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A Place to Die

Preferences for Place of Care and Place of Death in Terminally-Ill Patients and their Family Caregivers

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Every life is different from any that has gone before it, and so is every death. The uniqueness of each of us extends even to the way we die... Every man will yield up the ghost in a manner that the heavens have never known before: every woman will go her final way in her own way.

(Nuland, 1994, p. 3)

Abstract

Advances in healthcare, treatment and technology have profoundly altered the experience and place of dying. While caring for family members at home as they approached death was once the norm, the management of the dying has now become an increasingly complex medical science that often requires formal care in institutional settings. With these developments in mind, decisions regarding place of care and place of death have received considerable attention. Given the choice, the majority of people want to stay at home; however, the reality is that most die in hospitals. This thesis will explore the decision making concerning place of care and place of death in terminally ill patients and their family caregivers.

In this process, decision making has been examined from both a theoretical and an empirical perspective. Theoretical models of choice offer valuable insights into what influences intentions and subsequent behaviour. However, a review of the empirical literature showed that studies addressing place of care and place of death vary greatly in the precision, methods, timing and sources of their preference assessments. It could be concluded from these studies that in clinical practice, the question of where to spend one's last days is much more complex than most theories can grasp.

The mixed-methods research undertaken as part of this thesis was based on these theoretical and methodological considerations. Specifically, the current research examined the perspectives of terminally ill patients within their last year of life and further explored the role of family caregivers in the decision-making process. Study 1 used multiple-choice questionnaires to describe location preferences of patients and carers, identify factors that influence them, address the relationship between preferred and actual place of death, and examine the level of end-of-life agreement in patient-caregiver dyads. Study 2 included a series of semi-structured interviews to gain an in-depth understanding of the underlying processes and reasons that govern the decision making.

In this research three main findings were identified: firstly, family carers tended to have lower preferences for care and death at home than patients did and their ability to accurately assess their patient's wishes varied depending on the assessment task. This affirms that patients and carers must be acknowledged as two separate entities with sometimes different preferences and views. Secondly, some respondents' preferences for place of care were different from their preferences for place of death. The distinction most often observed was that participants wanted to be cared for at home, but they did not necessarily want to die there. This finding draws attention to the importance of clear communication at the end of life. Finally, preferences of terminally ill patients and their carers were influenced by a complex interplay of illness-related, personal, interpersonal and structural factors. Study 1 particularly addressed the role of physical and psychological symptoms, respondents' personality traits, experiences with different care settings as well as the quality of the patient-carer relationship. Study 2 further highlighted the role of uncertainty in the decision-making process. Respondents dealt with this uncertainty on a level of thoughts, emotions and actions as they balanced on a spectrum between not knowing enough and knowing too much.

Findings from this empirical research have implications for future studies and clinical practice as they emphasise the malleability of preferences, and define decision making at the end of life as a highly contextual, personal, relational, conditional and flexible process.

Declaration

This is to certify that:

- the thesis comprises only my original work toward the PhD;
- due acknowledgement has been made in the text to all other materials used;
- the thesis is less than 100,000 words in length, exclusive of tables, figures, bibliographies and appendices.

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Statement of Ethical Conduct

The research undertaken as part of this thesis abides by the National Statement on Ethical Conduct in Human Research and the rulings of the Human Ethics Research Committees of the University of Melbourne, Northern Health and Melbourne Health.

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For my mother.

I know you would have been proud.

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Introduction

CHAPTER ONE

1.1 Background

Elisabeth Kübler-Ross, one of the pioneers of end-of-life research, said that "dying is an integral part of life, as natural and predictable as being born" (2009, p. 5). Yet, in our modern world, how we prepare for birth and for death suggests otherwise. Birth is, in most cases, anticipated with joy. We talk about it and plan for it, so that we are ready when the time comes. In contrast, death is often considered a morbid, or, at the very least, depressing subject that needs to be avoided. The advances in medical knowledge and technology over the last century have changed how, when and where we face these important life events. The good news is that with modern medicine we can now expect to live longer than ever before (Roser, 2017). The bad news is that we still are all going to die. So how should we prepare and plan for this inevitability?

One central aspect of end-of-life decision making concerns where we want to spend our last days. This is pertinent because most people can confirm, from personal experience, how their living environment influences the quality of their life or how their work environment affects their work. It can, therefore, be argued that a person's "dying environment" also influences, to some extent, how they experience death. Questions surrounding place of care and place of death have received considerable attention within the last decade as healthcare systems are confronted with a growing number of terminally ill patients. Terminal illness can be defined as a "progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future" (Palliative Care Australia, 2008, p. 14). This may include malignant (cancerous) and non-malignant diseases as well as ageing-related conditions. As more and more people are approaching the end of their life, the rate of home deaths has become a dominant topic in research. Up until half a century ago, most deaths occurred at home under the informal care of family members (Kellehear, 2007; Sankar, 1994). Even today, home may still be seen as the most natural place of death and,

hence, something to aspire to (Barclay & Arthur, 2008; Thomas, Morris, & Clark, 2004). Being at home, surrounded by family and friends, can offer psychological comfort for patients as they are familiar with their surroundings and have some level of control over them (Bowling, 1983). As a consequence, dying at home is now often regarded as a marker of a "good death" and a success indicator of the healthcare system. This, however, is a development that some researchers and clinicians in the field are cautious about because dying at home may not always be as ideal as it sounds (De Roo et al., 2014; Higginson, Sarmento, Calanzani, Benalia, & Gomes, 2013; Stajduhar & Davies, 1998). For instance, based on interviews with 276 bereaved carers, Parkes (1978) found that symptom management and exhausted families were common problems in end-of-life care at home. Their conclusion was that "home can be the best place or the worst place to die" (p. 26). To some extent, this can be attributed to the fact that the care of the dying has become an increasingly complex medical science (in many cases maybe too complex for lay family caregivers) and hence, extensive professional support is now often needed in the last phase of life. Within the past 50 years, dying has therefore shifted from informal care at home to formal care in hospitals, hospices, or nursing homes.

This shift, however, has considerable financial implications for modern economies as institutional end-of-life support is more expensive than home care (Brumley et al., 2007; Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013; Palliative Care Australia, 2014; Worldwide Palliative Care Alliance, 2014). For instance, a review of Canadian health registry data found that the costs of caring for terminally ill patients rapidly escalated in the last six months of life, mainly due to the increased use of inpatient services, emergency room visits, and admissions to long-term care facilities (Fassbender, Fainsinger, Carson, & Finegan, 2009). Confronted with an increasingly ageing population, the healthcare system is now under tremendous pressure to find ways to meet the complex and prolonged care needs of those facing the end of their life.

For these reasons, there is a call for relevant research in this area in order to understand how people decide where they want to be cared for and where they want to die. It should be noted that many studies in this field have focussed predominantly on people's actual place of death as this data is easily obtainable from chart reviews, death registries and service records (Gomes & Higginson, 2006; Grande, Addington-Hall, & Todd, 1998). However, by addressing only the end result (that is where people actually die), we overlook how these choices are made and how important the decision-making process is for patients and their families. Instead of focussing only on a certain outcome, like the overall rate of home deaths, the World Health Organization (2004) suggested that meeting individual's preferences for place of care and place of death should be the "ultimate measure of success" (p. 17).

Hence, this thesis will address the questions: Where do people want to spend their last days, and what factors, reasons and processes influence these choices? Furthermore, are preferences for place of care at the end of life the same as those for place of death? There is a considerable need for studies that explore where terminally ill patients and their family carers would prefer to be in this critical time of their lives, rather than relying on the assumption that their preferences will coincide with the presumed ideal of a home death.

1.2 Contribution of this Thesis

The empirical research undertaken as part of this thesis examines location preferences by using a mixed-methods design. The thesis contributes to the current body of literature by:

- clearly differentiating between preferences for place of care and place of death;
- assessing the views of terminally ill patients expected to live less than 12 months;
- exploring the perspective, role, and involvement of family carers in decision making;
- addressing the influence of controversial and under-researched factors on location preferences; and by
- basing this research on an empirical and theoretical framework of decision making.

By understanding how and why patients and carers make certain decisions regarding place of care and place of death, it is hoped to gather insights into how we can better support them on this journey towards the end of life. The overall structure of this thesis will now be described.

1.3 Outline of this Thesis

The thesis consists of 12 chapters. The first four chapters provide the theoretical background to the current research and review the existing literature, the following seven chapters relate to the two empirical studies, and the last chapter draws these findings together in an overall discussion.

1.3.1 The Literature

The thesis will begin with an examination of the current literature about place of care and place of death. Medical advances have altered the way we die and how we perceive death. Chapter 2 will provide an overview of these historical changes and their influence on end-of-life caregiving and places of death. It will explore central concepts, such as palliative care, hospice and relocation stress, and address advantages and disadvantages of different care settings. It will further examine the importance and challenges of decision making regarding place of care and place of death, highlight the involvement of family caregivers, and analyse the role of end-of-life communication. To understand which concepts could be used to explain location preferences, Chapters 3 and 4 will explore how choices are made from two different perspectives; a theoretical and an empirical one. Chapter 3 will take a theory-driven approach and introduce four of the most widely used models of decision making and information processing, namely the Subjective Expected Utility Theory of Savage (1954), the Prospect Theory of Kahneman and Tversky (1979), the Theory of Planned Behaviour developed by Ajzen (1985), as well as the Two-System View supported by

Zajonc (1980) and Kahneman (2003). These theoretical frameworks propose factors that influence perception, choices and subsequent behaviours. Chapter 3 will critically examine their applicability to decisions concerning place of care and place of death. Chapter 4 will then take a more data-driven approach to explore how end-of-life choices are made in clinical practice. Previous end-of-life research has suggested a range of illness-related, personal, interpersonal and structural factors that may influence preferences of patients and carers. While some of these factors are well supported, many others show conflicting results or are considerably under-researched. Drawing on these findings, four main methodological challenges will be identified, which concern the precision, methods, timing, and sources of preference assessments. These ideas and reflections will then form the basis for the current research.

1.3.2 The Current Research

The theoretical, empirical and methodological considerations outlined will be drawn together in Chapter 5 to inform the rationale, aims and hypotheses of the current research. This will include two cross-sectional studies; the first using quantitative questionnaires and the second using qualitative interviews. The chosen mixed-methods approach is expected to provide more detailed insights into place of care and place of death decision making than would be possible with one methodology alone.

Study 1 – Quantitative Component. Study 1 will use multiple-choice questionnaires to elicit and describe the location preferences of terminally ill patients and their family caregivers, identify factors that influence these preferences, and examine end-of-life agreement between patients and carers. Chapters 6 to 8 will present the methods, results and discussion of the first study.

Study 2 – Qualitative Component. Study 2 will use semi-structured interviews with patients and carers to gain an in-depth understanding of the underlying processes and reasons that govern location decision making. Chapters 9 to 11 will outline the methods, results and discussion of the second study.

General Discussion. The final Chapter 12 will summarise, connect and discuss the findings of the two studies before addressing the contributions and limitations of this empirical research. It will also identify the application of this work for clinical practice and provide directions for future studies.

2

History and Importance of Place of Death

CHAPTER TWO

This chapter will provide an overview of the historical changes in end-of-life caregiving, the hospice movement and decision making at the end of life. It will introduce the concepts of palliative care, hospice and relocation stress. This chapter will further discuss the difference between institutional and home care settings, and examine positive and negative aspects of end-of-life caregiving. Finally, this chapter will address some the challenges in talking about death and dying, and highlight the role of family caregivers in location decision making.

2.1 Historical Changes in End-of-Life Care

Up until half a century ago, most people died mentally intact after a short and acute illness or infection (Kellehear, 2007). At the end of the 1800s, the average life expectancy in Australia was 47.2 years for men and 50.8 years for women, which is similar to most other parts of the Western world (Australian Institute of Health and Welfare, 2016; Roser, 2017). End-of-life care mainly occurred at home because this was, and may still be, seen as the most natural place of death (Barclay & Arthur, 2008; Thomas et al., 2004). As illustrated in Greuze's painting "Le Fils puni" (1778, see Figure 2.1), caring for loved ones as they approached death was a common part of family life. In her chapter on images of home deaths, Sankar (1994) described how children from an early age on learned to sit with the dying and care for them. Especially for women, this was a central part of their role throughout history as they dressed wounds and dispensed whatever medicine was available. During this time, neighbours, friends and relatives often helped with the care and other household responsibilities. So at the end-of-life, family members turned into nurses, and doctors turned into bystanders. Rothman (2014) discussed how in times of tuberculosis and prior to the invention of vaccines, "physicians, once they had ascertained that the disease was in its last stages, were peripheral to the process" (p. 2457).

Figure 2.1. Le Fils puni by Jean-Baptiste Greuze (1778), Louvre, Paris. Image ©2015 Réunion des musées nationaux agence photographique. Reprinted with permission.

This, however, began to change considerably in the early parts of the twentieth century when advances in healthcare, treatment and technology began to alter the experience of illness and, subsequently, of dying. The use of vaccinations and antibiotics, as well as the improvements of medical equipment and procedures, substantially decreased the number of infectious diseases. These changes in medical science now offered the possibility that death could be delayed through adequate hospital care. As a consequence, by the 1980s most deaths occurred outside the home setting (Sankar, 1994).

While caring for a terminally ill relative at home was once the norm, this task has now been increasingly put in the hands of healthcare professionals. Horsfall, Noonan, and Leonard

(2012) pointed out that "dying is now firmly located within the domain of medical science and its perceived experts. As a consequence, community knowledge about EOL [end-of-life] care has declined, thus further increasing reliance on healthcare and medical systems" (p.373).

As symbolised by the sculpture of the Greek god of medicine fighting off death (Harris, 1950, see Figure 2.2), the medical improvements of the past century have allowed us to postpone the end of life. This caused the focus of healthcare to shift from mainly easing patients' suffering to actually curing diseases. Hence, death has become perceived as "the ultimate enemy of medicine and represents the physician's final and absolute failure" (McCormick & Connors, 2002, p. 332).

Figure 2.2. Sculpture of Asclepius, god of medicine, fending off death by Harris (1950). Image ©2013 Woody Trend Studio. Reprinted with permission.

2.2 Longer Living – Longer Dying?

Much like in the rest of the modern world, life expectancy has now risen to 80.1 years for Australian men and 84.3 years for women (Australian Institute of Health and Welfare, 2016). Today, the most common causes of death are chronic conditions such as

cardiovascular diseases, cancers, diabetes and lung diseases (World Health Organization, 2011). With the advances in medical science, death is now in many cases predictable but dying also takes longer (Swerissen & Duckett, 2014). Kellehear (2007) argued that consequently "most of us will end up with an assortment of diseases that will not provide us with a clear death bed scene for ourselves or our families" (p. 213). The Australian Bureau of Statistics (2013) anticipated that the annual death rates will steadily rise by 1.5% to 1.8% each year and this incline will accelerate between 2022 and 2040 as a result of the ageing baby boomer generation. Based on one of their assumptions, by 2063, we will reach a state of population decrease, where deaths outnumber births. This means that the proportion of old and dying people will increase faster than our population grows. So issues regarding end-of-life care will directly or indirectly affect all of us. Therefore, we need to consider the consequences of our extended lifespan.

Gruenberg (1977) argued that the price for longer life is an increased prevalence and duration of chronic conditions and disabilities. Previously, these would have caused terminal infections, which due to the help of medication and technology are now less likely to be fatal. According to Gruenberg (1977), this unintended extension of disease that comes with the attempt to prolong life represents the "failures of success" in medical science (p. 5). Fries (1980), on the other hand, proposed a more optimistic view. He argued that medical advances can and will cause a "compression of morbidity", which means a shorter span between the onset of disability and the occurrence of death (p. 130). In this model, medical advances will be able to postpone chronic diseases so that the time of life spent ill and frail is shortened. In this "intuitive ideal", life is portrayed as "physically, emotionally and intellectually vigorous until shortly before its close… everything comes apart at once and repair is impossible" (Fries, 1980, p. 135). But even if ageing, death and disability now occur much later than before, they are still inevitable and need to be planned for.

2.3 Palliative Care and the Hospice Movement

Throughout history, places have been established specifically for the care of the dying. For instance, in 1065, the Knights Hospitallers of the Order of St John of Jerusalem founded a home in Malta for sick and dying pilgrims on their way to and from the Holy Land. These homes were called hospices, a term that can be simply defined as "a home providing care for the sick or terminally ill" (Oxford Dictionaries, 2010, p. 847). The Latin root *hospes* referred to both a host and a guest (Robbins & Moscrop, 1995). In 1600, a group of Catholic women who were called the Daughters of Charity cared for poor and dying members of the French society. This inspired an Irishwoman, Mary Aikenhead, in the late 1800s to found the Sisters of Charity and open hospices in Dublin and London. These developments spread in Europe and over to America, through the work of Rose Hawthorne and the establishment of the Marie Curie Foundation, which aimed to relieve the distress of patients dying with cancer and the strain on their families (Robbins & Moscrop, 1995). Yet even as recently as the 1950s, these establishments were an exception and there were very few services that promoted the care of the dying. Instead, the trend was moving towards acute medicine and rehabilitation while giving little attention to the demands of an ageing population with an increasing rate of malignant diagnoses (Clark, 2002).

This changed in 1967 when Dame Cicely Saunders founded the St. Christopher's hospice in London. Revolutionising the approach to pain control and holistic care for dying patients, this marked the start of the modern hospice movement. Saunders formulated principles for end-of-life care, which included: acceptance of death, interdisciplinary support for the patient, effective symptom control, home care and bereavement support as well as continuous research and education. Importantly, patients and families were recognised as a single unit of care (Bennahum, 1996). At about the same time, Swiss psychiatrist Elisabeth Kübler-Ross began to interview terminally ill patients in hospitals. In 1972, she spoke at the

first national hearings of the U.S. Senate Special Committee on Aging about death with dignity and pointed out that:

> We live in a very particular death-denying society. We isolate both the dying and the old, and it serves a purpose. They are reminders of our own mortality. We should not institutionalize people. We can give families more help with home care and visiting nurses, giving the families and the patients the spiritual, emotional, and financial help in order to facilitate the final care at home. (National Hospice and Palliative Care Organization, 2015)

This avoidance of the topic of death and the lack of involvement of patients and families in decision making led Cicely Saunders and Elizabeth Kübler-Ross to envision the development of palliative care as a specialised discipline of medicine. The Latin root *palliare* means "to cloak, ... [to] relieve pain without curing the cause of it,... to make a problem less severe without dealing with the cause" (Oxford Dictionaries, 2012, p. 517). Today, the World Health Organization (2014) defines palliative care as an "approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness". Specifically, palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies (World Health Organization, 2014)

The works of Cicely Saunders, Elizabeth Kübler-Ross and other pioneers have dramatically changed end-of-life care and led to now approximately 8,000 established hospices and palliative care programs in over 100 countries worldwide (Higginson & Costantini, 2008). This increased the focus on dying with dignity and quality, rather than quantity of life.

2.4 Psychological Function of Decision Making at the End of Life

Today, only approximately 25% of all deaths are sudden and unexpected (Blackmore, Verne, & Pring, 2011). Consequently, end-of-life decision making is relevant for the majority of us. Planning ahead, especially in the context of end-of-life care, serves an important psychological function for patients and their families. As Leotti, Iyengar, and Ochsner (2010) declared: "we are born to choose" (p. 461). Reviewing the biological and psychological value of choice, Leotti et al. (2010) argued that every decision reinforces the perception of control and self-efficacy, and these benefits can even exist in the absence of true control. In a discussion paper on ethical issues of place of care, Wheatley and Baker (2007) argued that by promoting choices about how and where healthcare is received, patients gain back a sense of control over their lives, which is otherwise often compromised by the illness. Similarly, Tang (2003) highlighted that having some autonomy and control over their dying circumstances is important for terminally ill patients in order to maintain dignity at the end of life. This freedom of choice is often incorporated into guidelines and frameworks of the country-specific healthcare systems. For example, the Australian Charter of Healthcare Rights states that patients have the right to be informed about treatment options and participate in the decision making (Australian Commission on Safety and Quality in Health Care, 2009).

Especially in the past decade, there has been a stronger emphasis on shared decision making and patient-centered care (Barry & Edgman-Levitan, 2012; Frank, 2009; Ngo-Metzger, August, Srinivasan, Liao, & Meyskens Jr, 2008; White, Braddock, Bereknyei, &

Curtis, 2007). The Cancer Council Australia (2016) defined patient-centered care as an approach that includes patients' preferences, values, culture, family situation and lifestyle, and makes them an integral part of the care team and the decision making process. This concept was further expanded by recognising the needs and influence of close family members on patients' choices (Kovacs, Bellin, & Fauri, 2006; Teno, Casey, Welch, & Edgman-Levitan, 2001). Hence, patient- and family-centred care was suggested as an approach to planning, delivering and evaluating healthcare based on the partnership between medical staff, patients and families. This highlights the vital role of family members in the care, health and well-being of the patient (Institute for family-centered care, 2010).

2.5 Decision Making regarding End-of-Life Care Settings

At the end of life, patients and their families are faced with a variety of challenging choices as they have to prepare for death and loss and the time after. One of the key aspects of choice concerns where they want to spend their last days. With the increase of symptoms, care needs and frailty, patients are likely to spend less time outside of their current place of care. Therefore, the importance of this decision grows as the illness progresses.

However, some have questioned if, and how much, location choices really matter to people who are faced with their own or their loved one's death. In an American study, Steinhauser et al. (2000) surveyed seriously ill patients, bereaved family carers, physicians and other care providers regarding the importance of certain aspects of the end of life. They gave participants a selection of nine attributes to rank, of which dying at home was rated as least important. However, this list included items like freedom of pain, presence of family and resolving conflicts, which are understandably ranked more important than place of death in a forced-choice format. Steinhauser et al. (2000) noted that the responses to dying at home varied greatly, with some participants finding it very important, whereas others neither agreed nor disagreed. Similarly, in a survey of 2055 British adults, only 10% rated being cared for

and dying in the place of one's choice as more important than aspects like being pain-free, retaining dignity and being with friends and family (National Council for Palliative Care, 2014). This illustrates that the way in which preferences are assessed seems to matter considerably because responses differ when participants are free to rate the importance of this choice without having to decide between potentially conflicting options. For instance, Tang (2003) conducted semi-structured interviews with 180 terminally ill cancer patients who rated dying in their preferred place as highly important (4.2 on a 5 point Likert scale). Similarly, based on a literature review, 52 one-on-one interviews and additional focus groups with 47 AIDS patients, Patrick, Engelberg, and Curtis (2001) found that dying in a place of one's choice was reported to be one of the central domains of a quality death.

It is reasonable to assume that our immediate surroundings have a clear and continuous effect on our experiences, health and well-being, especially at the end of life. In a discussion paper on research needs regarding the quality of death in older adults, Mezey, Dubler, Mitty, and Brody (2002) suggested that the setting affects the philosophy of care, the types and intensity of services, the relationship between care provider and care recipient, as well as the level of skill and availability of support. They concluded that patients' surroundings, therefore, have a noticeable, direct and immediate influence on the quality of life at the end of life. Despite the intuitive importance of location choices, there seems to be some disagreement and interpersonal variation in regard to how much this decision really matters to patients and their families.

2.5.1 Preferred versus Actual Place of Death

While the care setting in which people spend their last days is likely to influence some aspects of their experience at the end of life, there is a notable mismatch between people's preferred and their actual place of death. For example, Foreman, Hunt, Luke, and Roder (2006) asked 2,652 South Australians where they would want to die if they had a terminal

illness such as cancer. They found that 70% of respondents wished to die at home, 19.3% preferred hospital, 9.8% hospice and 0.8% nursing home. Yet, referring to the distribution of South Australian cancer deaths between 2000 and 2002, Foreman et al. (2006) suggested that only 14% of patients actually die at home. The majority (56%) die in hospitals, 18% in hospice care and 12% in nursing homes. There is further international support for this mismatch. In a pooled review, Billingham and Billingham (2013) examined 26 worldwide studies regarding the preferences of patients with malignant and non-malignant diagnoses. They found that 79.5% of those who expressed a preference wanted to die at home, yet responses varied greatly. Congruence between the preferred and actual place of death ranged between 20% and 81.9%. Reasons for these discrepancies are complex and depend on the care setting. The following sections will, therefore, consider relevant aspects of different settings in regard to end-of-life decision making.

2.5.2 Institutional Care Settings

Nowadays, the majority of terminal care is provided in institutional settings (Australian Institute of Health and Welfare, 2013, p. 6; National Center for Health Statistics, 2011, p. 43). This may include hospitals, hospices, specialised palliative care wards or even nursing homes. In formal settings, legal responsibility for care is transferred to professionals, while families often continue to provide large amounts of support (Stajduhar et al., 2010). This means that institutional end-of-life care is often provided by strangers (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). In a recent report, Swerissen and Duckett (2014) argued that dying in Australia is more institutionalised than in other parts of the world as home death rates are comparatively low. They referred to an international assessment of 45 reports from 36 nations by Broad et al. (2013), according to which only 14% of Australians aged 65 and older die at home. This is less than half compared to countries like New Zealand, the United States, Ireland and France.

There is a wide range of reasons why many patients receive terminal care in institutions rather than at home. According to a prospective study of 415 palliative care patients by Hinton (1994), end-of-life admissions were often caused by the need for symptom control, rapid and sometimes unexpected deteriorations, or the inability to manage at home due to high caregiving demands and emotional distress. This is particularly true for patients with multiple co-morbidities (Chen, Haley, Robinson, & Schonwetter, 2003), and those who suffer from mental confusion or pain (Cartwright, Hockey, & Anderson, 1973). Also, concerns about being a burden (Tang, 2003), shortage of available informal caregivers (Cartwright et al., 1973; Hu, Chiu, Cheng, Chuang, & Chen, 2004), or lack of formal care and support services (Wheatley & Baker, 2007; Wood, Storey, & Clark, 2007) can increase the likelihood of institutionalisation for terminally ill patients. Yet even if family carers and formal support services are available, patients' and families' location preferences often change as the illness progresses leading to a different place of death than initially favoured (Barclay & Arthur, 2008; Gerrard et al., 2011; Higginson & Sen-Gupta, 2000; Townsend et al., 1990). The following sections will explore the characteristics, advantages and disadvantages of different institutional settings that provide formal end-of-life care.

2.5.2.1 Hospitals as End-of-Life Care Settings

Hospitals offer easy access to full-time support, medical equipment and specialised skills (Bowling, 1983; Gott et al., 2004; Higginson & Sen-Gupta, 2000; Hu et al., 2004). Beyond these objective advantages, hospital care might also fulfil an important psychological function, as it reflects the process of actively fighting the disease and not giving up treatment. Higginson and Sen-Gupta (2000) reviewed 18 qualitative studies on place of care in advanced cancer and argued that a preference for hospital care might reflect patients' or families' refusal to admit that a cure is impossible. Similarly, in a discussion paper on family-centred end-of-life care, Kovacs et al. (2006) highlighted that the reliance on institutional

care might be driven by the hope and belief that life can be extended through the use of science-based care, technology and medical monitoring. Rothman (2014) discussed where we die and suggested that:

> By common agreement, hospitals are no longer the best place to die. But ... however strongly patients prefer to return home, they are often reluctant to do so until the most advanced medical technologies have been tried. The result is that a substantial number of patients die in ICUs [intensive care units] in the midst of extraordinary interventions to save them. (Rothman, 2014, p. 2459)

Hence, palliative care often comes late in the progress of the illness after all measures to cure the patient have been exhausted (Swerissen & Duckett, 2014). While institutional care has noticeable advantages as it takes the caregiving burden off the families, hospitals in particular can be rather sterile and anxiety-provoking places. In a national survey of death and bereavement among 359 elderly widows in the UK, Bowling and Cartwright (1982) found that 74% of people who passed away in a hospital died alone without family or friends present as opposed to only 15% of those who passed away at home. Thomas et al. (2004) interviewed 41 British cancer patients and 18 family carers about their place of death preferences and none of them wanted to die in a hospital because of previous distressing experiences with hospital care. In a similar study from the USA, Tang (2003) interviewed 180 terminally ill patients with cancer about their views on different places of death. In hospitals, people felt there was a lack of privacy and control compared to home care. A Canadian study by Mount, Jones, and Patterson (1980) highlighted further problems of isolation and depersonalisation of dying hospital patients. Finally, in a more recent review of 18 qualitative studies on family carers' perspectives regarding place of care, Woodman, Baillie, and Sivell (2015) found that hospitals were still often seen as an unsuitable palliative care environment, mainly due to their impersonal nature. These issues are likely to affect the dying experience. Swerissen and Duckett (2014) argued that medical attitudes and lack of

funding for community care increase the rate of institutionalisations at the end of life, resulting in lingering, lonely and disempowered deaths. This was also described by Buchan, Gibson, and Ellison (2011) in a reflective paper on death and dying: "Occupied by both the living and dying, the hospital bed and room is a general and impersonal setting - a borrowed space of transition rather than belonging" (p. 5). While hospitals can provide great physical care, patients and their families often perceive a lack of emotional support (Mount et al., 1980). Kellehear (2007) added that in our medicalised world the notion of a good death has been replaced by the concept of a well-managed death, which requires professional knowledge, equipment, and support. As a consequence, the experience of modern death is often "cellular, private, curtained, individualised and obscure" (Buchan et al., 2011, p. 4).

2.5.2.2 Palliative Care Wards and Hospices

More and more hospitals now offer specialised palliative care or hospice wards for terminally ill patients. These units may look similar to acute care wards but their focus is on easing symptoms rather than on curing them. The Australian Institute of Health and Welfare (2017) reported that 18.1% of the public hospitals and 7.8% of the private and psychiatric hospitals in Australia have a hospice unit. Since these wards are designed for end-of-life support, they often have the connotation of finality and hopelessness (Aranda & Peerson, 2001). The transition from a curative to a palliative approach to care is for some patients and families a sign of giving up. By ceasing restorative treatment, they are left with little hope to ever recover and live. In an interview study with 41 cancer patients and 18 family carers from England, Thomas et al. (2004) encountered the preconceived notion that hospices are "grim places that one entered to suffer and die" (p. 2440). Yet after some experience with hospice care, many respondents appreciated the welcoming and caring atmosphere there. In a study with 88 British cancer patients, Hinton (1980) pointed out that hospices offer more frank communication, allowing patients to speak freely about their illness if they choose to.

Furthermore, family carers are able to connect emotionally with their patients without being distracted and burdened by the task of providing physical support (Woodman et al., 2015). In his discussion paper on ageing, death and compression of morbidity, Fries (1980) argued that maintaining dignity at the end of life is more likely in a hospice than in a hospital:

> The older person requires opportunity for expression and experience and autonomy and accomplishment, not support and care and feeding and sympathy. High-level medical technology applied at the end of a natural life span epitomizes the absurd. The hospice becomes more attractive than the hospital. Human interaction, rather than respirators and dialysis and other medical support for failing organs, is indicated at the time of the "terminal drop". (Fries, 1980, p. 135)

But even these specialised units are under considerable financial pressure to discharge patients, vacate inpatient beds and hence, provide only short-term care (Sankar, 1994; Wheatley & Baker, 2007). This can lead to additional stress for patients and their families when having to organise and adapt to a new care situation in a different setting. Premature discharges can also result in the re-occurrence of health problems or a general deterioration, which then increases the likelihood of unexpected and stressful re-admissions (Soelver, Rydahl-Hansen, Oestergaard, & Wagner, 2013; Weaver et al., 2006). The availability of hospice support also depends on the region. For example, the Australian Institute of Health and Welfare (2017) reported that 25.2% of hospitals in major cities had a hospice unit attached, whereas only 10.5% in remote areas did. Hence, for rural communities, palliative care support might be less accessible than in metropolitan regions. In a large-scale American study, Pritchard et al. (1998) found that the likelihood of dying in hospital was increased for residents of regions with greater hospital bed availability and decreased in regions with greater nursing home and hospice availability. Similarly, in a chart review of 203 recently deceased people from Sweden, Axelsson and Christensen (1996) found that patients who lived more than 40 km away from the nearest hospital died more often in nursing homes than those who lived closer (33% versus 12%).

2.5.2.3 Nursing Homes as a Place of End-of-Life Care

Patients in nursing homes often have long-standing care needs (Fried, van Doorn, O'Leary, Tinetti, & Drickamer, 1999) and no family caregivers available for support (Tang, 2003). A comparison of 36 nations from 2001 to 2010 showed that 14% to 29% of people over 65 years died in aged care facilities (Broad et al., 2013). Hence, dying is a normal part of nursing home care. Mautner, Standl, and Pillau (1993) reported that 41% of the aged care residents in their study died within the first six months after admission and, of those, 81% passed away in the first month. Consequently, staff members should be prepared to care for the dying. However, that is not always the case as they may lack training in, and knowledge of, palliative care (Wilson, 2006; Wowchuk, McClement, & Bond, 2007). A large multi-method study by Komaromy, Sidell, and Katz (2000) found that nursing home staff often felt unable to cope with death and were afraid of dealing with dying residents. Lack of communication, respect and involvement in decision making, as well as untreated pain, are reported to be major problems of end-of-life care in nursing homes (Teno, 2003; Teno et al., 2004; Thompson, McClement, Menec, & Chochinov, 2012). In her chapter on long-term care in palliative nursing, Wilson (2006) described that there may not even be enough physical space in nursing homes to provide privacy in the care of the dying and for these reasons it is not surprising that residents are frequently admitted to hospital shortly before death occurs (Thompson et al., 2012; Wowchuk et al., 2007). For example, Miller, Gozalo, and Mor (2001) found that 44% of a sample of 27,500 nursing home residents were hospitalised in the last 30 days of life. The alternative to institutional care is to support the patient in their final days at home. This could include the patient's own, a relative's or friend's home.

2.5.3 Home as a Setting for End-of-Life Care and its Implications

Home can simply be defined as a place where a person lives (Merriam Webster Dictionary, 2015). Yet, clearly, it goes beyond that. Home is a representation of our lives and

it reflects "who we are and what (…) family means" (Barclay & Arthur, 2008, p. 230). Hence, dying at home is seen by many patients and their families as an opportunity to maintain dignity at the end of life (Funk et al., 2010) and assume control over the dying process (Bowling, 1983; Sankar, 1994; Tang, 2003). Home care may further provide a sense of normality, familiarity, autonomy and security (Bowling, 1983; Funk et al., 2010; Gott et al., 2004). Radin (1982) described the close relationship between property and personhood. A home is created when a person individualises a physical space to create a social or psychological space within. The connection people develop with their homes supports their identity (Rowles & Chaudhury, 2005; Twigger-Ross & Uzzell, 1996). Being the place that the patient is most exposed to and familiar with, home is the standard all other care settings are compared to. It is believed that dying at home can have social and psychological benefits (Lugton & McIntyre, 2005; Storey, Pemberton, Howard, & O'Donnell, 2003). It provides more opportunity for human contact and intimacy than other care settings (Aranda & Peerson, 2001). At home, the dying patient may feel less isolated and rejected by their family or community (Bowling, 1983). In ideal circumstances, home care provides the highest quality of life at the end of life (Wright et al., 2010). Nevertheless, Sankar (1994) emphasised that we must be careful not to idealise dying at home:

> Our current image of home death is informed by romantic notions of the past when, it was thought, families took care of their elderly better than they are cared for today. In these images, a dying elder is in his or her own bed, surrounded by devoted and caring family members. Often the dying person is articulate and alert enough to make deathbed pronouncements. (Sankar, 1994, p. 105)

But the way we die is different now and many socio-demographic and society-related changes of the past century have further challenged this historical model of dying at home. For example, the increasing dispersion of families, in the sense of family members living far away from each other, makes it difficult for them to provide immediate local support for a

terminally ill relative. This is intensified by the trend towards smaller family sizes and consequently fewer possible carers. In addition, the longer lifespan that we experience today can also result in patients sometimes even outliving their family caregivers (Kovacs et al., 2006). Despite these trends, the majority of end-of-life support, especially at home, is still provided by family members.

As informal carers, family members are not acting in a professional or occupational capacity (Stajduhar et al., 2010) and in contrast to medical staff, they may not have any caregiving background or formal training (Australian Senate, 2012). In many cases, there is one family member who takes on most of the caregiving task and this person is called the primary informal caregiver. Palliative Care Australia (2008) defines:

> The primary carer can be the patient's spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, e.g. the administration of medications. They provide the primary support role for the patient at all levels of need. (p.12)

In 2015, an estimated 1.9 billion hours of care have been provided by informal caregivers, which if paid, had a replacement value of 60.3 billion Australian Dollars (Deloitte Access Economics, 2015). Hence, family carers are a considerable workforce in our society given that they provide unpaid end-of-life support and have to complete mentally, emotionally and physically demanding tasks often without previous experience and sufficient support (Australian Senate, 2012).

Swerissen and Duckett (2014) pointed out that "in Australia people often do not have the opportunity to choose and control the manner of their death, we do not provide enough support for carers, end-of-life services are fragmented, and sufficient palliative care is often not available" (p. 16). As previously mentioned, lack of professional help is more of a

problem in rural rather than metropolitan areas. However, lacking or unavailable support can considerably increase the burden on the carer. The Australian Senate (2012) reported that the number of care packages for respite care is limited and hence, carers sometimes have to wait weeks or even months to access them. Some services are also only available for patients with certain diagnoses and prognoses (Palliative Care Queensland, 2012). Currently, just 37.5% of Australian patients whose death can be anticipated are involved with, and seen by, palliative care services (Palliative Care Australia, 2005).

Especially without adequate support, caring for a loved one at home can have considerable consequences for the family, the patient, and their relationship. Caregiving may arise from a sense of responsibility, duty and commitment, or simply the lack of alternatives (Funk et al., 2010). As people increasingly die from chronic and slowly progressing conditions, the demands of long-term care on the family increase. Informal caregivers often report psychological and physical challenges such as fatigue, weariness, depression, anger and sadness (Jo, Brazil, Lohfeld, & Willison, 2007). Furthermore, feelings of lack of preparation, knowledge and ability, as well as time pressure and social isolation are other reported negative aspects of end-of-life caregiving at home (Funk et al., 2010). Conflicting occupational and parental responsibilities (Dudgeon & Kristjanson, 1995), financial pressure (Funk et al., 2010), and no option to leave work or take extended breaks (Aranda & Peerson, 2001) may increase the perceived caregiver burden. Based on a literature review of 105 qualitative articles published from 1998 to 2008, Funk et al. (2010) described home-based end-of-life caregiving as "involving intense, conflicting, negative and/ or difficult emotions, such as fear and dread, anger and disillusionment, guilt and regret, anxiety, grief, helplessness, and hopelessness" (p. 597).

Home care can further have a noticeable effect on the home itself and what it means for the family. Stajduhar (2003) interviewed 60 family caregivers who discussed how their home was often turned into a hospital-like setting, filled with medical supplies and equipment.

While carers were grateful for outside support, they also sometimes felt pushed aside by the different healthcare providers, pharmacy services and supply deliveries that were coming into their homes. All these experiences are likely to influence caregivers' willingness to care for someone again in the future. As part of a larger interview study, Currow et al. (2011) surveyed 520 South Australians who had provided some level of hands-on end-of-life care within the last five years. They found that 7.4% of participants said that they would not do it again, and 16.5% were undecided. The Australian Senate (2012) highlighted that "as carers shoulder these responsibilities, pressure and exhaustion can easily build up and affect both the carer and the person being cared for, despite carers' genuine preference and desire to care for the person themselves" (p. 62).

While supporting a loved one at home is a demanding undertaking, informal caregivers also report positive aspects of their role. In the afore-mentioned qualitative review by Funk et al. (2010), family caregivers often reported a sense of pride, confidence, and accomplishment in mastering the task. They discovered emotional and physical resilience in themselves that they had not been aware of before. Providing care allowed them to demonstrate love and reciprocity, deepen their relationship with the patient and spend more time together. Many perceived end-of-life care as very meaningful because it enabled personal growth, broadened their outlook, renewed their appreciation for life and transformed their fear of death. From the patient's perspective, Funk et al. (2010) found that receiving care at home was connected with feelings of deep gratitude, while also being concerned about caregivers' emotional and financial well-being. These findings supported previous research by Gott et al. (2004) who conducted eight focus group discussions with diverse community groups and additional interviews with 45 elderly participants about end-of-life care at home. They found that caring for a dying relative was often considered an expression of affection and love. But patients worried about being a burden, the personal and intimate nature of care, as well as being seen to suffer. Also, some patients did not have an informal carer and that was one of the reasons

for them not wanting to die at home. In summary, all forms of end-of-life care, irrespective of the setting, are based on formal and informal support. In his *Social history of dying*, Kellehear (2007) wrote:

> After some two million years of human death and dying history we find ourselves at the beginning again. But with some reverse characteristics. The dying in the Cosmopolitan Age find themselves dependent on the community of others to assist them, not in some challenging otherworld journey but in an uncomfortable or distressing this-world journey. (p. 62)

This journey has become increasingly long and complex. As a consequence, dying patients are often admitted to hospital or hospice and then again discharged into community care. These frequent relocations, however, can have considerable consequences for patients and their families, which will now be addressed.

2.5.4 Relocation Stress

Changing places of end-of-life care can cause psychological, social and spiritual distress, or even emotional trauma for terminally ill patients and their family caregivers (Kallianis, 2011; Maccabee, 1994). This is connected to what the North American Nursing Diagnosis Association called *relocation stress*, which is defined as "physiologic and/or psychological disturbance following transfer from one environment to another" (Carpentio, 2013, p. 525). This is also known as admission stress, post-relocation crisis, transfer trauma or transplantation shock, and has been mainly described in regard to institutional care settings. According to Harkulich and Brugler (1988), individuals who experience this form of stress respond to a change in location with loneliness, depression, anger, apprehension, anxiety and confusion. Terminally ill patients are particularly vulnerable to this type of stress as they are less adequately equipped to cope with frequent location changes and the "intensive intrusion into their immediate environment" (Danermark & Ekstrom, 1990, p. 26).

Porock, Martin, Oldham, and Underwood (1997) also pointed out that the prognosis of a patient can be shorter than the time it takes them to adjust to the new location. Cases of severe debilitation and deterioration in physical and mental health, as well as early deaths, have been reported after location changes, especially to institutions. However, it has been widely debated whether these were mainly caused by the underlying illness and general frailty of the patient, or at least partly due to stress and lack of adaptation to the new care setting (Danermark & Ekstrom, 1990; Porock et al., 1997; Rantz & Egan, 1987). Danermark and Ekstrom (1990) highlighted that relocation is often differently perceived, depending on the meaning and the importance of the original and the new home to the patient. Furthermore, Schulz and Brenner (1977) suggested that the effect of relocation on mortality and health might be influenced by the sense of control, predictability and voluntariness of the location change. The distress caused by end-of-life admissions and discharges of dying patients could be potentially be eased by open discussions about what to expect. However, talking about death and dying is still a very challenging subject for many.

