expectancy: a global history* Cambridge University Press.

Robinson, A. and Thomson, R. (2001). Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. *BMJ Quality & Safety* **10**(suppl 1): i34-i38.

Rome, R.B., Luminais, H.H., Bourgeois, D.A., and Blais, C.M. (2011). The role of palliative care at the end of life. *The Ochsner Journal* **11**(4): 348-352.

Ross, J.S. (2002). The Committee on the Costs of Medical Care and the history of health insurance in the United States. *Einstein Quarterly* **19**(3): 129-134.

Rothstein, W.G. (1987). *American medical schools and the practice of medicine: A history* Oxford University Press.

Say, R., Murtagh, M., and Thomson, R. (2006). Patients' preference for involvement in medical decision making: a narrative review. *Patient education and counseling* **60**(2): 102-114.

Schofield, P., Carey, M., Love, A., Nehill, C., and Wein, S. (2006). 'Would you like to talk about your future treatment options?'Discussing the transition from curative cancer treatment to palliative care. *Palliative Medicine* **20**(4): 397-406.

Schulz, E. (2005). The influence of supply and demand factors on aggregate health care expenditure with a specific focus on age composition. *ENEPRI Research Reports*(16).

Seymour, J., Clark, D., and Winslow, M. (2005). Pain and palliative care: the emergence of new specialties. *Journal of pain and symptom management* **29**(1): 2-13.

Shapiro, H.T. and Field, M.J. (1993). *Employment and health benefits: a connection at risk* National Academies Press.

Sharkey, L., Loring, B., Cowan, M., Riley, L., and Krakauer, E.L. (2018). National palliative care capacities around the world: results from the World Health Organization Noncommunicable Disease Country Capacity Survey. *Palliative Medicine* **32**(1): 106-113.

Shen, M.J. and Wellman, J.D. (2019). Evidence of palliative care stigma: The role of negative stereotypes in preventing willingness to use palliative care. *Palliative & supportive care* **17**(4): 374-380.

Shlisky, J., Bloom, D.E., Beaudreault, A.R., Tucker, K.L., Keller, H.H., Freund-Levi, Y.*, et al.* (2017). Nutritional considerations for healthy aging and reduction in age-related chronic disease. *Advances in Nutrition* **8**(1): 17.

Shugarman, L.R., Decker, S.L., and Bercovitz, A. (2009). Demographic and social characteristics and spending at the end of life. *Journal of pain and symptom management* **38**(1): 15-26.

Singer, P.A., Martin, D.K., and Kelner, M. (1999). Quality end-of-life care: patients' perspectives. *Jama* **281**(2): 163-168.

Smith, T.J., Coyne, P., Cassel, B., Penberthy, L., Hopson, A., and Hager, M.A. (2003). A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs. *Journal of palliative medicine* **6**(5): 699-705.

Solomon, M.Z., O'Donnell, L., Jennings, B., Guilfoy, V., Wolf, S.M., Nolan, K.*, et al.* (1993). Decisions near the end of life: professional views on life-sustaining treatments. *American Journal of Public Health* **83**(1): 14-23.

SPICT. (2018). SPICT. Available: http://www.spict.org.uk/ (accessed: 17 January 2018).

StatsSA. (2003). *Census 2001: Investigation into appropriate definitions of urban and rural areas for South*

Africa: Discussion document. Report No. 03-02-20 (2001). Pretoria: Statistics South Africa. Available: http://www.statssa.gov.za/census/census_2001/urban_rural/urbanrural.pdf

StatsSA. (2019). CPI History. Available: http://www.statssa.gov.za/publications/P0141/CPIHistory.pdf? (accessed:

Steinhauser, K.E., Bosworth, H.B., Clipp, E.C., McNeilly, M., Christakis, N.A., Parker, J., *et al.* (2002). Initial assessment of a new instrument to measure quality of life at the end of life. *Journal of palliative medicine* **5**(6): 829-841.

Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., McIntyre, L., and Tulsky, J.A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Jama* **284**(19): 2476-2482.

Stevens, R. (1989). In sickness and in wealth: American hospitals in the twentieth century.

Stiglets, C. (2001). Unintentional injuries in the young adult male. *Journal of the American Academy of Nurse Practitioners* **13**(10): 450-454.

Sudore, R.L. and Fried, T.R. (2010). Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Annals of internal medicine* **153**(4): 256-261.

Swerissen, H., Duckett, S., and Farmer, J. (2014). *Dying well* Grattan Institute Melbourne.