2.6 Death Talk - Communicating about Death and Dying

As the care of the dying has become more technical and scientific over the course of the past century, conversations about end-of-life care have turned into sometimes sterile exchanges of information that are overflowing with medical jargon (Marco, Savory, & Treuhaft, 2010; Wittenberg-Lyles et al., 2013). This has two potential consequences: firstly, this may decrease patients' and carers' understanding of treatment and care options and, secondly, force them to acquire a whole new range of technical vocabulary. For example, in a telephone survey of 1000 American adults, National Journal and The Regence Foundation (2011) found that 61% were not at all familiar with the term "palliative care". Based on interviews with 48 advanced cancer patients and 23 family carers, Zimmermann et al. (2016) added that the term was often associated with negative and frightening stigmas of death,

hopelessness and dependency. The stigmas, ambiguity and vagueness encountered in end-of-life discussions may be an expression of what Elizabeth Kübler-Ross called our "very particular death-denying society" (National Hospice and Palliative Care Organization, 2015). Swerissen and Duckett (2014) pointed out that:

> As a community, we struggle to talk about death. We prefer euphemisms - "passed on" and "resting in peace" - to direct speech. We focus more on hopes for the next medical breakthrough than on the limits of health care when death is near. Public discussion of death may even be more cloaked than it was for earlier generations, when death was more common. Preparation for death has become technical, private and hidden. (p. 11)

Hence, conversations about end-of-life wishes are perceived as challenging for everyone involved and are consequently often avoided. Munday, Petrova, and Dale (2009) interviewed 17 general practitioners and 19 nurses, who reported that preferences for place of death were often co-created in discussions with the patient or even inferred by the health professional without direct questioning. Furthermore, Swerissen and Duckett (2014) argued that the quality of death is poorer and decision making is more stressful when treatment preferences have not been discussed, and choices have to be made in the "pressure cooker environment of a hospital" (p. 11). Talking about end-of-life wishes can transform death from a distant, unspoken fear to a tangible reality. It can be seen as the proverbial elephant in the room. Facing and acknowledging our own mortality is not only difficult for patients and families, but also for healthcare and medical staff. A study by Sullivan et al. (2007) found that 86% of physicians reported knowing that death of a patient was imminent. However, a review of 46 studies on discussions of life-limiting prognoses showed that in clinical practice many health professionals either avoid discussing end-of-life topics or withhold information (Hancock et al., 2007). Some of the reasons reported included lack of training or time, stress, uncertainty about the prognosis, fear of a negative impact on the patients, and requests from family members to not share certain information. In this sense, medical staff

themselves might be to some extent death-denying and avoid conversations about end-of-life matters because of their own discomfort. In addition, this can again be connected with the predominately curative approach of today's medicine, according to which doctors and healthcare staff "are trained to discuss cure and rehabilitation, not how to make the end of life easier" (Swerissen & Duckett, 2014, p. 12).

2.6.1 Preferences for Place of Care versus Preferences for Place of Death

One important example of the ambiguity in end-of-life discussions addresses the use of the terms *place of death* and *place of care*. In clinical practice as well as in research, these are often not clearly separated, and even used synonymously (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; Holdsworth & King, 2009; Townsend et al., 1990). Yet, Agar et al. (2008) suggested that the two terms represent different concepts. In their longitudinal study of 71 palliative care patients and their families in Adelaide, they asked participants separately every two to four weeks about their preferred place of care and place of death. Congruence between the two types of preferences was low, with only 56% matching responses for patients ($\kappa = 0.33$) and 36% for caregivers ($\kappa = 0.35$). Interestingly, participants often identified home as their preferred place of care, yet they did not always want to die there. Agar et al. (2008) criticised that that studies to date have not addressed these differences between preferences for place of care and place of death for patients, nor, separately, for carers. The study also found that as death approached, participants were asked less often about their preferred place of death and more about place of care. This reluctance to directly address the patient's imminent death and the tendency to substitute the term place of care when uncomfortable raising the topic of death can lead to misinterpretations, confusion and uncertainty about patients' and carers' actual wishes. Hence, a clear distinction between the two concepts is essential for patients, families, clinicians and researchers alike when discussing end-of-life preferences.

2.6.2 High Information Needs of Patients and Caregivers

Irrespective of how difficult it is for people to talk about death and dying, it appears that many patients and carers *do* want to know. Evans et al. (2009) found that 87% of 179 interviewed surrogates of incapacitated patients wanted physicians to discuss the prognosis, even if it was uncertain. Similarly, a study by Jenkins, Fallowfield, and Saul (2001) reported that 87% of 2,331 cancer patients wanted to receive all possible information, both good and bad news. A telephone study by Gallagher and Krawczyk (2013) with 90 bereaved family members whose relative had died in an institutional setting further illustrated this need for information and emotional support at the end of life. Overall, 45% of carers would have wanted more details about what to expect during the dying phase. More specifically, 56% said they were only usually, sometimes, or never informed about the patient's condition within the last two days of life, and 26% were not satisfied with the emotional support from nurses and doctors. These outcomes depended on the type of institutional setting where the patient had died. Acute and residential care had the most unmet needs amongst family members, followed by ICUs and palliative care wards, while hospices had the fewest unmet care needs.

What stands out in end-of-life conversations is that carers often seem to receive more information about patients' prognoses than patients themselves. Sullivan et al. (2007) found that the possibility of death was discussed with 88.6% of family members, and only with 66.7% of lucid patients. As a result, the communication between caregiver and patient would have a considerable influence on decision making at the end of life. A survey conducted by Palliative Care Australia (2013), however, suggested that 51% of patients did not discuss their wishes with their carers. In their press release, the organisation's CEO Dr Yvonne Luxford commented on these findings:

> Unfortunately the survey reveals Australians simply aren't having conversations about death and dying and are therefore flying blind when it comes to understanding the end of life wishes of their loved ones. ... In the same way we prepare a will, or let our families know if we want to be buried or cremated, we need to be telling our loved ones where we want to spend our final weeks and how we want to be cared for at the time. ... It also means that those left behind are not faced with the daunting prospect of making uninformed decisions on a person's behalf. (Palliative Care Australia, 2013, pp. 1-2)

This indicates how essential discussions at the end of life are, especially between patients and carers. However, communication is not a one-way street where only the patients share their preferences. Instead, the views of family carers also play a considerable role in the decision-making process.

2.6.3 Importance of Acknowledging the Carers' Views

In regard to treatment choices, the opinions of family members were shown to be second-most-important to cancer patients after those of the physicians (Stiggelbout et al., 2007). Large-scale reviews by Gomes and Higginson (2006) and Grande et al. (1998) found that the availability of informal caregivers increased the odds of dying at home. This is not surprising as family members often provide the majority of physical and emotional support to the dying patient (Dudgeon & Kristjanson, 1995). In order to stay at home, informal carers need to be, firstly, available (Barclay & Arthur, 2008; Brown & Colton, 2001; Grande et al., 1998; Stajduhar, Allan, Cohen, & Heyland, 2008), secondly, willing (Cantwell et al., 2000; Karlsen & Addington-Hall, 1998; Munday et al., 2009; Wheatley & Baker, 2007) and thirdly, able to provide the necessary support for the patient (Thomas, 2005).

The perspectives of these caregivers are likely to influence the patient's preferred and actual place of death. In a review of 18 international qualitative studies, Woodman et al. (2015) emphasised that even though family caregivers are crucial in facilitating end-of-life care, especially at home, little is known about their views on this topic. They found that

family caregivers often wanted to support the patient at home, but sometimes felt obliged to do so. Carers reported being emotionally and physically burdened by the task, which then often caused end-of-life admissions. Family caregivers indicated that their preference for home care had not changed, but instead, they felt unable to cope at home. In contrast, Stajduhar and Davies (2005) interviewed currently active and bereaved caregivers about their decision to provide end-of-life care at home and some of them felt that they did not always have a choice in this matter. The authors concluded that the emphasis on the patient and their end-of-life preferences might have caused the perspective of the carers to be neglected. Many active carers only focussed on the patient's needs and concealed how they truly felt in order to protect the patient. Interestingly, those who were able to negotiate decisions with the patient seemed to cope better and were more satisfied with their choices because they felt that they had a say in the decision-making process.

The core aspects of palliative care aim to focus on supporting patients *and* their families (World Health Organization, 2014). Even though informal carers play a central part in the provision of end-of-life support, their role and views have been largely overlooked (Kirby, Broom, Good, Wootton, & Adams, 2014; Kovacs et al., 2006). Following interviews with 20 palliative care specialists, Kirby et al. (2014) summarised the situation as follows: "Despite the theoretical importance of family and the allure of inclusive models of decision-making within medicine and palliative care, there remains considerable uncertainty about how (and whether) family members' views should be incorporated into clinical decisions" (p. 324). Similarly, after analysing interviews, field notes and reflective journals of 18 bereaved family carers, Topf, Robinson, and Bottorff (2013) concluded that discussions about place of death are an important component of end-of-life care and that the focus must be extended from patients to family members who provide the care on which most home deaths rest.

2.7 Chapter Summary

This chapter provided a brief overview of the historical changes in end-of-life care and place of death. It was discussed how medical advances have altered when, how and where we die. With increased life expectancy, more chronic illnesses and an overall ageing population, death can now in many cases be anticipated and consequently planned for. This chapter emphasised the importance of decision making regarding place of care and place of death. It was argued that patients' dying environment influences their experience of death in a similar way as the living environment influences their quality of life. Studies in this field suggest most people want to spend their last days at home as this setting represents family, love, identity, autonomy and familiarity. However, end-of-life care is nowadays more likely to occur in institutions such as hospitals or hospices rather than at home. It was discussed how each care setting is associated with its own unique advantages and disadvantages. In order to stay at home, it is essential that informal caregivers are available, willing and able to support the dying patient. This task can be connected with considerable challenges but also with rewards. Regardless of the current place of care, relocating terminally ill patients from one setting to another can be a stressful and burdensome experience. In this regard, open communication is an important factor when making location choices but discussions about death and dying can be challenging for patients, carers and even for medical staff. Patients tend to receive less information about their illness than carers do, and both are sometimes reluctant to discuss their wishes with one another. This chapter highlighted the importance of communication at the end of life and emphasised the role of informal caregivers in the decision making. Yet, carers' views and needs are not always clearly recognised in clinical reality. Given the implications of location choices for patients and their families, it is essential to ask which factors influence the decision making. This question can be approached from a theory- and a data-driven point of view. Both perspectives will now be explored.

3

Theory-Driven Approach to Decision Making

CHAPTER THREE

A theory can be defined as an "organized set of concepts that explains a phenomenon" (Gerrig, Zimbardo, Campbell, Cumming, & Wilkes, 2011, p. G15). In this case, the phenomenon of interest is the preference for a certain place of care and place of death. This chapter will explore which theoretical concepts can be used to explain these preferences in terminally ill patients and their informal caregivers. There is currently no overarching theory that focuses on this specific end-of-life decision. However, there are two ways of getting closer to an answer. Firstly, one can look for more general models of decision making and examine whether their suggestions are applicable to the phenomenon of interest. Secondly, one can draw from empirical data and explore what potential concepts have been proposed in previous end-of-life studies.

This chapter will focus on the first approach and examine decision making from a theoretical point of view. It will outline some of the most widely recognised decision-making and information-processing theories, and consider their applicability to place of care and place of death preferences. Specifically, this chapter will explore Savage's Subjective Expected Utility Theory (1954), Prospect Theory by Kahneman and Tversky (1979), Ajzen's Theory of Planned Behaviour (1985), and the Two-System View of Zajonc (1980), Kahneman (2003), and others. These theoretical frameworks propose factors that influence perception, choices and subsequent behaviour, and hence may also apply to decision making concerning place of care and place of death.

3.1 Decision Making from a Theoretical Point of View

The word *decision* comes from the Latin term *decidere*, which means to determine. The Oxford Dictionary defines a decision as "a conclusion or resolution reached after consideration" (2010, p. 453). On a theoretical level, decision making is therefore regarded as the cognitive process of selecting or rejecting possible options and choosing among

alternatives (Gerrig et al., 2011, p. 306). It can be seen as a problem-solving activity, which is terminated by a solution or clear outcome. According to Hatamura (2006), this process means setting the probability of one option to 1 (100%) and the others to 0 (0%) (see Figure 3.1, left). Situations when an individual faces multiple options from which one is chosen, such as where to be cared for at the end of life, are called single selection (see Figure 3.1, right).

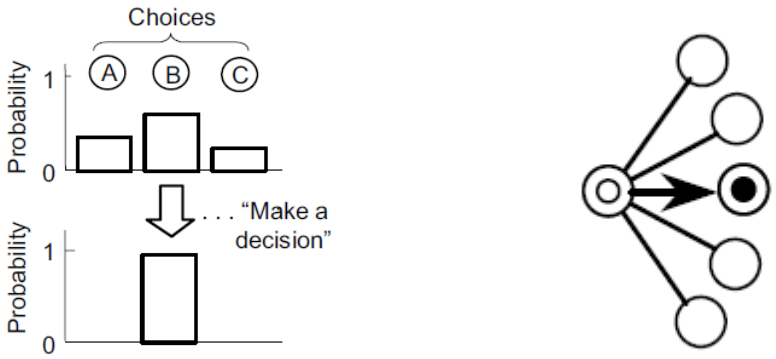

Figure 3.1. Decisions illustrated as a change of probability (left) and as a single selection (right) (Hatamura, 2006, p. 2). Image ©2006 Springer. Reprinted with permission.

What appears to be a relatively simple process of identifying and choosing among alternatives is in fact based on a variety of factors within and outside of the individual. In the decision-making literature, there is a clear distinction between how people *should* make choices (normative theories) and how they actually *do* make choices (descriptive theories) (Beresford & Sloper, 2008; Treadwell & Lenert, 1999).

3.2 Normative Decision-Making Theories

Most normative theories originate from the field of economics. They identify principles that decision makers should use to logically analyse all available options and consequently achieve the highest possible gain. One of the most well-known examples of this line of thinking is the Subjective Expected Utility Theory developed by Savage (1954). Based on the work of Von Neumann and Morgenstern (1947), Savage's theory suggests that a rational

agent should attempt to maximise his reward by choosing the action with the highest expected utility. The assessment of this utility should be based on the summed products of the subjective value of each outcome and the expected probability of its occurrence. The resulting theorem was mathematically summarised as follows:

$$SEU_j = \sum U_{ij} \cdot P_{ij}$$

SEU_j: subjective expected utility of action j
U_{ij}: subjective value or desirability of outcome i of action j
P_{ij}: perceived probability of outcome i of action j

Versions of this theory have been widely applied, discussed and extended in the field of mathematical and financial economics (Ellsberg, 1961; Fishburn, 1981; Friedman & Savage, 1948; Schoemaker, 1982; Skiadas, 1997). They were also considered in medical sciences and psychology, for example, in regard to decisions about health-protective behaviours (Weinstein, 1993), family planning (Davidson & Beach, 1981), smoking (Brandon & Baker, 1991) and cancer screenings (McDowell, 2011). As this theory has not specifically been applied to choices regarding place of care and place of death, I will construct an example to illustrate its possible use. Let us assume that a particular patient is experiencing troublesome symptoms and is faced with the decision to either stay at home for end-of-life care or go to a palliative care ward in a hospital. According to the theory, this patient would make his decision based on how desirable certain outcomes of his choice are and how likely it is that these will occur. For instance, it might be very important for him to lessen his burdensome symptoms and more probable to achieve this in a hospital rather than at home. In this case, he should choose hospital care as this would offer the highest subjective expected utility. However, these simple calculations become rather complex if additional outcomes are considered. Our patient might also value staying at home very highly and find the lack of privacy in hospitals especially undesirable, which would then weigh considerably on the decision-making process. According to Savage (1954) our patient should add these aspects to his considerations and choose the action that offers the highest expected utility.

Contributions and Limitations of the Subjective Expected Utility Theory. This precise, analytical theory is based on carefully controlled laboratory studies and mathematical gambling experiments (Hastie, 2001). This makes its application to non-numerical scenarios and real-world decisions somewhat challenging. The concept of optimal choices is based on the assumption of a rational decision maker who has complete access to and control over all relevant information (Edwards, 1954; Evans, 1993). However, Grunet (1982) criticised that people do not consciously engage in this form of cognitive algebra by multiplying and adding attribute evaluations in order to arrive at an optimal judgment. In real life, the overall problem, the available options and the decisional context are often ambiguous and unstable. Savage himself cautioned that for this reason the theory was mainly intended for "small worlds" (Savage, 1954, p. 82), which are defined as relatively simple situations where possible consequences, values and probabilities are known or at least imaginable. Outside of these situations and in more complex scenarios, the usefulness of the theory is questionable. Especially at the end of life, choices are made with limited information and understanding by sometimes emotionally loaded and even irrational beings. Human decision makers do not work like economic calculators and hence, a less mechanistic approach is needed. Dillon (1998) therefore suggested to "humanise" normative theories by incorporating the limitations of actual human behaviour into more descriptive theories (p. 99).

3.3 Descriptive Decision-Making Theories

Descriptive decision-making models seek to explain how decisions are made in real life rather than how they should be made in theory under ideal circumstances. Two of the best established descriptive approaches to decision making are the Prospect Theory developed by Kahneman and Tversky (1979) and the Theory of Planned Behaviour by Ajzen (1985). Much like the Subjective Expected Utility model, these theories focus on the cognitive components

of decision making and the expected outcomes of an action. However, they also provide deeper insights into what might influence choices from a theoretical perspective.

3.3.1 Prospect Theory

Similar to the Subjective Expected Utility Theory, Prospect Theory was originally developed in the field of economics. Kahneman and Tversky (1979) suggested a mathematical model for decision making to explain under which circumstances people tend to be risk-seeking and risk-averse. The theory is based on three central concepts: reference dependence, diminishing sensitivity and loss aversion. Firstly, Kahneman and Tversky (1979) argued that people make choices based on the value of anticipated outcomes relative to their current point of reference. As illustrated in Figure 3.2, the value of a prospect follows an S-shaped curve, and everything on the right side of a reference point is seen as a gain, whereas everything on the left equals a loss. Interestingly, the theory suggests that people can differ in their points of reference and consequently arrive at different decisions. For example, what is cheap for one person may be expensive for another. Secondly, Kahneman and Tversky (1979) proposed that the value of gains and losses is perceived depending on their distance to the reference point. For instance, the difference between paying $100 or $200 for something is seen as greater than the difference between paying $1100 or $1200. This diminishing sensitivity suggests that the further away something is from our current reference point, the less sensitive we are to change. Finally, Kahneman and Tversky (1979) suggested that "losses loom larger than gains" (p. 279), which means that decision makers will try to avoid losses more than they will try to achieve gains. This is illustrated in Figure 3.2 where the curve on the side of losses is steeper than on the side of gains.

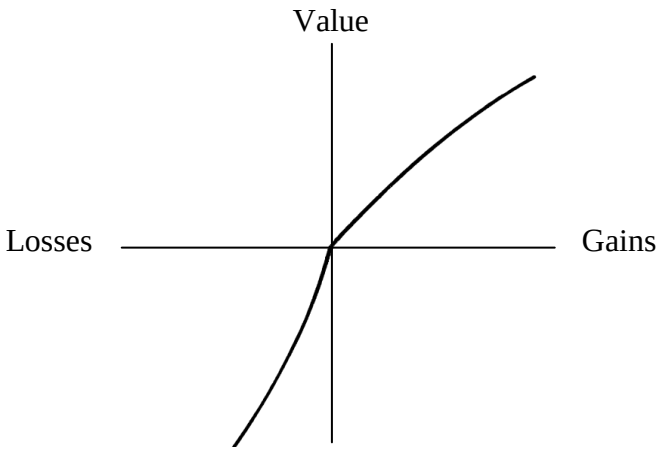

Figure 3.2. Hypothetical value function of gains and losses proposed by Kahneman and Tversky (1979, p. 279); reprinted with permission by publisher John Wiley & Sons, Inc.

Loss aversion explains, for example, why the aggravation of losing $100 is greater than the pleasure of winning the same amount, and it also highlights the importance of how information is presented. If a problem is framed as an opportunity to gain something, the theory suggests that people will be risk-seeking, but if the outcome is presented as a potential loss, people will be risk-adverse. This was, for example, empirically supported in a study by McNeil, Pauker, Sox, and Tversky (1982) who explored the effect of loss aversion and framing on treatment decisions. They asked outpatients, radiologists and students to choose either surgery or radiation therapy to treat a hypothetical case of lung cancer. Surgery had a 10% chance of peri-operative death but better long-term survival rates, whereas radiation had no risk of dying during the treatment but lower chances of surviving the next five years. The experimental conditions differed in the way the statistical information was presented, either as a gain or a loss. In agreement with the theory, being told that 90% of patients live through the surgery made this treatment more acceptable to respondents than the prospect that 10% die during the procedure. Even though the facts were identical, the way the information was framed influenced participants' decisions. This can be further applied to location choices. Depending on a person's reference point and the way information is presented, moving from

home to institutional care might be seen as a gain of support and symptom control or as a loss of independence, familiarity and freedom. Since the need to avoid losses is greater than the desire to achieve gains, negative aspects of treatment settings or changes in place of care are likely to be magnified and weigh more on the decision-making process than potential positive outcomes.

In a discussion paper, Weinfurt (2007) applied Prospect Theory to end-of-life decision making. He argued that due to different reference points and diminishing sensitivity, some patients seek expensive or risky treatments in the hope of achieving benefits that to healthy individuals may not even seem worthwhile. To illustrate, gaining six months of life would be valued considerably more by a terminally ill patient with a life expectancy of less than one year compared to a relatively healthy individual with a life expectancy of over ten years (see Figure 3.3).

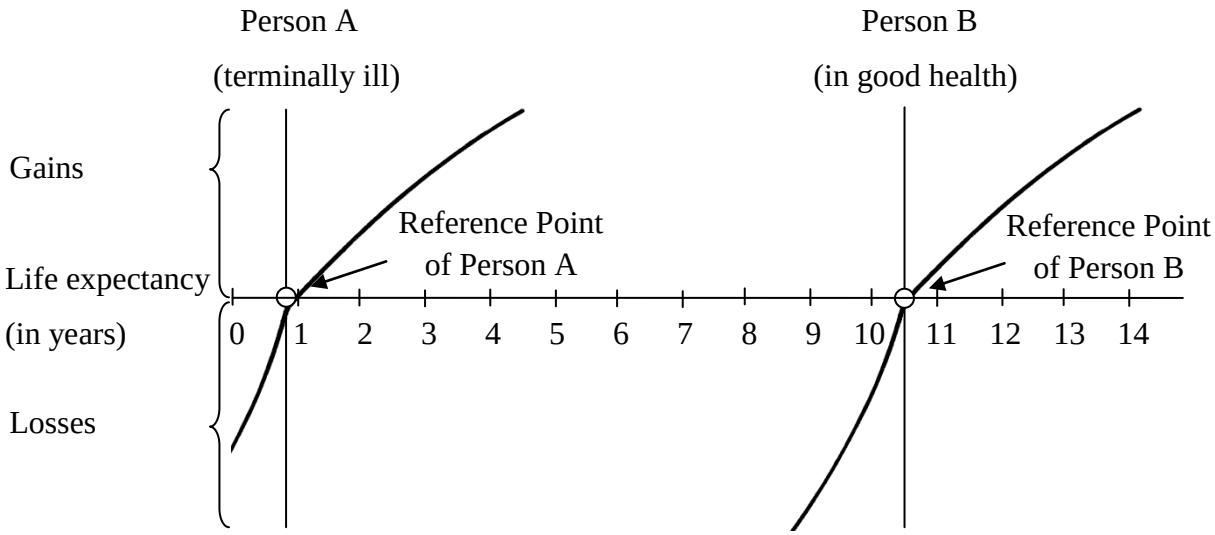

Figure 3.3. Value function of gains and losses according to the reference point of a terminally ill patient and a healthy, older person; based on Winter and Parker (2007), and Weinfurt (2007).

While Weinfurt's (2007) considerations were solely theoretical in nature, Winter and Parker (2007) provided empirical evidence for the use of Prospect Theory in end-of-life decision making. The authors argued that to healthy individuals dying appears to be a distant prospect and hence they might not value small changes in potential health outcomes as much as individuals who are unwell. To illustrate this, they asked 304 Americans over the age of 60 years about their current state of health and their preferences for life-prolonging treatment in different end-of-life scenarios. For example: "If you had had a stroke and had no chance of recovery, how much would you want to receive (antibiotics/ gall bladder surgery/ CPR/ tube feeding)?" (p. 1705). Winter and Parker (2007) found that healthy participants indeed expressed consistently weaker preferences for all life-prolonging treatments than less healthy respondents in the various scenarios. It was argued that for the healthy group, the difference between death and life in poor health was less noticeable as these prospects were far away from their current point of reference. In contrast, respondents with poor health saw a considerable difference between being alive but impaired and being dead, and as a consequence, they were more accepting of life-sustaining treatments. It can therefore be inferred that the closer people get to dying the more sensitive they become to subtle aspects of end-of-life choices.

This highlights a common problem in palliative care research, which is that many studies rely on healthy, older participants or non-terminal samples instead of asking terminally ill patients directly. Similarly, the reference points of patients and carers may also differ in some cases, which can result in different views and preferences. Kahneman and Tversky (1979) further noted in their Prospect Theory that a person's reference point can shift when the situation changes and new information is added. This could explain why location preferences often change as the illness progresses (Barclay & Arthur, 2008; Gerrard et al., 2011; Higginson & Sen-Gupta, 2000; Townsend et al., 1990).

Contributions and Limitations of Prospect Theory. Prospect Theory offers a flexible, descriptive model of choice, which explains why people with access to the same information sometimes arrive at entirely different decisions. The theory brought Kahneman the Nobel Memorial Prize in Economic Sciences in 2002 and has been widely applied in experimental, mathematical and finance-related contexts. It has been used, for example, to predict the stock and betting market, finance and consumer decisions, as well as health-related behaviours (Ajzen, 2011; Barberis, 2013; Jacob & Ehret, 2006; Levy, 2003). However, its relevance for end-of-life decision making has mainly been addressed with regard to life-sustaining treatment choices (Weinfurt, 2007; Winter & Parker, 2007). In a review paper on the application of Prospect Theory in economics over the past 30 years, Barberis (2013) pointed out that it can be challenging to measure an individual's reference point. It is likely that this is particularly true when gains and losses are not quantifiable in units such as dollars or years of survival, but include abstract, normative and idealistic concepts such as the meaning of home for one's identity, or the notion of control, independence and dignity in care settings. Furthermore, in a discussion paper, Nwogugu (2006) criticized Prospect Theory as being too rigid for complex human decision making, which is influenced by dynamic and multi-dimensional factors such as emotions, mood, ethical considerations, perceived constraints, personal aspirations, social pressure, cognitive differences and many more. Based on this, Nwogugu (2006) concluded that decision making cannot be defined accurately by static quantitative models and hence, more realistic theories are needed. We will therefore now move from mathematical to more psychological models of choice.

3.3.2 The Theory of Planned Behaviour

The Theory of Planned Behaviour by Ajzen (1985) suggests that human actions are goal-directed and governed by intentions, which may or may not result in behavioural outcomes. In the context of the current study, the wish to be cared for in a certain setting can be seen as an intention that may result in specific actions. To give examples of these behavioural outcomes: a patient could discuss his preferences for a place of care with his family or doctor, he could incorporate his decision into an advanced care plan, and make arrangements like organising home care support or contacting palliative care wards. According to the theory, these behaviours and intentions are shaped by a person's attitudes, subjective norms and perceived control (see Figure 3.4).

Firstly, attitudes are defined as "a learned disposition to respond in a consistently favorable or unfavorable manner with respect to a given object" (Fishbein & Ajzen, 1975, p. 6). They are influenced by subjective behavioural beliefs such as anticipated positive or negative aspects of a given action and its consequences. Secondly, subjective norms refer to the "perceived social pressure to perform or not to perform the behavior" (Ajzen, 1991, p. 188). This re-emphasises the importance of others in the decision-making process as subjective norms are shaped by a person's concerns about social approval and their beliefs about the expectations of others. Finally, similar to the concept of Subjective Expected Utility in Savage's theory (1954), perceived control concerns the extent to which a person believes that they are able to perform an intended action and have control over the outcome. This strongly depends on the actual behavioural control, which describes how realistic someone's assessment of the situation and their abilities is. In this regard, Ajzen (1985) specifically pointed out that a person's level of control over the situation can be considerably limited as intentions strongly depend on the availability, decisions and actions of others.

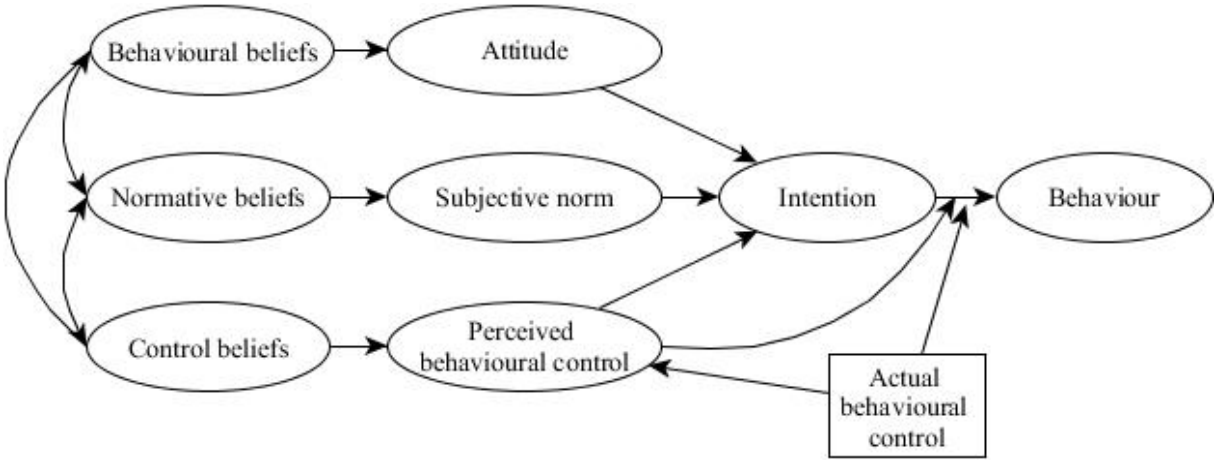

Figure 3.4. Factors that influence intentions and behaviour according to the Theory of Planned Behaviour based on Ajzen (2006). ©2006 Icek Ajzen. Reprinted with permission.

Coming from a psychological background, the theory has been applied to various health-related behaviours. Studies in this area range from the use of alcohol, tobacco and illicit drugs to health-screening, sexual and risk-related behaviours (Godin & Kok, 1996; McEachan, Conner, Taylor, & Lawton, 2011). Regarding end-of-life choices, Murray, Wilson, Kryworuchko, Stacey, and O'Connor (2009) used the Theory of Planned Behaviour as a conceptual framework to guide semi-structured interviews with 22 nurses about helping patients in their place of care decision making. They found that respondents' attitudes, norms and perceived control influenced their intentions to provide support in this regard. While nurses generally had positive attitudes toward supporting patients' decision making, some felt that they lacked the skills, time and resources necessary for the task. Normative pressure and potential conflicts with team members, physicians and employers were further barriers in the process.

Based on these findings it is reasonable to assume that the concepts of the Theory of Planned Behaviour can also be applied to patients' and carers' decision making for place of care and place of death. In this regard, beliefs about the characteristics of treatment settings and the consequences of choosing one place over another are likely to result in specific

attitudes towards these settings. A person's history and past experiences might, therefore, be essential aspects of the decision-making process. To illustrate the role of attitudes, Schoenberg and Coward (1997) interviewed 98 community-dwelling women over the age of 65 years about the possibility of moving to a nursing home. While their study did not explicitly address the Theory of Planned Behaviour, their results strongly relate to the central constructs of Ajzen's model (1985). Schoenberg and Coward (1997) found that over half of the respondents had negative attitudes towards nursing home care, however, normative concerns about being a burden to others also influenced their views. It can be inferred that patients might feel social pressure to choose a place of care other than home if they think that their family would prefer a more formal care setting. Furthermore, the level of control over the decision is likely to influence patients' choices. In a study of 502 newly admitted nursing home residents, Reinardy (1992) found that 59% did not make the decision to move to the facility themselves and 39% said that they had not wanted to move at all. The perceived lack of control was associated with more difficult adjustment to the new care setting. This again highlights the role of significant others in the decision-making process.

Contributions and Limitations of the Theory of Planned Behaviour. The Theory of Planned Behaviour is one of the most widely-applied decision-making models and provides a useful descriptive approach to understanding certain behaviours. It has, however, been criticised by some researchers. For example, Sniehotta, Presseau, and Araújo-Soares (2014) pointed out that experimental tests of the theory are surprisingly rare and those that have been conducted do not always find supporting evidence (see, for example, Hardeman et al., 2002; Sniehotta, 2009). The theory also simplifies multi-dimensional factors and interactions in a mechanical and static way, which appear to be more complex in real-life decision making. In clinical practice, end-of-life choices are often made in emotionally challenging and unpredictable situations. Contextual aspects, as well as individual differences such as personality traits and personal experiences, are likely to influence the decisional process more

than the model acknowledges. Coming from a non-medical and largely conceptual background, the Theory of Planned Behaviour has also been criticised for its assumption that intention forming is a mainly cognitive and rational process (Sniehotta et al., 2014). In particular, the role of emotions is considerably neglected by the model (Conner, Godin, Sheeran, & Germain, 2013; Sniehotta et al., 2014) - a gap that has been addressed in the Two-System View.

3.4 The Two-System View

The Two-System View is not a decision-making theory per se but rather a framework of how information is processed and this, in turn, has implications for decision making. This line of thinking is therefore also known as Dual-Processing Theory. While most rational models of choice mainly focused on the role of cognition, Zajonc (1980) suggested that information can also be processed through an emotional system and that the affective quality of a stimulus could even cause responses outside of conscious awareness (see Figure 3.5). An example of this is the well-known *mere exposure effect*. According to the theory, repeated exposure to a stimulus increases recognition, familiarity, and even liking of that stimulus. This can be applied to the process of forming preferences for place of care and place of death. It is reasonable that being exposed to a certain treatment location influences how familiar this place is. In this regard, patients would have had the most exposure to their own home, which could explain why this setting often represents a strong sense of familiarity and intense emotional bonds (see section 2.5.3; also Bowling, 1983; Funk et al., 2010; Gott et al., 2004). Interestingly, Zajonc (1980) argued that emotional responses can precede and even influence cognitive judgements.

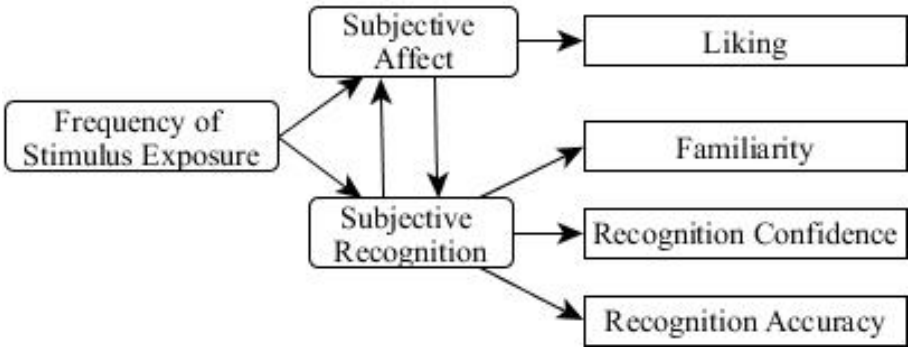

Figure 3.5. Model of exposure, affect and recognition by Moreland and Zajonc (1979, p. 1086); no permission required according to APA Copyright Information (2017).

The idea that information is not only processed cognitively but also emotionally has since been used in various theories of reasoning and decision making. This led to a broad range of comparable terms for the two proposed systems, such as rational versus experiential (Epstein, Lipson, Holstein, & Huh, 1992), rule-based versus associative (Sloman, 1996), deliberative versus affective (Loewenstein & O'Donoghue, 2004), and System 2 versus System 1 (Evans, 2003; Kahneman, 2003; Stanovich & West, 2000). Going beyond the mere distinction, Kahneman (2003) provided further insights into the content and processes of these theoretical structures. As shown in Figure 3.6, the reasoning System 2 is believed to operate in a slow, serial and controlled manner. This is understandable as rational decision making in its most detailed form requires a person to first define the problem, identify decision criteria, allocate weights to these criteria, develop alternatives of possible solutions, evaluate these alternatives, and then select the best one (Parker, 1995). Kahneman (2003) suggested that this process is effortful and governed by rules. For example, a terminally ill patient may consider the pros and cons of different places of care and try to find solutions by deliberation and rational elimination of unrealistic options. However, according to the Two-System View, this is just one aspect of the decision-making process. The other relevant component is intuition.

Similar to perception, intuition is believed to be automatic, fast and effortless. It is more associative, emotionally charged, and governed by habit. Intuitive responses are therefore difficult to control or modify. During a talk at the Harvard Business school, Kahneman even argued that the intuitive System 1 is the more influential one of the two, often guiding the reasoning of System 2 (Walsh, 2014). In its most rudimentary form, this intuitive component has an important survival function as fast, emotional responses motivate approach or avoidance (Izard, 1984; Zajonc, 1980). The influence of the affective system is particularly strong when facts are unavailable, or choices are difficult in nature, which is often the case at the end of life. For instance, a patient might have an intuitive aversion to hospitals that is more based on an underlying emotional, rather than a rational process.

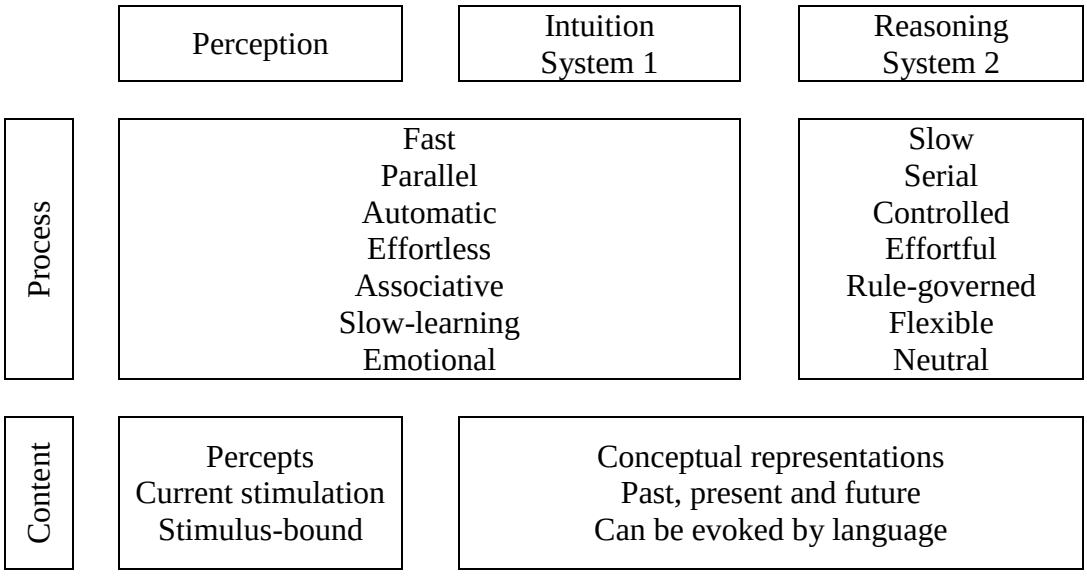

Figure 3.6. Process and content of the two systems proposed by Kahneman (2003, p. 698); no permission required according to APA Copyright Information (2017).

The Two-System View has been applied to marketing and consumer behaviour (Samson & Voyer, 2012), learning and memory tasks (Lewis, Sullivan, & Michalson, 1984; Morewedge & Kahneman, 2010; Smith & DeCoster, 2000), social cognition (Evans, 2008) and moral judgements (Haidt, 2001). In the domain of medical science, the theory was used

to explain diagnostic reasoning (Durning et al., 2015) and health risk behaviours (Gibbons, Houlihan, & Gerrard, 2009), as well as end-of-life choices. Gramling et al. (2013) recorded 71 palliative care discussions between clinicians, seriously ill patients and families about the patient's prognosis. They found that prognostic information was shared in ways that engaged both cognition and emotion. Similarly, Hussain, Flemming, Murtagh, and Johnson (2015) reviewed 12 studies on decision making about renal dialysis and found that choices to commence or withdraw treatment were based on careful deliberation as well as respondents' gut instinct. Interestingly, there is further neuro-physiological evidence for the Two-System View, which suggests that different parts of the brain may be responsible for the two kinds of information processing. For example, a strong involvement of the amygdala has been found in emotion-based, impulsive decisions, whereas the role of the prefrontal cortex has been highlighted especially in reflective and planned choices (Bechara, 2005; De Martino, Kumaran, Seymour, & Dolan, 2006; Gupta, Koscik, Bechara, & Tranel, 2011; Starcke & Brand, 2012). It is worth mentioning that, while emotion and cognition are considered separate systems, they also share neural pathways, brain structures and neurotransmitters, and are hence strongly interconnected (Bechara, 2005; Izard, 1984; Starcke & Brand, 2012).

Contributions and Limitations of the Two-System View. Being one of the few conceptual models to acknowledge the role of intuition and emotion in decision making, the Two-System View provides an important extension of previous cognitive models. However, Keren and Schul (2009) argued that many Dual-Processing Theories neglect to define what a mental system actually is, and given the range of suggested terms in this field of research, it is questionable that they all mean the same. Hence, where previous theoretical models might have been too specific to be able to include all aspects of decision making, this theory appears in some ways too broad. Furthermore, Kahneman (2003) argued that intuitive thinking is sometimes erroneous and associated with poor performance because it is less under cognitive control. Yet, it can also be powerful and accurate when the decision maker is

highly skilled. An experienced nurse, for example, might detect subtle signs of heart failure faster by trusting her intuition rather than engaging in a detailed case analysis. However, it is unclear what happens if the outcome cannot be plainly categorised as right or wrong. While this theoretical approach contributes greatly to the understanding why people deviate from rational decision making, it also remains uncertain how distinct the proposed two systems actually are, given their shared neurological basis.

Following on from this, it appears that most of the existing decision-making theories are in many ways incomplete and fail to fully capture the intricacies of human choices. Therefore, to find out how decisions concerning place of care and place of death are made in clinical reality, a more data- rather than theory-driven approach might be needed.

3.5 Chapter Summary

This chapter examined some of the most widely used decision-making and information-processing theories and considered their applicability to place of care and place of death preferences. Normative models like the Subjective Expected Utility Theory highlighted the relationship between the subjective value of an outcome and the perceived probability of its occurrence (Savage, 1954). Real-life decision making, however, appears to be much more complex than a simple value times probability calculation. Especially at the end of life, many outcomes are out of the control of the decision maker and simply cannot be predicted. Instead, choices are often made with limited information and understanding. Prospect Theory expanded this static approach by acknowledging the role of individual reference points, diminishing sensitivity and loss aversion in decision making (Kahneman & Tversky, 1979). The theory particularly emphasised the challenges of long-range predictions for distant events and offered an explanation why terminally ill patients may differ in their preferences from carers or healthy individuals in general. Moving from mathematical to more psychological models of choice, the Theory of Planned Behaviour highlighted the role of personal attitudes,

social norms and perceived control in the decision-making process. Ajzen (1985) further suggested that the views of significant others might considerably influence people's choices. Yet overall, these theories appear to be rather general and simplistic compared to the more intricate realities of clinical practice and day-to-day experiences. They also seem to neglect the role of emotions in the decision-making process, which is particularly prominent at the end of life. The Two-System View went beyond these cognitive models of choice and acknowledged that decisions can be made based on reasoning as well as intuition, which occurs more automatically and is often emotionally loaded (Kahneman, 2003; Zajonc, 1980).