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., *et al.* (2010). Early palliative care for patients with metastatic non–small-cell lung cancer. *New England Journal of Medicine* **363**(8): 733-742.

Teno, J.M., Clarridge, B.R., Casey, V., Welch, L.C., Wetle, T., Shield, R., *et al.* (2004). Family perspectives on end-of-life care at the last place of care. *Jama* **291**(1): 88-93.

Teno, J.M. and Mor, V. (2005). Resurrecting treatment histories of dead patients. *Jama* **293**(13): 1591-1592.

The Economist. (2017). A better way to care for the dying. Available: https://www.economist.com/news/international/21721375-how-medical-profession-starting-move-beyond-fighting-death-easing-it-better?fsrc=scn/fb/te/bl/ed/endoflifecareabetterwaytocareforthedying (accessed: 24 January, 2018).

Tomes, N. (1990). The private side of public health: sanitary science, domestic hygiene, and the germ theory, 1870-1900. *Bulletin of the History of Medicine* **64**(4): 509.

Tseng, E.K. and Hicks, L.K. (2016). Value based care and patient-centered care: divergent or complementary? *Current hematologic malignancy reports* **11**(4): 303-310.

Turner, H.C., Lauer, J.A., Tran, B.X., Teerawattananon, Y., and Jit, M. (2019). Adjusting for Inflation and Currency Changes Within Health Economic Studies. *Value in Health*.

Van den Block, L., Deschepper, R., Bilsen, J., Van Casteren, V., and Deliens, L. (2007). Transitions between care settings at the end of life in Belgium. *Jama* **298**(14): 1635-1639.

van den Heever, A.M. (2015). TOWARD A THEORY OF MARKET FAILURE IN THE SOUTH AFRICAN PRIVATE HEALTH SYSTEM.

Wang, H., Naghavi, M., Allen, C., Barber, R.M., Bhutta, Z.A., Carter, A.*, et al.* (2016). Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015. *The lancet* **388**(10053): 1459-1544.

Wang, X., Knight, L.S., Evans, A., Wang, J., and Smith, T.J. (2017). Variations among physicians in hospice referrals of patients with advanced cancer. *Journal of oncology practice* **13**(5): e496-e504.

Weisbrod, B.A. (1991). The health care quadrilemma: an essay on technological change, insurance, quality of care, and cost containment. *Journal of economic literature* **29**(2): 523-552.

Weissman, D.E. (2001). Managing conflicts at the end of life. *Journal of palliative medicine* **4**(1): 1-3.

Wenger, N.S. and Rosenfeld, K. (2001). Quality indicators for end-of-life care in vulnerable elders. *Annals of internal medicine* **135**(8_Part_2): 677-685.

WHO. (2011). A System of Health Reports. *2011 Edition*. European Union, 84.

WHO. (2015). *World report on ageing and health* World Health Organization.

Wilkinson, D.J. and Truog, R.D. (2013). The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. *Intensive care medicine* **39**(6): 1128-1132.

Wilkinson, P., Pattenden, S., Armstrong, B., Fletcher, A., Kovats, R.S., Mangtani, P.*, et al.* (2004). Vulnerability to winter mortality in elderly people in Britain: population based study. *Bmj* **329**(7467): 647.

Wilson, D., Smith, S., Anderson, M., Northcott, H., Fainsinger, R., Stingl, M.*, et al.* (2002). Twentieth-century social and health-care influences on location of death in Canada. *The Canadian journal of nursing research= Revue canadienne de recherche en sciences infirmieres* **34**(3): 141-161.

Winter, L. and Parker, B. (2007). Current health and preferences for life-prolonging treatments: an application of prospect theory to end-of-life decision making. *Social science & medicine* **65**(8): 1695-1707.

World Health Organization. (2011). Scaling up action against noncommunicable diseases: how much will it cost?

Wright, A.A. and Katz, I.T. (2007). Letting go of the rope—aggressive treatment, hospice care, and open access. *New England Journal of Medicine* **357**(4): 324-327.

Wright, A.A., Zhang, B., Ray, A., Mack, J.W., Trice, E., Balboni, T.*, et al.* (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama* **300**(14): 1665-1673.

Yang, Z., Norton, E.C., and Stearns, S.C. (2003). Longevity and health care expenditures: the real reasons older people spend more. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* **58**(1): S2-S10.