While the theoretical perspectives examined offer useful insights into decision making, in clinical practice choices appear to be much more multifaceted than most models can grasp. Theories are often constructed through a continuous process of making empirical observations and modifying their assumptions to a broader theoretical framework. Hence, to identify which concepts explain preferences for place of care and place of death, both theory- and data-driven approaches need to be used, as the two are, in fact, inseparable. The next chapter will, therefore, focus on empirical end-of-life studies to identify how choices are made in clinical reality.

4

Data-Driven Approach to Decision Making

CHAPTER FOUR

The previous chapter looked at decision making from a theoretical perspective and explored the applicability of this approach to choices concerning place of care and place of death. The current chapter will now examine decision making from a more data-driven perspective to understand what influences location preferences of patients and carers. The previous theoretical considerations highlighted that decisions are often based on a variety of factors within and outside of the individual. In clinical reality, factors within the individual may concern aspects related to the illness and the person as a whole. In contrast, factors outside the individual may include a person's immediate social relationships and the broader network that surrounds them. This chapter will therefore examine the influence of illness-related, personal, interpersonal and structural factors on preferences regarding place of care and place of death. It will further address how expressing these preferences relates to the chances of actually achieving them, and what role discussions and agreement between patients and carers play in this process. This chapter will conclude with a summary of methodological considerations that will guide the empirical research of this thesis, in light of the end-of-life literature reviewed.

4.1 Illness-related Factors

When a person is faced with a terminal illness, factors related to that illness influence most, if not all, aspects of their life. This includes their decision making. Many terminal diseases are associated with specific co-morbidities, symptom patterns and illness trajectories that vary depending on the diagnosis and the stage of the disease (Murray, Kendall, Boyd, & Sheikh, 2005). Particularly the number and types of symptoms as well as the length of the illness need to be considered as influencing factors on end-of-life preferences.

4.1.1 Number and Type of Symptoms

Symptom management is one of the main reasons for hospital admissions in end-of-life care. Barbera, Taylor, and Dudgeon (2010) reviewed Canadian healthcare data of 91,561 cancer patients over three years and found that 83.8% had gone to the emergency room in their last six months of life. All admissions were related to the management of symptoms such as pain, pneumonia, nausea or constipation. Similarly, Hinton (1994) followed 77 palliative care patients in a prospective study over two years. According to medical staff, most admissions were related to symptom control, overburdened carers or sudden deteriorations. Specifically, changes in place of care were often associated with physical problems like pain and weakness but also with psychological issues like anxiety, depression and confusion. It is intuitively understandable that the number and type of symptoms would influence not only people's actual place of care and place of death, but also their preferences.

In a qualitative study of 41 terminally ill patients and 18 informal carers, Thomas et al. (2004) reported that patients' concerns about the management of culturally stigmatised symptoms, such as incontinence, had a particularly strong bearing on them considering institutional care. Furthermore, for carers, encountering frightening symptoms in the patient like extreme pain or mental confusion could override their preference for a home death. However, there is a lack of quantitative research in this area and the few studies that have addressed the association between symptoms and preferences did not include terminal samples or clearly differentiated between patients and carers. For example, in a questionnaire study with 238 older adults from Japan, Ohmachi et al. (2015) found that good self-rated health was associated with a preference for home death. Similarly, in the previously mentioned population health survey of 2,652 South Australians, Foreman et al. (2006) found that respondents with poor physical health were less likely to express a wish to die at home. However, in both studies, participants were not necessarily close to the end of their lives. Foreman et al. (2006) themselves noted that people with ill health might understand the

realities and challenges of home care better than those who are well, which consequently can lead to increased preferences for inpatient care. It, therefore, can be argued that these long-range predictions of healthy participants are not transferable to a dying population. To illustrate this, Slevin et al. (1990) presented different groups of respondents with end-of-life scenarios and asked them to assess their personal cost-benefit of chemotherapy. In these scenarios, only 10% of the healthy participants and none of the surveyed physicians would have accepted intense chemotherapy for a gain of three more months to live. Interestingly, 42% of cancer patients would have done so for even one extra month. Loewenstein (2005) concluded that "people seem to have a cavalier attitude toward their own demise, until they actually have to face it" (p. 102).

This raises the question why it is so challenging to predict what we will want or how we will feel about something in the future. As discussed in the previous chapter, Kahneman and Tversky (1979) suggested in their Prospect Theory that the further away something is from our reference point or current situation, the less sensitive we are to change. Hence, on a theoretical level, our assessments of a distant future are more prone to biases. Cognitive biases can be defined as "predictable errors in the ways that individuals interpret information and make decisions" (Kahneman & Renshon, 2009, p. 79). According to Wilson and Gilbert (2005), people base many of their choices on affective forecasts, which are predictions about their emotional reactions to future events. In this regard, we tend to overestimate the intensity and duration of these emotions and underestimate how quickly we will cope with the new situation (*impact bias*). Loewenstein (2005) added that people often struggle to disregard their current thoughts, feelings and preferences, and consequently project these onto themselves in the future (*intrapersonal projection bias*). Especially when patients are experiencing troublesome symptoms, it might be challenging for them to imagine that they will ever feel better and this can influence their choices for the future. In this regard, the length of the illness may also play an important role in the decision making.

4.1.2 Length of the Illness

Over the course of an illness, the circumstances that patients and their families are faced with change frequently. It is therefore not surprising that a number of studies have reported that people frequently change their mind about where they want to be cared for and die. For example, in the afore-mentioned prospective research by Hinton (1994), all 77 terminal cancer patients and their relatives initially wished to stay at home, yet, regular assessments of their preferences showed that respondents changed their views as the illness progressed. Hinton (1994) described that over time, first carers, and then patients reached a "realistic preference for inpatient care" (p. 209). The proportion of patient admissions, therefore, steadily increased as the period of care lengthened. Similarly, Townsend et al. (1990) examined data from a subsample of 59 terminally ill patients who had died during their study and found that the preference to stay at home dropped from 58% to 49% as death approached, while the acceptance of institutional care increased. As a consequence, changes in location preferences are frequently witnessed by healthcare professionals. For example, Munday et al. (2009) interviewed 17 general practitioners and 19 nurses who pointed out that preferences often evolved over time. The most widely reported change was a reversal of the preference to die at home. This was often due to the patient experiencing distressing symptoms or becoming concerned about their family. These findings were further supported by a case note review of 236 recorded deaths in a large London teaching hospital. Gerrard et al. (2011) reported that about one-third of admitted patients had changed their minds regarding their preferred place of care at least once during the audit cycle of two years. Specifically, the number of patients wishing to be cared for in hospital significantly increased over time, from 9% to 31%. It must be noted that the authors of this study assumed that the preference for place of care recorded prior to the patients' discharge would be a true reflection of their preferred place of death. While acknowledging that these are two separate questions, they argued that in hospitalised patients there is considerable overlap between the

two preferences. This stands in direct contrast to the distinction brought forth by Agar et al. (2008), as discussed in Chapter 2 (see section 2.6.1). Agar et al. (2008) advocated that preferences for place of care are not synonymous to preferences for place of death, and strongly criticised the approach of not clearly differentiating between the two terms. This re-emphasises the debate regarding the how preferences should be assessed, especially since they seem to change over time.

While the evidence to date indicates that preferences for home death decrease over the course of an illness, longer survival has often been associated with a higher chance of actually dying at home. This was, for instance, found in a review of 45 international studies by Grande et al. (1998) as well as a more recent review of 58 studies from 13 countries by Gomes and Higginson (2006). Grande et al. (1998) argued that longer survival could indicate that patients had more time to develop relationships with care providers and adjust to the disease. This was believed to make access to home care more likely. However, Grande et al. (1998) also highlighted that survival is not equivalent to the length of the terminal phase.

In summary, longer illnesses may provide more time to prepare for the end of life and the caregiving task, organise support and set up the home for care. There seems to be a threshold, however, regarding how long family members can manage to support their dying relative at home before all carer resources are depleted. As a consequence, this can cause preferences to change and result in increased admissions at the end of life.

4.2 Personal Factors

Beyond illness-related aspects, personal factors are also likely to influence location preferences of patients and carers. Many studies in this area have focussed on demographic factors and their connection to people's actual place of death. As discussed in the introduction, this information is easily accessible through chart reviews, death registries and service records (see section 1.1). The focus, however, needs to be extended to people's

preferences in order to find out whether respondents from different backgrounds also have different wishes and chances of achieving these. Beyond the demographic aspects, under-researched personal factors need to be considered in this regard, which particularly include the role of personality traits and experiences in end-of-life decision making. These will now be addressed.

4.2.1 Demographic Factors

A range of demographic aspects has been suggested to influence patients' location preferences. This was explored, for example, by Wilson, Cohen, Deliens, Hewitt, and Houttekier (2013) in a population-based telephone survey of 1203 Canadians. Home was often preferred by men and younger respondents. Hospices or palliative care facilities were chosen by women and those with post-secondary education. Hospitals were favoured by older people and those with less than a high school education. Not surprisingly, people who were widowed were more likely to prefer an institutional place of death over home. Comparable results have been found in the previously described South Australian survey by Foreman et al. (2006), who reported that respondents with a preference for hospice care often lived in metropolitan areas, were employed, and had higher levels of income. As certain demographic groups appear to differ in their preferred place of death, similar trends were suggested in regard to people's actual place of death. For example, in their review of 58 international studies, Gomes and Higginson (2006) found that favourable social conditions such as education, social class and income were associated with higher odds of dying at home. Furthermore, according to the review by Grande et al. (1998), women, older people, and those from lower occupational backgrounds were less likely to die at home, arguably because of the lack of caregiver support. These findings suggest that certain socio-demographic groups might be at a disadvantage when it comes to dying in their preferred place.

Going beyond these demographic aspects, the influence of other personal factors, such as personality, also needs to be considered when exploring location preferences.

4.2.2 Personality

Personality can be defined as the "dynamic and organized set of characteristics possessed by a person that uniquely influences his or her cognitions, motivations, and behaviors in various situations" (Ryckman, 2012, p. 4). McCrae and John (1992) postulated five main dimensions of personality: openness, conscientiousness, extraversion, agreeableness and neuroticism. In many phenomenological descriptions and qualitative discussions, personality has been considered as an underlying factor that influences how choices are made. For instance, based on her interviews with terminally ill patients, Elizabeth Kübler-Ross reported that "different patients react differently... depending on their personality makeup and the style and manner they used in their past life" (Kübler-Ross & Byock, 2014, p. 31). Beresford and Sloper (2008) reviewed psychological decision-making models for a qualitative panel study on choices of people with disabilities. They argued that personality traits are likely to affect how people perceive a situation, to what extent they seek information and justify their choices, how much they want to be involved in the decision-making process, and how much they want others to play a part. While personality could be a driving factor in how we make choices, Beresford and Sloper (2008) also noted that this is a highly under-researched question. In particular, the relationship between end-of-life choices and the personality of the decision maker has been neglected in previous studies.

Up to this point, there has mainly been anecdotal evidence and only a few studies have attempted to systematically examine and quantify this connection. In a survey of 266 elderly primary care patients, Chapman, Duberstein, Sörensen, and Lyness (2006) found that personality influenced how respondents assessed their current state of health. Specifically, higher neuroticism and lower extraversion were associated with worse perceived health.

Personality traits can also have a considerable effect on the experience of dying, which was suggested in a quantitative study of 211 patients with end-stage cancer by Chochinov et al. (2006, 2007) . They found that neuroticism was significantly associated with several sources of end-of-life distress including depression, poor quality of life, worries about the future, lack of concentration, and feelings of being a burden.

Personality does not only alter our perception of a situation but also how we react to it. In a study of 355 primary care patients over the age of 65 years, Sörensen, Duberstein, Chapman, Lyness, and Pinquart (2008) found that higher levels of neuroticism, openness and agreeableness were associated with greater awareness of care needs. Furthermore, higher openness was positively related to more gathering of information and less avoidance of future care planning. Surprisingly, this study found no significant association between respondents' personality traits and their actual decision making or concrete planning for future care needs, which were mainly driven by the level of medical burden that the older adults experienced. In contrast, a longitudinal study by Ha and Pai (2012) provided evidence for the influence of personality on healthcare planning behaviour. In a subsample of 3,838 older adults, they found that higher levels of conscientiousness and openness were associated with a greater likelihood of informally discussing end-of-life care plans. Moreover, higher levels of conscientiousness and agreeableness were connected with a greater likelihood of formal care planning.

In summary, personality is likely to be an important personal contributor to end-of-life decision making. However, no quantitative study has been identified that addressed this in regard to place of care or place of death preferences. This might be partly because of the perceived lack of influence that we have on these core traits. Costa and McCrae (1994) argued that personality is relatively stable over time, so one might raise the question: Why should we examine the influence of traits on end-of-life choices if personality is "set like plaster" (Costa & McCrae, 1994, p. 21)? In response, there are two main reasons why this

would be of value. Firstly, there is evidence that some aspects of personality can change over time and that major life events such as trauma, childbirth and the death of a loved one may contribute to this shift. In a longitudinal study of 14,718 Germans, Specht, Egloff, and Schmukle (2011) found complex changes of personality traits across the lifespan. Older participants showed lower extraversion, openness and higher agreeableness than younger adults. Interestingly, they also found that women decreased in their conscientiousness after the death of their spouse, whereas men became more conscientious. One reviewer called this the "dirty underpants effect" (p. 51). They explained that, according to traditional gender roles, the death of the wife might force the man to learn how to run a household and become more conscientious, whereas women are less likely to have this experience after losing their partner. Secondly, independent of the actual stability of personality, Block et al. (2007) argued that by being aware how these traits influence treatment choices we can at the very least facilitate more appropriate counselling to clients. The considerable lack of quantitative research in this area therefore needs to be addressed.

Beyond the demographic background and the personality of the decision maker, choices regarding place of care and place of death are likely to be further influenced by the experiences that people have made over the course of their lifetime.

4.2.3 Past Experiences

Experiences can be a source of information for future decision making. It is reasonable to assume that when faced with a variety of options, a decision maker might base their choices on previous positive or negative experiences. This can be applied to location preferences. Specifically, past experiences with different places of care are likely to shape people's attitudes about these care settings and ultimately their decisions. While this would align well with the Theory of Planned Behaviour (Ajzen, 1985), it was not explicitly acknowledged in this decision-making model (see section 3.3.2). However, some studies

have considered the potential relationship between experiences and location preferences at the end of life. In a retrospective case note review of 1,127 British hospice patients, Arnold, Finucane, Mullin, and Oxenham (2013) found that 80% of patients who had never been admitted to a hospice wanted to die at home. Yet, 79% of those with at least one hospice admission also preferred to die there. Furthermore, a systematic review of 18 qualitative studies on location preferences by Higginson and Sen-Gupta (2000) found that those with close experiences of death and dying had a stronger preference for hospice care than those without these experiences. Similarly, Webb and Tucker (2009) collected survey data from 1,035 psychology students, 44% of whom had lost a family member. They found that those participants whose relative passed away at home had significantly more positive opinions of home death than those whose relative died elsewhere. Finally, Gott, Small, Barnes, Payne, and Seamark (2008) interviewed 40 heart failure patients and noted that participants often referred to unpleasant memories of the institutional death of a family member to explain why they wanted to stay at home. Based on these findings, it appears that past experiences strongly affects decision making.

Potential reasons for this were suggested by Tang (2003), who interviewed 180 terminally ill patients about their preferences for place of death and found that several patients wanted to die in the same hospital where they had previously received their cancer treatment. In the interviews, participants explained that they had built trusting relationships with the staff and these experiences influenced their choices. Adding to this, Thomas et al. (2004) argued that the connection between experiences and place of death preferences is "simple and direct" (p. 2439). Following interviews with 41 cancer patients and 18 carers, Thomas et al. (2004) identified experiences with services and places of care as one of four thematic domains that shaped preferences for place of death. They explained that if the service was perceived as good, then that site could be considered as a place where one might spend one's last days. In contrast, if aspects of a service were perceived to be bad or

indifferent, then that service site was discounted as a place of death option. Assuming that the relationship between experiences and preferences is as straightforward as it intuitively seems, this should be assessable through quantitative measures as well as through qualitative interviews. Yet, there is a substantial lack of quantitative research in this area, which might be at least partly due to the challenges of capturing constructs like past experiences and preferences in general.

While quantitative studies can use surveys that are relatively cheap and anonymous (Smith, 2010), their format also often forces participants to reduce long, complex answers down to a simple, multiple-choice response. This poses a particular problem for intricate end-of-life experiences and complex decisions. Hence, it is not surprising that most of the studies in this area use qualitative designs, often interviews, which allow participants to explain their views in depth. In their book on qualitative research in nursing and healthcare, Holloway and Wheeler (2013) argued that "qualitative research is a coherent way of researching human thoughts, perception and behaviour... In qualitative health research, the 'voices' of patients and clients are heard, and feelings and experiences can be grasped." (p. 28).

4.2.4 Current Experiences

Not only past but also current experiences are likely to influence respondents' preferences for place of care and place of death. Yamagishi et al. (2012) surveyed 3,795 participants from the general public in Japan and compared them to a subgroup of 189 respondents who had a cancer diagnosis. They found a significantly lower preference to be cared for and die at home amongst cancer patients compared to healthy respondents. This discrepancy underscores the role of personal experiences in decision making. To illustrate this further, McCall (2005) interviewed eight terminally ill cancer patients and found that their attitudes and preferences for places of care had been developed over many years and were associated with respondents' past as well as their current circumstances. In this regard,

Munday et al. (2009) described an interesting trend based on their interviews with 17 general practitioners and 19 nurses about their patients' preferences. As previously discussed, patients frequently changed their minds regarding where they wanted to die and became more accepting of institutional care as the illness progressed. However, patients also often replaced their initial preference to die in a specific place with a desire to remain in their current care setting. It is reasonable to assume that this might have been chosen to avoid relocation stress (see section 2.5.4) or alternatively, patients might have learned that their current place of care was more acceptable than initially anticipated.

The effect of current experiences is particularly noticeable when examining preferences of people who have been recruited from different care settings. To illustrate this, Figure 4.1 was generated, which compares the results of three different studies. Firstly, Arnold et al. (2013) reviewed the records of 1,127 hospice patients and of those who nominated a preferred place of death, 60% wanted to die in hospice, only 37% chose home, and 3% preferred hospital or nursing home care. In contrast, Gerrard et al. (2011) examined 166 hospitalised patients, and 38% wanted to stay in hospital, whereas only 31% chose hospice, 24% preferred home and 7% nursing home. Finally, in the previously mentioned population-based survey of 2,652 healthy respondents who most likely lived at home, Foreman et al. (2006) found that 70% reported a preference for home death, 19% favoured hospital, 9.8% hospice and 0.8% nursing home. Based on this comparison, it appears that people's preferences often match their current place of care. Yet, to draw clear conclusions, location preferences would need to be assessed using the same methodology in different settings, ideally within the same study.

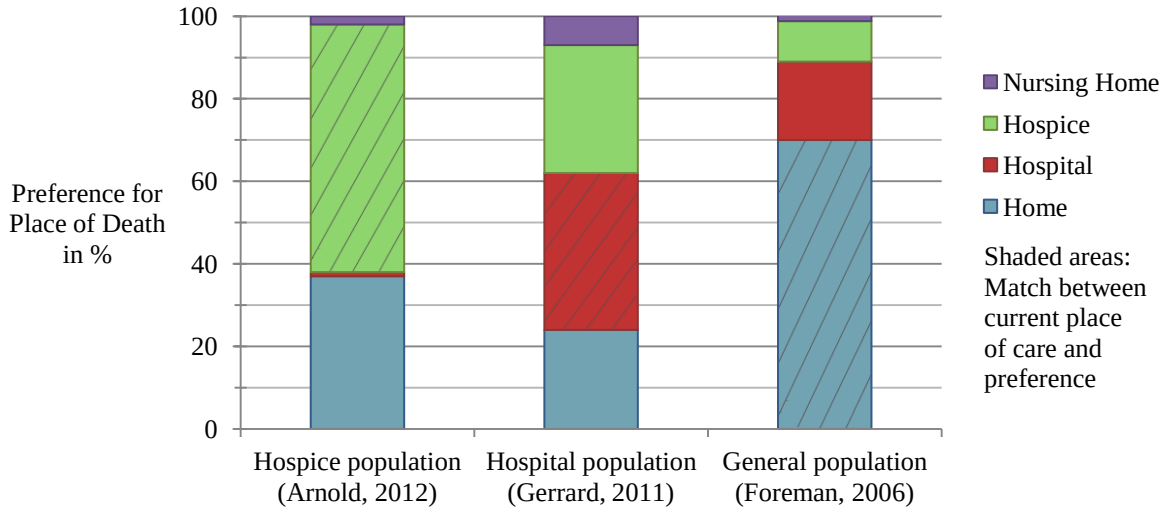

Figure 4.1. Location preferences in hospice patients, hospital patients, and the general population who are currently at home.

4.3 Interpersonal Factors

Decisions are not only influenced by illness-related and personal factors but also by the views of significant others, such as close family members or spouses, especially when the implementation of the decision requires the support of these people. When considering different options for place of care and place of death, interpersonal aspects of the patient-carer relationship are likely to play a role in the decision-making process. These will be reviewed in the next section.

4.3.1 Quality and Length of the Patient-Carer Relationship

As discussed throughout Chapter 2, informal caregivers play an essential role in end-of-life care, especially when the patient wants to remain at home. In their review of 58 studies on place of death, Gomes and Higginson (2006) found that living with relatives, having extended family support, and being married increased the odds of dying at home. Similarly, the afore-mentioned prospective study by Hinton (1994) found that nearly all of the palliative care patients who lived alone or without a competent carer had to be admitted for end-of-life

care. Hence, the availability and presence of a carer influences patients' actual place of death. Yet, it is not clear if and how aspects of the patient-carer relationship also affect their preferences. For example, Ohmachi et al. (2015) surveyed 238 older adults from Japan about their end-of-life wishes and found an association between having their spouse as the preferred caregiver and the desire to die at home. It is intuitively understandable that in long-standing relationships, especially spousal ones, partners had time to develop trust, understanding and commitment. However, the type and length of a relationship are not necessarily directly related to its quality. For example, Hinton (1980) asked 80 hospice patients with whom they had spoken about the prospect of dying. Of the 62 patients who indicated that they had discussed the topic of death, 69% had talked to their spouse whom they had known the longest, 35% to the staff whom they had known for some time, and 85% to the researcher who they had never met prior to the interview. Hinton (1980) concluded that the nature and the quality of the relationship was more important than its duration. However, previous studies have not yet explored how the length and quality of the relationship between patienst and carers would influence location preferences at the end of life.

4.4 Structural Factors

Structural factors concern the availability of and proximity to healthcare services. As outlined in Chapter 2, end-of-life support might be fragmented in certain regions, include waiting periods and may be connected to specific health conditions (see section 2.5.3; Australian Senate, 2012; Palliative Care Queensland, 2012; Swerissen & Duckett, 2014). Furthermore, hospitals with hospice units are often located in major cities and consequently, patients who live too far away from the nearest hospital tend to die more often in nursing homes, if those are available (see section 2.5.2.2; Australian Institute of Health and Welfare, 2017; Axelsson & Christensen, 1996; Teno et al., 2004). The previously discussed systematic review by Gomes and Higginson (2006) found that the intensity of home care was associated

with the rate of home deaths. Specifically, patients who died at home had more home care input and more frequent home visits than those who died elsewhere, which makes the availability of support all the more essential. The review also found that people in some rural areas were more likely to die at home, arguably because of the lack of available healthcare services. This was supported for the US, Italy and Spain, with conflicting findings for Canada, Australia and the UK. Six years later, Gomes et al. (2012) published further evidence for country-specific differences in place of death, this time with focus on respondents' preferences. Their population survey of seven European countries found that in England, Spain and Germany the preference to die at home ranged between 64% and 67%, whereas participants from Belgium, Italy and the Netherlands reported the strongest home preference with 72% to up to 84%. The authors suggested that, beyond the cultural beliefs in the respective countries, the availability of services is likely to have a considerable influence on people's preferences. To illustrate this, they reported very limited community resources for home care in Portugal, which had the lowest home preference in the study with only 51%. Hence, in summary, where people want to be at the end of their life is likely to be shaped by the services that are available to them at the time.

Up until this point, this chapter has explored the influence of illness-related, personal, interpersonal and structural factors on preferences for place of care and place of death. The next section will address how expressing these preferences relates to actually achieving them. Particularly, the role of discussions and agreement between patients and carers regarding end-of-life choices will be further explored.

4.5 Achieving Preferences and the Role of Discussions

Meeting individuals' location preferences is considered to be one of the measures of success of the healthcare system (World Health Organization, 2004). Yet, as discussed in Chapter 2, in many cases, preferred and actual place of death do not match (see

section 2.5.1). Despite this discrepancy, people's preference itself for where they want to be is still one of the best predictors of where they will end up. This was, for instance, suggested by McWhinney, Bass, and Orr (1995) who reviewed the deaths of 75 home care patients from London and found that their preference for dying at home was positively associated with achieving this wish. Furthermore, according to the systematic review of 58 international studies by Gomes and Higginson (2006), the odds of dying at home were not only associated with a preference to stay at home, but also with the expression of that preference. Open discussions about wishes and views could, therefore, be an essential factor in achieving them.

Chapter 2 addressed some of the challenges of communication at the end of life (see section 2.6). Going beyond the difficulties of talking about death and dying, some studies have suggested that open discussions about preferences may increase the chances of actually achieving them. For instance, in a survey of 229 bereaved carers, Karlsen and Addington-Hall (1998) found that patients who had died at home were over 2.5 times more likely to have expressed a location preference than those who died elsewhere. Similarly, Brazil et al. (2005) interviewed 216 bereaved carers and found that the odds of dying at home were almost three times greater when the patient had stated a preference compared to when no specific wish had been expressed. However, these studies rely on retrospective carer assessments, which makes their accuracy questionable for two main reasons. Firstly, as discussed in the current and the previous chapter, how we perceive a situation and consequently make decisions may not always be a completely rational process and instead, biases can occur. For instance, Hoffrage and Pohl (2003) suggested that once people know the outcome of a series of events, they tend to overestimate what could have been anticipated in foresight and might change their responses accordingly. This *hindsight bias* or *knew-it-all-along effect* could mean that when bereaved carers are asked about their patient's preferred place of death they might unconsciously alter their response in favour of the actual place of death. Secondly, Wilson and Gilbert (2005) pointed out that when people recover from negative or emotional events,

such as a loved one's passing, their psychological immune system becomes active. This system fights threats to the well-being through psychological defences, coping mechanisms and post-decisional rationalisation. This means that bereaved carers are likely to try to make sense of what has happened, which influences their retrospective views. To illustrate, a study by Brazil et al. (2005) found that, according to reports of 216 bereaved carers, 30% of their patients did not die in their preferred place. Yet, 93% of carers still believed that this was the right place for the patient. In hindsight, they might have focussed on information that was consistent with the final outcome and neglected conflicting details. Retrospective reports may, therefore, vary considerably in their accuracy.

Due to the lack of prospective evidence regarding the effect of discussions on achieving patients' location preferences, we need to turn to other areas of end-of-life decision making to find out more. For example, Suhl, Simons, Reedy, and Garrick (1994) asked 50 hospitalised patients and their surrogates about the patients' views on life support. Here, the amount of prior discussions regarding treatment preferences correlated moderately with the accuracy of surrogate decision making. This was further supported by Sulmasy et al. (1998) who interviewed 250 patients with terminal diagnoses, 50 general medical patients and their surrogates about their treatment preferences for different clinical scenarios. They found that prior discussions were significantly associated with higher accuracy of carer predictions.

However, it seems that discussions between patients and carers do not always lead to better understanding of each other's views. Ditto et al. (2001) asked a group of 401 elderly outpatients to complete their advance directives in the presence of their surrogates and openly discuss the reasons for their responses. After that, carers were asked to assess their patients' wishes. Surprisingly, Ditto et al. (2001) found that the discussions did not significantly improve the accuracy of surrogate predictions. Similar findings were suggested by Matheis-Kraft and Roberto (1997) who asked 30 older women to discuss their values regarding certain treatment options with their surrogates. They compared this experimental group to a control

group who did not discuss their views beforehand. Again, previous discussions did not increase carers' accuracy. In fact, those participants in the control group who did not talk about their wishes agreed on 11 out of 30 treatment scenarios, whereas the experimental group with prior discussions only agreed on six scenarios. In these cases, talking about their views seemed to have an adverse effect on the accuracy of surrogate predictions.

So far, studies addressing the influence of discussions have mainly focused on life-sustaining treatment preferences rather than on achieving one's preferred place of death, and the findings in this regard are mixed. If talking about one's end-of-life wishes actually helps to fulfil them, then the connection seems to be not as clear as one would intuitively expect. This also highlights that patients and carers might not always be on the same page when it comes to their preferences and views – an issue that will now be addressed.

4.6 Agreement between Patients and Carers

Chapter 2 highlighted the importance of informal carers in end-of-life decision making. Acknowledging their role and hearing their voices is an essential but sometimes neglected part of clinical reality and of research. It therefore seems to be necessary to explore the perspective of the carers separately instead of implying that their wishes are similar to those of the patient. The following section will examine to what extent patients and carers agree regarding certain end-of-life issues such as their preferences for place of death and their assessments of symptoms and final arrangements.

4.6.1 Agreement regarding Place of Death Preferences

The shared desire of both patients and caregivers for a home death is the main predictor for achieving this preference. This was found in a Canadian study of 73 palliative care patients with advanced cancer and their family caregivers by Cantwell et al. (2000). The agreement between patients and carers was even more important than having multiple

informal carers and the support of doctors at home. Yet, the problem is that patients and carers may not always agree with one another in their end-of-life choices. For example, Stajduhar et al. (2008) asked 138 terminally ill hospital patients and their informal caregivers from Canada if they preferred death at home or in the hospital, assuming that they could achieve the same level of quality care in both places. Dyads agreed in 49.3% of the cases (k = 0.16) and interestingly, carers had a stronger preference for hospital care than patients did (39.9% versus 27.5%). In a Taiwanese palliative care hospital study, Tang, Liu, Lai, and McCorkle (2005) asked 617 patient-carer pairs about their views on place of death and also found a stronger institutional preference in carers than in patients (32% versus 26.2%). In this sample, dyads agreed in 74.1% of the cases (k = 0.55). Based on this, congruence between patients and carers seems to vary greatly.

Nonetheless, agreement may be an important factor for patients in achieving their preferred place of death. Grande and Ewing (2008) examined the wishes of 255 patients who had died during the study and the views of their carers concerning home deaths. They reported that the likelihood of dying at home was 72.2% when patients and caregivers agreed regarding their preferences, but when carers disagreed, chances dropped to only 25%. Furthermore, Chen et al. (2003) interviewed 173 hospice patients and found that 41.6% of the final hospice enrolment decisions were made by family members, compared to only 27.7% by patients themselves and 27.8% by healthcare professionals. So, in order to stay at home, it seems to be essential to have the carer on board.

In this regard, agreement may not only be of benefit for patients, but also for their caregivers. Kristjanson (1983) interviewed ten families who had lost a close relative within the last year. She found that those who reported differences of opinion with their patient at the end of life experienced considerable conflict, confusion, guilt and regret upon bereavement. Similarly, Topf et al. (2013) interviewed bereaved caregivers who were committed to taking care of their loved ones at home, yet despite this fact, their patients died

in an institutional setting. The authors reported that, in retrospect, the pledge of home care was often made without hesitation or conditions: “The promise idealized the notion of dying at home. It was rooted in the living aspect of dying; being in the comfort and privacy of home spending meaningful time together surrounded by the love of family and friends.” (p. 876). Soon after the promise was made, however, carers felt unsupported, frustrated and unprepared for the workload of caregiving. In addition, carers were reluctant to talk about their problems with healthcare professionals, fearing the patient would not be allowed to stay at home. Over time, issues such as this led to hospital or hospice admissions, which were mostly intended to be temporary. When death occurred outside the home setting, caregivers reported feelings of guilt, betrayal, regret, disappointment and failure. These “shattered promises” (p. 877) contributed to complicated bereavement, which lasted from a few months to up to 17 years. Taken together, findings suggest that agreement regarding location choices is relevant for patients and carers alike. This may also play a role in other end-of-life areas, such as symptom assessments, which will now be addressed.

4.6.2 Accuracy of Symptom Assessments

Being able to accurately assess the patient’s state of health is essential to determine necessary care and treatment strategies. Because health-related issues are highly subjective, the patients’ own interpretation of their current symptoms is seen as the most accurate measure of their experiences. However, particularly at the end of life, patients are often very unwell and not always able to speak for themselves. The healthcare system therefore relies on the assessments of informal carers and their patient-specific knowledge. Studies suggest that carers’ estimates of patients’ symptoms seem to be particularly prone to biases. Specifically, caregivers tend to overestimate the functional impairment and the symptom burden of their patients (Higginson, Wade, & McCarthy, 1990; McPherson, Wilson, Lobchuk, & Brajtman, 2008). Overestimation in this context means that carers believe their patients to have a higher

number of symptoms or a higher symptom burden than patients report themselves. For instance, a questionnaire-based study of 65 terminally ill cancer patients and their carers by Higginson et al. (1990) found that families' ratings of pain control, symptom control and the effects of anxiety on the patient were significantly worse than patients' self-reports. Similarly, McPherson et al. (2008) interviewed 66 cancer patients and their caregivers, who also tended to overestimate the frequency, severity and distress of the patients' symptoms. The study added that agreement was good for visible symptoms like nausea and vomiting, and moderate for pain, lack of appetite, and constipation. The absence or presence of these symptoms would have been easily observable by the carer, which made their assessments more accurate. In contrast, agreement for less visible issues was low. These included lack of energy, dry mouth, changes in taste, dizziness, worrying, feelings of nervousness, sadness and irritability. In particular, psychological symptoms were often overestimated by the carers. Factors that influenced this discrepancy were the carers' emotional state, the burden of providing care, the carer being male and the patients' perception of being a burden to others. McPherson et al. (2008) concluded that especially in regard to psychological symptoms caregivers' reports may be a projection of their own feelings.

As previously addressed, projection occurs when our immediate preferences, thoughts and feelings influence our assessments of a situation (Loewenstein, 2005). It has been discussed in this chapter that we tend to project our current views onto ourselves in the future (intrapersonal projection; see section 4.1.1). It is therefore not surprising that we also seem to project our views onto other people when we are trying to assess how they feel about something. Loewenstein (2005) called this *interpersonal projection*, while Cronbach (1955) coined the term *assumed similarity*. Additional support for this bias was found in a study of 275 chronically ill veterans and their surrogates by Rothman, Hedrick, Bulcroft, Hickam, and Rubenstein (1991). Here, proxy-generated scores regarding psychological symptoms were

mainly explained by the caregivers' own distress and perceived burden. In a discussion paper on perspective-taking in carers, Lobchuk (2006) explained this further:

> Optimal caregiving skill reflects the ability to maintain some degree of objectivity in therapeutic relationships. In order to truly understand and meet patients' needs informal caregivers, in particular, must make a conscious effort to prevent their personal positions from dictating their inferences of patients' situations. However, sympathy, personal distress and projection tend to promote a self-centred or egoistic need to identify with one's own distress, which is a real threat to caregivers who are involved in situations where it is often difficult to maintain objectivity. (p. 333)

When carers are burdened and emotionally distressed, their ability to accurately assess the patient's symptoms might be affected. In clinical practice, passing on incorrect information about the intensity of the symptoms to medical staff could result in under- or over-treatment, which is especially concerning at the end of life.

4.6.3 Predictions of End-of-Life Arrangements and Treatment Preferences

Assessing how someone else feels or what they want is one of the most challenging aspects of medical decision making because choices are often made under tremendous pressure and have potentially severe and long-lasting consequences. Informal carers are not only frequently asked to assess their patient's symptoms but also to provide information about their end-of-life arrangements and even treatment preferences. To explore the accuracy of these predictions, Shalowitz, Garrett-Mayer, and Wendler (2006) reviewed 16 papers on surrogate decision making. They found that carers predicted patients' treatment preferences with an average accuracy of 68%. However, findings varied greatly depending on the considered health scenario. Twelve of their studies further assessed the direction of the prediction errors that surrogates made. Three studies found that carers believed the patient wanted more treatment than patients actually did, one study found that surrogates withheld

interventions that the patient wanted, and eight studies found no consistent trends in surrogates' mistakes.

This raises the question of where these errors originate. Similar to the findings regarding symptom assessments, some authors suggest that surrogates might base their end-of-life predictions on their own wishes rather than those of the patient. Fagerlin, Ditto, Danks, and Houts (2001) interviewed 361 elderly outpatients and their surrogates about life-sustaining treatment preferences in different hypothetical scenarios. They reported that surrogates' predictions more closely resembled their own preferences than the wishes of the patient. In agreement with this, Sulmasy et al. (1998) found that surrogates of 250 terminally ill patients stated their own preferences in 65% to 89% of the cases, depending on the given scenario, when actually asked about patients' views. This provides further evidence for interpersonal projection in end-of-life decision making.

Instead of solely depending on the assessments of a surrogate or proxy, patients can put their treatment wishes in writing by, for example, signing a living will and completing CPR orders. Making their preferences "visible" in that way should make it easier for carers to follow these wishes. However, even if the patient has made their own formal arrangements, the carer might not necessarily know about them. Fried, Redding, Robbins, O'Leary, and Iannone (2011) asked 216 pairs of elderly Americans and their surrogates about the patients' end-of-life preparations. Overall, 81% of dyads agreed on whether a living will had been completed (k = 0.61), but only 68% knew whether a healthcare proxy had been appointed (k = 0.39), and 64% agreed on whether they had talked about life-sustaining treatment (k = 0.22). If the carer is not aware that specific end-of-life arrangements have been made and what they entail, it can be very challenging for them to assess the patients' wishes in an actual life-threatening situation.

In summary, clinicians as well as researchers often strongly rely on carer assessments regarding the patient's preferences, symptoms and arrangements. Capturing these views is

essential to understand and ultimately support respondents' decision making. However, it has been discussed that this process is not as straightforward as it seems. When assessing end-of-life wishes and specifically location preferences, certain methodological aspects need to be acknowledged. These have been highlighted throughout and will now be summarised.

4.7 Methodological Considerations

During the review of the literature, it became clear that studies on end-of-life decision making vary greatly in regard to four main questions. These include: what, how, when, and who to ask about location preferences. The ways in which researchers chose to answer these questions seemed to influence their results. This section will draw together these methodological considerations and identify their implications for the present research.

4.7.1 Precision of Preference Assessments – What to ask?

Chapter 2 emphasised the importance of communication about end-of-life issues and also outlined some of its challenges (see section 2.6). Many patients and carers would prefer to receive more information about the illness and its progression. However, talking about death and dying is not easy for anyone involved and therefore often avoided. In this context, "What to ask?" may seem like a trivial question. When we are interested in where people want to spend their last days, we could probably simply ask them that. Unfortunately, it is not quite that easy. Chapter 2 examined the rarely acknowledged distinction between preferences for place of care and place of death (see section 2.6.1). Agar et al. (2008) suggested that these are two different concepts and using the terms interchangeably can lead to misinterpretation of people's true preferences. They found that congruence between the two questions was low and that, as death approached, respondents were less often asked about their preferred place of death and more about place of care. A clear distinction between the two concepts is therefore essential to accurately examine end-of-life views.

4.7.2 Methods of Preference Assessments – How to ask?

The methods used to assess location preferences also vary greatly between studies. Some have used self-administered questionnaires, face-to-face or telephone surveys, semi-structured or open-ended interviews, or even chart reviews. As addressed in this chapter, different methodologies can lead to different results and each method has their specific advantages and disadvantages (see section 4.2.3). For example, quantitative surveys can be cost-effective, anonymous and easy to administer. However, especially in end-of-life research, patients may be too ill and family members too distressed to complete a questionnaire. Surveys also tend to overlook valuable aspects and dynamics of a person's life by focussing on specified questions and answers.

To avoid the reductionism associated with a solely quantitative approach, qualitative methods have been found useful (Dougall, Russell, Rubin, & Ling, 2000; Kendall et al., 2007; Wiegand, Norton, & Baggs, 2008). Especially when addressing emotionally complex and multi-layered decisions regarding one's own or a loved one's death, interviews provide a certain level of flexibility and depth seldom reached in multiple-choice questionnaires. Researchers can prompt for information, follow up on what was said, and clarify questions if necessary. However, much like surveys, interviews can be time-consuming and hence draining for frail patients and the strong involvement of an interviewer has the potential to influence participants' answers (Hughes, 2008). Furthermore, social desirability is a particular concern in face-to-face interviews where respondents might modify their answers to present themselves in a certain light (Fisher, 1993; Holloway & Wheeler, 2013). Batchelor, Owens, Read, and Bloor (1994) addressed this in a discussion paper on measuring satisfaction with healthcare services. They pointed out that care recipients might be unwilling to openly criticise staff members in an interview or express dissatisfaction with a service, for fear of antagonising the care providers and receiving even worse service in the future.

The fundamental differences between qualitative and quantitative measures are not only practical in nature but also based on their different ontological and epistemological frameworks. Ontology concerns the study of reality, whereas epistemology is the study of the nature of knowledge (Sale, Lohfeld, & Brazil, 2002). The ontological position of quantitative research is realism, which assumes that an objective reality exists outside of human perception (Slevitch, 2011). Epistemologically, this means that the investigator and the investigated are separate entities and that researchers can uncover an objective reality by applying reliable, valid and unbiased research methods (Slevitch, 2011). Therefore, sample size is a critical concern in quantitative research to ensure generalisability of findings.

In contrast, the ontological position of qualitative research is constructivism, which assumes that there is no one objective reality (Sale et al., 2002). Instead, different realities exist, which are constantly changing and depend on one's personal interpretation. Epistemologically, that means that the investigator and the investigated are interactively connected (Slevitch, 2011). Findings are co-created through an exchange between both entities and hence qualitative methodologies do not seek objectivity and generalisability. Furthermore, sample size in qualitative research is only relevant insofar as it provides access to rich information (Slevitch, 2011).

While the underlying worldviews of qualitative and quantitative research seem inherently different, Sale et al. (2002) argued that they can be combined in a single study. Through mixed-methods, it is possible to achieve complementary results by using the strengths of one method to enhance the other. Newman and Benz (1998), therefore, suggested that qualitative and quantitative research methods should not be seen as separate scientific absolutes but rather as an interactive continuum. Each addresses different aspects. Quantitative measures examine the extent of a phenomenon, whereas qualitative measures explore its nature. Combining both approaches is therefore likely to provide the most detailed insights into location decision making.

4.7.3 Timing of Preference Assessments – When to ask?

As addressed in this and the previous chapter, another crucial methodological aspect concerns the timing of preference assessments. Often in palliative care research and clinical practice, non-terminal or healthy elderly respondents are presented with hypothetical scenarios that may have little in common with their current situation, and asked to foresee their end-of-life wishes for some distant time in the future. However, these long-range predictions are problematic. On a theoretical level in Chapter 3, Kahneman and Tversky's Prospect Theory (1979) argued that the further away something is from our current point of reference, the harder it is to make accurate predictions (see section 3.3.1). Wilson and Gilbert (2005) highlighted that people tend to overestimate the impact that future events will have and underestimate how quickly they will cope with a new situation. Loewenstein (2005) added that we tend to project our current thoughts, feelings and preferences onto our self in the future. This intrapersonal projection poses a particular problem when patients are asked about their end-of-life wishes even though they are nowhere near the end of their life.

In order to identify true preferences of terminally ill patients, research needs to include people who are actually in the last stage of their life. Using predictions of healthy elderly participants instead can be seen as measuring preferences too early. On the other hand, end-of-life views are also sometimes assessed too late when researchers use post-death interviews with bereaved caregivers to identify patients' pre-death preferences. These assessments are likely to be biased. As previously noted, carers may try in retrospect to make sense of what has happened and justify their decisions. The effects of coping mechanisms, post-decisional rationalisation (Wilson & Gilbert, 2005) and hindsight biases (Hoffrage & Pohl, 2003) can influence their assessments of past events. For example, when asked about their own and their patient's initial preferences for place of death, bereaved carers may unconsciously alter their response in favour of the actual place of death. Consequently, as the reliability of

retrospective assessments is questionable, end-of-life preferences need to be captured prospectively and, if at all possible, close to the end of the patient's life.

4.7.4 Sources of Preference Assessments – Who to ask?

The main focus of palliative care research is often on patients' preferences with little to no regard for the wishes of the family carers. In their review of 129 quantitative studies on home-based end-of-life caregiving, Stajduhar et al. (2010) criticised that many studies do not clearly distinguish between patients' and carers' preferences, describing them as if they were similar. As addressed in the previous chapter, Prospect Theory argues that different people are likely to have very different points of reference that they base their views and decisions on (see section 3.3.1; Kahneman & Tversky, 1979). Adding to this, the present chapter discussed that decision makers may also have difficulties disregarding their current feelings and emotions when predicting their own preferences for the future (intrapersonal projection) and consequently mispredict the wishes of others even more so (interpersonal projection) (Cronbach, 1955; Kenny, 1994; Loewenstein, 2005). In this regard, carers' emotional state can strongly influence the accuracy of their predictions. This projection bias has mainly been considered in studies on treatment preferences and symptom assessments, but not in regard to place of care and place of death. Therefore, the focus in this field of research needs to be extended and studies should examine the views of patients and carers separately instead of assuming that they are the same.

4.8 Chapter Summary

This chapter has explored the influence of illness-related, personal, interpersonal and structural factors on preferences for place of care and place of death. Some of these, such as demographic variables and symptoms, have been frequently addressed in previous studies, but most other factors suggested showed either conflicting findings or are considerably under-researched. Specifically, the influence of personality traits, experiences and discussions has not sufficiently been examined in regard to location preferences. Studies from other areas of end-of-life research suggest that these factors might influence decision making, but so far it is unclear how and to what extent. This review of the current literature also highlighted some methodological issues in previous studies that need to be considered. These included the precision, methods, timing and sources of preference assessments. This summary will now be used to inform the rationale, aims and methodology of the current research.

5

Rationale,

Aims and Hypotheses

CHAPTER FIVE

This chapter will summarise the rationale for this research on preferences for place of care and place of death, which has been informed by the theory-, and data-driven evidence as well as the methodological considerations discussed in the previous chapters. Following on from the suggested framework, this chapter will outline the aims and hypotheses of the current research.

5.1 Rationale

The preceding chapters highlighted that examining location preferences at the end of life may not be as simple and straightforward as it seems. Studies in this area vary considerably in the precision, timing, sources and methods of their assessments, which influences their results. To address the issue of lacking precision, this research will clearly distinguish between preferences for place of care and place of death to determine whether these are, in fact, two separate concepts. Concerning the timing of assessments and sources of information, it was discussed that end-of-life studies often rely on easily accessible samples that include respondents from the general public, healthy older participants or bereaved carers. It was argued that the generalisability of preferences from healthy to dying samples is just as problematic as indirect post-death assessments of preferences through bereaved family members. As Kübler-Ross and Byock (2014) pointed out: "The best possible way we could study death and dying was by asking terminally ill patients to be our teachers" (p. 21). Hence, the current research will directly address patients who are close to the end of their life in order to gain more accurate insights into true end-of-life preferences.

In addition, the previous chapters highlighted the importance of informal caregivers in end-of-life choices and gaps have been identified that call for an expansion of the focus to acknowledge and include family caregivers in systematic studies. Earlier research indicated that carers tend to prefer an institutional death for the patient more often than patients

themselves (Stajduhar et al., 2008; Tang et al., 2005). However, it is unclear whether these differences persist when assessing place of care and place of death preferences separately. Distinguishing between the views of patients and carers will shed light on this and other controversial aspects that surround the decision making. This concerns, for example, the perceived importance of the location choice in general. As discussed in Chapter 2, some researchers have argued that where people spend their last days is a highly relevant part of end-of-life decision making (Munday et al., 2009; Patrick et al., 2001; Tang, 2003), while others suggested that it might not matter as much as we thought (Steinhauser et al., 2000).

To gain detailed insights into the perspectives of patients and carers and to identify factors that influence their location preferences, the current research will comprise two studies; the first using a quantitative and the second using a qualitative design. As discussed in the previous chapter, both methods can answer different questions and complement each other. Based on the theoretical and empirical literature reviewed, three sets of controversial and under-researched factors will be addressed in this thesis. These include a selection of illness-related, personal and interpersonal aspects, which are illustrated in Figure 5.1 and will now be summarised.

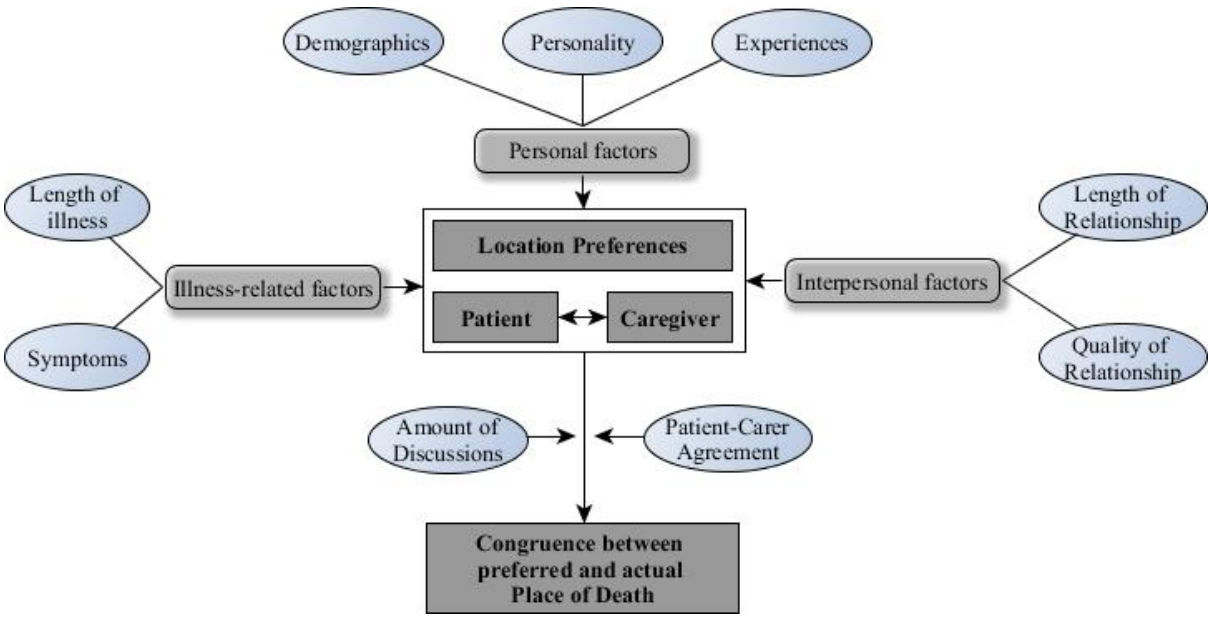

Figure 5.1. Schematic overview of factors examined in the current research.

5.1.1 Illness-rated Factors

The literature reviewed suggested that increased symptom burden in terminally ill patients is associated with more frequent end-of-life admissions and stronger preferences for institutional care (see section 4.1.1). These symptom assessments often rely on reports from family caregivers. However, it was highlighted that carers are not always able to accurately assess their patient's health and preferences as they struggle to detach themselves from their own feelings and emotions. These difficulties in affective forecasting and interpersonal projection have been discussed in regard to symptom assessments and surrogate decision making (see section 4.6.2 and 4.6.3). It was shown that carers tend to overestimate patients' symptoms and this appears to be more common for less visible, psychological symptoms than for more visible, physical problems. If and how overestimation influences location preferences is unclear, but it is reasonable to assume that it could be associated with a stronger preference for institutional care. Another influencing factor that has been addressed in the previous chapter was the overall length of the illness. Studies showed that patients and carers frequently changed their minds as the illness progressed and, specifically the wish to stay at home, often decreased over time (see section 4.1.2). Hence, the length of the illness and the number of symptoms seem to have a strong influence on location preferences but it is unclear if this affects patients and carers in similar ways.

5.1.2 Personal Factors

According to the literature reviewed, aspects within the individual play a considerable part in the decision-making process. Past research has often focused on demographic factors. Specifically, the previous chapter discussed that older patients and women were less likely to prefer home death than younger patients and men (see section 4.2.1). Also, favourable social conditions such as education, social class and income were associated with higher odds of actually dying at home. Yet, beyond these demographic aspects, the role of other personal

factors, like personality traits and experiences, has received limited attention. For example, the Theory of Planned Behaviour suggested that attitudes strongly shape people's intentions without clearly defining where these attitudes come from (see section 3.3.2). It is reasonable to assume that personality and past experiences would play a considerable role in forming attitudes and ultimately intentions. Studies from other areas of end-of-life decision making suggest that personality traits can influence people's health-related perceptions and behaviours (see section 4.2.2). However, this has not been explicitly researched in regard to preferences concerning place of care and place of death. Perhaps due to the complexity of the phenomenon of interest, there is also a lack of quantitative research that addresses the role of past and current experiences in the decision-making process. The Two-System View by Zajonc (1980) suggested that repeated exposure to a stimulus would increase familiarity, emotional responses and liking of that stimulus (see section 3.4). This can be applied to location choices as frequent experiences with certain care settings might be associated with a stronger preference for these settings. Given the paucity of systematic evidence in this area, the current research will explore the role of these under-researched personal factors on location choices.

5.1.3 Interpersonal Factors

The previous chapters have highlighted the importance of having family support for end-of-life care, especially at home (see for example sections 2.6.3 and 4.6.1). Yet, it is still unclear if and how aspects of the patient-carer relationship influence people's location preferences. It was discussed in Chapter 4 that long-standing relationships might be associated with more trust, understanding and commitment, which could, in turn, be connected with a stronger preference for home care (see section 4.3.1). However, it was also argued that the quality of the patient-carer relationship might be more important than its overall length when it comes to end-of-life decision making. Based on the findings reviewed,

it is reasonable to expect that a high-quality relationship between patients and carers would be associated with a desire to attempt care at home. Despite the intuitive importance of these interpersonal aspects, their influence on location preferences has neglected in previous studies and this gap will be addressed in the current research.

5.1.4 Discussions and Agreement between Patients and Caregivers

Meeting individuals' location preferences is considered one of the measures of success of the healthcare system (World Health Organization, 2004). Some studies have argued that discussions between patients and carers can increase the odds of dying in their preferred place (see section 4.5). However, from other areas of end-of-life decision making, we know that discussions may not always lead to better understanding of each other's views. Findings regarding patient-carer agreement on place of death, symptom assessments and predictions about end-of-life arrangements have been mixed. The previous chapter argued that being able to accurately evaluate the patient's situation is important for patients themselves if they want to achieve their end-of-life preferences, and also for carers if they want to avoid guilt and regret upon bereavement (see section 4.6.1). These factors will therefore be included in this research.

5.1.5 Aspects outside of the Scope of this Research

The framework presented for this thesis mainly focuses on controversial and under-researched factors in end-of-life decision making. However, this selection is not exhaustive. At this point, it is important to clearly distinguish what this research will *not* focus on. Firstly, patients without an informal carer and those who are underage are outside the scope of this research because they have limited choices regarding their place of care and place of death. Patients without a carer are more likely not to be referred to home care and ultimately die in institutional settings (Grande et al., 1998; Karlsen & Addington-Hall, 1998). So without carer

support their options are limited. It is also the case that the place of care of terminally ill adolescents and children is often decided by their parents. To understand how end-of-life choices are made, we need to focus on those who actually have a choice in this regard. Secondly, structural factors such as the availability and proximity of palliative care services will not be examined in this research. As outlined in the previous chapters, support services in certain areas might be fragmented, include waiting periods or are connected to defined conditions (see sections 2.5.3 and 4.4). However, this was argued to be less relevant in metropolitan areas of major cities such as Melbourne, where the current research will take place, because these areas are believed to offer well-established and accessible healthcare networks. Structural factors may be spontaneously addressed by patients and carers in the qualitative study but will not be specifically included in the quantitative part of this research. Guided by this framework, the overall aims and hypotheses will now be presented.

5.2 General Research Aims

The current research will examine the views of terminally ill patients at the end of their lives, and further expand the focus by including the perspective of their primary informal caregivers. In doing so, it is hoped to establish their respective roles in the process of decision making regarding place of care and place of death. This research will also address controversial and under-researched factors to examine their influence on location preferences. Ultimately, it is hoped that this will contribute to the current body of literature as well as future clinical practice by gathering information that can be used to support terminally ill patients and family carers in their end-of-life decision making. As previously mentioned, the current research will consist of a quantitative and a qualitative study. This mixed-methods approach is believed to provide more detailed insights into place of care and place of death decision making than would be possible with one methodology alone. The two studies will address the following general research aims:

I. ***Describe preferences for place of care and place of death in terminally ill patients and their family caregivers.***

II. ***Identify factors that influence preferences for place of care at the end of life in patients and carers.***

III. ***Explore the relationship between preferred and actual place of death.***

IV. ***Examine end-of-life agreement between patients and carers and the accuracy of carer assessments.***

V. ***Gain an in-depth understanding of the underlying processes and reasons that govern location decision making.***

5.3 Research Questions and Hypotheses

The research aims presented will be addressed by including different sub-samples in the analyses. To describe location preferences in patients and carers, and identify factors that influence them, the first set of analyses will use the entire sample of recruited participants. This will include individual patients or carers as well as matched patient-carer pairs. To explore the relationship between the preferred and actual place of death, the second set will focus exclusively on those patients who have died during the study period and the carers who have lost their patient in this time. The third set of analyses will include only matched patient-carer dyads to analyse agreement in the pairs. Finally, the last set of analyses will address the sub-sample of participants who volunteered for the interviews. Based on the literature reviewed and the general aims, the following specific research questions and hypotheses will be examined:

SET A) HYPOTHESES FOR THE FULL SAMPLE OF ALL RECRUITED PATIENTS AND CARERS

1. Do terminally ill patients and their family caregivers differ in their location preferences and their views concerning the importance of this choice?

H1.1 Location preferences

- Caregivers will be more likely to have a preference for an institutional place of care than patients.
- Respondents' preferences for place of care at the end of life will differ from their preferences for place of death.

H1.2 Importance of location choice

- Patients and caregivers will differ in their views concerning the importance of the location choice.

2. Do illness-related, personal and interpersonal factors influence respondents' preferences for place of care at the end of life?

H2.1 Illness-related factors

- Length of illness: Longer illnesses will be associated with a preference for an institutional place of care.
- Symptoms: A higher number of reported symptoms will be associated with a preference for an institutional place of care.

H2.2 Personal factors

- Demographics: Older participants, women, and those with a lower educational and socio-economic status will be more likely to prefer an institutional place of care than younger participants, men, and those with a higher educational and socio-economic status.

- Big Five personality traits: Personality traits will influence location preferences, but given the paucity of research regarding in this area, it is not possible to generate specific hypotheses. Therefore, these analyses will be exploratory and examine the potential relationship between location preferences and neuroticism, agreeableness, conscientiousness, openness and extraversion.
- Past experiences: The amount and quality of previous experiences with each place of care will correlate positively with the preference rank of that location.
- Current experiences: Respondents who are currently at home will be more likely to prefer home care at the end of life than respondents who are currently in an institutional setting (match between current and preferred place of care).

H2.3 Interpersonal factors

- Relationship factors: The length and perceived quality of the patient-caregiver relationship will correlate positively with the preference rank of home care.

SET B) HYPOTHESES FOR SUB-SAMPLE WITH RECORDED PLACE OF DEATH

3. Is the actual place of death associated with the initial preference and previous patient-carer discussions?

- Respondents with a preference for home death will be more likely to die at home than those with a preference for an institutional death (match between preferred and actual place of death).
- Participants who died in their preferred place will have had more discussions about their preferences than those who did not die in their preferred place.

SET C) HYPOTHESES FOR THE SUB-SAMPLE OF MATCHED PATIENT-CARER DYADS

4. To what extent do patient-carer dyads agree on their location preferences and how accurate are carers' assessments of patients' wishes and symptoms?

H4.1 Location preference agreement

- Patient-carer dyads who agree regarding their preference for place of death will be more likely to achieve this preference than dyads who do not agree.

H4.2 Accuracy of assessments regarding end-of-life arrangements

- Caregivers will differ in their assessments from patients' self-reports concerning the patient's CPR preferences and end-of-life arrangements such as having a living will and a medical power of attorney.

H4.3 Accuracy of symptom assessments

- Caregivers will report more symptoms for their patient than patients themselves (overestimation).
- Overestimation will occur more often for less visible, psychological symptoms than for visible, physical symptoms.
- Caregivers who overestimate their patient's symptoms will be more likely to prefer an institutional place of care than those carers who do not overestimate their patient's symptoms.

H4.4 Projection

- The numbers of symptoms that caregivers report for their patient will correlate positively with the number of symptoms they report for themselves (projection).
- Projection will occur more often for less visible, psychological symptoms than for visible, physical symptoms.

SET D) INTERVIEW SUB-SAMPLE

5. How are preferences for place of care and place of death formed?

The final aim is to gain an in-depth understanding of the processes and reasons that govern decision making of patients and carers at the end of life. This will be examined in a series of semi-structured, qualitative interviews in Study 2 to establish whether aspects can be identified that have not been addressed in the quantitative Study 1. The following chapter will now provide a detailed description of the methodological design chosen for Study 1.

6

Method

Study 1

CHAPTER SIX

The empirical research undertaken as part of this thesis will use a cross-sectional, mixed-methods design. Study 1 will include a series of multiple-choice questionnaires, whereas Study 2 will use qualitative interviews. The following chapter will introduce the recruitment sites, the methods of sampling, the study procedure and the participants of Study 1. It will also highlight ethical considerations of this research before outlining the materials and data handling of this study.

6.1 Settings

Participants were recruited from three palliative care sites in and around Melbourne in the state of Victoria, Australia. All sites had connections to the PhD supervisors through previous projects and expressed a strong interest in supporting end-of-life research. Recruitment from three different sites allowed a comparison of palliative home care with acute and sub-acute institutional settings.

Palliative Home Care Service of Melbourne City Mission. The first site through which participants were recruited was Melbourne City Mission Palliative Care, a non-denominational, community-based palliative care service that operates 24 hours, seven days a week with the assistance of the Royal District Nursing Service. Melbourne City Mission provides non-institutional home care support for terminally ill patients and their families. Their interdisciplinary team includes 18 permanent nursing staff, 12 allied health professionals, one nurse practitioner and a palliative care registrar, as well as a number of volunteers. The service covers an approximate area of 628km^2 in the northern parts of Melbourne and is funded primarily by the state government and donations. The average length of care is about 60 days. Of the approximately 753 admissions per year, 78% present with malignancies and 40% come from non-English speaking backgrounds. The average age of clients is 71.5 years, of whom 56% are male and 75% have a live-in carer.

Palliative Care Ward of the Royal Melbourne Hospital. The second recruitment site was the Department of Palliative and Supportive Care at the Royal Melbourne Hospital. This specialised palliative care unit is an acute, institutional setting embedded within a major metropolitan teaching hospital in the centre of Melbourne. The ward comprises up to 12 beds, 16 full-time equivalent nurses and two junior and senior medical staff. It offers services such as: palliative pain and symptom management; occupational, music and physical therapies; social work; and pastoral care. It further provides help with treatment and advance care planning as well as bereavement support. Approximately 69% of patients seen on the ward have English as their preferred language, while only 43% are Australian. Overall, 57% of patients are male and the vast majority are 65 years or older. The average length of stay is 11 days, and 70-75% of patients present with malignant diagnoses. Approximately 350 patients are admitted each year, of whom 60% die on the ward, while 40% are discharged to home care or other services.

McKenna House at Broadmeadows Health Service. The third recruitment site was McKenna House, a 24-bed palliative care ward that provides physical, psychosocial and spiritual support for patients with a life-limiting illness and their families. The unit is located at Broadmeadows Health Service, a care provider that offers a variety of general and specialised health services for inpatients as well as outpatients in the north-west of Melbourne. In contrast to the palliative care ward of the Royal Melbourne Hospital, McKenna House is a sub-acute, hospice-like setting. The main reasons for admission are symptom management, end-of-life care and respite. The ward has approximately 50 staff members, including nurses, rotating palliative care consultants, registrars, junior doctors, social workers, pastoral care, ward clerks and patient services assistants. Additional support is provided by allied health teams such as occupational-, speech- and physiotherapists, as well as dieticians, podiatrists, psychologists and volunteers. Patients are on average 73 years old with the trend over recent years for an increasing number of younger patients aged

between 45 to 64. Of all admitted patients, 51% are male and 70% are English-speaking. Overall, 78% of patients present with malignancies. The ward receives between 440 and 490 admissions each year and the average length of stay is 15.4 days. In general, 76% of patients die during their time on the ward, while 20% are discharged home and 4% go on to residential aged care facilities.

All three recruitment sites are participating members of the National Standards Assessment Program and the Palliative Care Outcomes Collaboration, a network that assists services to improve the quality of palliative care they provide through analysis and benchmarking of patient outcomes.

6.2 Sampling

Purposive criterion sampling was used to select terminally ill patients and caregivers for this study. As outlined in the introductory chapter, terminal illness in the context of this research was defined as a "progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing" (Palliative Care Australia, 2008, p. 14; also see section 1.1). The rationale for this study emphasised that, in order to elicit true end-of-life preferences, patients had to be close to the end of their lives (see section 5.1). However, they also had to be well enough to participate, which resulted in a very narrow window of time during which patients could be approached. Primary informal caregivers were invited to take part as well. As outlined in Chapter 2, a primary informal carer is defined as the person, for example, a family member, neighbour or friend, who is most involved in the patient's care and who provides physical, social or psychological assistance to them (see section 2.5.3).

Overall, the eligibility criteria for this study were as follows: Patients had to be at least 18 years of age and have a primary informal caregiver, who was also invited to participate.

Eligible patients had to be diagnosed with a life-limiting illness that was deemed unresponsive to any curative treatment, with a predicted life expectancy of less than 12 months. They had to be aware of the diagnosis and the terminal nature of the illness. Participants had to have sufficient English skills to give informed consent and complete the study. Finally, they had to be physically well enough to participate and have no severe cognitive impairment as assessed by the treatment team. Eligible respondents were invited to complete either the questionnaires of Study 1 or the interviews of Study 2, or both, while priority was given to recruit participants for the questionnaires. The procedure for Study 1 will now be outlined.

6.3 Procedure

Data collection took place from February to December 2014 at the Royal Melbourne Hospital and Melbourne City Mission. McKenna house was added as an additional recruitment site in May 2014 to increase the number of respondents. Potential participants were identified by staff members, often during the weekly client review meetings. It was not possible to record the exact number of referred patients and carers as many staff members suggested participants informally, whenever they saw the researcher on the ward. At the Royal Melbourne Hospital and McKenna House, the researcher approached the referred patients and carers in person to assess and confirm their eligibility for the study. As suggested by Schulman-Green, McCorkle, and Bradley (2010), a staff member was asked to be present during this introduction, whenever possible. However, due to the high workload of the staff, the majority of first contacts were initiated by the researcher alone. Suitable participants were given details about the nature of the study and invited to take part.

At Melbourne City Mission the recruitment procedure differed from the other two settings, which was at their request to avoid the involvement of their nursing staff. Here, potentially eligible participants were selected from the patient database and contacted by the

researcher via postal mail. They received a cover letter signed by the acting manager of Melbourne City Mission and a flyer with general information about the study (see Appendices 1 and 2). If they were interested in participating, they were asked to contact the researcher via phone or e-mail, and make an appointment to be visited at home. Of the 308 mail-outs, 23 callbacks were received (7.47% response rate).

At all recruitment sites, eligible and interested participants were asked to read a detailed plain language statement and sign a consent form (see Appendices 3 and 4), before receiving the self-administered survey. The researcher was always present during the completion of the questionnaire, for three reasons: firstly, this was chosen to ensure that participants were not distressed by the end-of-life questions and the sensitive nature of the topic. If respondents seemed upset, the researcher offered support and informed staff members. Secondly, if both patients and carers were eligible, available and interested in participating, they needed to answer the questions independently of one another. Hence, supervision during the survey was necessary to ensure that patients and carers did not engage in discussions about their preferences as this would distort the measures of agreement. Finally, the presence of the researcher allowed the participants to seek clarification of any questions or unfamiliar terms.

Recruitment, particularly of patients, proved to be extremely challenging. It was often found during the initial meeting that either patients or carers were not available or interested in participating. Many had insufficient English skills, were physically too unwell to take part, or were unable to read or concentrate due to age, illness or medication. Patients' medical conditions were also very unstable, which led to sudden deteriorations or discharges to other care facilities. Furthermore, the initial data collection process required both patients and caregivers to complete the questionnaire in order to compare their views. This meant that incomplete pairs were, at first, not recruited. However, after five months of data collection, only eight pairs had completed the questionnaire. As a consequence of these recruitment challenges, the procedure was amended in June 2014 to allow patients and carers to

participate individually without their dyad partner, if they chose to. Furthermore, quickly discharged patients were contacted via postal mail and received an adapted version of the cover letter and flyer used at Melbourne City Mission (see Appendices 1 and 2).

Taking together all three recruitment sites, 98 potential participants were assessed as eligible during the first contact with the researcher. Of those, 38 declined consent because they were not interested in the study, did not want to discuss end-of-life topics, felt overwhelmed with their current situation, or were too busy. The remaining 60 participants consented to take part in Study 1, out of which three respondents were unable to finish the questionnaire due to health, concentration or language issues, and were consequently excluded. The remaining 57 participants completed the survey in one sitting either on the ward of the participating sites or in their own homes.

At the end of the survey, respondents were offered to receive a study summary of the main findings sent via postal mail. No compensation payments were made. However, each participant received a written note via postal mail or in person to thank them for their support (see Appendix 9). Figure 6.1 presents a schematic overview of the procedure of Study 1.

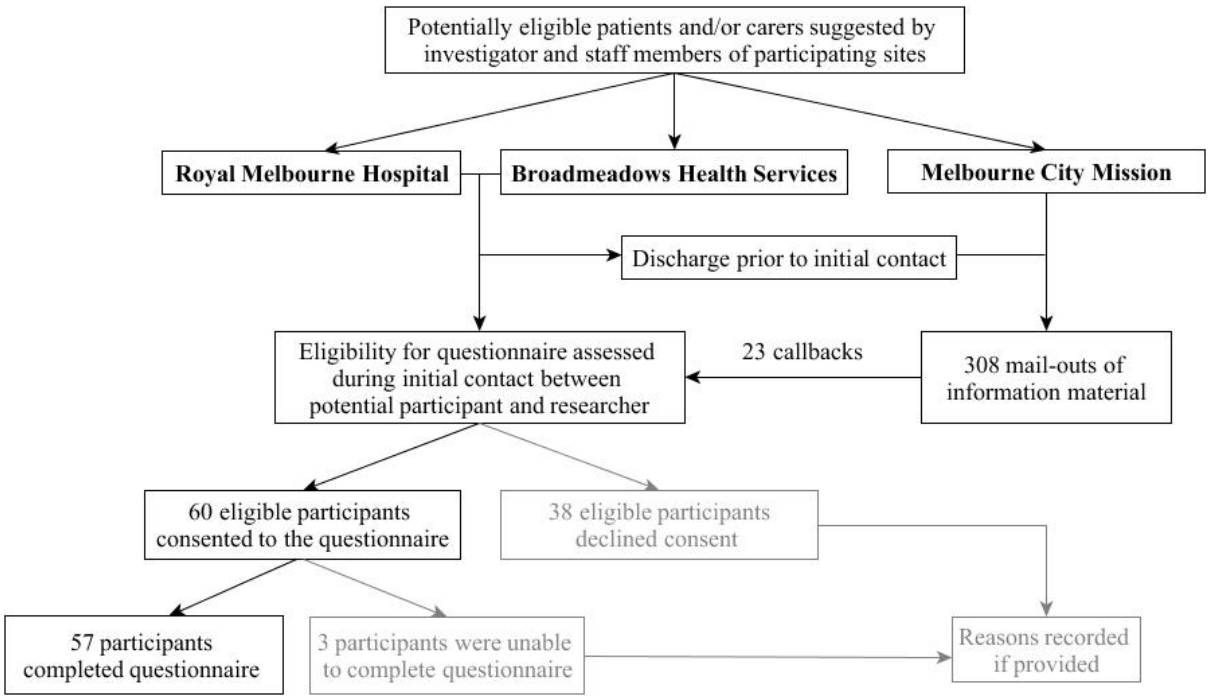

Figure 6.1. Schematic overview of the procedure of Study 1.

6.4 Participants

A total of 57 questionnaires were collected of which 40 had been completed by carers and 17 by patients. This sample consisted of 15 dyads in which both patients *and* carers filled out the questionnaires, as well as two individual patients and 25 individual caregivers who completed the survey without their dyad partner. Table 6.1 provides a detailed overview of the number of questionnaires collected from each recruitment site.

Table 6.1

Number of questionnaires completed by patients and/ or caregivers at each recruitment site (number of dyads in brackets)

Recruitment site	Patients	Caregivers	Total
Royal Melbourne Hospital	4	8	12 (3)
Broadmeadows Health Service	5	23	28 (4)
Melbourne City Mission	8	9	17 (8)
Total	17	40	57 (15)

6.5 Ethical Considerations

Given the sensitive nature of the topics addressed in this research, and the particularly vulnerable group of participants, there were some ethical considerations related to this study that need to be acknowledged. Firstly, the researcher had no personal or work-related connections with any of the recruitment sites prior to the study that could have given rise to a conflict of interest. Secondly, participants were assured that their involvement in the research was entirely voluntary and had no implications for the care provided by the recruitment sites. Before collecting any information about the participants, patients and caregivers had to provide written consent. They were informed that the confidentiality of their responses would be protected by de-identifying and safely storing all information provided. To ensure this, a coding system was used and relevant electronic files were password protected. Participants

were further informed that the data would be kept securely for five years from the date of publication, before being destroyed. It was made clear that they had the right to access or correct all information concerning them and that they could withdraw from the study at any given point without further explanation or consequences. No details about the patients' or carers' responses were communicated to staff members of the recruitment sites, unless participants seemed upset during the study and required further support. In this case, a member of the treatment team was asked to follow up with the participant to ensure their well-being. Furthermore, after completing the study, respondents were advised to contact either the researcher or a member of the treatment team if any questions or signs of distress arose. Additional psychological support was available through the primary PhD supervisor, A/Prof Christina Bryant, a clinically trained psychologist.

All procedures of this study followed the National Statement on Ethical Conduct in Human Research outlined by the National Health and Medical Research Committee (2007). The research was approved by the Human Research Ethics Committees of Melbourne Health and Northern Health. That approval was further registered with the University of Melbourne and endorsed by the acting manager of Melbourne City Mission (see Appendix 10 for site-specific ethics approval letters).

6.6 Materials

For Study 1, an invitation letter and single-page flyer was used during the recruitment phase (see Appendix 1). The letter briefly introduced the research and the investigator, and was signed by each head of the respective participating sites. The flyer provided further details about the content of the study and included the contact details of the researcher. Respondents also received a thank you note after they had participated (see Appendix 9) and, if they wished, a summary report of the central findings.

The main instrument of data collection in Study 1 was the multiple-choice questionnaire, which was available as a version for patients and caregivers (see Appendix 5). The questionnaire was developed by strategically searching for measures that examined the constructs of interest. Scales were selected according to brevity and their use in other empirical studies. When no appropriate measure was found, items were carefully constructed by the researcher. While no pilot testing was done, the wording and flow of the questionnaire was reviewed and approved by the thesis supervisors. The structure of the questionnaire followed a stepped approach moving from easier, less intrusive to more sensitive questions. It was further guided by a logical order of progression from general information to personality and symptom assessments, and finally to end-of-life preferences and arrangements. The multiple-choice format of the questions offered a distinct number of response categories. All scales were kept as short as possible to minimise the burden on patients and carers.

6.6.1 Questionnaire Part 1

The first part of the questionnaire contained a total of 77 items and assessed demographic information, aspects of the patient-carer relationship as well as personality traits. This part took approximately 10 minutes to complete.

Demographics and Background Information. The first 13 multiple-choice items asked about the demographic background of the respondents. This included: date of birth, gender, cultural background, years lived in Australia, educational level, employment status, gross annual household income, suburb, and the number of children. It further assessed respondents' relationship status, living situation and religious affiliation.

Patient-Carer Relationship Assessment. Six items were used to evaluate the nature and quality of the relationship between patients and carers. Two questions addressed the type and length of this relationship and the remaining four were derived from the Quality of Caregiver-Care-Recipient Relationship Scale. This tool was initially developed by Gronvold

(1988) as part of a longer scale to measure the quality of intergenerational relations and affectional solidarity within families. Ten years later, Lawrence, Tennstedt, and Assmann (1998) selected four items to assess the effects of relationship quality on caregiving burden, stressors and emotional well-being in caregivers of disabled older people. This version of the scale asked how close respondents' felt in their relationship, how well they could exchange ideas, how similar their views about life were, and how well they got along, In contrast to Lawrence et al. (1998), the current study used five instead of four response categories, which ranged from *not all close/ well/ similar* (1) to *very close/ well/ similar* (5). These changes were made for consistency purposes, as most other scales in the questionnaire also used five response options. Lawrence et al. (1998) reported a standardised Cronbach's alpha for their scale of .85. The current study found a Cronbach's alpha of .80, which shows good internal consistency of the test scale.

Personality and Value of Choice. Based on the Five-Factor theory by McCrae and John (1992), the 50-item version of the International Personality Item Pool (IPIP) was used to assess the personality traits: neuroticism, agreeableness, conscientiousness, extraversion and openness to new experiences (Goldberg, 1992). Each of the five dimensions was measured by ten personality-related statements, of which half were negatively phrased. The five response options ranged from *very inaccurate* (1) to *very accurate* (5). Goldberg (1992) reported a Cronbach's alpha for the subscales between .77 and .86. Similarly, in the current study, these ranged between .70 and .83, indicating good internal consistency. In addition to the Big Five, an 8-item Value-of-Choice scale was initially added to measure the importance of having and making medical choices. Ogden, Daniells, and Barnett (2008) had created and used this scale on non-terminal patients in general practices and found that having choices was more important to respondents than making them. In the current study, however, the Cronbach's alpha of these scales was poor, with .60 for having choices and .56 for making them. Due to the lack of internal consistency, the measure was later excluded from the analyses.

6.6.2 Questionnaire Part 2

The second part of the questionnaire had 107 items, which assessed patients' and carers' symptoms, end-of-life preferences and arrangements as well as previous discussions and experiences. This part took approximately 30 minutes to complete. When assessing each other's wishes and preferences, participants were asked to take different perspectives, usually starting with the patient's point of view and then moving on to the carer's. Each of these components will now be explained further.

Symptom Assessments. Participants were asked to rate the extent to which certain symptoms had been a problem within the last week. This assessment used the Symptoms-and-Concerns-Checklist by Lidstone et al. (2003). Eleven of the 29 items related to physical symptoms such as pain, constipation or shortness of breath. The remaining 18 items addressed psychological and cognitive symptoms as well as worries and concerns. These ranged from feeling depressed, fearful or angry to worries about important people in their lives or about the future. Lidstone et al. (2003) had used this scale with four-point response options to assess the needs of 480 outpatients with different types of cancer. However, they did not report measures of internal consistency in their study. To match the majority of the other scales in the current questionnaire, five response categories instead of four were used. These ranged from symptoms being *not at all* (1) to *very much* (5) of a problem. In the current study, Cronbach's alpha for this measure was .79. While most of the symptoms and concerns were specifically named, the checklist also included an additional undefined item labelled "*Other symptoms - Please specify*", which allowed participants to identify problems that were not in the list. Also, two of the items, which addressed concerns about work and intimate or sexual relationships, could be left blank if they were not applicable. The symptom assessment ended with two self-constructed questions that asked how participants felt overall, considering all parts of their life, and how much support they believed they had. Respondents were first asked to answer these 32 health-related questions in regard to the patient and then

in regard to the carer. When assessing the symptoms of their dyad partner, participants further had the option of responding with "*I don't know"* (6). This illness-related assessment was followed by questions about location preferences.

Location Preferences. Participants first rated their satisfaction with the current place of care from *very dissatisfied* (1) to *very satisfied* (5). Patients were then asked about their preferred place of care: "Given your current circumstances, where would you like to be cared for in your last days?" (Respectively, carers were asked where they would like the patient to be cared for in his or her last days.) This was followed by questions about their preferred place of death. Patients were asked: "Given your current circumstances, where would you like to be when you die?" (Congruently, carers were asked where they would like the patient to be when he or she dies.) These preferences for place of care and place of death were assessed using a hierarchical ranking. There were five response options, which included: hospital, nursing home, hospice, patient's/ carer's home and somebody else's home. Participants had to rank these options from *most* (1) to *least preferred* (5). They were then asked how important it was for them to achieve the first preference and avoid the last preference. They further rated the importance of their own participation in this decision and how likely they thought it was that they could influence the actual outcome. Response options could range from *not at all important/ likely* (1) to *very important/ likely* (5).

Past Experiences. Participants were asked how much experience they have had with hospitals, nursing homes, hospices and home care. Answers could range from *none* (1) to *a lot* (5). They then rated their overall experiences with each care setting from v*ery negative* (1) to *very positive* (5). Respondents were also asked how much their personal experiences with these treatment settings have influenced their place of care choices. Answers again varied from *not at all* (1) to *very much* (5).

End-of-Life Arrangements. Following on from this, participants were asked about their dyad partner's and their own end-of-life arrangements. This included whether they had made a living will, appointed a medical power of attorney, and wanted CPR. Further explanations about the meaning of these medical terms were given in plain language. Response options were *yes* (1), *no* (2), and *I don't know* (3). Patients were further asked to rate how confident they were that their carer knew about their arrangements and similarly, carers were asked about their confidence in knowing their patient's wishes. Answers could range from *not at all* (1) to *very confident* (5).

Discussions. Most components of the questionnaire consisted of self-contained sections that separately addressed the different concepts of interest. For instance, there was one distinct symptom section, one preference section, and so on. In contrast, questions regarding previous patient-carer discussions were included after each relevant component to follow a logical order of progression. For example, after assessing their own symptoms, participants were asked to what extent they had discussed these health issues with their dyad partner and how satisfied they were with these discussions. Response options ranged from *never* (1) to *very often* (5), and from *very dissatisfied* (1) to *very satisfied* (5), respectively.

Open-ended Comments. The questionnaire ended by asking for any final comments, highlighting the option of also participating in the interviews of Study 2, and offering to receive a study summary by postal mail. Table 6.2 summarises the measures used in the questionnaire.

Table 6.2

List of measures used in the questionnaire.

Construct	Measures	No. of Items
Demographics	Date of birth, gender, cultural background, time lived in Australia, education, employment status, household income, relationship status, number of children, living situation, suburb, religious affiliation and importance of spiritual beliefs	13
Interpersonal Aspects	Type and length of relationship	2
	Quality of caregiver-care-recipient relationship scale (Lawrence et al., 1998)[1]	4
Personality and Value of Choice	IPIP Big Five short scale (Goldberg, 1992)[2]	50
	Value-of-Choice Questionnaire (Ogden et al., 2008)[1]	8
Symptoms	Symptoms-and-Concerns-Checklist for physical and psychological symptoms (Lidstone et al., 2003)[1] Including overall well-being and perceived level of support	
	for patients and	32
	for caregivers	32
Location Preferences	Satisfaction with current location, preference for place of care and place of death of patients and carers, importance of location choice, perceived influence on the outcome	14
Past Experiences	Extent and quality of previous experiences with locations, perceived influence of experiences on location preference	9
End-of-life Arrangements	Living will, medical power of attorney, CPR and confidence in their assessment	
	for patients and	4
	for caregivers	4
Discussions	Extent of and satisfaction with previous discussions about symptoms, location preferences and end-of-life arrangements	12
Total		184

[1] *Note*: Permission obtained from author

[2] *Note*: Open source, no permission required

6.7 Data Handling and Statistical Considerations

All data collected was anonymised by assigning participant identification numbers. The questionnaire responses were coded and entered into IBM SPSS Statistics Version 23. In the design stages of the study, a series of logistic regressions was planned to examine which personal, interpersonal and illness-related factors predict end-of-life preferences. However, this analytical strategy had to be revised given the small sample size, especially in the patient group. Conducting regression analyses with 17 patients was not feasible, especially because most statistical references recommend at least 10 to 15 participants per predictor variable (Field, 2009, p. 222; Pituch & Stevens, 2016, pp. 121-123; Steptoe et al., 2010, p. 857). A range of questions in the survey also aimed to assess agreement in patient-caregiver pairs and more detailed investigations of this data were initially planned. Given the small number of dyads in the sample, however, some of these analyses were simply not reasonable and the overall analytical plan of Study 1 was therefore adjusted to account for these difficulties. As a consequence, a more descriptive approach had to be chosen.

Since the majority of the dependent variables were measured on a nominal or ordinal level, mainly non-parametric tests were used. More specifically, categorical variables were analysed with χ^2 or alternatively, with Fisher's exact tests whenever the expected cell frequencies were less than five. Mann-Whitney U tests were used to compare the ordinal or continuous medians and mean rank of two independent groups. This non-parametric version of the independent sample *t*-test was suggested to be more appropriate for small data sets because it does not require a normal distribution of the dependent variable and is robust to outliers (Laerd Statistics, 2015a; Mulhern & Greer, 2011, pp. 128-129). The distributions in the groups of interest were assessed by visual inspection of histograms. Laerd Statistics (2015a) advised reporting medians to illustrate group differences when distributions are similar, and mean ranks when they are dissimilar. For consistency, both medians and mean ranks will be presented in the respective analyses. All *p*-values of the Mann-Whitney U tests

conducted will be reported using the exact sampling distribution for *U* (Dinneen & Blakesley, 1973). To analyse paired observations within the same participant or within dyads, McNemar's test was used for binary dependent variables and Wilcoxon signed-rank test for ordinal variables. The strength and direction of two ordinal or continuous associations of paired groups was measured using Spearman's rank-order correlation, which again is robust to outliers and does not require normality. In general, outliers were kept in the data set as there was no evidence that they were based on any measurement or processing errors, and were hence considered valid data points.