You, J.J., Downar, J., Fowler, R.A., Lamontagne, F., Ma, I.W., Jayaraman, D.*, et al.* (2015). Barriers to goals of care discussions with seriously ill hospitalized patients and their families: a multicenter survey of clinicians. *JAMA internal medicine* **175**(4): 549-556.

Young, K.M. and Kroth, P.J. (2017). *Sultz & Young's Health Care USA* Jones & Bartlett Learning.

Youngner, S.J. and Arnold, R.M. (2001). Philosophical debates about the definition of death: who cares? *Journal of Medicine and Philosophy* **26**(5): 527-537.

Yu, W., Ravelo, A., Wagner, T.H., and Barnett, P.G. (2004). The relationships among age, chronic conditions, and healthcare costs. *Am J Manag Care* **10**(12): 909-916.

Appendix 1

This appendix sets out an extract of the episode of care/ICD-10 code mappings to allocating the sample of decedent beneficiaries to the various trajectories of dying. The most costly episode of care/ICD-10 combination per beneficiary over their last twelve months of life is assumed to be the primary diagnosis or condition driving their particular trajectory of dying. The allocation is performed sequentially to allocate each beneficiary to one trajectory only. The "Other" trajectory contains all lives that could not be sensibly grouped in one of the four main trajectories of dying. These included beneficiaries for whom no episode of care/ICD-10 codes were assigned, pregnancy-related deaths, trauma-related deaths, episode of care/ICD-10 combinations unlikely to have resulted in death, and those younger than fifty who are thus unlikely to be frail, in general.

Table A1 – Mapping to trajectories of dying

Trajectory	Rand limit (12m)	Age range	'Episode of care' code	ICD-10 code
Sudden death	< R24 000	< 80	All	All
Cancer	>=R24 000	Any	TUM510 - Malignant neoplasm of hepatobiliary tract	C240 - Malignant neoplasm| extrahepatic bile duct
Cancer	>=R24 000	Any	TUM200 - Malignant neoplasm of breast	C509 - Malignant neoplasm| breast| unspecified
Cancer	>=R24 000	Any	TUM470 - Malignant neoplasm of gastrointestinal system	C169 - Malignant neoplasm| stomach| unspecified
Cancer	>=R24 000	Any	TUM280 - Malignant neoplasm of male reproductive system	C61 - Malignant neoplasm of prostate
Cancer	>=R24 000	Any	TUM020 - Non-Hodgkin's lymphoma	C839 - Non-follicular (diffuse) lymphoma| unspecified
Cancer	>=R24 000	Any	…	…
Organ failure	>=R24 000	Any	CAR120 - Congestive cardiac failure	I500 - Congestive heart failure
Organ failure	>=R24 000	Any	RES170 - Respiratory failure	J9691 - Respiratory failure| unspecified| Type II [hypercapnic]

Organ failure	>=R24 000	Any	NEP040 - Chronic renal failure	N189 - Chronic kidney disease| unspecified
Organ failure	>=R24 000	Any	HEP080 - Liver failure	K729 - Hepatic failure| unspecified
Organ failure	>=R24 000	Any	…	…
General frailty	>=R24 000	>= 50	CAR060 - Ischaemic heart disease	I259 - Chronic ischaemic heart disease| unspecified
General frailty	>=R24 000	>= 50	NEU010 - Ischaemic stroke	I64 - Stroke| not specified as haemorrhage or infarction
General frailty	>=R24 000	>= 50	RES280 - Pneumonia	J180 - Bronchopneumonia| unspecified
General frailty	>=R24 000	>= 50	NEU150 - Alzheimer's disease	G309 - Alzheimers disease| unspecified
General frailty	>=R24 000	>= 50	…	…
Other	>=R24 000	Any	NULL	NULL
Other	>=R24 000	Any	TRA120 - Burn of Non-specific region	T312 - Burns involving 20-29% of body surface
Other	>=R24 000	Any	EAR110 - Sinusitis	J340 - Abscess| furuncle and carbuncle of nose
Other	>=R24 000	Any	OBS010 - Post-partum complication	O721 - Other immediate postpartum haemorrhage
Other	>=R24 000	Any	…	…

The classification is done pragmatically where it unclear to exactly which trajectory a particular episode of care/ICD-10 combination belongs. A more robust classification of the multitude of episode of care/ICD-10 combinations, with expert clinical input may result in more credible results from analysing the main trajectories of dying. However, from this high-level analysis, it is clear that treatment and cost patterns do vary considerably by trajectory of dying.