Effect sizes were calculated where appropriate. Bornstein and Emler (2001) pointed out that researchers tend to focus on *p*-values as a substitute for effect sizes and assume that a significant *p* implies a large effect, whereas a non-significant one implies a trivial or meaningless effect. The *p*-value indicates the likelihood to find the observed effect if the null hypothesis was true, which is partly a function of the effect size but also dependent on the sample size. Hence, the Publication Manual of the American Psychological Association (2010) recommends reporting *p*-values as well as effect sizes whenever possible. Due to the small sample size in Study 1, reaching statistical significance was challenging and therefore, non-significant trends were considered if the effect sizes indicated it. For Mann-Whitney U and Wilcoxon signed-rank tests, *r* was used as an effect size measure, and for Fisher's Exact and χ^2 tests, odds ratios were calculated to examine the magnitude of the effects (Bowers, 2002, p. 92; Field, 2009, pp. 550, 558; see Appendix 6 for used formulae). As suggested by Cohen (2013), an *r* of .10 is considered a small effect whereas .30 represents a medium and .50 a large effect (pp. 79-80). Correspondingly, Rosenthal (1996) suggested that an odds ratio of 1.5 indicated a small, 2.5 a medium, 4 a large, and 10 a very large effect.

The data set for Study 1 consisted of 15 patient-caregiver pairs and additional 27 unpaired participants who completed the questionnaire individually. In accordance with the hypotheses, the first set of analyses used the entire sample of 57 participants to describe

respondents' location preferences and identify factors that influence them. In these analyses, both patients and carers were treated as separate groups. While assuming independence of the two groups is likely to underestimate potential associations, this conservative approach was chosen because approximately half of the sample did not have a matched dyad partner who could participate. It is worth noting that these missing partners were almost always the patients, rather than the carers. Furthermore, they were not missing randomly, but because they were often too sick to participate. Treating patients and carers as independent groups in the first set of analyses was also chosen for conceptual reasons to make clear statements about each group. The second set of analyses focussed on the 13 patients who had died during the study period and the 30 carers who had lost their patient during this time. Finally, the third set of analyses included only matched patient-carer dyads to analyse agreement in the pairs and compared them directly. Kappa was used to examine the level of agreement in these dyads. The classification of Landis and Koch (1977) suggests to assess a kappa of 0.00 to 0.20 as slight agreement, 0.21 to 0.40 as fair, and 0.41 to 0.60 as moderate agreement.

Following the publication guidelines of the American Psychological Association (2010), statistics presented in the following chapter will be rounded to two decimal places, with the exception of p, r and κ values. For readability, percentages without decimal places will be presented as whole numbers in the main body of the text. This means that, for example, 75.00% will be shortened to 75% because the decimal places do not add any further numerical information. In contrast, tables will consistently report two decimal places for all percentages and other descriptive statistics. The following chapter will now present the results of Study 1.

7

Results

Study 1

CHAPTER SEVEN

The aims of Study 1 were to describe location preferences in patients and carers, identify factors that influence these preferences, explore the relationship between preferred and actual place of death, and examine end-of-life agreement in patient-carer dyads. This chapter will outline the findings of Study 1. The characteristics of the sample will be presented first, followed by the results of the tested hypotheses.

7.1 Sample Characteristics

A total of 57 participants completed the questionnaire. This included: a subset of 15 patient-caregiver dyads; two individual patients; and 25 individual carers. The personal, interpersonal and illness-related background of this sample will now be described.

7.1.1 Personal Background

Patients were on average 67 years old and two-thirds of them were male. The majority of patients currently received an aged pension or were unemployed (88.24%). In contrast, carers were about ten years younger than patients and just under two-thirds of them were female. Exactly half of the carers were currently part- or full-time employed. Most participants identified themselves as Australian or New Zealanders, whereas approximately a third came from a European background (mainly English, Italian or Greek). Overall, 66.67% were married and 71.93% lived in a household with their partner or spouse. Participants had on average two children and over one-third currently had a child living with them in the same household. Around half of the respondents had attended school up to year 12 and reported a gross annual household income of up to 50,000AUD. Most of the participants were either Protestant or Catholic (61.40%), and their religious and spiritual beliefs were moderately important to them (M = 2.72, SD = 1.37, possible and observed range 1-5). Table 7.1 presents a detailed overview of the demographic background of the full sample.

Table 7.1

Demographic background of the full sample (N = 57)

	Patients *n* = 17	Caregivers *n* = 40
Average age in years (*SD*), Range	66.77 (12.54), 32-92 years	56.78 (13.56), 32-84 years
Percentage of females (exact number)	35.29% (6)	62.50% (25)
Cultural background		
Australian	70.59% (12)	62.50% (25)
New Zealand	5.88% (1)	2.50% (1)
European	23.53% (4)	35.00% (14)
Education		
Up to year 10	23.53% (4)	27.50% (11)
Up to year 12	35.29% (6)	22.50% (9)
Trade/ TAFE certificate	11.76% (2)	25.00% (10)
Undergraduate degree	23.53% (4)	15.00% (6)
Postgraduate degree	5.88% (1)	10.00% (4)
Employment status		
Not employed	41.18% (7)	15.00% (6)
Part-time employed	0.00% (0)	30.00% (12)
Full-time employed	5.88% (1)	20.00% (8)
Full-time house duties	0.00% (0)	7.50% (3)
Disability/ sickness benefits	5.88% (1)	7.50% (3)
Aged Pension	47.06% (8)	20.00% (8)
Annual household income		
Under 25,000AUD	17.65% (3)	17.50% (7)
25,000AUD - 50,000AUD	23.53% (4)	30.00% (12)
50,001AUD - 100,000AUD	11.76% (2)	22.50% (9)
100,001AUD - 150,000AUD+	17.75% (3)	15.00% (6)
Prefer not to say	11.76% (2)	10.00% (4)
Don’t know	17.65% (3)	5.00% (2)

Relationship status		
Single/ Never married	0.00% (0)	12.50% (5)
In a relationship	11.76% (2)	5.00% (2)
Married	58.82% (10)	70.00% (28)
Separated/ Divorced	17.65% (3)	12.50% (5)
Widowed	11.76% (2)	0.00% (0)
Children		
Having children	76.47% (13)	75.00% (30)
Average number of children (*SD*),	2.47 (1.94),	2.08 (1.97)
Range	0-8 children	0-9 children
Living situation		
Living alone	17.65% (3)	5.00% (2)
With partner/ no children in household	47.1% (8)	32.5% (13)
With partner and children	23.53% (4)	40.0% (16)
With children/ no partner	0.00% (0)	2.50% (1)
With relatives	11.76% (2)	20.0% (8)
Religious affiliation		
Protestant	41.18% (7)	20.00% (8)
Catholic	11.76% (2)	45.00% (18)
Buddhist	5.88% (1)	0.00% (0)
Agnostic	5.88% (1)	5.00% (2)
Atheist	23.53% (4)	17.50% (7)
Other (e.g. Orthodox, Jehovah's Witness, Brethren)	11.76% (2)	12.50% (5)

7.1.2 Interpersonal Background

Patients and carers had known each other on average for 42 years, which is not surprising given that the patient was often the carer's spouse or parent. Just under half of the carers reported that they had known the patient all their life (47.50%). Respondents rated the quality of their relationship as very high (*M* = 17.75, *SD* = 2.55, possible range: 4-20, observed range: 9-20). Table 7.2 provides an overview of the characteristics of the patient-caregiver relationship.

Table 7.2

Characteristics of the patient-carer relationship of the full sample (N = 57)

	Patients (*n* = 17)	Carers (*n* = 40)
Relationship type (exact numbers in brackets):		
The patient/carer is your...		
Current or former partner/ spouse	70.59% (12)	47.50% (19)
Parent	0.00% (0)	45.00% (18)
Child	29.41% (5)	0.00% (0)
Sibling	0.00% (0)	7.50% (3)
Length of the relationship in years	*M* = 37.12, *SD* = 15.68, 10-65 years	*M* = 44.65, *SD* = 14.79, 10-65 years
Quality of the relationship (Lawrence et al., 1998)	*M* = 18.65, *SD* = 1.58	*M* = 17.38, *SD* = 2.80

7.1.3 Illness-related Background

Overall, two-thirds of patients who took part in the study, or had their carer participate for them, presented with malignancies (28). On average, they had been diagnosed 3.54 years ago (*SD* = 5.78, observed range 0.1 - 29 years). The remaining one-third of patients had non-malignant diagnoses (14), such as renal failure, and severe heart or lung diseases, which had been diagnosed about 5.66 years ago (*SD* = 8.57, observed range 0.1 - 34 years).

Symptoms were assessed using the checklist by Lidstone et al. (2003) (see section 6.6.2). A symptom was recorded as present when it had been *moderately* (3), *quite a bit* (4) or *very much* (5) of a problem within the last week. Patients reported on average $M = 8.35$ of the 29 symptoms ($SD = 4.43$, observed range: 4-18). This included $M = 4.47$ physical problems ($SD = 2.32$) and $M = 3.88$ psychological symptoms ($SD = 2.83$). Table 7.3 presents the most frequently recorded symptoms and concerns of patients. Considering all parts of their life, including physical, emotional, spiritual and financial aspects, patients rated themselves as feeling *neutral* ($M = 3.47$, $SD = 1.01$) and as having *quite a bit* of help and support from others ($M = 4.35$, $SD = 0.86$).

Table 7.3

Ten most frequently reported symptoms and concerns of patients (n = 17)

Rank	Symptom or Concern of Patients	Patients' Symptom Ranking
1	Feeling weak, tired or lacking energy	$M = 4.24$, $SD = 0.97$
2	Not being able to do the things I usually do	$M = 3.53$, $SD = 1.33$
3	Worries or concerns about important people	$M = 2.88$, $SD = 1.54$
4	Mouth/ taste problems	$M = 2.82$, $SD = 1.55$
5	Shortness of breath or a cough	$M = 2.76$, $SD = 1.56$
6	Caring for yourself	$M = 2.65$, $SD = 1.32$
7	Pain	$M = 2.59$, $SD = 1.42$
8	Worries or concerns about future	$M = 2.47$, $SD = 1.46$
9	A change in appetite and/ or weight	$M = 2.47$, $SD = 1.46$
10	Constipation	$M = 2.35$, $SD = 1.32$

In contrast, carers reported on average $M = 7.93$ symptoms and concerns for themselves ($SD = 5.95$, observed range: 0-22), of which $M = 2.30$ were physical ($SD = 2.39$) and $M = 5.63$ were psychological symptoms ($SD = 4.47$). Table 7.4 summarises the ten highest ranked symptoms and concerns of carers. Taking everything into account, carers rated

themselves as feeling *neutral* (*M* = 3.18, *SD* = 0.90) and as having *quite a bit* of help and support from others (*M* = 3.63, *SD* = 1.13). It is worth noting that one item asked if work had been a problem within the past week, which could be left blank if it was not applicable to them. For the 67.50% of carers who did answer this question (27), work had been a moderate problem (*M* = 2.59, *SD* = 1.60), which would give it rank 6 if included in the list.

Table 7.4

Ten most frequently reported symptoms and concerns of carers (n = 40)

Rank	Symptom or Concern of Carers	Carers' Mean Ranking (*SD*)
1	Feeling tense, worried or fearful	*M* = 2.95, *SD* = 1.38
2	Sleeping problems	*M* = 2.93, *SD* = 1.37
3	Worries or concerns about important people	*M* = 2.90, *SD* = 1.48
4	Feeling weak, tired or lacking energy	*M* = 2.78, *SD* = 1.10
5	Feeling low in mood or depressed	*M* = 2.65, *SD* = 1.12
6	Feeling irritable or angry	*M* = 2.55, *SD* = 1.11
7	Worries or concerns about your future	*M* = 2.43, *SD* = 1.39
8	Change in appetite or weight	*M* = 2.30, *SD* = 1.40
9	Your finances	*M* = 2.25, *SD* = 1.45
10	Not being able to do the things you usually do	*M* = 2.23, *SD* = 1.44

7.2 Location Preferences of Patients and Caregivers

Four research questions were proposed for Study 1. The first question asked whether patients and carers differed in their location preferences and the views concerning the importance of this choice. The corresponding analyses used the full sample of all 57 recruited participants, which included 17 terminally ill patients and 40 family caregivers. The following section will present the results of these analyses.

7.2.1 Preferences for Place of Care and Place of Death

To address the hypothesis that ***caregivers would have a greater preference for an institutional place of care than patients***, participants were asked where they would like (the patient) to be cared for in their last days and rank the five given location options from most (1) to least preferred (5). As shown in Table 7.5, patients' most preferred place of care was their own or their carer's home, followed by hospice and hospital. In contrast, carers' first preference for the patient's place of care was hospice, followed by home and hospital. Nursing homes and somebody else's home received the lowest ratings from both patients and carers, making these the least preferred places of care.

Table 7.5

Mean rank and standard deviation of patients' and carers' place of care preferences (full sample N = 57)

Rank	Patients (n = 17)	Carers (n = 40)
1st	Patient's/ carer's home (M = 2.06, SD = 1.39)	Hospice (M = 2.03, SD = 1.10)
2nd	Hospice (M = 2.53, SD = 1.28)	Patient's/ carer's home (M = 2.35, SD = 1.35)
3rd	Hospital (M = 3.00, SD = 1.06)	Hospital (M = 2.50, SD = 0.99)
4th	Nursing home (M = 3.24, SD = 1.30)	Nursing home (M = 3.63, SD = 1.03)
5th	Somebody else's home (M = 4.18, SD = 1.24)	Somebody else's home (M = 4.50, SD = 0.91)

The ordinal rankings of patients and carers for each location were compared using Mann-Whitney U tests. Visual inspection of the histograms showed that the distributions in the groups were similar and hence, the results refer to the differences in the group medians (Laerd Statistics, 2015a). As summarised in Table 7.6, hospitals were ranked as marginally

more preferable by carers than by patients. The effect sizes also indicated small trends of carers having lower preferences for home and nursing home care and higher preferences for hospice care than patients. However, these effects did not reach statistical significance.

Table 7.6

Results of the Mann-Whitney U tests comparing patients' and carers' median place of care rankings (full sample N = 57)

	Patient		Carer		Mann-Whitney U			
Place of Care Ranking	*Mdn*	*Mean ranks*	*Mdn*	*Mean ranks*	*U*	*z*	*p*	*r*
Home	1.00	26.24	2.00	30.18	293.00	-0.87	.393	-.115
Hospice	2.00	33.44	2.00	27.11	264.50	-1.38	.171	-.183
Hospital	3.00	34.41	2.00	26.70	248.00	-1.68	.094	-.223
Nursing Home	3.00	25.68	4.00	30.41	283.50	-1.03	.305	-.136
Somebody else's home	5.00	27.06	5.00	29.83	307.00	-0.70	.500	-.093

Note: Higher numerical ratings mean lower preferences as rank 1 represents the most preferred place of care.

When focussing on respondents' first preference only, just under 60% of patients ranked home as their most preferred place of care, whereas the remaining 40% preferred an institutional setting (see Table 7.7). Interestingly, the pattern was reversed for carers. Here, 60% of carers ranked an institution as their first preference for place of care while the remaining 40% favoured home care for their patient. The odds of naming an institution as the most preferred place of care were 2.14 times higher for carers than for patients, 95% CI [0.67, 6.80]. However, χ^2 test showed no significant association between the two groups and their first binary preference, $\chi^2 = 1.70$, $p = .192$.

In summary, the effect sizes and odds ratios suggested a trend in family caregivers to have a greater preference for an institutional place of care than patients. While this provided some support for the initial hypothesis, these effects did not reach statistical significance.

Table 7.7

First preference of patients and carers for home versus institution in percent (full sample N = 57, exact numbers in brackets)

Place of care	Patients (*n* = 17)	Carers (*n* = 40)	Total (*N* = 57)
Patient's/ carer's home	58.82% (10)	40.00% (16)	45.6% (26)
Institution	41.18% (7)	60.00% (24)	54.4% (31)
Place of death			
Patient's/ carer's home	52.94% (9)	37.50% (15)	42.11% (24)
Institution	47.06% (8)	62.50% (25)	57.89% (33)

Participants were not only asked where they would like (the patient) to be cared for but also where they would like (the patient) to die. As shown in Table 7.7 above, 52.94% of patients wanted to die at home (9), yet only 37.50% of carers preferred this option for their patient (15). Hence, carers were 1.88 times more likely to prefer an institutional death for their patient compared to patients themselves, 95% CI [0.60, 5.91]. That said, this association was not statistically significant, $\chi^2 = 1.17$, $p = .280$.

To test whether ***respondents' preferences for place of care at the end of life would differ from their preferences for place of death***, a series of within-subject comparisons of these two questions was conducted. For 88.23% of patients (15) and 85% of carers (34), the first preference for place of care was the same as their first preference for place of death. For those eight participants who responded differently to the two questions, 50% (4) preferred home care and an institutional death, 25% (2) wanted to be cared for in an institution but die at home, and the remaining 25% (2) preferred care in one institution but death in another.

An exact McNemar's test showed no significant difference in the most preferred place of care and place of death in patients, $p = .999$, and carers, $p = .999$.

Going beyond the first preference, further testing explored whether any of the specific location rankings differed for place of care and place of death. As illustrated in Figure 7.1, 70.59% of patients (12) ranked all five place of care options in the same order as their options for place of death. The remaining 29.41% (5), however, changed at least one of their answers when asked about place of death instead. The same was found for carers, where 72.50% (29) responded with the same ranking for both questions, whereas the remaining 27.50% (11) changed at least one of their answers (see Figure 7.1).

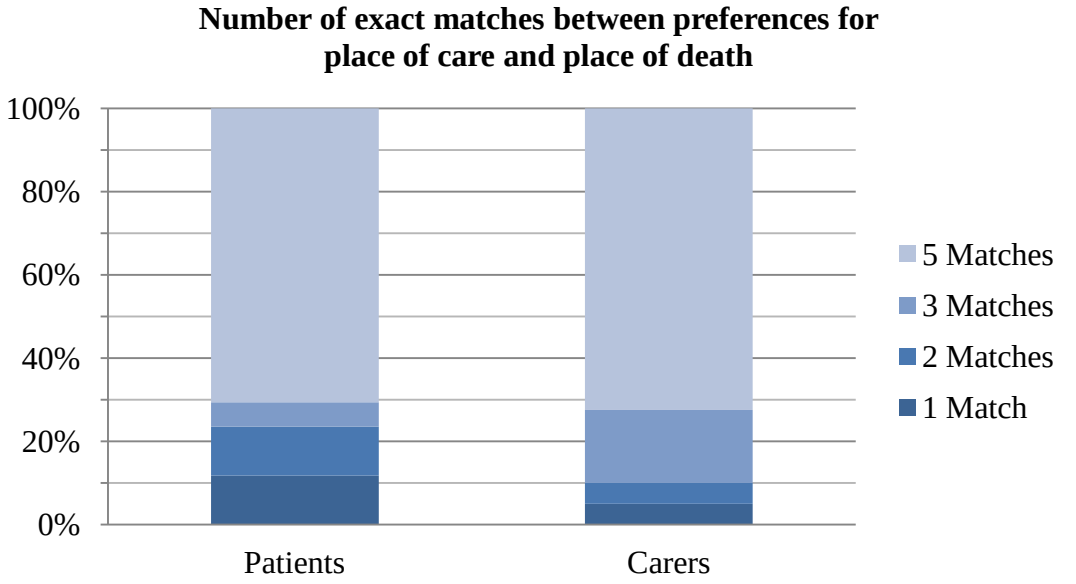

Figure 7.1. Exact matches between participants' place of care and place of death ranking (full sample $N = 57$); *Note*: Five matches mean that all five options for place of care were ranked in the same order as the ones for place of death.

Inspection of the histograms showed that the differences between the place of care and place of death rankings were symmetrical and therefore, a Wilcoxon signed-rank test was chosen to examine potential within-subject differences in the rankings. Small effects were found for patients' location ranking of home, hospice, nursing home and somebody else's home, as well as for carers' rankings of hospital and somebody else's home. However, none

of these differences in the place of care and place of death rankings reached statistical significance (see Table 7.8). An additional between-subject comparison also showed no significant difference in the number of preference matches between patients (*Mean rank* = 27.91) and carers (*Mean rank* = 29.46), $U = 321.50$, $z = -0.41$, $p = .683$, $r = -.054$. It can be concluded that, in contrast to the initial hypothesis, preferences for place of care and place of death did not differ for the majority of participants.

Table 7.8

Results of the Wilcoxon signed-rank test comparing participants' median rankings for place of care and place of death (full sample N = 57)

	Mdn Place of	*Mdn* Place of	Wilcoxon signed-rank test		
Patients (*n* = 17)	Care Rank	Death Rank	*z*	*p*	*r*
Home	1.00	1.00	-1.00	.317	-.171
Hospice	2.00	2.00	-1.09	.276	-.187
Hospital	3.00	3.00	-0.58	.564	-.099
Nursing Home	3.00	3.00	-1.00	.317	-.171
Somebody else's home	5.00	5.00	-0.81	.414	-.189
Carers (*n* = 40)					
Home	2.00	2.00	0.00	.999	-.000
Hospice	2.00	2.00	-0.58	.564	-.065
Hospital	2.00	2.00	-1.30	.194	-.145
Nursing Home	4.00	4.00	-0.14	.886	-.002
Somebody else's home	5.00	5.00	-1.13	.257	-.126

Note: Higher numerical ratings mean lower preferences as rank 1 represents the most preferred place of care and place of death.

7.2.2 Importance of Location Choices

Decisions concerning place of care and place of death were a central topic in every client review meeting at the participating sites. Mann-Whitney U tests were used to examine whether ***patients and caregivers would differ in their views concerning the importance of the location choice***. Distributions of the importance ratings in both groups were similar, as assessed by visual inspection of the histograms. Patients rated it as *very important* to achieve their first preference (M = 4.53, SD = 0.80) and avoid the last preference (M = 4.76, SD = 0.44). Participating in this decision was also *quite important* to them (M = 4.35, SD = 1.06). In comparison, carers perceived it as *quite important* to achieve their first preference (M = 4.03, SD = 1.27), avoid the last preference (M = 4.13, SD = 1.28) and participate in this decision (M = 4.48, SD = 0.96).

As shown in Table 7.9, none of the median ratings differed significantly between the patients and carers. However, the effect sizes indicated a small trend in patients to rate it as more important to achieve their first and avoid the last preference than carers did. In this regard, it is worth noting that carers' responses to these two questions varied considerably from *not at all important* (1) to *very important* (5). In contrast, patients' responses ranged only from *moderately* (3) to *very important* (5) and thus, none of the patients rated these issues as *not at all* (1) or *not very important* (2).

Table 7.9

Results of the Mann-Whitney U tests comparing patients' and carers' median importance ratings (full sample N = 57)

	Patients (n = 17)		Carers (n = 40)		Mann-Whitney U			
	Mdn	*Mean ranks*	*Mdn*	*Mean ranks*	*U*	*z*	*p*	*r*
Importance of...								
Achieving the first preference	5.00	33.15	5.00	27.24	269.50	-1.38	.179	-.183
Avoiding the last preference	5.00	33.59	5.00	27.05	269.20	-1.60	.115	-.212
Participating in the location decision	5.00	27.21	5.00	29.76	309.50	-0.64	.546	-.085

7.2.3 Summary of Location Preferences of Patients and Caregivers

In summary, there was a consistent, yet non-significant trend of carers to have a greater preference for an institutional place of care than patients did. The majority of participants ranked their place of care options in the same order as the ones for place of death. However, just under 30% of respondents changed at least one of their rankings between the two questions. Overall, the location decision was quite to very important for patients and carers. While both groups did not significantly differ in their views concerning the importance of this choice, the effect sizes indicated small trends in patients to rate the importance of achieving the first and avoiding the last preference higher than carers did. The next sections will examine which factors influenced location preferences of patients and carers.

7.3 Factors that Influence Place of Care Preferences

The second research question of Study 1 asked whether illness-related, personal and interpersonal factors influenced respondents' preferences for place of care at the end of life. The following sections will describe the findings of the analyses conducted, beginning with factors related to the illness.

7.3.1 Illness-related Factors

To examine whether ***a longer illness would be associated with a preference for an institutional care setting***, Mann-Whitney U tests were applied. The binary first preference for place of care at the end of life (home versus institution) was used as a grouping variable and the length of illness as the dependent variable. The distribution in both groups was similar, as assessed by visual inspection of the histogram. Patients who preferred an institutional place of care had been ill for significantly longer (*Mdn* = 5.00, *Mean rank* = 11.93) than those who favoured home care (*Mdn* = 1.75, *Mean rank* = 6.95), $U = 14.50$, $z = -2.02$, $p = .043$, $r = -.490$. In carers, a small but non-significant effect size suggested a similar trend (home: *Mdn* = 1.37, *Mean rank* = 19.00; institution: *Mdn* = 2.00, *Mean rank* = 21.50), $U = 168.00$, $z = -0.67$, $p = .521$, $r = -.106$.

Mann-Whitney U tests were also used to examine whether ***a higher number of reported symptoms would be associated with a preference for an institutional place of care***. Patients were asked to rate their physical and psychological symptoms and correspondingly, carers were asked to assess their patient's symptoms. As before, a symptom was recorded as present when it had been *moderately* (3), *quite a bit* (4) or *very much* (5) of a problem in the last week. The distributions in both groups were not similar, as assessed by visual inspection of the histograms and hence, the results represent the test of the mean ranks instead of the medians (Laerd Statistics, 2015a). The binary first preference for place of care was again used as the grouping variable and the number of symptoms as the dependent variable.

For patients, small to medium effect sizes indicated that more reported symptoms, both physical, psychological and overall, were associated with a preference for an institutional place of care. These differences, however, did not reach significance in the Mann-Whitney U tests conducted (see Table 7.10). With that in mind, there were three specific symptoms that were significantly or marginally associated with a preference for an institutional place of care amongst patients. These included physical issues like constipation, and psychological concerns such as problems with concentrating or remembering things, as well as concerns about not being given enough information about the illness or treatment (see Table 7.10).

Table 7.10

Summary of differences in symptoms reported by patients who preferred an institutional place of care or home care (n = 17)

	Home		Institution		Mann-Whitney U			
Number of symptoms	*Mdn*	*Mean Ranks*	*Mdn*	*Mean Ranks*	*U*	*z*	*p*	*r*
Symptoms Total	6.00	7.35	9.00	11.36	18.50	-1.62	.109	-.393
Psychological Concerns	3.00	7.85	5.00	10.64	23.50	-1.14	.270	-.276
Physical Symptoms	4.00	7.60	5.00	11.00	21.00	-1.40	.193	-.340
Specific symptoms	*Mdn*	*Mean Ranks*	*Mdn*	*Mean Ranks*	*U*	*z*	*p*	*r*
Constipation	1.50	6.35	4.00	12.79	8.50	-2.67	.007	-.648
Concentration/ memory	2.00	7.10	3.00	11.71	16.00	-1.93	.070	-.468
Lack of information	1.00	6.70	2.00	12.29	12.00	-2.64	.025	-.640

Patients' symptoms were not only assessed by patients themselves but also by caregivers. The total number of symptoms that carers reported for their patient as well as the number of psychological concerns was not significantly higher in carers who preferred an institutional place of care than in those who wanted home care (see Table 7.11). However, carers who favoured an institutional setting reported significantly more physical symptoms

for the patient than those who wanted home care at the end of life. This was supported by the effect sizes, which indicated a large effect of the physical symptoms. Furthermore, there were nine specific symptoms that were significantly associated with a higher preference for an institutional place of care amongst family caregivers (see Table 7.11). Physical problems included: pain; constipation; bladder/ urinary problems; mouth/ taste problems (e.g. dry/ sore mouth); swallowing problems. Psychological symptoms included: feeling low in mood or depressed; feeling tense, worried or fearful; feeling irritable or angry; and concerns about not being given enough information about the illness or treatment (see Table 7.11).

Table 7.11

Summary of differences in symptoms assessed by carers who preferred an institutional place of care or home care (n = 40).

	Home		Institution		Mann-Whitney U			
Number of symptoms	*Mdn*	*Mean Ranks*	*Mdn*	*Mean Ranks*	*U*	*z*	*p*	*r*
Symptoms Total	9.50	17.09	12.50	22.77	137.50	-1.51	.134	-.239
Psychological Concerns	5.00	19.06	6.00	21.46	169.00	-0.64	.539	-.101
Physical Symptoms	5.00	15.72	7.00	23.69	115.50	-2.14	.034	-.338
Specific symptoms	*Mdn*	*Mean Ranks*	*Mdn*	*Mean Ranks*	*U*	*z*	*p*	*r*
Constipation	1.00	13.53	4.50	25.15	80.50	-3.16	.002	-.500
Pain	2.00	14.34	3.00	24.60	93.50	-2.79	.006	-.441
Mouth/ taste problems	2.00	14.88	4.00	24.25	102.00	-2.26	.012	-.357
Swallowing	1.00	15.56	4.00	23.79	113.00	-2.26	.029	-.357
Low mood/ depressed	2.50	15.72	4.00	23.69	115.50	-2.18	.030	-.345
Tense/ worried/ fearful	2.00	15.72	4.00	23.69	115.50	-2.16	.034	-.341
Lack of information	1.00	15.78	2.50	23.65	116.50	-2.18	.036	-.345
Feeling irritable/angry	2.00	16.13	3.00	23.42	122.00	-1.98	.054	-.313
Bladder problems	1.00	16.22	3.00	23.35	123.50	-2.01	.058	-.318

In summary, there was evidence that location preferences were associated with illness-related factors. Patients who preferred institutional care had been ill significantly longer than those who wanted to be at home. Carers with a preference for an institutional place of care reported significantly more physical symptoms for their patients than those who preferred home care. A similar but non-significant trend was found in patients' self-reports. Effect sizes also indicated a small effect of psychological concerns in both groups. The next section will examine the influence of personal factors on location preferences.

7.3.2 Personal Factors

Personal factors that have been addressed in Study 1 included respondents' demographic background, personality traits and experiences. Regarding demographic factors, it was hypothesised that ***older participants, women, and those with a lower educational and socio-economic status would be more likely to prefer an institutional place of care than younger participants, men, and those with a higher educational and socio-economic status***. To compare the demographics of respondents who preferred home versus institutional care, Mann-Whitney U and Fisher's exact tests were used.

There was no gender difference in the ten patients who preferred home care, with five of them being male and five female (50%). In comparison to this, six of the seven patients who preferred an institutional place of care were, in fact, male (85.71%; see Table 7.12). The odds ratio showed that, in this sample, men were six times more likely to prefer an institutional setting over home compared to women, 95% CI [0.52, 69.76]. Due to the small cell count, Fisher's exact test was chosen to assess the significance of this gender effect. Despite the observed difference in the odds ratio, there was no statistically significant association between patients' gender and their preferred place of care, $p = .304$. The pattern for the carers, however, was reversed. Of the 24 carers who preferred an institutional place of care, 16 were female (66.67%) and only eight were male (33.33%). In contrast, nine female

carers wanted home care (56.25%) whereas only seven male carers did (43.75%). The odds ratio showed that female carers were 1.56 times more likely to prefer an institutional setting over home than male carers, 95% CI [0.42, 5.72]. However, this association was again not statistically significant, according to Fisher's exact test, $p = .527$. Hence, the hypothesis that women would be more likely to prefer an institutional place of care than men was not supported.

Table 7.12

Summary of gender differences of participants who preferred an institutional place of care or home care (full sample N = 57)

	First preference for place of care		
Patients (n = 17)	Patient's/ carer's home	Institution	Total
Male	5	6	11
Female	5	1	6
Carers (n = 40)			
Male	7	8	15
Female	9	16	25

To examine the effect of age, educational status and income, the binary location preference was used as a grouping variable in a series of Mann-Whitney U tests. The distribution of age in both groups was not similar, as assessed by visual inspection of the histograms. As shown in Table 7.13, there was no significant difference in age, education level and income of patients who preferred home or institutional care. The effect sizes did, however, indicate a medium trend that higher levels of income were associated with a home preference amongst patients. There were no significant differences in age, education level or income in those carers who preferred home versus institutional care (see Table 7.13).

Table 7.13

Summary of differences in age, educational level and income of participants who preferred an institutional place of care or home care (full sample N = 57)

	Home		Institution		Mann-Whitney U			
Patients (*n* = 17)	*Mdn*	*Mean Rank*	*Mdn*	*Mean Rank*	*U*	*z*	*p*	*r*
Age	66.98	9.10	66.15	8.86	34.00	-0.10	.962	-.024
Education level	2.00	8.70	2.00	9.43	32.00	-0.30	.813	-.073
Income	2.00	7.43	1.00	5.20	11.00	-1.08	.343	-.262
Carers (*n* = 40)	*Mdn*	*Mean Rank*	*Mdn*	*Mean Rank*	*U*	*z*	*p*	*r*
Age	58.15	20.63	55.33	29.42	190.00	-0.06	.967	-.009
Education level	2.50	20.44	2.50	20.54	191.00	-0.03	.989	-.005
Income	2.00	17.23	2.00	17.63	123.50	-0.11	.913	-.017

Note on education level: *Mdn* = 2.00 equals up to year 12.

Note on income: *Mdn* = 1.00 equals up to 25,000 AUD and *Mdn* = 2.00 equals up to 50,000 AUD per year. Also note that the income analysis was based on *n* = 12 patients and *n* = 34 carers, excluding those who did not know their annual income or preferred not to say.

In summary, the analyses showed mixed findings regarding the role of demographic factors. Contrary to the initial hypothesis, there was a non-significant trend of male rather than female patients to favour an institutional place of care. Similarly, a medium but non-significant effect of income was found, which suggested that patients with an institutional preference came more often from a lower socio-economic background than those who wanted home care. Age and education were not associated with a specific location preference in either patients or carers.

In addition to the demographic background of the respondents, the influence of personality traits on location preferences was examined. Given the paucity of research in this area, no specific hypotheses had been suggested. Instead, the analyses were exploratory. To ***examine the potential relationship between location preferences and the Big Five personality traits***, a series of Mann-Whitney U tests was conducted. The binary first preference for place of care was used as a grouping variable. Distributions of the personality scores in the two groups were not similar, as assessed by visual inspection of the histograms. Patients who preferred home versus institutional care did not differ significantly in any of the five personality dimensions (see Table 7.14). The effect sizes, nonetheless, did indicate small to medium effects of three personality traits. Specifically, there was a trend that higher openness, lower agreeableness and lower extraversion scores were associated with a preference for an institutional place of care in patients (see Table 7.14).

Table 7.14

Summary of differences in Big Five personality traits of patients who preferred an institutional place of care or home care (n = 17)

	Home		Institution		Mann-Whitney U			
Big Five traits	*Mdn*	*Mean Rank*	*Mdn*	*Mean Rank*	*U*	*z*	*p*	*r*
Openness	29.50	7.95	37.00	10.50	24.50	-1.03	.315	-.250
Conscientiousness	37.00	9.40	35.00	8.43	31.00	-0.39	.740	-.095
Extraversion	36.00	10.70	31.00	6.57	18.00	-1.67	.109	-.405
Agreeableness	41.00	10.55	35.00	6.79	19.50	-1.52	.133	-.369
Neuroticism	20.00	8.65	20.00	9.50	31.50	-0.34	.740	-.082

Note: The possible range of each subscale was 10 to 50.

Similar to patients, carers with a preference for home versus institutional care did not differ significantly in any of the five personality dimensions (see Table 7.15). However, the effect sizes indicated small effects for two personality traits: there was a trend that higher openness and lower conscientiousness scores were associated with a carer preference for an institutional place of care.

Table 7.15

Summary of differences in Big Five personality traits of carers who preferred an institutional place of care or home care (n = 40)

	Home		Institution		Mann-Whitney U			
Big Five traits	*Mdn*	*Mean Rank*	*Mdn*	*Mean Rank*	*U*	*z*	*p*	*r*
Openness	31.00	18.47	35.00	21.85	159.50	-0.90	.374	-.142
Conscientiousness	39.00	22.34	37.00	19.27	162.50	-0.82	.420	-.130
Extraversion	30.00	19.16	31.50	21.40	170.50	-0.60	.557	-.095
Agreeableness	40.00	20.78	40.00	20.31	187.50	-0.13	.902	-.021
Neuroticism	29.50	20.72	26.50	20.35	188.50	-0.10	.924	-.016

In summary, the relationship between personality traits and location preferences was only observable in the effect sizes. A preference for institutional care tended to be associated with higher openness, lower agreeableness and lower extraversion in patients, and with higher openness and lower conscientiousness in carers.

Past experiences with different care settings were also believed to influence respondents' location preferences. As summarised in Table 7.16, patients and carers stated that they had *quite a bit* of hospital experience, which they rated overall as *quite positive*. On average, they also reported having had *none* to *a little* nursing home and hospice experience, which was consequently rated as *neither positive nor negative*. Finally, patients and carers had only *a little* experience with home care, which they rated to as *quite positive*.

Table 7.16

Means, standard deviations and medians of the amount and quality of previous experiences with different treatment settings rated by patients and carers (full sample N = 57)

	Patients (*n* = 17)			Carers (*n* = 40)		
Amount of Experience	*M*	*SD*	*Mdn*	*M*	*SD*	*Mdn*
Hospital	3.71	1.05	4.00	3.98	1.05	4.00
Nursing Home	1.53	0.87	1.00	1.85	1.05	1.00
Hospice	2.12	1.36	2.00	1.78	0.97	1.00
Home	2.35	1.27	2.00	2.50	1.26	2.00
Quality of Experience	*M*	*SD*	*Mdn*	*M*	*SD*	*Mdn*
Hospital	4.24	0.83	4.00	4.03	0.66	4.00
Nursing Home	2.65	0.79	3.00	2.90	0.93	3.00
Hospice	3.59	1.23	3.00	3.43	0.87	3.00
Home	3.82	0.88	4.00	3.58	0.78	4.00

It was hypothesised that ***the amount and quality of previous experiences with each place of care would correlate positively with the preference rank of that location***. Due to the ordinal nature of the measure, Spearman's rank-order correlations were chosen to test this hypothesis. The relationships between the location rankings and the experience variables were monotonic, as assessed by visual inspection of the scatter plots. For patients, there were small to medium but non-significant correlations between the amount of experiences and their preference for place of care (see Table 7.17). These trends suggested that more

experience with hospices was associated with a higher preference ranking for hospice care. However, more hospital and nursing home experience tended to correlate with a lower preference for these settings. Most surprisingly, more experience with home care also tended to be associated with a lower preference for home. Inspection of the scatter plot showed that this negative association was mainly caused by the default preference for home care in patients even if they had no or very little home care experience. Regarding the quality of past experiences, non-significant trends indicated that higher satisfaction with experiences tended to correlate with higher preference ranks for these locations (see Table 7.17).

Table 7.17

Spearman's rank order correlation of patients' location preferences and their previous experiences with these settings (n = 17)

	Amount of experience		Quality of experience	
Location Preference Rank	r_s	*p*	r_s	*p*
Hospital	-.365	.149	.203	.435
Hospice	.195	.453	.416	.097
Nursing Home	-.372	.141	.370	.143
Home	-.205	.430	.128	.623

Note: For better readability, the location ranks were reverse-coded for this analysis so that higher numerical ranks represented a stronger preference for that location. Hence, a positive correlation suggests that more experience with a care setting was associated with a stronger preference for that setting.

For carers, greater amounts of hospice experience correlated significantly with a higher preference for that location. There were further medium but non-significant negative effect sizes indicating that more hospital and home care experience tended to be associated with a lower preference for these places of care (see Table 7.18). Regarding the quality of the

experiences that carers reported, higher satisfaction with hospice and nursing home experiences correlated significantly with a higher preference for that location.

Table 7.18

Spearman's rank order correlation of carers' location preference and their previous experiences with these locations (n = 40)

	Amount of experience		Quality of experience	
Location Preference Rank	r_s	*p*	r_s	*p*
Hospital	-.249	.122	.029	.857
Hospice	.652	.001	.536	.001
Nursing Home	.044	.786	.332	.036
Home	-.200	.215	.024	.885

Note: As before, ranks have been reverse-coded for this analysis.

Interestingly, most participants felt that their past experiences with different treatment settings had only *moderately* influenced their preferences for place of care (patients: $M = 3.00$, $SD = 1.46$; carers: $M = 2.90$, $SD = 1.26$).

To summarise, past experiences with treatment settings correlated with current preferences for future places of care. Yet, contrary to the initial hypothesis, more experience did not always mean a stronger preference, as would have been expected according to the mere exposure effect. There were non-significant trends in both groups suggesting that more hospital and home care experiences were associated with a lower preference for these settings. The one exception was hospice care. More hospice experience was significantly associated with a higher preference for this care setting amongst family caregivers. A similar, yet non-significant, trend was also found in patients. As predicted, the perceived quality of previous experiences correlated positively with a preference for these locations. These effects were significant for hospice and nursing home care amongst carers and marginally significant for hospice care amongst patients.

Not only past but also current experiences were believed to influence participants' preferences. Specifically, it was predicted that ***respondents who were currently at home would be more likely to prefer home care at the end of life than respondents who were currently in an institutional setting***. On the one hand, 47.06% of patients were presently cared for at home (8) and of these, 75% also wanted to be at home for future end-of-life care (6). On the other hand, 52.94% of patients were currently receiving care in an institution (9) and of these, 55.55% also preferred institutional care at the end of life (5). These findings are depicted in Figure 7.2, in which the shaded areas illustrate the match between the preferred and current place of death. According to the odds ratio, patients who were presently receiving care at home were 3.75 times more likely to express a preference for home care at the end of life than patients who were currently in an institution, 95% CI [0.47, 29.75]. This is a medium effect according to the classification of Rosenthal (1996). However, the association between current and preferred place of care was not statistically significant, according to Fisher's exact test, $p = .335$.

As shown in Figure 7.2 below, 22.50% of carers took care of their patient at home (9) and of those, 66.67% also favoured home care for the patient at the end of life (6). In comparison, 77.50% of all carers currently supported their patient in an institutional setting (31) and of those, 67.74% also preferred that their patient receive end-of-life care in an institution (21). The odds ratio showed that family carers in an institutional setting were 4.2 times more likely to prefer institutional end-of-life care for their patient than those who had been recruited from home, 95% CI [0.87, 20.33]. This is a large effect according to Rosenthal (1996), although, it did not reach statistical significance in a Fisher's exact test, $p = .120$.

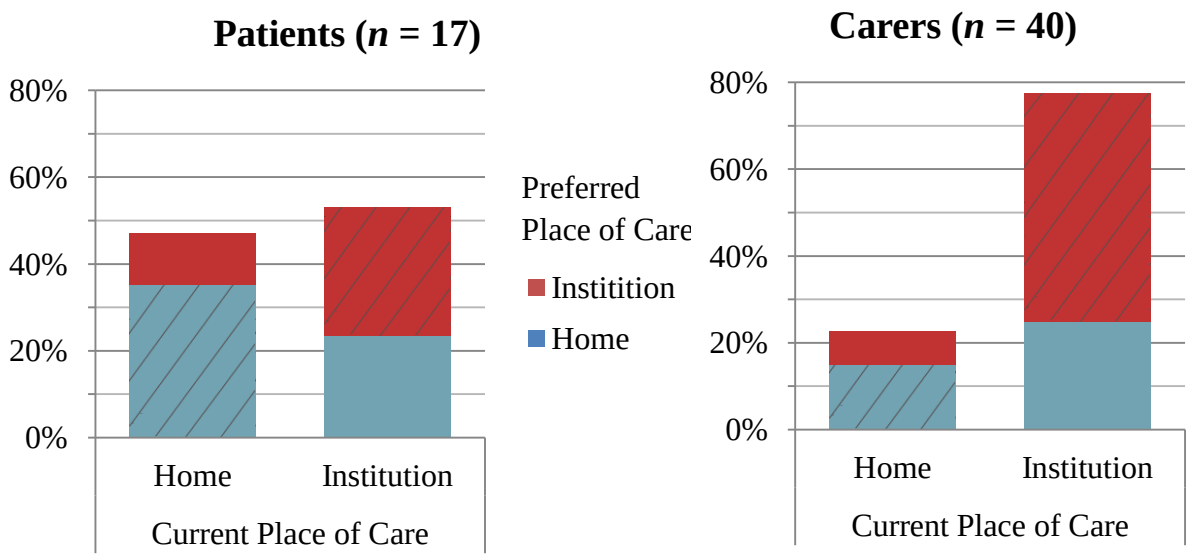

Figure 7.2. Patients' and carers' first preference for place of care in percent according to their current place of care (full sample N = 57). *Note*: Shaded areas illustrate the match between the current and preferred place of care.

In summary, not only past but also current experiences with treatment settings influenced respondents' decision making. There was a non-significant trend in both patients and carers to prefer a place for end-of-life care that matched their current place of care. Moving on from factors within the individual, the next section will now examine the effects of interpersonal variables on location preferences.

7.3.3 Interpersonal Factors

To test the hypothesis that ***the length and perceived quality of the patient-caregiver relationship would correlate positively with the preference rank of home care***, Spearman's rank-order correlations were conducted. The relationship between the ordinal home ranking and the interpersonal variables were monotonic, as assessed by visual inspection of a scatter plot. A medium but non-significant trend suggested that longer relationships tended to correlate with a higher preference for home care in patients (r_s = .307, p = .231) but not in carers (r_s = .076, p = .643). However, there was a significant correlation between the quality

of the relationship and the home rank in both patients (r_s = .608, p = .010) and carers (r_s = .342, p = .031). Hence, the initial hypothesis was partly supported. While the length of the patient-carer relationship was not significantly associated with a certain location preference, the quality of the relationship correlated positively with the preference for home care at the end of life.

7.3.4 Summary of the Influences on Location Preferences

The second research question examined the influence of illness-related, personal and interpersonal factors on participants' location preferences. Longer illnesses were significantly associated with a higher preference for an institutional place of care in patients. A similar but non-significant trend was found in carers. The number and type of symptoms also influenced respondents' preferences. Specifically, carers who favoured an institutional place of care reported significantly more physical symptoms for their patient than those who preferred home care. A comparable, yet non-significant trend was observed in patients.

The analyses of personal factors yielded mixed findings. While age and education were not associated with a certain preference for a place of care at the end of life, there were non-significant trends regarding gender and income. Male patients, as well as those from lower socio-economic backgrounds, tended to prefer an institutional place of care more than female patients and those from higher socio-economic backgrounds. Personality also showed only non-significant trends with regard to participants' choices. A preference for an institutional place of care appeared to be associated with high openness, low agreeableness and low extraversion scores in patients, and high openness and low conscientiousness scores in carers. Furthermore, past and present experiences with different treatment settings had a bearing on future location choices. More hospice experience was associated with a higher preference for this setting. However, the effects for some of the other care settings were reversed. Surprisingly, there were trends of more hospital and home care experience being

connected with a lower preference for these settings in patients and carers. Furthermore, there were non-significant but medium to large effects of the current experiences on respondents' preferences. In both groups, home care was favoured by those who were presently at home and similarly, institutional care was preferred by those who were currently in an institution.

Regarding interpersonal factors, the quality rather than the length of the patient-carer relationship seemed to influence respondents' preferences. The perceived quality of the relationship correlated significantly with a higher the preference for home care. After examining location preferences in detail, the next set of analyses will now focus on patients' actual place of death.

7.4 Actual Place of Death

The third research question of Study 1 asked whether the actual place of death would be associated with the initial preference and previous discussions about one's wishes. Of the 17 patients who had completed the questionnaire, 13 were no longer living by the beginning of data analysis (76.47%). Overall, six had died at home and seven in an institutional setting. Similarly, 30 of the 40 carers had lost their patient during the study (75%), of whom six had died at home and 24 in an institution. Patients died on average less than three months after their own or their carers' participation in the study (M = 85.24 days, SD = 82.27, Mdn = 46.00). The survival rate was not normally distributed, as assessed by Shapiro-Wilk's test ($p < .01$). Hence, a Mann-Whitney U test was chosen to compare the length of survival in both types of settings. Participants who had been recruited from home survived significantly longer (M = 203.00 days, SD = 51.49, Mdn = 203.00) than those who had been recruited from an institution (M = 54.52 days, SD = 56.95, Mdn = 37.00), U = 6.00, z = -3.396, $p < .001$, r = -.631.

It is noteworthy that participants had died most often in the place they had been recruited from. Recruitment location and actual place of death matched for 76.92% of the

patients (10) and 83.33% of the carers (25). Fisher's exact test showed a significant association between recruitment site and place of death for patients, $p = .002$, and carers, $p < .001$. The effect of preferences and previous discussions on the actual place of death will now be addressed.

7.4.1 Influence of Initial Location Preferences on the Actual Place of Death

To examine the influence of respondents' preference on their actual place of death, participants' first preference for a place of death was used instead of their preference for place of care. As the previous analyses had suggested that for some participants these were separate questions, it was most appropriate to focus on their preferences for place of death in the analyses that concerned their actual place of death. It was hypothesised that ***respondents with a preference for home death would be more likely to die at home than those with a preference for an institutional death***. Of the 13 patients who had died during the study, 53.85% had preferred to pass away at home (7). Of these, 71.43% achieved their preference (5). Similarly, of the 46.15% of patients who had favoured an institutional place of death (6), 83.33% achieved their wish (5). This is illustrated in Figure 7.3, in which the shaded areas indicate the match between the preferred and actual place of death. According to the odds ratio, patients with a preference for a home death were 12.5 times more likely to die there than those who preferred death in an institution, 95% CI [0.84, 186.31]. This is a very large effect according to the classification of Rosenthal (1996). Yet, Fisher's exact tests showed no significant association between the binary preferred and actual place of death, $p = .103$.

In contrast to patients, of the 30 carers who had lost their patient during the study, only 33.33% wanted their patient to die at home (10) and of these, 40% achieved this (4). The remaining 66.67% of carers had preferred an institutional place of death for the patient (20) and 90% of them achieved this (18). Hence, carers who wanted their patients to die at home were six times more likely to fulfil this preference than those carers who favoured an

institutional death, 95% CI [0.87, 41.44]. This is a large effect according to Rosenthal (1996). Yet, again, Fisher's exact tests showed no statistically significant association between carer's preference and patient's actual place of death, p = .141.

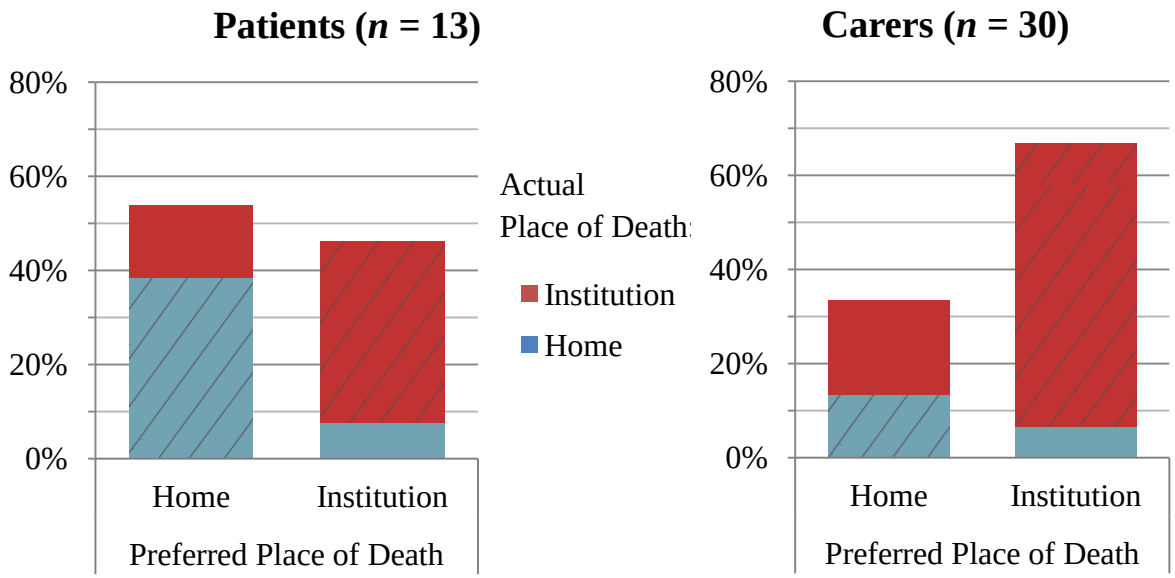

Figure 7.3. Preferred and actual place of death according to patients and carers in percent (sub-sample of confirmed deaths n = 43). *Note*: Shaded areas illustrate a match between preferred and actual place of death.

7.4.2 Influence of Previous Discussions on the Actual Place of Death

To explore the role of previous discussions about location choices in achieving one's preferences, respondents were asked how much they had talked about their wishes with their patient or carer. The 13 patients who had died during the study reported that they had discussed their preferences only *occasionally* (M = 3.15, SD = 1.46), but overall felt *quite satisfied* with these discussions (M = 4.08, SD = 0.86) and *quite confident* that their carer would know their location preferences (M = 4.23, SD = 1.30). With that in mind, patients' confidence levels ranged considerably from *not at all* to *very confident* (1-5). The 30 carers who had lost their patient during the study also reported occasional discussions with the patient about their wishes (M = 2.73, SD = 1.41). Much like patients, they felt *quite satisfied*

with these discussions (*M* = 3.60, *SD* = 1.35) and *quite confident* that they would know their patient's location preferences (*M* = 4.43, *SD* = 0.77). Their responses ranged from *not very confident* to *very confident* (2-5).

It was hypothesised that ***participants who died in their preferred place would have had more discussions about their preferences than those who did not die in their preferred place.*** A binary, within-subject variable was calculated to assess whether participants' first preference for place of death matched the actual place of death. This was used as the grouping variable in the Mann-Whitney U tests conducted. The distribution of the reported discussions in the two groups was not similar, as assessed by visual inspection of the histogram. There was no significant difference in the extent of discussions for those who had achieved their preference and those who had not (see Table 7.19). However, the effect sizes indicated a medium trend that more discussions had been reported by patients who did not achieve their preference. Interestingly, the opposite seemed to apply to carers. In accordance with the initial hypothesis, there was a marginal effect indicating that carers who had achieved their location preference had also discussed this preference more with the patient than those who had not achieved their wish.

Table 7.19

Summary of patients' and carers' extent of location discussions for those who had, and had not, achieved their preference (sub-sample of confirmed deaths n = 43)

	Preferred and actual place of death							
	Match		Mismatch		Mann-Whitney U			
Extent of discussion	*Mdn*	*Mean Rank*	*Mdn*	*Mean Rank*	*U*	*z*	*p*	*r*
Patients (*n* = 13)	3.00	6.35	4.00	9.17	8.50	-1.15	.287	-.319
Carers (*n* = 30)	3.00	17.16	1.00	10.94	51.50	-1.77	.087	-.323

7.4.3 Summary regarding the Actual Place of Death

By the beginning of data analysis, about two-thirds of patients in Study 1 had died. The majority had passed away in an institutional setting. More specifically, participants had died most often in the place they had been recruited from. About three-quarters of patients and carers achieved their preference for a place of death. However, the association between preferred and actual place of death did not reach statistical significance. There were conflicting findings regarding the effect of discussions. For patients, there was a non-significant trend that more discussions had occurred in the group that did not die in their preferred place. In contrast, carers who had achieved their preference for place of death reported marginally more discussions than those who had not achieved their wish. The final set of analyses will now examine the subset of matched patient-caregiver dyads.

7.5 Agreement and Accuracy of Carer Assessments

The fourth and final research question of Study 1 asked to what extent patient-carer dyads would agree regarding their location preferences and how accurate carers' assessments of patients' wishes and symptoms would be. At first glance, these analyses may appear to be similar to the ones presented under research question 1 (Do patients and carers differ in their location preferences? - See section 7.2.1) and aspects related to research question 2 (Is the number of symptoms associated with a certain location preference? - See section 7.3.1). However, the previous analyses aimed to examine location preferences in the full sample to make statements about patients and carers as independent groups. In contrast, the following analyses will focus on a subset of 15 patient-carer dyads. This paired data is particularly valuable as it allows one to directly compare carers' estimates with patients' self-reports. Hence, accuracy of predictions and the levels of agreement in these matched dyads can be examined.

7.5.1 Agreement regarding Location Preferences

Pair-wise agreement was recorded when patient's first preference for one of the five location options was identical with the preference of their family caregiver. Regarding place of care, 66.67% (10) of the 15 recruited pairs matched in their first preference (see Table 7.20). Kappa analysis showed fair agreement between the patients and carers, $\kappa = .390$, 95% CI [0.03, 0.75], $p = .023$, using the classification of Landis and Koch (1977). In regard to place of death preferences, only 53.33% of patient and carer dyads agreed (8), which was not statistically significant, $\kappa = .271$, 95% CI [0.09, 0.45], $p = .123$.

Table 7.20

Patient-Carer Agreement regarding place of care and place of death (dyads only n = 15)

		Patient's preference				
		Hospital	Nursing Home	Hospice	Home	Total
Place of care						
Carer's preference for the patient	Hospital	**1**	0	1	1	3
	Nursing Home	0	**0**	0	0	0
	Hospice	0	1	**1**	1	3
	Home	0	0	1	**8**	9
	Total	1	1	3	10	15
Place of death						
Carer's preference for the patient	Hospital	**2**	0	1	0	3
	Nursing Home	0	**0**	0	0	0
	Hospice	1	0	**1**	1	4
	Home	2	0	2	**5**	9
	Total	1	0	4	6	15

Note: Numbers in bold illustrate when patients and carers agreed on their first preference.

It was hypothesised that ***patient-carer dyads who agreed regarding their preference for place of death would be more likely to achieve this preference than dyads who did not agree***. Of the 15 recruited pairs, 11 patients had died by the beginning of data analysis (73.33%). Of the five pairs that had agreed regarding their first preference for place of death, all had achieved this preference. In contrast, of the six pairs who had different preferences, three achieved the patient's wish, one fulfilled the carer's preference, and two passed away in a setting that had been favoured by neither patient nor carer. To calculate the odds ratio in this analysis, a zero cell count correction was necessary. The continuity approach was chosen by adding a small constant of 0.5 to all four cells of the 2 x 2 contingency table (Cox, 1970). The odds ratio showed that patients were 11 times more likely to achieve their preference when they agreed with their carer, 95% CI [0.43, 284.32]. Carers were even 40.33 times more likely to achieve their wish if they agreed with the patient, 95% CI [1.33, 1223.05]. In both groups, these represent very large effects according to the classification of Rosenthal (1996). Fisher's exact test showed a statistically significant association between the preference match in dyads and achieving the preference of carers, $p = .015$, but not of patients, $p = .182$.

7.5.2 Accuracy of Assessments regarding End-of-Life Arrangements

It was hypothesised that ***caregivers would differ in their assessments from patients' self-reports concerning the patient's CPR preferences and end-of-life arrangements such as having a living will and a medical power of attorney***. Table 7.21 shows the overall responses of the patient-caregiver pairs in regard to these three questions.

Table 7.21

Patients' preference for CPR, as well as living will and medical power of attorney arrangements, and carers' assessment of patients' wishes in percent (dyads only n = 15, exact numbers in brackets)

Do you want/ does the patient want CPR?	Patients (n = 15)	Carers (n = 15)
Yes	26.67% (4)	20.00% (3)
No	53.33% (8)	60.00% (9)
Don't know	20.00% (3)	20.00% (3)
Do you have/ does the patient have a living will?		
Yes	80.00% (12)	66.67% (10)
No	20.00% (3)	26.67% (4)
Don't know	0.00% (0)	6.67% (1)
Do you have/ does the patient have a medical power of attorney?		
Yes	86.67% (13)	60.00% (9)
No	13.33% (2)	33.33% (5)
Don't know	0.00% (0)	6.67% (1)

A case-by-case comparison of the dyads showed that eight out of 15 patients (53.33%) did not want CPR, which was correctly assessed by 75% of the carers (6). On the other hand, four out of 15 patients (26.67%) did want CPR, which was only guessed correctly by 25% of carers (1). The remaining three patients were unsure about their wishes (20%). Overall, patients' and carers' answers regarding CPR did not match in 53.33% of cases (8), as depicted in Figure 7.4. Kappa analysis showed that the agreement between patients' and carers' CPR responses was not significant, $\kappa = .091$, $p = .627$. Hence, there was evidence for the hypothesis that carers differed in their assessments from patients' self-reports concerning CPR.

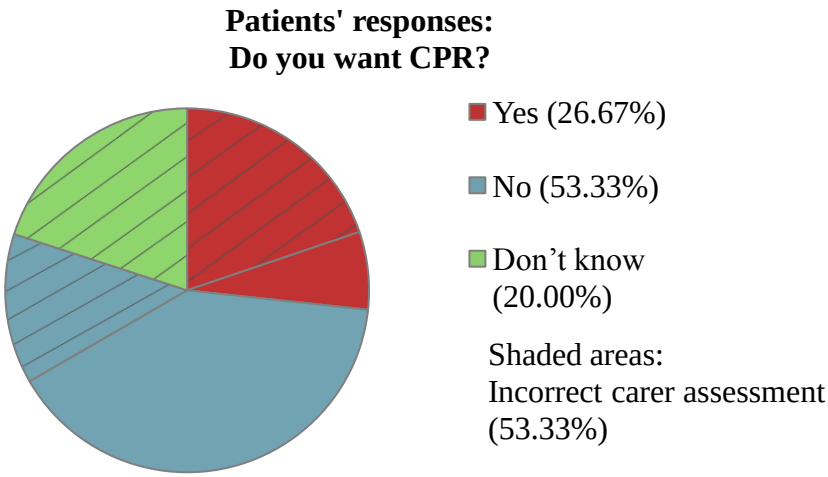

Figure 7.4. Percentage of patients' responses and carers' assessments in regard to the patient's preference for CPR (dyads only $n = 15$).

As illustrated in the figure below, 12 out of 15 patients (80%) reported having made a living will, which was correctly assessed by 75% of the carers (9). The remaining three patients (20%) did not have a living will, which was correctly assessed by 66.67% of the carers (2). Overall, patients' and carers' responses in regard to the patients' living will arrangements matched in 73.33% (11) and their level of agreement was fair, $\kappa = .355$, $p = .106$. Based on this, the evidence did not support the hypothesis that carers differed in their assessments from patients' self-reports concerning living will arrangements.

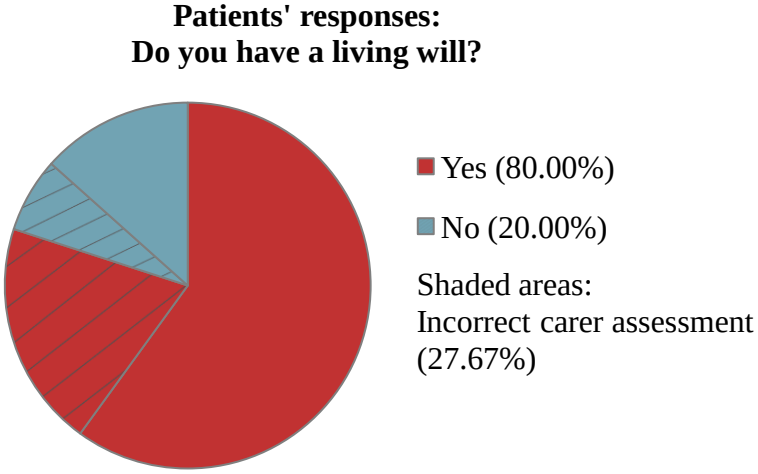

Figure 7.5. Percentage of patients' responses and carers' assessment in regard to having a living will.

Finally, as illustrated in Figure 7.6 below, 13 out of 15 patients (86.7%) reported that they had appointed a medical power of attorney, which was correctly assessed by 69.23% of carers (9). Two patients did not have a medical power of attorney (13.33%), which was correctly assessed by all of the carers (2). Hence, patients' and carers' responses matched in 73.33% of the cases (11). Agreement in regard to this question was fair, $\kappa = .388$, $p = .038$. Hence, there was no support for the hypothesis that carers differed in their assessments from patients' self-reports concerning their appointment of a medical power of attorney.

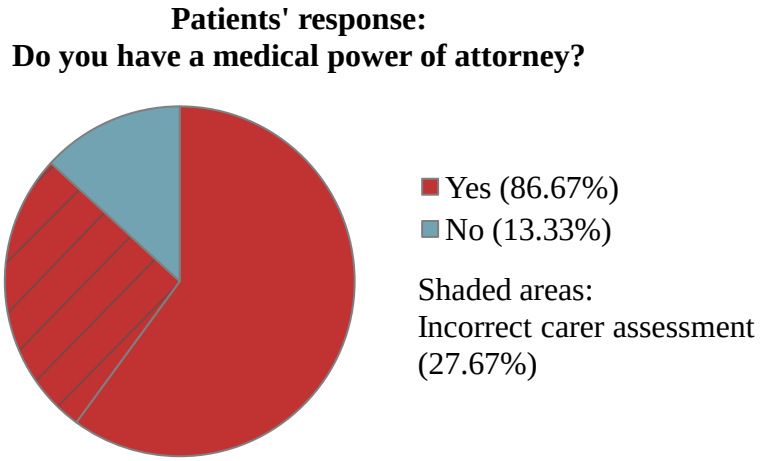

Figure 7.6. Percentage of patients' responses and carers' assessment in regard to having a medical power of attorney (dyads only $n = 15$).

7.5.3 Accuracy of Symptom Assessments

To examine how well carers would evaluate their patients' symptoms, carers' assessments were again compared to patients' self-reports. Overall, 42.5% of caregivers (17) responded that they did not know at least one of their patient's symptoms ($M = 2.13$, $SD = 3.44$, observed range 0-12). It was hypothesised that ***carers would report more symptoms for their patient than patients themselves***, which was defined as symptom overestimation. Given the small sample size of 15 dyads and the presence of an outlier, the more robust Wilcoxon signed-rank test was chosen to examine the median differences

between the number of reported symptoms in the patient-caregiver pairs (Laerd Statistics, 2015b). The score differences of patients and carers were symmetrically distributed, which was assessed by visual inspection of the histograms. As shown in Table 7.22, carers believed their patient to have significantly more symptoms and concerns than patients reported for themselves. More specifically, carers noted significantly more psychological symptoms for their patient compared to patients' self-reports. The number of physical symptoms assessed by carers was also marginally higher than those reported by patients. In conclusion, the hypothesis that carers would overestimate the patients' symptoms was supported.

Table 7.22

Median number of symptoms according to patients' self-reports and carers' assessments (dyads only n = 15)

	Patient	Carer	Wilcoxon signed-rank test			
Number of Symptoms	*Mdn*	*Mdn*	*z*	*p*	*r*	% (*n*)
Total Symptoms	7.00	10.00	-2.39	.017	-.436	
Carer reports more						80.0% (12)
Exact agreement						0.0% (0)
Patient reports more						20.0% (3)
Physical Symptoms	4.00	5.00	-1.91	.056	-.349	
Carer reports more						53.3% (8)
Exact agreement						33.3% (5)
Patient reports more						13.3% (2)
Psychological Concerns	3.00	7.00	-2.456	.014	-.449	
Carer reports more						73.3% (11)
Exact agreement						6.7% (1)
Patient reports more						20.0% (3)

It was further hypothesised that this ***overestimation would occur more often for less visible, psychological symptoms than for visible, physical symptoms.*** In support of this, the effect sizes of the previous analysis indicated that carers' tendency to overestimate patients' symptoms was more prominent for psychological than for physical issues. Furthermore, a Wilcoxon signed-rank test showed that the differences between carers' and patients' assessments were marginally larger for psychological symptoms (*Mdn* = 3.00) than for physical ones (*Mdn* = 1.00), $z = -1.69$, $p = .094$, $r = -.309$. Hence, there was evidence for the hypothesis that overestimation was more likely for less visible than for visible symptoms.

It was hypothesised that ***caregivers who overestimated their patient's symptoms would have a greater preference for an institutional place of care than carers who did not overestimate the patient's symptoms***. As previously described, overestimation was recorded when the number of symptoms and concerns assessed by the carer exceeded the patient's self-reports. Exactly half of the 12 carers who overestimated patients' symptoms reported an institutional place of care as their first preference (6), as opposed to none of the three carers who did not overestimate their patient's symptoms. To calculate the odds ratio, a zero cell count correction was necessary. As before, the continuity approach was chosen by adding a small constant of 0.5 to all four cells of the 2 x 2 contingency table (Cox, 1970). The odds ratio showed that carers who overestimated patients' symptoms were approximately seven times more likely to prefer an institutional place of care than carers who did not overestimate, 95% CI [0.30, 164.40]. This is a large effect according to Rosenthal (1996). However, the association did not reach statistical significance in a Fisher's exact test, $p = .229$.

Finally, it was hypothesised that ***the number of symptoms that caregivers report for the patient would correlate positively with the number they report for themselves and that this potential projection bias would occur more in less visible, psychological symptoms than in visible, physical symptoms.*** The relationship between the different symptom assessments was monotonic, as determined by visual inspection of a scatter plot. Due to the

presence of outliers in the plot, the more robust Spearman's rank-order correlation was chosen. As shown in Table 7.23, the number of patients' self-reported symptoms correlated significantly with the assessments of their carers. Interestingly, carers' assessments of patients' symptoms also correlated with carers' own symptoms. This effect was strongest in regard to their psychological concerns (r_s = .679, p = .005) and only marginally significant in regard to physical symptoms (r_s = .458, p = .086). This supports the hypothesis that the number of symptoms that carers report for their patients would correlate positively with the number they report for themselves and that this correlation would be more noticeable in less visible than in visible symptoms.

Table 7.23

Correlation of the number of patients' symptoms as assessed by themselves and by their carers and the number of symptoms that carers reported for themselves (dyads only n = 15)

	Correlation of	
	Patients' self-reports and carers' assessment of patients'	Carers' assessment of patients' symptoms and their own
Number of	symptoms	symptoms
Total Symptoms	r_s = .617, p = .014	r_s = .659, p = .008
Physical symptoms	r_s = .589, p = .021	r_s = .458, p = .086
Psychological concerns	r_s = .495, p = .061	r_s = .679, p = .005

7.5.4 Summary of Agreement and Accuracy of Carer Assessments

Overall, the level of congruence in patient-caregiver dyads varied depending on the assessment task. There was fair agreement in regard to preferences for place of care, but not in regard to place of death. Carers who agreed with their patient on a preference for place of death were significantly more likely to achieve their wish than those who did not agree. A similar but non-significant trend was found for patients. Interestingly, over half of the CPR

assessments of carers did not match the patient's actual preference. In contrast, carers' assessments of patients' living will and medical power of attorney arrangements were more accurate and matched in almost three-quarters of the cases. Caregivers also believed that the patient had significantly more symptoms and concerns than patients reported for themselves and this was more prominent in less visible, psychological concerns than in visible, physical issues. There was a large but non-significant trend in carers with an institutional preference to overestimate their patients' symptoms. Finally, carers' assessments of patients' symptoms positively correlated with the number of their own symptoms. This effect was again stronger for psychological than for physical problems.

7.6 Participants' Comments regarding the Questionnaire

At the end of the questionnaire, participants were asked if there is anything else they would like to add. Eight participants provided written feedback. Additional verbal feedback was also often given. Overall, the questionnaire was perceived as interesting and sensibly phrased. Comments often included expressions of gratitude for the care services received and the support through loved ones. Participants frequently reported that the survey questions drew attention to end-of-life topics, made them think about their preferences and about the arrangements they still needed to make. The questionnaire also prompted participants to discuss their responses with each other, their family or even with staff members. Especially the recruited dyads often reported that they had talked about the content after the completion of the survey and asked each other about their respective answers. The next chapter will now discuss the findings of Study 1.

8

Discussion

Study 1

CHAPTER EIGHT

The purpose of Study 1 was to describe preferences for place of care and place of death in terminally ill patients and their family caregivers. Using multiple-choice questionnaires, this study aimed to identify factors that influenced these preferences, explore the relationship between preferred and actual place of death, and examine end-of-life agreement in patient-caregiver dyads. The following chapter will discuss the key findings of Study 1.

8.1 Sample Characteristics

The current study examined the preferences of 17 patients and 40 caregivers who were currently supporting a patient in their last 12 months of life. Two-thirds of the patients presented with malignancies and the length of their illnesses varied noticeably, from only a few weeks to over 30 years. Patients were on average 67 years of age while carers were approximately ten years younger, which provided diverse end-of-life views from respondents between the ages of 32 to up to 92 years. Patients were often the carer's spouse or parent, and many had known each other for a considerably long time, on average for 42 years.

The majority of patients were male, while most of the carers were female. This is consistent with previous literature that found that the caregiving role is often taken on by women (Emanuel et al., 1999; Family Caregiver Alliance, 2003; Fulton & Epstein-Lubow, 2011; Sankar, 1994). Many respondents were married and lived with their partner or other relatives. It must be noted that while almost all of the patients were currently not working, exactly half of the carers were still part- or full-time employed while taking care of their dying family member. In addition, most of the carers had children who often still lived with them in the same household. Chapter 2 discussed how these conflicting occupational and parental responsibilities can substantially increase the caregiving burden on the family (see section 2.5.3). It is therefore not surprising that carers reported that they had experienced a range of symptoms and concerns within the last week. They often felt tense and fearful; had

sleeping problems; were worried about their loved ones; and struggled with tiredness. Despite having quite a bit of support from others, they reported feeling only "neutral", which is understandable given the challenging situation they were in. Patients also reported a variety of symptoms and concerns as a problem within the past week. This included: lack of energy; not being able to do the things they would usually do; and worries about important people in their life. These descriptive findings illustrate two important points: firstly, carers have symptoms as well, and this needs to be acknowledged. And secondly, the symptoms that respondents experienced were not only physical but also psychological in nature, and hence, treating both types of needs is essential for high-quality end-of-life care. The following sections will discuss the results of the four research questions of Study 1.

8.2 Do terminally ill patients and their family caregivers differ in their location preferences and their views concerning the importance of this choice?

To answer this question, Study 1 compared the responses of patients and carers in the full sample. Overall, choices concerning place of care and place of death were rated as quite to very important by patients. This is similar to the findings of Tang (2003), who reported that dying at the place of one's choice was ranked as highly important by terminally ill cancer patients (see section 2.5). Study 1 added the views of the informal carers, who stated that the location choice was quite important to them. Interestingly, there was a small but non-significant trend in patients to rate achieving their first preference and avoiding their last preference as more important than carers did. This may be because patients are more directly affected by the consequences of the location choice than carers.

Study 1 found that just under 60% of patients wanted to be cared for at home, while only 40% of the carers chose this as their most preferred place of care for the patient. Similarly, just over half of the patients wanted to die at home, while less than 40% of carers favoured this option. Even though there was a clear pattern of different preferences for

patients and caregivers, due to the small sample and the unequal group sizes, these differences did not reach significance. (These statistical challenges will be discussed in greater detail in section 8.6.) At this point, it must be acknowledged that, to date, only very few studies have clearly differentiated between the views of patients and carers, and the ones that did, have focussed mainly on preferences for place of death. For example, Stajduhar et al. (2008) found that 39.9% of the surveyed carers preferred for their patient to die in hospital, whereas only 27.5% of the terminally ill patients did. Similar results were found by Tang et al. (2005) in a Taiwanese study of 617 hospitalised palliative care patients and their carers, as presented in Chapter 4 (see section 4.6.1). However, it was unclear whether these differences would persist when assessing preferences for place of care and place of death separately. Based on the findings of Study 1, this seems to be the case. Carers tended to favour institutional settings more often than patients did and this applied to their preferences for place of care as well as for place of death. However, does this mean that these are the same questions?

In the current study, the majority of patients and carers answered the question concerning place of care in the same way as the one concerning place of death. Yet, a small group of 29% of patients and 27% of carers changed at least one of their five rankings for the two questions. This change concerned respondents' first preference in 12% of patients and 15% of carers. Even though it might only apply to a minority of care recipients, it must be concluded that it is still clinically relevant to address these questions separately, as discussed in Chapter 2 (see section 2.6.1). In their longitudinal interviews with 71 patient-caregiver dyads, Agar et al. (2008) found that respondents often wanted to be cared for at home, yet they did not want to die there. During the last interview conducted, their responses regarding the two questions differed in about 43% of cases. Based on this, Agar et al. (2008) proposed that place of care and place of death could, in fact, be two entirely different concepts. In the present study, these discrepancies were less pronounced but still noticeable. This might be at

least partly due to the differences in the methodology and the wording of the questions. In the current study, patients were asked: "Given your current circumstances, where would you like to be cared for in your last days?" This somewhat resembles the follow-up question: "Where would you like to be when you die?" In the study by Agar et al. (2008), the exact wording of the questions was not specified as a palliative care nurse assessed respondents' preferences in person. It is possible that in face-to-face interviews subtle differences in the two questions may be more noticeable than in a multiple-choice survey because, in interviews, respondents can talk about their views in more detail. As discussed in Chapter 4, this re-emphasises the issue of how to best assess location preferences (see section 4.7.2) and highlights the importance of clear communication at the end of life (see section 4.7.1).

Capturing preferences accurately, furthermore, requires that respondents understand what their options are and what certain terms actually mean. During the completion of the questionnaire in Study 1, participants sometimes asked for clarifications, especially concerning the different location options. There seemed to be some confusion about whether a palliative care ward would be seen as a hospital or a hospice. Hence, the distinction between home versus institution was used in the majority of the analyses. It is understandable that certain location terms may be ambiguous. For instance, at Broadmeadows Health Services, there is no visible difference between the palliative care ward and the aged care or rehabilitation unit, other than that they are located in different parts of the same building. Similarly, the palliative care beds within the Royal Melbourne hospital may be seen as part of the regular hospital or as a specialised hospice ward. The use of these terms might also depend on the extent to which respondents have acknowledged the terminal status of their illness. For instance, some patients or carers might find treatment in a hospital more acceptable than in a hospice if, to them, the latter has a connotation of finality. As another example of a term that might have subjective meaning, if someone is usually living in a residential aged care facility, then they would consider that their home. These ambiguities of

location options might make it challenging for patients and carers to accurately express their preferences and for healthcare professionals to assess them.

Surprisingly, the option of being cared for in somebody else's home was rated as the least preferred place of care and place of death. This was often ranked even lower than nursing home care. Initially, this item was believed to create a balance between the three institutional responses (hospital, hospice and nursing home) and home. Furthermore, including this option examined whether the preference to be in a home-like environment was strong enough that the home of somebody else, for example, another relative or friend, would also be considered. However, this was rarely the case. Some participants commented after the completion of the survey that their responses depended on their interpretation of who "somebody else" is. If they had someone in mind, the option of being cared for in somebody else's home was understood and ranked accordingly. In contrast, if they could not think of anyone, they would rate this option lower. Based on this it can be concluded that the general preference to stay at home only extends to one's own or the carer's home.

These findings highlight some of the complexities of location preferences and the challenges in assessing them. The next section will discuss which factors influence these choices according to the findings of Study 1.

8.3 Do illness-related, personal and interpersonal factors influence respondents' preferences for place of care at the end of life?

Based on the literature reviewed, a selection of illness-related, personal and interpersonal factors was hypothesised to influence the preference for a place of care at the end of life. Patients' and caregivers' responses were analysed separately to examine if different patterns existed in either of these groups.

8.3.1 Illness-related Factors

Patients who preferred an institutional place of care had been ill significantly longer than those who preferred home care. A similar but non-significant trend was found in carers. In agreement with this, previous research has suggested that location preferences are rarely stable and that the wish to stay at home often decreases as the illness progresses (Hinton, 1994; Munday et al., 2009; see section 4.1.2). As discussed in Chapter 2, as more and more people die from chronic and slowly progressing conditions, the burden of long-term care on the family increases (see section 2.2). A prolonged illness is likely to drain most available personal and interpersonal resources over time. One carer in Study 1 commented: "The patient has been close to death and then stabilised, so there has been quite a reflective and challenging journey of facing end of life" (Carer 10, male, non-home). Karlsen and Addington-Hall (1998) proposed that patients potentially alter their preferences over time according to the likelihood of achieving them. Patients might also actively avoid frequent changes of care settings as this can cause anxiety, confusion and relocation stress (see section 2.5.4). Barclay and Arthur (2008) suggested that a change of preferences in favour of institutional care might reflect a "resigned acceptance to save relatives and friends the burden of caring at home or a positive decision seeking better care as an inpatient, or a combination of these and other factors" (p. 230).

Over the course of a terminal illness, symptoms often become more distressing and care needs increase. Study 1 found an association between the preference for place of care and the number of symptoms experienced. Specifically, caregivers who preferred institutional care believed their patients had significantly more physical symptoms than those who preferred home care. A similar but non-significant trend was found in patients. It is reasonable to assume that some of the respondents had experienced incidents firsthand where extra medical support was needed and care at home was no longer sustainable. The effect of the number of symptoms on the location preference was particularly strong in regard to physical symptoms

and there could be three main reasons for this: firstly, physical problems, such as pain or shortness of breath, might be more visible and noticeable than psychological concerns like depressive mood or fear. Secondly, physical symptoms might also be more distressing to patients and carers, and thirdly, they might be perceived as being more easily treatable in a formal care setting. Study 1 further found that some specific symptoms, such as constipation and pain, were associated with a preference for institutional care. Amongst the psychological concerns, carers who favoured institutional care believed their patient to be more depressed, fearful and irritable than those carers who supported home care. This adds depth to findings discussed in Chapter 4, which argued that symptom management is the main reason for end-of-life admissions (Barbera et al., 2010; Hinton, 1994; see section 4.1.1).

What stood out in Study 1 was that patients and carers with a preference for institutional care also reported more worries about not being given enough information about the illness or treatment than those who wanted home care. And this concern might be warranted as discussed in Chapter 2. For example, a review by Hancock et al. (2007) of 46 studies on discussions of life-limiting prognoses, found in that many health professionals either avoided discussing end-of-life topics or withheld information for various reasons (see section 2.6). Similarly, Gallagher and Krawczyk (2013) suggested that 45% of bereaved family members would have wanted more information about what to expect when their relative died in an institutional setting, and 56% said they were only usually, sometimes or never informed about the patient's condition within the last two days of life (see section 2.6.2). Hence, not only physical symptoms but also psychological concerns have a bearing on preferences for place of care at the end of life.

8.3.2 Personal Factors

Moving from illness-related to personal factors, the following sections will discuss the influence of demographic variables, personality and experiences on respondents' preferences.

8.3.2.1 Demographic Factors

As discussed in Chapter 4, a range of studies have focused on the role of demographic factors in location decision making (see section 4.2.1). For instance, Grande et al. (1998) found that men were more likely to die at home than women, arguably because women are more efficient carers, making home care and home death, therefore, more achievable for their male spouses. This was supported by Wilson et al. (2013) who found that home was often preferred by men, whereas hospices or palliative care facilities were chosen by women. In contrast, in the present study, there was a non-significant trend of male rather than female patients to prefer institutional care. The reasons for this are not entirely clear. However, it is worth noting that two-thirds of the female patients had been recruited from home, which might have influenced their preferences for home care. In contrast, just under two-thirds of male patients had been recruited from institutional settings, which may indicate that they lacked carer support at home or had experienced particularly burdensome symptoms that caused them be admitted into formal care. These aspects may play a role in the observed gender effect.

Regarding the other demographic aspects, there was a medium but non-significant trend in patients with an institutional preference to report a lower household income than those with a home preference. This draws useful comparisons with the review of Grande et al. (1998) who found that higher socio-economic status was associated with home death in cancer patients. They argued that this might be due to better access to support services and being able to pay for additional help, which would put low-income groups at a disadvantage. Similarly, Gomes and Higginson (2006) reviewed 58 international studies on place of death

and found that home death was more likely for those with favourable social conditions, such as education, social class and income. Yet, in the present study, educational status was not associated with a specific location preference in patients or carers. Grande et al. (1998) also found that older patients were less likely to die at home than younger ones, potentially because of the lack of a carer, less access to home support services, or increased care needs. While this might be true in regard to the actual place of death, age did not seem to influence participants' overall preferences for place of care in the current study.

8.3.2.2 Personality Traits

Study 1 found no significant differences in the Big Five personality traits of respondents with a preference for home or institutional care. With that said, the effect sizes indicated trends of higher openness, lower agreeableness and lower extraversion to be associated with a preference for an institutional care in patients. Up to this point, only a few studies have explored the relationship between personality and end-of-life decisions (see section 4.2.2). In one of them, Sörensen et al. (2008) collected data from 355 older primary care patients and found that neuroticism, openness and agreeableness were associated with greater awareness of care needs. They argued that highly open individuals have a greater tolerance for ambiguity, which allows them to consider a variety of health-planning scenarios. When applying this to the findings of Study 1, it is likely that patients who are open to new experiences are also more accepting of care in an institution. Conversely, less open patients might prefer home care because this setting offers a stronger sense of familiarity. Sörensen et al. (2008) argued that more agreeable individuals may be easily influenced by relatives, which, if applied to place of care decision-making, should result in a stronger preference for institutional care. Yet surprisingly, in Study 1, more agreeable patients tended to favour home over institutional care. Furthermore, lower extraversion was associated with a preference for an institutional setting. To explain this, introverted patients

might be less able to express their wish to stay at home and ask others for help with home care. It is also reasonable that introverted patients might be more protective of their private home space and less likely to want strangers coming into their house. As a consequence, they may be more willing to accept institutional care. In their study of 266 older primary care patients, Chapman et al. (2006) found lower extraversion to be associated with worse perceived health in response to the item "I expect my health to get worse" (p. 362). This pessimism about their health could also explain the higher preference for institutional care in introverted patients.

For carers, higher openness and lower conscientiousness tended to be associated with a preference for an institutional place of care. As in patients, openness to new experience would also include openness to treatment settings other than home. Furthermore, it is not surprising that highly conscientious carers would be more willing to support their patient at home as they tend to be particularly dutiful, orderly and goal-oriented.

It is worth noting that after the completion of the survey, participants often commented that their responses to the personality questions depended on their health and the current situation of the patient. For example, agreement to items like "I find it difficult to get down to work" or "I'm the life of the party" was reported to be based on the respondents' current level of activity and health. They often pointed out that some items had been applicable to them before they became ill, but that this had changed now. It is reasonable to assume that over the course of a serious illness, there might be less opportunity to express certain personality traits or that they change to some degree. Chapter 4 provided evidence for this (see section 4.2.2). In the longitudinal study by Specht et al. (2011), women showed a decrease in conscientiousness after the death of their spouse, whereas men became more conscientious. It appears that traumatic events such as facing one's own or a loved one's death can influence someone's personality, which may, in turn, have a bearing on how they make decisions.

8.3.2.3 Past Experiences

Participants often commented after the survey that their end-of-life preferences were strongly shaped by their past experiences with care facilities and the deaths of other family members or friends. Congruently, in Study 1, past experiences with different treatment settings correlated with respondents' current preferences for future places of care. Specifically, higher satisfaction with experiences was associated with a higher preference for these locations. This was significant for hospice and nursing home preferences in carers, and marginally significant for hospice preferences in patients. For the other settings, home and hospital, non-significant trends showed an effect in the same direction. This supports the argument of Thomas et al. (2004) that the relationship between experiences and location preferences may be "simple and direct" (p. 2439). As discussed in Chapter 4, in their interviews with cancer patients and carers, Thomas et al. (2004) identified experiences with services and locations of care to be one of four thematic domains that shape the preference for a place of death (see section 4.2.3). If a service was perceived as good, then that site could be considered as a potential care setting and if not, it was discounted as a place of death option. In the current study, this effect was strongest for hospice experiences. In agreement with this, Thomas et al. (2004) found that cancer patients and their carers often initially perceived hospices to be grim and hopeless places. Yet, upon personal acquaintance, they were surprised by the caring and welcoming atmosphere encountered there.

Based on the mere exposure effect addressed in Chapter 3 (see section 3.4), Study 1 hypothesised that more exposure to certain treatment settings would be associated with a higher preference for these places of care. This, however, was only significant for the hospice ranking of carers. For all other treatment settings, only non-significant trends could be considered. Specifically, more hospital experiences in patients and carers tended to be associated with a lower preference for this place. It was discussed in Chapter 2 that while hospitals can provide great physical care, patients and carers often report a lack of emotional

support (Mount et al., 1980), privacy and control (Tang, 2003), as well as fear of dying alone in hospital (Bowling, 1983; see section 2.5.2.1). The current study also found a trend that more nursing home experiences in patients were associated with lower preferences for this setting. Previous research suggests that the staff in nursing homes often lack training in palliative care (Wilson, 2006; Wowchuk et al., 2007), and may consequently even be afraid of dealing with dying residents (Komaromy et al., 2000). Limited communication and involvement in decision making, concerns about not being treated with respect, as well as untreated pain were reported to be major problems of end-of-life care in nursing homes (Mishel (1988); Teno, 2003; Teno et al., 2004; Thompson et al., 2012; see section 2.5.2.3). It is possible that participants in Study 1 had similar experiences with institutional care, which may have influenced their preferences.

Regarding home care, patients and carers reported having had only a little experience with this setting. This might be a true reflection of their views but it is also worth considering that home is often not recognised as an actual care site in the same way that, for example, hospital care is. Home is where people live, but when does it actually become a place of care? This shift in perception might happen for some right at the start of their illness, or when nurses visit regularly to support the family, or when medical equipment such as electric beds or oxygen machines are brought in. In contrast, experiences with institutional care settings are distinct in the sense that patients and carers go to a place outside of their home to be treated. However, home care often does not have a definite start and end point, which could explain why most patients and carers reported that they only had a little experience with this setting even though some of them had been ill for a considerably long time.

Interestingly, Study 1 found a non-significant trend in both patients and carers, which indicated that more experience with home care was associated with a lower preference for this setting. This might be the result of a long and burdensome illness, as discussed in this chapter (see section 8.3.1). In contrast, one could argue that those patients who preferred

home care were often well at home and their symptoms were manageable with the resources available to them. In Study 1, both patients and carers had experienced a range of troublesome symptoms and concerns within the past week. Many carers were also juggling occupational and parental responsibilities. Chapter 2 showed that high caregiving demands of home care, unexpected deteriorations and psychological distress often caused end-of-life admissions (Hinton, 1994; see section 2.5.2). Hence, it is perhaps not surprising that more experience with home care can mean that patients and carers have encountered the challenges and realities of this care setting, which may, in turn, have affected their preferences.

8.3.2.4 Current Experiences

Not only past but also current experiences with different treatment settings were predicted to influence location choices. A non-significant trend indicated that respondents who had been recruited from home were about four times more likely to prefer home care and, concurrently, those who had been recruited from an institution were four times more likely to favour institutional care. However, the causal direction of this association is unclear. It is reasonable to assume that the preference for a place of care was formed first, which caused patients to be treated there. Alternatively, it is also possible that the experience of being currently cared for in a certain setting increased participants' acceptance of this place of care. The latter explanation would support the findings of Munday et al. (2009) who interviewed 36 healthcare professionals regarding their experiences with location preferences of terminally ill patients. They reported a tendency for patients to replace their previously expressed preference to die in a specific place with a desire to remain in the place where they were currently being cared for (see section 4.2.4). This again could reflect a true change in preferences or a "resigned acceptance" of the fact that care in their previous setting was not possible anymore (Barclay & Arthur, 2008, p. 230). However, favouring one's current place of care could also be an attempt to avoid relocation stress (see section 2.5.4). Using the

theoretical perspective outlined in Chapter 3, the current place of care may be seen as a reference point that decisions are based on (Prospect Theory; see section 3.3.1). Kahneman and Tversky (1979) argued that decision makers have a strong desire to avoid losses. In that sense, relocation from one place of care to another could be seen as a loss of a setting that is already familiar and this, hence, needs to be avoided.

8.3.3 Interpersonal Factors

Regarding interpersonal factors, the quality rather than the length of the patient-carer relationship seemed to be important in location decision making. Higher perceived quality of the relationship significantly correlated with a higher preference ranking of home care in patients and carers. This complements the findings of Hinton (1980) who interviewed hospice patients about their end-of-life discussions concerning their prognosis and the prospect of dying (see section 4.3.1). They found that 69% of patients had addressed the topic of dying with their spouse whom they had known the longest, 35% had talked to the staff whom they had known for some time and 85% had spoken to the researcher they had never met prior to the interview. Hinton (1980) concluded that the nature of the relationship had a greater effect than its duration. Up until now, these interpersonal factors have not been explored in regard to location preferences. The present study, therefore, adds that the perceived quality of the patient-carer relationship is more relevant for care at home than its overall length.

8.4 Is the actual place of death associated with the initial preference and previous patient-carer discussions?

About three-quarters of the patients in Study 1 had died by the time data analysis commenced. Most patients passed away less than three months after their own or their carers' participation in the study. Those recruited from home survived approximately five months longer than those who had been recruited from an institution; the latter group died on average less than eight weeks after participating in the study. This illustrates that respondents who were receiving care in an institutional setting had been more unwell than those who were cared for at home. Consequently, the recruited sample reflects preferences of patients who were very close to the end of their lives and the views of the carers who supported them.

Overall, 28% of patients had died at home and the remaining 72% in an institution. The number of home deaths in Study 1 was higher than the rate suggested by Foreman et al. (2006) who reported that only 14% of South Australians from 2000 to 2002 had died at home. This might be a testament to the improvements of end-of-life care at home over the past 15 years. Alternatively, as highlighted in Chapter 1, this may also reflect the initiative of the current healthcare system to increase the number of home deaths as this is seen as a measure of success of end-of-life care (see section 1.1). It is critical to note that, in the present study, the majority of patients had died in the same place they had been recruited from. This could be an expression of their actual preference, as patients and carers often reported their current location of care as their preferred one. Alternatively, it could also be another indication of how close patients were to the end of their life as there might have been not enough time to move to another care setting before they died.

Billingham and Billingham (2013) found in an international review of 26 studies that congruence between the preferred and actual place of death varied greatly, from 20% to up to 81.9% (see section 2.5.1). Overall, they reported congruence rated of 62.4% for participants who preferred home death and 69% for those who wanted to die elsewhere. In the present

study, the wish to die at home was fulfilled for 53.8% of patients and 40% of carers. In contrast, the preference for an institutional death was fulfilled for 83.3% of patients and 90% of carers. Based on this, it can be concluded that the preference to die in an institution is easier to achieve than a home death, arguably because it does not rely on the availability, involvement and commitment of informal carers.

While participants in Study 1 reported only occasional discussions about their location preferences, patients were quite confident that their wishes were known and carers were similarly certain that they knew their patient's preferences. Study 1 found a medium but non-significant association between the amount of previous discussions about location preferences and the congruence between the preferred and actual place of death. More discussions about the carers' wishes had occurred in the group that had achieved their preference. In contrast, for patients, higher amounts of discussions were reported by those who did not die in their preferred place. It can be inferred that more discussions do not necessarily indicate the clarity of these conversations. The need to talk frequently about someone's preferences may mean that that the person is not being heard or not being taken seriously. It might also suggest arguments and disagreements about the topic. As addressed in Chapter 4, previous studies have reported mixed findings concerning the effect of discussions on other medical decisions (see section 4.5). On the one hand, Sulmasy, Haller, and Terry (1994) found that discussions about treatment preferences of terminally ill patients were associated with higher accuracy of carer predictions. Ditto et al. (2001), on the other hand, suggested that a discussion intervention, in which older outpatients and their surrogates had to talk about their wishes, did not improve the accuracy of their end-of-life assessments. The current study adds to these findings by suggesting that more discussions do not necessarily result in achieving one's preference for a place of death. Instead, the quality of discussions might be more important than the quantity. This, in turn, is likely to be influenced by other factors such as the quality of the patient-carer relationship.

8.5 To what extent do patient-carer dyads agree on their location preferences and how accurate are carers' assessments of patients' wishes and symptoms?

To examine agreement at the end of life, the final set of analyses focused on the paired data of 15 patient-caregiver dyads. Congruence regarding location preferences varied greatly among the pairs. Overall, 66.7% of dyads had matching first preferences for the patient's place of care (κ = .390), but only 53.3% agreed in regard to patient's place of death (κ = .271). Hence, agreement regarding of place of care dropped by 13.3% to a non-significant level when dyads were asked about place of death instead. This provides further evidence for the argument made earlier in this chapter that, for some participants, these are two separate questions. It is possible that dyads had talked more about where they wanted the patient to be cared for and, as Agar et al. (2008) suggested, less about the place of death because this was too confronting. In other studies, the congruence between patients' and carers' location preferences varied greatly. For example, Stajduhar et al. (2008) reported agreement in only 49.3% of patient-caregiver pairs (k = 0.16), whereas Tang et al. (2008) found agreement of up to 78.1% (k = 0.55). The current study adds that this congruence appears to be a central component in fulfilling one's wishes for place of death.

Study 1 found that the odds for carers to achieve their preference were significantly higher when they agreed with their patient. A similar, yet non-significant trend was also observed in patients. This supports the findings by Grande and Ewing (2008) who reported a significant association between the odds of dying at home and patient-carer agreement regarding their location preferences. The preceding chapters discussed that the majority of hospice enrolment decisions are made by family members (see section 4.6.1), and if a patient wishes to stay at home, informal caregivers need to be available, willing and able to provide care for their patient (see section 2.6.3). Disagreements regarding end-of-life preferences can also be an indicator of underlying family conflicts, diverging expectations and overburdened caregivers. However, not only the carers' ability to cope with the caregiving demands is

essential in this context, but also their ability to accurately assess the patient's current state, needs and wishes.

Study 1 showed that the accuracy of carers' predictions varied considerably. Lowest accuracy was found when asked about the patient's CPR preferences, with only 46.7% congruence between carers' assessments and patients' actual wishes (κ = .091). The high disagreement could be partly due to the fact that 37.5% of patients reported that they were not sure about whether they wanted CPR or not. This uncertainty clearly makes it challenging for carers to accurately assess patients' preferences. Agreement in regard to other end-of-life decisions was higher. Overall, 73.3% of carers correctly guessed whether the patient had made a living will (κ = .355) and had appointed a medical power of attorney (κ = .388). This supports previous research that found differing accuracy rates depending on the assessment task, as discussed in Chapter 4. For example, Fried et al. (2011) reported agreement of 54% on CPR, 81% on completion of a living will, and 68% on appointing a healthcare proxy (see section 4.6.3). It is reasonable to assume that arrangements concerning a living will and power of attorney are easier to assess for carers as they are captured in writing, while CPR preference may or may not have been written down.

Accuracy rates regarding patients' symptoms also varied greatly. Carers believed that the patient had significantly more symptoms than patients reported for themselves. It must be highlighted that overestimation was more prominent in the assessments of psychological rather than of physical symptoms. This strengthens the argument put forth in Chapter 4 that the accuracy of carers' predictions would decrease as health-related issues become less visible (see section 4.6.2). For example, McPherson et al. (2008) reported good agreement for visible symptoms like nausea and vomiting; moderate agreement for pain, lack of appetite and constipation, and low agreement for less visible symptoms such as worrying or feeling nervous, sad and irritable. When symptoms do not have clearly observable referents, there is more room for interpretations as to how the patient may or may not be feeling. Lacking

accuracy of symptom assessments may further influence respondents' preferences. In the present study, there was a large but non-significant trend in carers with a preference for an institutional place of care to overestimate their patients' symptoms more than carers with a home preference. This is intuitively understandable, as carers are likely to favour professional support if they believe their patient is particularly unwell.

Carers' assessment of the patient's health might also be influenced by the carer's own emotional state and the burden of providing care. This was found by McPherson et al. (2008) who concluded that carers might project their own feelings onto their patient (see section 4.6.2). There was evidence for a potential projection bias in the current study: carers' assessments of patients' symptoms correlated significantly with the symptoms that carers had reported for themselves, which was particularly noticeable for psychological concerns. Here, carers' assessments of patients' symptoms correlated even more with their own psychological symptoms than with patients' actual self-reports. This supports the findings of McPherson et al. (2008) who suggested that caregivers' emotional distress is likely to affect the accuracy of their assessments and that patients frequently worry about overburdening their family with their care needs. Hence, the psychological and physical state of the carer is an important aspect to consider when examining end-of-life preferences.

8.6 Challenges and Limitations

The present study examined the preferences of patients in their last few months of life, as well as the wishes and views of their informal caregivers. This approach was chosen to provide more accurate insights into end-of-life decision making than would have been possible by recruiting healthy, older participants or patients who have not yet reached the end of their lives. As discussed in Chapter 6, this methodology resulted in a particularly challenging data collection and an overall smaller number of recruited patients and dyads than initially hoped for (see section 6.3). In her book *On Death and Dying*, Elizabeth

Kübler-Ross posed the question: “How do you do research on dying, when the data is so impossible to get?” (2014, p. 21). The limited accessibility of sensitive participant groups is what Alty and Rodham (1998) called the “Ouch! factor” and these challenging methodological obstacles can force researchers to reconsider their options and develop new strategies. Alty and Rodham (1998) described this phenomenon mainly in regard to qualitative enquiries but it applies to quantitative practice as well. The authors pointed out that studies often “go for the more accessible, easy-to-reach part, leaving the rest as not tenable for research” (p.276). In contrast, the present study has chosen a more challenging approach, and as a consequence, the following methodological difficulties and considerations have to be acknowledged.

Firstly, despite their interest in the study, patients were often too unwell to complete the questionnaire, as their health quickly deteriorated or necessary medications made it difficult for them to concentrate. Thomas et al. (2004) confirmed that high drop-out rates are an inherent problem in many palliative care studies and a testimony to the uncertainties involved in undertaking research with dying patients. A shorter or verbally administered version of the questionnaire could have been beneficial to suit the needs of the patients. However, given the sensitive nature of some of the questions, a written form ensured greater privacy.

Secondly, the small number of recruited patients also caused some statistical challenges that needed to be considered. Given the ordinal nature of most of the variables, the unequal group sizes and dissimilar distributions in some of these groups, nonparametric tests were chosen to analyse the data. This approach did not require normal distribution of the dependent variables, was more robust to outliers, and hence, indicated for smaller samples. It also provided more conservative results than its parametric equivalent would have, which made it even more challenging to reach statistical significance (Martin & Thompson, 2002). In their series on evaluating scientific publications, du Prel, Hommel, Röhrig, and Blettner (2009) pointed out that if the sample is too small, even large differences may lead to non-

significant results. The reader would be aware by now that this problem has frequently been encountered in Study 1. In this regard, du Prel et al. (2009) remarked that statistical significance should not be seen as equivalent to clinical relevance. Specifically, they expressed concern that researchers, readers and journals are trained to ignore findings that could be clinically very useful only because they are not statistically significant.

In agreement with this, Bornstein and Emler (2001) argued that a non-significant *p*-value does not imply a trivial or meaningless effect as it strongly depends on the sample size. Accordingly, the current study also reported additional effect sizes and discussed noticeable non-significant trends, where appropriate. In some cases, the confidence intervals of these effects were fairly large, which suggests low precision of the parameters (Szumilas, 2010). This, however, was again a result of the small sample (du Prel et al., 2009). As a consequence, it would be important to replicate the findings presented with a larger sample.

Thirdly, as discussed in Chapter 6, the first set of analyses used the full sample of all recruited participants and treated patients and carers as independent groups. In contrast, the final set of analyses included only matched patient-caregiver dyads to examine areas of agreement and disagreement. It is worth considering that the paired data might potentially overestimate patient-caregiver congruence to some extent because the recruited dyads had agreed to participate together in the first place. This willingness to take part in a study together could be an indication of more communication, understanding, closeness and support in this group compared to the overall sample. At the same time, patients and carers who were less connected might have participated alone rather than as part of a pair.

Finally, it should be highlighted that the chosen questionnaire format of Study 1 forced participants to make clear decisions regarding their preferences and views. One carer commented that even though they had already discussed most end-of-life topics, seeing the answers written down was very direct (Carer 5, male, home). Hence, the questionnaire is likely to have over-simplified complex answers of respondents and this reductionism is a

considerable limitation of quantitative, forced-choice designs. Thomas et al. (2004) suggested that preferences for a place of death are rarely categorical statements but, rather, expressed as a "leaning in one direction" or another (p. 2436). Based on this, one could argue that complex end-of-life choices might be more accurately assessed in qualitative interviews rather than in closed-ended questionnaires.

8.7 Chapter Summary

This chapter discussed the findings of Study 1, which used multiple-choice questionnaires to examine location preferences at the end of life. The results presented highlight the importance of examining the preferences for place of care and place of death separately, for both patients and carers. It was found that carers tended to have a stronger preference for institutional care than patients did. Most participants gave the same answers when asked about their preferred place of care and place of death. However, for a small subgroup of respondents, these seemed to be different questions. While the within-subject comparison between place of care and place of death did not reach statistical significance, it was argued that asking these questions separately might still have considerable clinical relevance.

Study 1 further examined which factors influenced respondents' preferences for place of care at the end of life. Concerning illness-related aspects, the length of the illness and the number of symptoms were found to affect location choices. In regard to personal factors, the role of demographic aspects like gender, personality traits as well as past and current experiences was discussed. The findings implied that more experience with different treatment settings might not always mean more liking of that setting, as suggested by the mere exposure effect. Concerning interpersonal factors, it was found that the quality rather than the length of the patient-caregiver relationship was important, especially for home care. Many patients had died in the place they had been recruited from and it was noted that this

could be an expression of their true preferences or otherwise a testament to how close this sample was to the end of life. The effects of previous discussions on achieving one's location preference were mixed as these discussions could be used to communicate one's wishes or to argue about conflicting views. An in-depth analysis of a subgroup of patient-carer dyads showed that carers predicted patients' views with varying accuracy. For instance, in regard to symptom assessments, carers' responses depended on the visibility of the symptom and their own state of health. Lowest patient-carer agreement was observed in CPR preferences.

Study 1 highlighted the complexity of end-of-life decision making and the limitations of quantitative, multiple-choice designs in preference assessments. To examine the nuances of decision making in more detail, additional semi-structured interviews were conducted in Study 2. The following chapter will outline the methodological design of this qualitative research.

9

Method

Study 2

CHAPTER NINE

When answering particularly complex research questions, quantitative and qualitative methods can complement each other and provide greater insights than one methodology alone could. Ambert, Adler, Adler, and Detzner (1995) discussed the goals and procedures of qualitative research and argued that by its very nature qualitative methods can generate a type of data that no quantitative methods can produce because they allow for "the emergence of the unexpected" (p. 883). Similarly, in their book on qualitative research, Liamputtong and Ezzy (2005) proposed that some interpretations and meanings cannot be measured and dealt with statistically, as they require a more fluid approach. The authors suggested that it is, for example, often difficult to know what people really mean when they rate themselves on a particular scale. Hence, qualitative methods are useful to strengthen and explain the results of quantitative data and explore the why and how of complex behaviours. This is particularly true when dealing with vulnerable populations that require flexible investigative methods. Therefore, the aim of Study 2 was to gain an in-depth understanding of the process and reasons that govern decision making of patients and carers at the end of life. The following chapter will provide details about the materials, procedure, participants and data processing of Study 2.

9.1 Materials

The interviews of Study 2 used a semi-structured guide of open-ended questions (see Appendix 8). This ensured that the same general information was collected from every interviewee while maintaining the flexibility to follow respondents' line of thought and explore new topics as they arose. The first questions aimed to build rapport and establish comfort with the researcher. If participants had taken part in Study 1, the interview began by asking them for comments on the questionnaire, for example, how they found it overall and if there were any questions that stood out to them. If participants had not completed the

questionnaire, a general introduction to the interview topic was given by explaining that many people have different views about where they want to spend their last days and that in the interview we would like to find out more about their views on this matter. After this brief introduction, participants were encouraged to talk about where they would like to be cared for. This was followed by more specific questions to address what this particular care setting meant to them, and what made it the most preferred place. Participants were also asked what would be needed to achieve this preference and what might prevent it. Interestingly, these aspects were often spontaneously addressed while respondents described their location preferences. Other place of care options were also discussed. For example, participants were asked about their second most preferred place of care as well as their least preferred place of care. More detailed follow-up questions were further included, for instance: "What would have to happen for you to be okay with being in [least preferred location]?" and "How important is this decision for you?"

The interview guide evolved as the study progressed. For instance, based on the experiences during the first few interviewing sessions, it became clear that further questions regarding participants' understanding of palliative care and hospice care would be useful. Hence, questions were added that asked: "What do you know about palliative care?" and "Have you heard of hospice care?" This was followed by questions about the difference between place of care and place of death. Specifically, respondents were asked: "Do you think where you want to be cared for and where you want to die are two different questions? Or is it the same? Can you explain why you think that?" If not mentioned spontaneously, patients and carers were also asked to what extent they had discussed their preferences and views with each other. At the end of each interview, participants had the opportunity to make final, open-ended remarks. While the detailed interview schedule loosely structured the conversation, the interviews were entirely guided by the participants and new topics were explored whenever they were brought up by the respondents.

9.2 Procedure

The interviews of Study 2 took place between February and June 2014. Data for Study 1 and 2 was collected concurrently. In both studies, purposive criterion sampling was used. The eligibility criteria, recruitment process and settings were also identical (see Chapter 6). The treatment team of the three participating sites identified potentially eligible patients and carers, who were then approached by the researcher either in person at the Royal Melbourne Hospital or McKenna House, or they received an invitation letter from Melbourne City Mission. Detailed information about the nature of the study was given, and interested participants had to provide written consent before the interviews commenced (see Appendix 7). In total, 41 potential participants were assessed as eligible during the first contact with the researcher. Of those, 24 declined consent because they were not interested in participating, did not want to discuss end-of-life topics, were too busy, or had already completed the questionnaire and did not also want to be involved in the interview. Overall, 17 participants consented to take part in Study 2.

All interviews were audio-recorded and followed the semi-structured guide of open-ended questions, as outlined (see section 9.1). Interviews were conducted in a conversational manner (Schulman-Green, McCorkle, & Bradley, 2010). The length of each session was determined by the participants and varied from 15 to 86 minutes with an average time of 51 minutes. All respondents were interviewed during a single session in a place of their choice. Overall, 12 interviews were conducted at home, one took place in the patient's private work office, and four were interviewed in a quiet room on the participating wards. It is worth mentioning that three participants, who had been introduced to the study during their time in inpatient care, were then discharged and subsequently interviewed at home. No compensation payments were made. However, similar to Study 1, respondents received a written note in person or via postal mail to thank them for their participation (see Appendix 9).

It was noted that while many patients were physically too weak or unwell to complete the questionnaire of Study 1, they were often still able and also very much interested in participating in the interview. Consequently, the recruitment difficulties experienced in Study 1 did not occur in Study 2. As suggested throughout the literature, conceptual saturation for the interviews was reached when major categories began to recur and no new subthemes were found (Ambert et al., 1995; Corbin & Strauss, 2007; Glaser & Strauss, 2009; Lincoln & Guba, 1985). This was the case after about five months of data collection. Figure 9.1 presents a schematic overview of the procedure of Study 2.

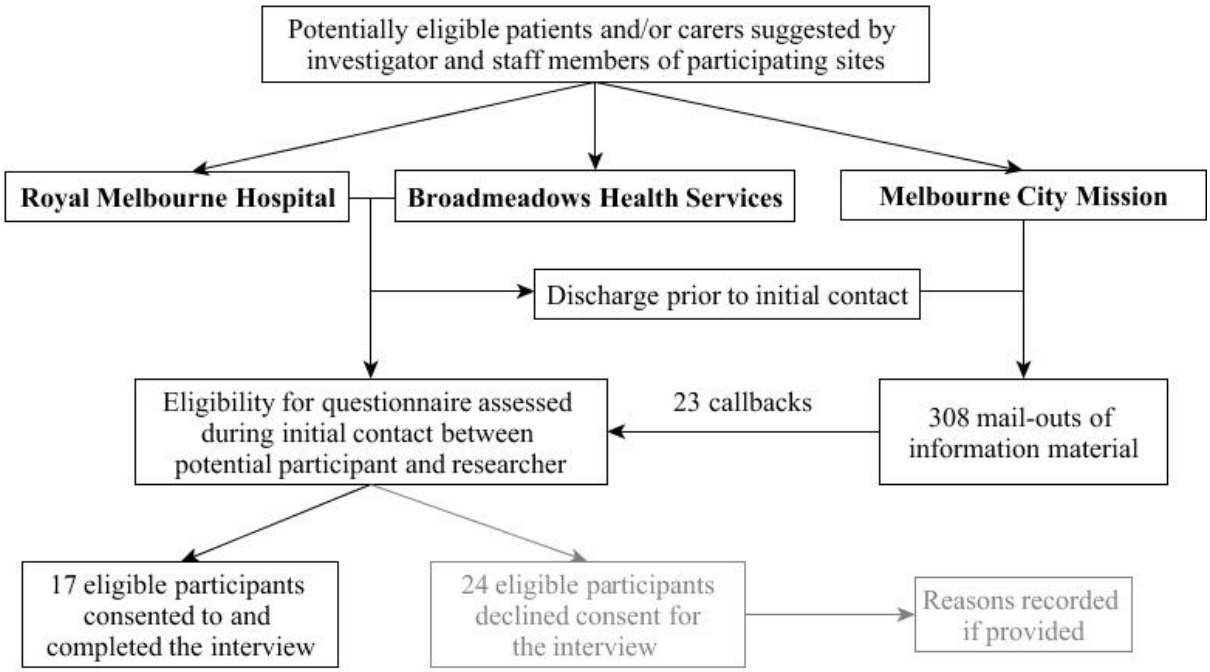

Figure 9.1. Schematic overview of the procedure of Study 2.

9.3 Participants

In total, 12 interviews with 17 participants were conducted, which included eight patients and nine carers. Five dyads chose to do the interviews together while three patients and four carers were interviewed individually. Overall, seven participants (three patients and four carers) completed both Study 1 and 2, while the remaining ten respondents (five patients and five carers) took part in the interview only. Table 9.1 provides an overview of the participants recruited from each site.

Table 9.1

Number of interviews completed by patients and/ or caregivers at each recruitment site

Recruitment site	Patients	Carers	Total
Royal Melbourne Hospital	2	2	4
Broadmeadows Health Service	1	2	3
Melbourne City Mission	5	5	10
Total	8	9	17

9.4 Data Processing

The interview data was processed and analysed thematically. Braun and Clarke (2006) described thematic analysis as a method for identifying, analysing and reporting patterns, so-called themes, within data. The first step was to transcribe the audio-recorded interviews, which was done using an Olympus DSS Pro Release 5 Transcription Module. Braun and Clarke (2006) provided the following general recommendations for the transcription process:

> As there is no one way to conduct thematic analysis, there is no one set of guidelines to follow when producing a transcript. However, at a minimum it requires rigorous and thorough "orthographic" transcript - a "verbatim" account of all verbal (and sometimes nonverbal [...]) utterances. (Braun & Clarke, 2006, p. 17)

Following these suggestions, responses were transcribed verbatim including contractions such as *gonna* or *could've* and non-verbal aspects such as laughing, crying or gasping, which were indicated by square brackets. Included were also filler words, interjections and non-word utterances such as *um*, *hmm*, *ah*, *oh* or *mhm*. Direct speech was indicated by using quotation marks. Ellipses were used to highlight short pauses and interrupted sentences, however, pauses were not timed. Those parts of the audio recording that were incomprehensible or difficult to decipher were noted as such. It was further indicated when participants interrupted each other or spoke at the same time. All transcriptions were proofread against the audio and revised if necessary. The interviews were de-identified during the initial transcription process with removal of any mentioned names of people or places apart from the ones of the three recruitment sites.

The next step was to code and analyse the transcribed interviews using NVivo 10 by QRS. Data analysis was an iterative process, as suggested throughout the literature (Carter & Little, 2007; Lingard, Albert, & Levinson, 2008; Srivastava & Hopwood, 2009). For instance, Berkowitz (1997) described this approach as loop-like patterns of re-reading and working through the transcripts as new questions, connections and themes are developed along with a deepened understanding of the material. It was not assumed that themes would "emerge" from the data as this denies the active role that the researcher plays in identifying, selecting and interpreting the codes and themes (Braun & Clarke, 2006; Richards & Morse, 2007).

The coding process as outlined by Corbin and Strauss (1990, 2007) consisted of three components. Firstly, during open coding, the raw data was broken down analytically into initial codes and conceptual labels. Braun and Clarke (2006) described this process as working "systematically through the entire data set, giving full and equal attention to each data item, and identify interesting aspects in the data items that may form the basis of repeated patterns" (p. 89). Secondly, this initial phase was complemented by axial coding during which codes with similar information were merged or excluded. Furthermore,

preliminary themes, hierarchies and relationships between these themes were established. Thirdly, during selective coding, all established codes were organised into meaningful groups and unified around overarching themes. The appropriateness of these themes was checked through continuous iterations and reapplied to earlier transcripts. This process was repeated until no new themes or sub-themes were found in the data.

The findings of Study 2 will be presented in the following chapter. Participants' quotes will be included to illustrate specific aspects of the themes. In these, unimportant filler words, repetitions and interjections will be omitted to improve readability. Concept maps will be used to represent the data visually. For descriptive purposes, the exact number of participants who preferred home or an institution as place of care and place of death will also be included. It is acknowledged that these quasi-statistics are only simple numerical counts of events within qualitative data, as Becker (1970) described. They are not meant to create the illusion of a pseudo-statistical approach but are believed to provide a more detailed and accurate overview of participants' preferences than vague statements that simply refer to "some" or "most" of the respondents (Maxwell, 2010). Many researchers support the use of numbers in qualitative studies as useful and legitimate (Becker, 1970; Hammersley, 2008; Maxwell, 2010; Sandelowski, Voils, & Knafl, 2009). However, knowing about the controversy, as discussed for example by Maxwell (2010), it was decided to use them sparingly.

9.5 Reflexivity

Study 2 involved direct, face-to-face interactions between the participants and the interviewer who consequently became an integral part of the research. The role that the interviewer plays in shaping the research is not necessarily a problem as long as it is critically examined and acknowledged (Guillemin & Gillam, 2004; Malterud, 2001). Hence, at this point it is important to describe my own background and experiences, and how they contributed to this research.

During my Master's degree, I volunteered for a hospice and a palliative home care organization for over two years. Initially, this involved eight months of extensive training, which addressed a broad range of end-of-life issues as well as strategies of communication, interpersonal support and self-care. After completing the training, I was employed as a caseworker in a hospice for children while continuing my work as a volunteer in home care. During this time between 2010 and 2012, I encountered patients and families from diverse backgrounds, age groups and settings. This challenging, yet deeply rewarding work motivated me to choose a palliative-care-related topic for my PhD.

My training and experiences were, to some extent, applicable to the research for this thesis. As a volunteer, I learned how to connect with patients and carers who were often in a very vulnerable situation, support them along their way by providing emotional, psychological and practical help, and then detach myself again after the patient had died or when my help was no longer needed. So, in some ways, my time as a volunteer was a useful preparation for this research. In other ways, however, I learned that the relationship between care recipient and volunteer was fundamentally different from the relationship between participant and researcher. As a volunteer, my task was to help patients and their families in whatever way I could; but as a researcher, my role was very different. Instead of providing support to them, I now wanted something from them - their involvement in the study. While participating in the interviews allowed respondents to have their voices heard, I sometimes could not help but feel that I was intruding. Given the severity of their condition, I was concerned that my approaching them in this vulnerable time of their lives could upset, burden or bother them in some way. It is possible that my concern and hesitation might have influenced the data collection and I wondered if a more experienced end-of-life researcher would have been more successful in recruiting participants for the study. Yet, another very personal experience with the end of life has led me to believe that this might have not been the case.

After the data collection of both studies had been completed, a close family member of mine became terminally ill. As a consequence, I paused my studies and became a primary informal caregiver myself. This experience with caregiving, death and grief has profoundly changed me and also the way I looked at my data when I returned. I frequently thought that if a researcher had come to me while I was caring for my dying family member, I would have turned them away - as I so often had been turned away by the people that I had approached for this research. I understand this much better now and am all the more grateful for those respondents who invested some of their precious time and energy to speak with me.

The influence of this (then very recent) personal experience on the process of data analysis was two-fold. On the one hand, it made data analysis an emotionally more challenging task than it would have been for someone without these experiences. I could now not only relate on a theoretical but also on a personal level to many of the stories that participants had shared with me. This made self-care and self-reflection a very important part of my research practice. On the other hand, while this experience considerably enriched my understanding of end-of-life matters, I was determined to ensure that it would not distort my interpretation of what participants had said. In other words, I wanted to capture *their* stories and not *mine*. To do this, I worked closely with my supervisors and frequently reviewed transcripts, cases and themes in consultation with them to ensure the accuracy of the data analysis. The results of this process will now be presented in the next chapter.

10

Results

Study 2

CHAPTER TEN

This chapter will outline the findings of Study 2. After providing information about the sample characteristics, patients' and carers' location preferences will be described and how these were formed. In the interviews, four overarching themes have been identified. These concern how participants perceived the context in which they had to make choices and how they responded to this context. The chapter will conclude with a summary of the attributes that characterised the process of forming preferences for place of care and place of death.

10.1 Sample Characteristics

Eight patients and nine carers participated in the interviews. As outlined in Table 10.1, patients were on average 75 years old, the majority were male and presented with malignancies. Carers had a mean age of 69 years and were most often the patient's spouse. By the beginning of data analysis, all patients who had participated, or whose carer had taken part in the interviews, had died. Of these, 63.64% (7) had passed away in an institutional setting, while the remaining 36.36% (4) had died at home.

Table 10.1

Personal, interpersonal and illness-related background of interviewed participants (N = 17)

	Patients *n* = 8	Caregivers *n* = 9
Age in years, Range	*M* = 74.63, *SD* = 9.54, 64-87 years	*M* = 69.00, *SD* = 11.20 54-84 years
Percentage of females	37.50% (3)	44.44% (4)
The patient/carer is your...		
Current or former partner/ spouse	87.50% (7)	77.78% (7)
Parent	0.00% (0)	22.22% (2)
Child	12.50% (1)	0.00% (0)
Malignant diagnoses of the patient	75.00% (6)	66.67% (6)

Note: Exact numbers in brackets.

10.2 Preference for Place of Care and Place of Death

Preferences for place of care and place of death were often reported in form of an unprompted ranking. Seven out of eight interviewed patients preferred home care (87.50%), while one wanted to remain in hospice. Correspondingly, all nine carers supported their patient's wish for place of care, which meant in eight out of nine cases home (88.89%). In their descriptions of end-of-life decision making, the main focus of both patients and carers was on the patient's wishes. As one patient explained:

> You get a bit self-centered when you're the one dying. *(Patient 6, male, home)*

For carers, in particular, preferences were often described in connection with certain conditions or circumstances. Most of them articulated strong concerns and hesitation about what would be achievable, manageable and realistic, as this carer indicated:

> I'd like him (the patient) to come home. But I want him to go home when he is ready. 'Cause if he were to come home and then after two, three days he gets sick again, it's a bit too much for him to come and go. So we have to ask the doctor what they think - if he is good enough to come home. *(Carer 9, female, non-home)*

Looking at this statement categorically, this would be a preference for home care. In reality, however, preferences were rarely absolute but instead often expressed as a conditional tendency to favour one place over another. If homecare was not possible, palliative care hospital or hospice wards were considered, as this carer explained:

> It depends on the circumstances, you know, what your answer is... Clearly, we prefer her (the patient) to be... and she prefers to be at home. But if she's going to need medical support then she has to be in the right place for that... If she was not well enough to stay here (at home), I would then have to investigate. And the thing is with all of these sorts of alternatives, it depends on what's available at the time really. If she's critically ill and she has to go to hospital, that's one thing. But you get to a stage in hospital when you then need to go on to respite care or palliative care or whatever it is... That's what has to be decided at the time, if it should be necessary. *(Carer 8, female, home)*

One key point is that while seven out of eight patients preferred to be cared for at home (87.50%), only three wanted to die there (37.50%). This was often chosen to avoid long-term harm to the carer and the family more broadly.

> I don't want to die at home here, because if I do it'll haunt [carer]. He doesn't think it but I know from my own self that it'll haunt him knowing that he's seen me die at home. I think it's better if I'm dying in the hospital. That would relate better to him, you know. That's what we've decided. *(Patient 3, female, home)*

Similarly, the following hospice patient preferred to remain in institutional care, and to die there, in the interests of her carer and the family:

> It'll be too much for my husband to care for me at home. I just ask him at the very start: "Do you want me to die somewhere else? Or do you want me to die at home?" I didn't want any member of my family visiting our home and say: "I can't go into that room because mum died in there." So I asked my husband. Very hard. It's very private. He said: "I feel that that should be your choice." That's how he got away with it. No, I don't mind dying here (in hospice) at all. I don't think he'd, or any of my family, would prefer me dying at home. I mean I can't see me going home… You know, taking me home, seeing me lying in a bed half-dead, is that fun? *(Patient 2, female, non-home)*

A comparable tendency also was found in caregivers. While they generally endorsed their patient's wish to stay at home for as long as possible, only three of the nine carers indicated a preference for a home death (33.33%). Carers worried about not being able to adequately fulfil the patients' care needs when they were imminently dying. Some felt that providing good care in the terminal phase would require a more professional setting. In addition, like many of the patients, some carers also expressed concern about the images and memories that would stay with them if the patient died at home. These memories would then be connected to the home that they had to continue to live in.

> I have talked to [patient] and I don't think I would be able to cope with looking after him here, at the very end. You know, because I don't want those memories of how sick he was at the end each time I come in through the door... I would rather remember the time where we just sat and laughed, you know, the happy times. Not that time when that person passed away... You want to keep the good memories. You don't want to keep a memory of seeing your loved one just laying in that room, in that bed. Because that would stay with me forever. *(Carer 1, female, home)*

In these cases, preferences had already been negotiated between patient and carer. Yet some respondents preferred to leave these discussions for later.

> Interviewer: Have you talked to her (the patient) about this?
>
> Carer: A little bit, but not yet. I think it's a bit early. She's not keen on it necessarily. *(Carer 7, male, non-home)*

It is worth noting, that this patient died only one week after the interview with the carer. An inference is that the timing of discussions may depend on whether the individual is ready to address end-of-life issues rather than on the imminence of death. In some instances, the interview itself prompted these conversations. For example, the following couple was asked if the question about where they would like to be cared for was the same as where they would like to die. This caused them to discuss their views:

> Patient: Yep, feels like the same. One and the same to me…
>
> Carer: I haven't actually thought of you passing away here (at home)... I don't see that happening here. I see it happening there (in the hospital).
>
> Patient: Do you? Yeah...
>
> Carer: I think the care you'd need here would be difficult to give you. I'd need help… to make you feel as comfortable as I can make you feel. And I don't think I could do it here myself… I think physically, I would struggle with that. Whereas in hospital I think, I'd be there all the time.
>
> Patient: Yeah. You'd have the nurses around you, too, to give you comfort and say that everything is okay. *(Patient 5, female and Carer 5, male, home)*

In summary, patients and carers preferred to be at home while being generally accepting of institutional care. There was, however, one exception: nursing homes were consistently reported as the least preferred place of care and place of death. While acknowledging that

nursing homes were sometimes necessary and inevitable, participants often felt very strongly about avoiding them at all cost. One patient said:

> If I was put in a place like that, I'd die. *(Patient 4, male, home)*

Participants felt that nursing homes offered no quality of care. People there were described as "abandoned", "left alone", "drugged up", and even "locked up". Nursing homes were said to offer no stimulation, no dignity and hence, people were believed to die there more quickly. It was seen as the last resort for those with high and long-standing care needs. One patient described her views by saying:

> I don't want to go to a nursing home. I don't want to go! Full stop! ... No, it's not for me. I couldn't put up with it. Seeing others suffer like that. And I don't see why I should die suffering in that way... No one likes staying at a nursing home. *(Patient 2, female, non-home)*

Preferences for place of care and place of death were often formed based on personal experiences, views and attitudes. They were negotiated between patients, families and doctors, while considering individual circumstances such as the patient's needs, carer's ability to cope, as well as structural factors such as the availability of services and support. Consequently, the answer to the question: "Where would you like (the patient) to be cared for?" and "Where would you like (him or her) to die?" was often: "It depends."

10.3 Forming Preferences at the End of Life

In regard to how preferences were formed, the following four overarching themes were extracted from the interviews:

- Uncertainty
- Emotional responses
- Cognitive responses
- Behavioural responses

Uncertainty was the most dominant theme reported by all participants, which was broadly expressed as a state of not knowing what to expect from an unpredictable future. This stood in contrast to a need to seek certainty and achieve a sense of predictability in order to feel safe. However, too much certainty was perceived as very confronting and therefore sometimes even avoided. To find a balance on this continuum of too much certainty and too much uncertainty, a range of emotional, cognitive and behavioural responses were described by patients and carers. This is illustrated in Figure 10.1. The following sections will describe the themes in more detail.

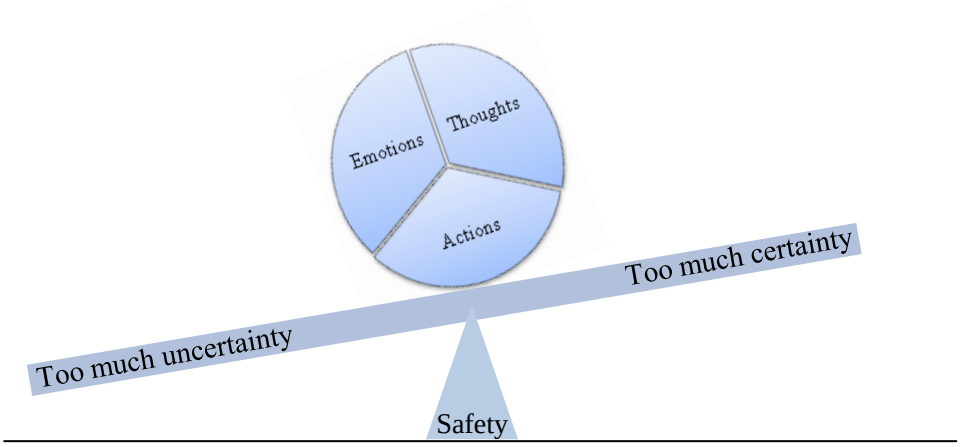

Figure 10.1. Balancing (un-)certainty through emotions, thoughts and actions.

10.3.1 Theme One: Uncertainty

Decisions at the end of life were described as being made in highly unpredictable situations. This triggered a strong need to seek certainty and thereby achieve a sense of safety. Different care settings were associated with different levels of (un-)certainty.

Home was initially often seen as the safest option for place of care because it was familiar and connected with memories and self-identity. Here, participants described feeling comfortable, free, independent and at peace. It can be inferred that at home people were in control of their environment.

> Home is where I'm familiar with, I know where everything is. All my interests are there, you know, computer systems, books, all that sorts of things. You know, it's comfortable, it's familiar, I know how the toilet works, I know where the toilet is, I know how to turn the taps on in the shower to get just the right amount of heat out, that sort of stuff. So it's whatever makes it a home. It's where conversation takes place and I'm, you know, I don't have to behave. I do have to behave as a civilized person. But, you know, if I'm angry, I can shout. *(Patient 7, male, home)*

Participants also highlighted the emotional connection to their home.

> Oh, home... it's being with the family, number one. Make it be a home rather than a house. There is a big difference between a home and a house. Well, a house to me is where there doesn't need to be love there. You just, you know, you walk there, do your meals, have your showers, or go to work the next day, come back to it. Doesn't matter. A home is where you want to invite and have all your loved ones around you. And make it comfortable and nice for everybody and friendly. That's my kind of home. I never called our home a house. Always home. *(Patient 2, female, non-home)*

Similarly, the following carer summarised:

> I just feel, you know, everything in my home somehow means something to me. *(Carer 4, female, home)*

The need to seek certainty in a familiar home setting was perceived as being in tension with the uncertainty about how long home care would be manageable. Participants felt that they had limited control over some aspects of end-of-life decision making and this uncertainty related to the three following sub-themes:

- Illness-related uncertainty
- Carer-related uncertainty
- Service-related uncertainty

10.3.1.1 Illness-related Uncertainty

Without exception, all participants expressed a sense of uncertainty about the illness progression, the symptom development and the future care needs. They were unsure what treatment might be needed, how much time the patient had left and how they would die. This Illness-related uncertainty was strongest at home – depending on the confidence, knowledge and support of the carer. When home care was not possible anymore, participants considered hospital or hospice wards. There, patients had access to instant medical help, equipment and procedures if needed. The following carer, for example, talked about an incident in the hospital when her husband had suddenly deteriorated:

> He [the patient] said: "What's wrong with me?" And then the nurse came. The oxygen was very low. They called the doctor, checked, I don't know what things they gave him. He said: "If I was home, you didn't know what to do." I said: "Of course. I'm not a nurse." *(Carer 9, female, non-home)*

This illustrates that preferences were often negotiated between patients, carers and doctors. The available emergency support in institutional care offered a sense of security and reduced the illness-related unpredictability to some extent. Yet uncertainty about how and when the patient would die remained. In institutional settings, respondents were also unsure how long they could, or had to stay, and if they would be able to return home. This carer explained:

> I think she (the patient) would rather be with me at home. I think that. You can ask her that. I'm not sure. But at this point, it depends on how she dies. And I can't get anything out of the doctors, could be a slow decline, or it might be bang... You're always working with that sort of dimension called hope or lack of hope. Of course you are. Particularly with what I mentioned a while ago that, you know, prognoses aren't certain. Cause it's not like they say: "OK, here is a chart and here is this point, this is when they're dead". Cause it's not what happens. *(Carer 7, male, non-home)*

While most participants accepted that hospital or hospice care was sometimes necessary, nursing homes were described as extremely unsafe. They were perceived to be understaffed, underbudgeted, providing very poor quality of care at high financial cost. It is important to

realise that moving to a nursing home meant to permanently give up their old home, whereas going to a hospital or hospice for a certain time allowed them to hold on to their home for a little bit longer. One patient described his experience with nursing homes like this:

> When I was a public servant I built nursing homes. And my attitude is that they are waiting rooms. You go there to wait to die. Sometimes it takes a long time. Sometimes it doesn't. But essentially it's where you deposit people that you don't want to care for at home or you can't care for at home... I've been in nursing homes that, you know, I walk out to the car and burst into tears... But essentially they're just waiting rooms. It's like coming to Queensland. Queensland is God's waiting room. *(Patient 7, male, home)*

The following dyad expressed similarly negative views of nursing homes:

> Patient: They set up a home for old people and then just leave them bored and leave them there, you know, leave them there to rot, as you may say. ...
>
> Carer: There were a lot of nursing homes that were just absolutely disgraceful in their attitude... People that are poor, particularly in the nursing homes, they get treated as second rate citizens... If [patient] was in a nursing home she'd feel abandoned, you know. That's what it was like for a lot of old people who go to nursing homes. They're abandoned because they only see their family once a week and then they wouldn't take them out. *(Patient 3, female and Carer 3, male, home)*

The poor quality of care that was associated with nursing homes strongly increased the level of illness-related uncertainty. As a result, nursing homes were seen as the very last option if the carer could not cope at home and if the patient's care needs became unmanageable in all other settings.

10.3.1.2 Carer-related Uncertainty

Having carer support was acknowledged to be vital in order to stay at home. Yet there was considerable uncertainty in regard to how well the carer would cope. Patients were very concerned about the needs of their carers and worried that home care would over-burden them. This carer-related uncertainty strongly influenced patients' choices. One patient explained:

> I've got to be reasonable about this. It's no good me staying home either. 'Cause I don't wanna be a drain, you know… It would be most convenient but it also puts responsibility on lots of other people. Which as I become more incapable of doing things for myself becomes more burdensome… I understand the practicalities of it. *(Patient 7, male, home)*

Another patient clearly stated that:

> If I felt I was being a burden, then I'm very willing to forego my desire to be at home, to go where I'm not a burden. *(Patient 6, male, home)*

Carers were similarly unsure about how well they would deal with the caregiving demands. To create a sense of certainty and provide good care at home, caregivers acknowledged needing extra help. This could include family members, neighbours, the community, as well as doctors and nurses.

> If it ever got to the point where I personally couldn't cope, then I would need to have help. You know, I know I've got help from [home care service], but what I'm saying is I need a permanent back up because even though [patient] is good at the moment, I've had fifteen years of caring for him and a couple of times we've nearly lost him. And when you're just there on your own, you do need someone, you know, that you can sort of... it doesn't have to be a family member, it's just someone... to help you. *(Carer 1, female, home)*

Carer-related concerns were strongest at home where the majority of the caregiving task fell to the informal carers. The demands on the carer depended on the availability of support, as well as the patient's medical and personal care needs, conflicting responsibilities like work, and the carer's own physical and mental health. For example, this carer expressed concerns about how her own health would influence her ability to provide good care for her mother:

> If that became an issue where she (the patient) was not able to do everything for herself in the sense of that she might wander off or do something in the kitchen where she could hurt, harm herself, or something like that, that could become a worry... The other problem is that I'm not a particularly well person either. I have very poor kidneys, and often I've had emergency visits to hospital and if I'm not here, who is going to be caring for mum? If we get to that stage where she can't be here overnight on her own, that could be a real big issue. *(Carer 8, female, home)*

Despite this overall uncertainty, carers were often very committed. Their main focus was on honouring the patient's wishes and providing the best care possible, as this respondent explained:

> Me as a carer, I know that [patient] wants to stay home as long as she possibly can. And we'll do anything possible we can to make that happen. *(Carer 5 male, home)*

However, there was a threshold at which the illness-related demands of home care exceeded the carer's abilities to cope and at this point, providing best care meant relocating to an institution. Under those circumstances, home was not the safest option anymore. So while most carers described focussing primarily on the patients' wishes, overruling or re-evaluating these wishes was sometimes considered necessary - in the best interest of both. This internal conflict was described by the following carer:

> We really don't know much what happens when [patient] gets to a point where even I can't look after him completely. It's gonna be a big decision, if this happens, it's gonna be a big decision for me to let him go anywhere. Unless I'm absolutely sure that it's gonna be the best thing. *(Carer 1, female, home)*

Institutional care eased the burden on the family, but there care was provided by strangers in an unfamiliar setting and unfamiliar routines, as discussed by this carer:

> I think being here's a bit alienating. It's not the fault of the place, it just is… It's not your familiar surroundings. So that changes things a bit much and my theory is that the better people feel the longer they'll survive, to put it brutally. That's my feeling. And [patient] is feeling, on her account, a bit alienated here, you know. It's inevitable. People she doesn't know bathing her, and the succession of them. And that irritates, I think. But that's the hospital situation. There's nothing much you can do about that. *(Carer 7, male, non-home)*

In hospital, hospice and even in nursing homes, the majority of the caregiving task was handed over to professional staff, but the carer still had to cope with the fact that their close family member was dying and the prospect that this might happen in an unfamiliar setting rather than at home.

10.3.1.3 Service-related Uncertainty

Participants were often unsure what support services would be available. Some had also only a vague and incomplete understanding of what palliative care is and how to access it. For instance, the following dyad had heard "fairly good reports" about "this palliative care business" while being unsure what it actually meant. They associated it with a special, more attentive type of hospital care that patients receive when they are imminently dying. During the interview, they noticed their limited understanding and began to raise questions:

> Carer: Where do you get this palliative care? In any of the hospitals? (…) It might be more to our advantage if we know a bit more about palliative care, what it, you know, what happens and that later on... I don't know. Cause I don't have much of an idea.
>
> Patient: Yeah, when the nurse comes out, you might have to ask her. *(Patient 1, male and Carer 1, female, home)*

Interestingly, the nurse this couple talked about was a palliative home care nurse - something they seemed to be unaware of. Especially the term "hospice" was often misunderstood. It was considered a one-way street, a place where you only go to die, like this patient explained:

> You go in one end of the tube and you come out dead at the other. And in the journey, in the middle of the tube, they do the best they can to make life presumably as comfortable because they know that you have no other choices. *(Patient 7, male, home)*

In a similar way, the following couple was also very unsure about what hospice care entailed:

> Carer: Oh I don't know anything about it.
>
> Patient: Now, hospice is where the husband comes and stays or is it? Or hospice is where they come into your home? (…)
>
> Carer: So hospice could be like a home that someone has bought, like a hospital is bought, a property? (…)
>
> Patient: I don't know a lot about it, to be honest. I only know what [palliative care nurse] has told me and we haven't gone into it a lot... But I looked at that and it being the same as pretty much being in the hospital. I don't know for what reason because I don't know a lot about it. *(Patient 5, female and Carer 5, male, home)*

At home, service-related uncertainty mainly referred to what support would be available and how to access it. Yet in institutional care, service-related uncertainty included open questions about the communication, structure and hierarchy of the setting, as illustrated by this carer:

> I don't know who runs things here, if there's one top person, I don't think it is. There are doctors and there are nurses. And the only person I've discussed the kind of thing I've been talking about to you is a particular doctor. I've spoken to her twice. The impression I gained from talking to her is, it's probably the doctors that ultimately say yay or nay here. But I'm not sure of that. And I'm not sure that they're always in agreement, you see... There's a bit of uncertainty there... Because when you come into a place like this there is no one who says: "This is the structure." You just come in and pick up what's happening. No one ever says: "This is how it works." *(Carer 7, male, non-home)*

This carer expressed his dissatisfaction regarding the communication with the doctors somewhat strongly, which was not a common occurrence in the interviews. Most other participants did not openly criticise the treatment team, especially while receiving care from them.

In summary, uncertainty was discussed in regard to the illness, the carer, and the services (see Figure 10.2). Different settings were associated with different levels of (un-)certainty. At home, the environment, people and routines were familiar, yet the unpredictability of the illness and the carer's ability to cope caused considerable uncertainty that shaped how decisions were made. In institutional settings, instant access to medical help offered a sense of certainty, yet here care was provided by strangers in an unfamiliar place with unfamiliar routines. Interestingly, individuals differed in how well they could tolerate this uncertainty and which strategies they used to feel safe. In this regards, three types of responses were identified in the interviews: emotions, thoughts and actions. These will now be explained.

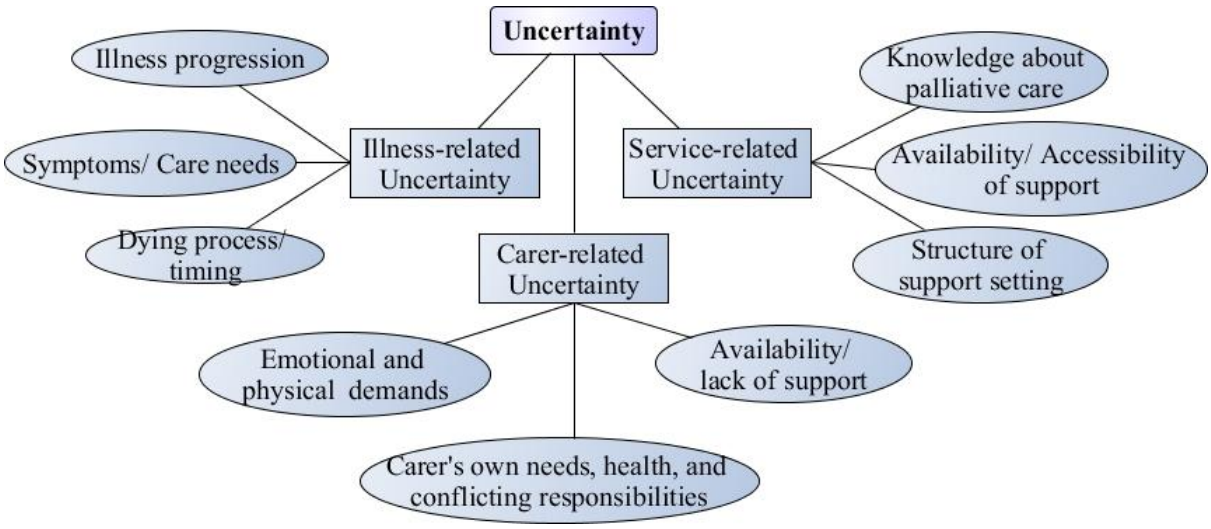

Figure 10.2. Summary of types of uncertainty discussed in the interviews.

10.3.2 Theme Two: Emotional Responses

Participants reported a wide range of feelings in response to the unpredictable and uncertain situation they found themselves in. These were sometimes subtle and sometimes intense or even conflicting, but always very interconnected. One key point is that emotions strongly influenced decision-making. The emotional responses discussed in the interviews can be grouped under the following sub-themes:

- Challenging emotions
- Strengthening emotions

10.3.2.1 Challenging Emotions

Patients and carers indicated a variety of challenging feelings such as fear, shock, sadness, disappointment and regret. Some felt unprepared and not yet ready to deal with the prospect of death and dying. Participants frequently reported being upset, emotionally stressed and helpless. They also felt that some decisions were out of their hands. One patient described her emotional response like this:

> I can feel now, I could get emotional if I wanted to. And you have to be very careful of that when you're in my condition. I just said to [carer] tonight: "I could be here for five years, I could be here for five weeks. I don't know." But no, I've learned to know that nobody knows that either. In a way, I have a bigger risk, sure. But I was very fearful. Terrified! I felt terrified of death and dying and the unknown. I was always a person, I had my life in check and knew where I was going. Like you know you are going to do this PhD and you have a plan in life and that's where you're going. When this happens to you, everything stops. It's like someone sliced your life down the middle and you're not going to do any of the things you thought you're going to do. And so with that comes fear of the life ending and wanting that life. *(Patient 5, female, home)*

Carers talked frequently about being exhausted and tired. They were willing to support their patient and neglect their own needs - despite sometimes feeling overwhelmed. This was described as being connected to a strong sense of responsibility. Two carers started crying during the interview. Some also indicated a lack of confidence in their own caregiving abilities, which contributed to the overall uncertainty of the situation. Support from others was perceived as a way to overcome these challenging emotions, as this carer described:

> I think for the number of years that I've cared for him (the patient) I've coped pretty well, but occasionally I do have a breakdown. I don't break down, but I do, you know, need somebody to just put their arms around you and say: "Look, we'll get through this". *(Carer 1, female, home)*

While facing the end of life and making decisions in such an unpredictable context was often described as challenging and upsetting, emotions were also a source of great strength.

10.3.2.2 Strengthening Emotions

Participants reported a range of positive feelings, which included hope, courage, trust, happiness and contentment. For example, this patient expressed gratitude and admiration while describing some of the tasks her carer did for her:

> Here in the house, we have got a system going, you know. I take my tablets at a certain time in the morning and then at breakfast time I take another lot of tablets and [carer] knows all about that. He organizes all my scripts with the pharmacist and he organizes through [palliative care doctor] the writing of the scripts and the keeping of the medication for me. Which is a really big part, you know, of what he does for me, you know, and keeps up to date on that. God, I think, I don't know what I would be taking. I would be, I'd be everywhere. *(Patient 5, female, home)*

In this regard, staying positive regardless of the uncertainty was described as being important by patients and carers.

> [Patient] has got such a positive, well we both have a positive outlook on life that you've got to make the most of it. *(Carer 1, female, home)*

Participants frequently made humorous comments during the interviews, and everyone laughed at least once. For example, this carer said jokingly:

> When this one passes on (referring to his mother, the patient) I have to find a girlfriend to order around [laughs]. *(Carer 3, male, home)*

They also expressed a sense of reciprocity towards their dyad partner by looking after one another, like this patient-carer pair:

> Patient: I'd stay at home, battle it out at home.
>
> Carer: Always the two of us…
>
> Patient: As long as the two of us got our marbles together, we'll battle through. *(Patient 4, male and Carer 4, female, home)*

While only some carers felt confident and prepared for the caregiving task, all of them were committed to their role and wanted to be there for their patient. In that sense, feeling responsible for the patient was also a strengthening emotion as it increased carers' commitment.

> You have to be a coordinator. It's up to you to say: "What's [palliative care doctor] doing? And what's [oncologist] doing? And what does [patient] need now?' And that's what I do. *(Carer 5, male, home)*

The decision to take on the caregiving role was sometimes explained by the need to give something back and repay the patient for things they had done. This can be seen as the flip-side of challenging emotions such as guilt and regret. The following carer, for example, described how his mother (the patient) would never buy anything for herself and would invest everything to support her children "while she wore dusters". Hence, his commitment came from a deep sense of reciprocity.

> When I was sixteen I've seen what she (the patient) went through. And my sister and me made a pact that we both would look after mum when we grew up. And if one of us wasn't able to, the other one had to take on the responsibility. I've done that. I've taken that responsibility on for her, to help her through it. *(Carer 3, male, home)*

The following mind map provides an overview of the range of emotional responses discussed in the interviews. These emotions were strongly connected to participants' cognitive and behavioural responses when dealing with uncertainty in decision making.

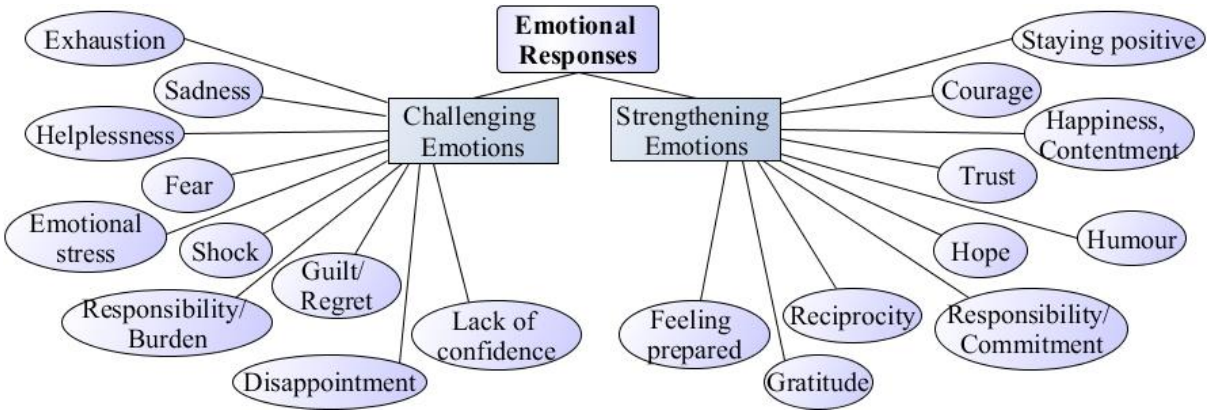

Figure 10.3. Summary of emotional responses discussed in the interviews.

10.3.3 Theme Three: Cognitive Responses

The unpredictability of the situation triggered a variety of cognitive responses that had a strong emotional basis and can be categorized into the following three sub-themes:

- Memories and past experiences
- Hypothetical scenarios
- Worries about the future

10.3.3.1 Memories and Past Experiences

During the interviews, patients often reminisced about their life, which brought up feelings of gratitude and contentment but also regret and guilt. All participants talked about their first-, second-, or third-hand experiences with different places of care. These descriptions were often volunteered unprompted and used to explain, illustrate and rationalise preferences to the interviewer. Some of these experiences had been recent ones whereas others had occurred several years or even decades ago. Knowledge gained through previous experiences strongly influenced participants' attitudes towards places of care and was used to predict how safe a given care setting would be. For example, positive past experiences with institutional care helped to reduce uncertainty about what to expect and increased the sense of safety with going there. In contrast, unfamiliar wards were considered to be much more frightening, as this patient described:

> Over the last couple of years I've been to the same ward in the hospital. And knowing that the staff would change but it becomes familiar. So, the scary part of it is gone for me. I didn't want to go there initially. I was scared of it, frightened of it. I thought, you know, palliative care [gasps]. Oh, no! I sort of got a one-way ticket in there, you know. But now I don't feel like that at all. And that's because of the staff and the way they are and the way my palliative care nurse treats me as well. And I know all of that. It makes it easier for me. So, I'm not worried so much anymore. It's not as scary anymore. It was really scary and I was terrified and fearful. *(Patient 5, female, home)*

Similarly, another patient talked about her first-hand experience with institutional care and how it influenced her preferences for place of death:

> I've been in hospital there a couple of times, I've had three minor strokes but they were very good to me while I was in there. So, you know, I decided that I wanna finish me days there. *(Patient 3, female, home)*

Furthermore, second-hand experiences were also used to inform preferences. For example, this patient explained his preference to avoid nursing home care by referring to his experience with his mother-in-law:

> I don't want a nursing home. I know, euthanasia or suicide is not really an option either but... I don't wanna be a burden to anybody, and I certainly don't wanna be a dribbling idiot in a nursing home... They smell of urine and, you know, old ladies and old men shuffling around. Just generally not nice places to be in. My mother-in-law was in one for about six months and it wasn't nice. They had that smell about them, that death or decay or whatever you like to call it, I don't know. But it's just something about them. *(Patient 8, male, home)*

Another carer had had similar experiences:

> I have seen nursing homes. I've seen people lying in bed, covered in urine all day. The smell of them, just pathetic. And I know a lady that went in there, she was perfectly healthy but her kids put her in there. Twelve months later, she's like a bag of bones. And she was very upset that her family wouldn't come and see her... About three weeks later, she passes away. Sometime during the night she died, no one checked on her, cause she was in a corner, whatever. It was eleven o'clock in the morning before somebody checked on her and that was the doctor that was coming to see her. No one knew she was dead. *(Carer 3, male, home)*

Finally, when participants had insufficient first- or second-hand experiences to draw from, they often referred to reports they had heard from others or in the media. For instance, this couple explained their negative views of nursing homes by referring to third-hand experiences in form of stories they had heard about these care settings:

> Patient: It's just a money-making venture and it's not about the care of the patients. And I, you hear that a lot with what's reported in the media. So that influences the way I think about it.
>
> Carer: From a personal point of view, I haven't had a lot to do with nursing homes, so it's not from a personal experience.
>
> Patient: Yeah, it's only hear-say. *(Patient 6, male and Carer 6, male, home)*

First-, second- and third-hand experiences strongly influenced respondents' preferences for place of care and place of death, as this patient explained:

> You hear things like people being left in beds and things like this for hours on end, given wrong drugs, and just not cared for. No sort of hygiene or anything. I couldn't hack that. I'd rather go and jump off a building somewhere than face that. I mean that! Seriously! *(Patient 1, male, home)*

In summary, drawing on past experiences and reports from others helped to reduce uncertainty and was used as a source of information to make decisions for an unpredictable future.

10.3.3.2 Hypothetical Scenarios

Participants considered their options for the future using a range of self-constructed hypothetical scenarios - good and bad. For example, patients and carers thought about conditions under which home care would be manageable and at which point institutional care would become necessary. Concerns often addressed the carer's ability to cope and the patient's ever-changing health. "If... then..." scenarios were frequently used as a form of mental preparation for what might be coming. This was illustrated by the following carer:

> The bottom line about [patient] is: the pain management just has to continue. I would never take her home without the nursing referral. Cause as soon as she gets more pain, they can deal with it. Or if they can't, the doctor comes in. Well, that's how it was explained to me. If I have a problem and she seems to be in pain, I ring the nursing service, they talk me through it. Tell me what to give her because they've been giving her the breakthrough tablets. They're strong opioids that we can use. And I might say:

> "I'll try that. If that doesn't work, they will come." And if they decide they can't do anything about it, it's triple O again and off to [hospital]. So the fail-safe's there. She's not going out into a place without a safety net. *(Carer 7, male, non-home)*

For some respondents, this hypothetical "if... then..." approach of was helpful to reduce uncertainty. Yet again, there was a tipping point at which too much thinking ahead caused more uncertainty instead of less. Consequently, worrying was a frequently observed cognitive response, which also had a strong emotional component.

10.3.3.3 Worries about the Future

Participants expressed a wide range of concerns, which differed according to the place of care they were considering. At home, worries regarding the patient included effective pain and symptom management, and aspects of personal care. Worries regarding the carer included being a burden, the carer's health, as well as his or her ability to deal with the physical and emotional demands of caregiving. In the following example, a carer used "if... then..." scenarios to balance their concerns about home care:

> It's dependent on where mum would get the most support. She "wants to be comfortable", is her words, and she doesn't want to "be a bother". And so, if she's needing medical assistance, I know the palliative care, we've talked with them. We have all the details and stuff. That if mum's just suffering from pain, then people can come and give her relief. And that's good because then it's at home. It's more, the more complicated medical procedures that might be necessary that I'm not able to deal with. Or it depends on my availability and so this is probably why it's not something I really nailed down because I know that I might not be available. *(Carer 8, female, home)*

Leaving home, as the place of care, was a challenging decision for patients and carers - particularly when they were uncertain about if and when they could return. Worries regarding institutional care included issues of privacy, especially in shared rooms. A carer described:

> I wasn't happy with it, to be honest (referring to their latest hospital experience)... Little privacy, you know, little privacy. And that's what one of the nurses said to me when she was doing seventeen hours, she said: "There's no privacy when you're in a hospital."*(Carer 2, male, non-home)*

Similarly, another carer discussed the importance of this especially in end-of-life care:

> You need your privacy, you know... Your loved ones have to prepare themselves that now this coming to the end. And you don't want to be in a room where there's other people in the same situation. *(Carer 1, female, home)*

Other concerns regarding institutional care included cleanliness of the care setting, personal hygiene, dignity and independence, as described by this patient:

> That sort of worries me a little bit. Because I don't wanna be just left, on my own, for hours on end and not being able to do the things…with your natural body functions and all that sort of thing, you know, which I'm very conscious of, even at this point in time. And my hygiene and everything. I have to be... I think that's a problem of the people who run the hospitals. I always said: "You always come out with more than you go in with." So, that wasn't my only concern at the time, because I was so susceptible to infections... I mean my biggest concern is having been so independent all my life since I was fourteen years old, but okay. You get to a point where you can't be independent because you just can't cope with it. But it's all the unpleasant things like the hygiene and things like that that concerns me now. *(Patient 1, male, home)*

When contemplating place of care options, participants further considered structural aspects like proximity to the family, availability of palliative care services and financial concerns. Respondents discussed the cost of health insurance, highlighted the importance of governmental support such as carer allowances and implied that the quality of a care setting often depended on whether or not it was sufficiently funded. As previously mentioned, nursing homes were connected with the highest number of concerns and hence, often avoided. The following mind map provides an overview of the range of cognitive responses discussed during the interviews. The emotions and thoughts outlined were often the basis of behavioural responses in end-of-life decision making.

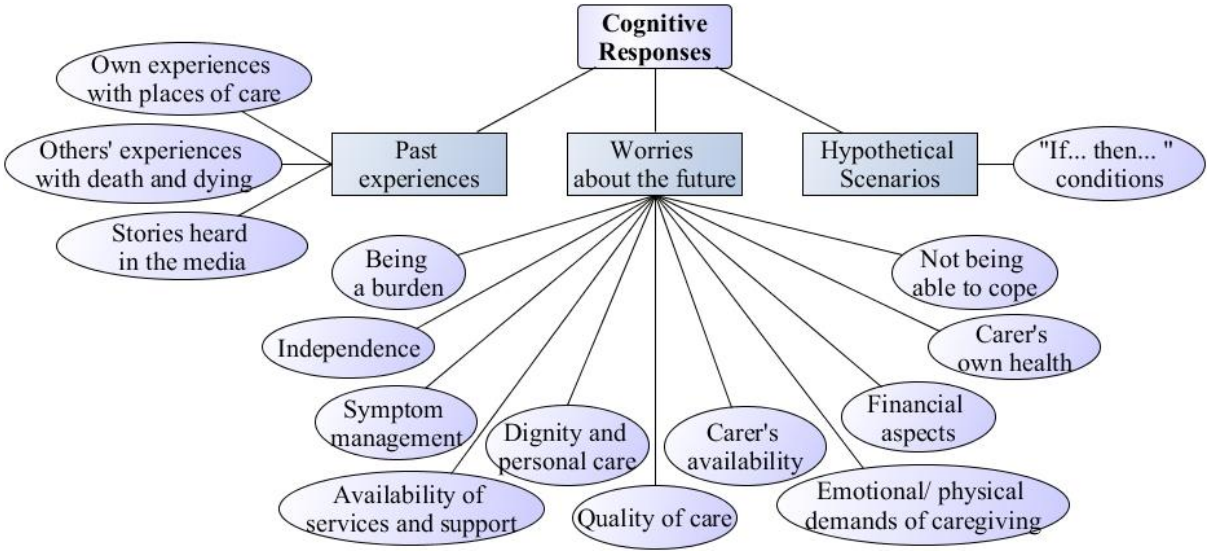

Figure 10.4. Summary of cognitive responses discussed in the interviews.

10.3.4 Theme Four: Behavioural Responses

The unpredictability of the illness and the uncertain manner and timing of death made planning ahead very difficult. This applied to end-of-life preparations as well as to day-to-day activities, as described by the following patient:

> It's a nuisance because it's hard to plan things cause you're not sure how you're going to be on that day. *(Patient 5, female, home)*

During the interviews, participants discussed different behavioural strategies to deal with uncertainty. These responses can be grouped into two sub-themes:

- Active Avoidance
- Active Preparation

10.3.4.1 Active Avoidance

For some participants, too much certainty about the illness was perceived as too confronting and anxiety provoking. In these cases, considering end-of-life decisions made them feel unsafe. They were still hoping for more life with further treatment or even "miracle cures". They were unwilling or unable to contemplate dying yet. Instead, avoidance was chosen as a strategy to cope with the unpredictable situation. Some preferred not to receive too much information about the illness or focused on more hopeful reports. For example, this carer was asked about her husband's preferred place of care and said:

> We never talk about that. Cause he doesn't say. Last time he said: "What the doctor said to me doesn't seem very nice." I said: "There is always hope." *(Carer 9, female, non-home)*

It can be inferred that leaving room for uncertainty allowed them to hope. In contrast, discussing the possibility of death and planning for it, even when prompted by doctors, was considered a sign of giving up. Instead, these conversations and decisions were often postponed to sometime in the future when death was closer - "down the track", "not yet", "we cross that bridge when we come to it". Now was for the living.

> Interviewer: Have you discussed this with your wife? Do you feel she knows these things?
>
> Patient: No, no, no. Not yet. Because we're still in the positive mode. These are things that occupy my thoughts, you know, when I wake up in the middle of the night and need to use the toilet and I'm lying there going back to bed and think: "Hmm, how are we going to organize the funeral? Who is going to say what? Who will carry the coffin?" We both know that we want to be cremated, that's just general theory. But the specifics of the process, you know, we haven't, we haven't discussed, yet. It's a conversation that will take place, you know, but at the moment, it's a long way away. And I'm happy for it to stay there, for the minute. Because the more I think about that, it means the time focus is narrowing. Very depressing subject. *(Patient 7, male, non-home)*

Hence, not dealing with it (yet) was their way of dealing with it. Avoidance was also chosen as a strategy to protect others. Some patients and carers did not discuss certain end-of-life

issues or actively concealed information that would lead to conflict or upset their family. This carer explained his hesitation to discuss end-of-life preferences with his partner as follows:

> It always means you've got to bring up things with the person that… the person's going to die. I think she (the patient) would rather not..., you understand? She'd rather not…, you know. You'd rather not bring those things up because it's projecting the situation where you're not going to be here. You don't want to, you know, depress them... That's my own view of people but there are things that are really personal and I wouldn't go there. I can come at it from another direction, but not directly. *(Carer 7, male, non-home)*

Similarly, another carer talked about how she might not be able to provide sufficient care for the patient given her own health issues and how she avoided discussing these issues:

> That's not something we've actually talked about with her (the patient) because I think that would throw her into tumult, and we thought: Oh, let's wait until that needs to be dealt with... It would just upset her. *(Carer 8, female, home)*

So for some, avoiding end-of-life information, discussions and planning felt safer than actively preparing for death and dying.

10.3.4.2 Active Preparation

While avoidance was one strategy to cope with uncertainty, many participants reported that they had openly discussed their preferences, and prepared for caregiving and the end of life. Learning new skills was a central part of the carers' preparations. They gathered information about the illness, learned medical jargon and looked for alternative treatments to lessen patient's symptoms.

> I've decided a while back that I wanted to see what this cancer looked like and I wanted to research it more to know what was going on... So we've demanded a scan and I had learned how to read them. *(Carer 5, male, home)*

Carers also had to learn new skills to deal with the physical challenges of caregiving, such as lifting and moving a person:

> We had a bit of a practice of me moving her [the patient]. Because she's lost the use of her legs. So, when I'm going to have her at home, I have to be able to do that right and it's not that easy... Moving a person who can't help themselves much is hard. Not easy. And that surprised me, because, in the past, she's had enough strength to help herself a little bit and that makes a huge difference. *(Carer 7, male, non-home)*

Preferences for place of care were often actively negotiated between patients and carers with regard to each other's wants and needs. Preparation in this context meant for some to inquire about different places of care and to seek support through palliative care teams, doctors and family members. Many carers had set up their home to cater to the patient's needs.

> Our bedroom upstairs has got an electrical, a single bed for her (the patient) that we've got through our palliative care nurse... And we'll stay here (at home) as long as we can. I mean, you know, I'll bring the bed down here, on this floor, rather than being upstairs, before I take her back to hospital. You know, because we can live down here. It's not a problem. *(Carer 5, male, home)*

As carers prepared for the caregiving task, patients prepared themselves as well by making end-of-life arrangements. For example, they ensured that family members and doctors knew their wishes, gave belongings away or arranged their funeral. This patient explained:

> I thought to open up a church and all that would be a bit too much for maybe two dozen people if I'm lucky [laughs] to have at my funeral. So [carer] said: "Oh, I'd like a requiem mass for you". And I said: "Mass, nice, quiet and so forth." I said: "I'd be happy with that." So, the priest knows what I want, sort of. And he said he'll arrange it all for me... But it's nice to know in a way, you know, when you're going to die... I think it is because you can make some of your own arrangements. Like I had a ring that [carer] bought me for our 25th wedding anniversary. And at the back of my mind, I always thought that my daughter-in-law will have that... And I gave it to her yesterday. Why wait till after I die? *(Patient 2, female, non-home)*

Some patients actively planned for death, whilst being unsure how far away it was. For these patients, planning ahead reduced uncertainty and created safety as it provided a sense of control and lessened the burden on the family. This patient said:

> I will be going down and seeing the funeral people, and organizing things there, organize a wake at one of the hotels, how much is it gonna cost, and eventually will... book a room [laughs]. *(Patient 8, male, home)*

Yet, the unpredictability of the context demanded a certain degree of flexibility from everyone involved. While planning ahead provided some degree of certainty, planning too far ahead was often simply not possible, as this dyad explained:

> Carer: Situations change, you know.
>
> Patient: Yeah, we're pretty flexible. I know I'm pretty flexible. If circumstances meant that I couldn't stay or come home, you know, well what's the next option? It's not gonna be the end of the world sort of thing. That's how I think about it now. I don't know whether my feelings would change on that if it got critical. But I don't think so. You just move on, you know. Whereas some people: "It's got to be this" and force that issue. Whereas I don't. I just…: "If that's not going to happen, well, let's look at the next option."*(Patient 6, male and Carer 6, male, home)*

The following mind map provides an overview of the range of behavioural responses discussed during the interviews. Avoidance and planning ahead were strategies used in a highly unpredictable context and were strongly interconnected with the emotional and cognitive responses outlined. These behavioural strategies changed frequently depending on the demands of the situation. For example, after making some challenging end-of-life choices, patients and carers often returned to ordinary day-to-day activities, which provided a sense of normality. Similarly, those who preferred not to deal with end-of-life issues were sometimes forced to make decisions and pause their avoidance. A comparable structure was noticed in the interviews. For example, after talking intensively and openly about death and dying for a while, participants sometimes suddenly avoided the question and changed the subject to a lighter topic such as food, travel or work. Using an analogy, it often seemed like they needed to catch their breath by talking about something else before diving back into the topic. In summary, active planning, as well as avoidance, were strategies used to cope with an

uncertain future. While some preferred one approach over the other, many appeared to change from avoidance to planning and vice versa, depending on the context.

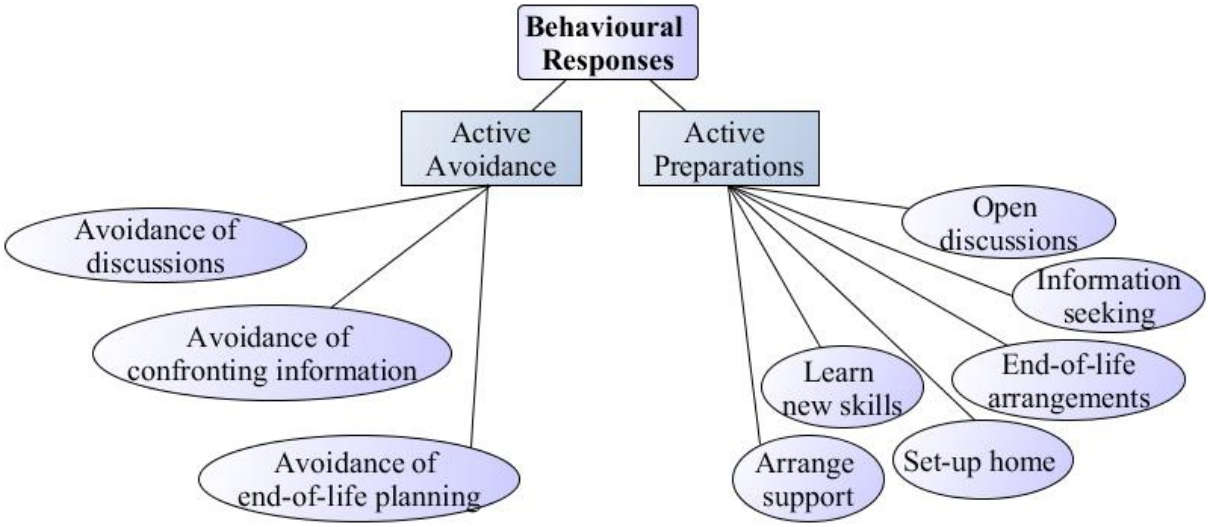

Figure 10.5. Summary of behavioural responses discussed in the interviews.

10.4 Summary and Conclusions

The process of forming preferences for place of care and place of death was influenced by aspects within and outside of the decision maker. Uncertainty was one of the central themes discussed by patients and carers. To seek safety in this unpredictable situation, emotional, cognitive and behavioural responses were used. These aspects were strongly interconnected. Based on the themes presented, the process of forming location preferences can be described as: contextual, personal, relational, conditional and flexible.

Contextual Decision Making. Participants discussed that choices were made within a highly unpredictable context. Uncertainties related to aspects of the illness, the carer and the healthcare system. Participants used different strategies to deal with these uncertainties. Many tried to achieve a sense of certainty through information seeking, discussions and planning. Yet, too much certainty was perceived as confronting and hence, sometimes avoided.

Personal Decision Making. Preferences were often based on the participant's personal history. Past experiences with different care settings played a considerable role in choosing a place of care and place of death as they influenced participants' attitudes about care settings. There were also individual differences in the degree to which people could tolerate uncertainty or sought control over the situation. The resulting emotions, thoughts and actions were hence a unique combination of personal attributes and external circumstances. Some participants felt safer by not knowing what was to come, while others actively made plans for different scenarios.

Relational Decision Making. Preferences were often negotiated in discussions between patients and carers. The views of medical staff and other family members also played a part. While the main focus was on the patient's wishes, decision-making was shared. Preferences were based on concerns for each other, relationship aspects as well as a sense of responsibility and reciprocity.

Conditional Decision Making. Preferences for place of care and place of death were rarely absolute but instead often expressed as a conditional tendency to favour one place over another. If the first preference was not a feasible option, other settings were considered. The resulting "if... then..." statements allowed patients and carers to make plans in highly unpredictable circumstances.

Flexible Decision Making. Even when a clear preference for a certain place of care had been established and expressed, there was a general acceptance that these preferences might not be achievable. This flexibility made room to allow respondents to change their mind if they wanted or had to. It also created a "taking it day by day" mentality as planning too far ahead was often regarded as not possible due to the unpredictability of the context.

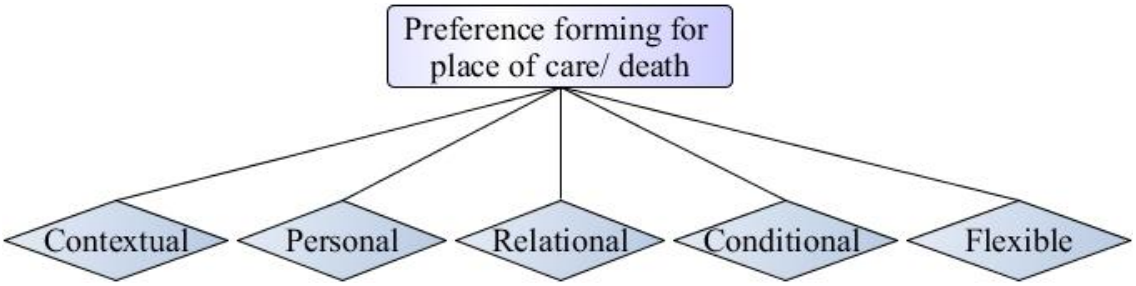

Figure 10.6. Attributes of the process of forming preferences for place of care and place of death.

Overall, end-of-life decision making was described as challenging given the complex, unpredictable and emotionally loaded situation respondents found themselves in. The following chapter will now discuss the themes established in Study 2 in light of the previous literature.

11

Discussion

Study 2

CHAPTER ELEVEN

The purpose of Study 2 was to gain an in-depth understanding of the processes and reasons that governed decision making of patients and carers at the end of life. Thematic analysis of a series of semi-structured interviews identified four overarching themes. The theme of uncertainty represented the context in which choices had to be made. The themes concerning emotions, thoughts and actions captured the dominant responses to this uncertainty. This chapter will discuss the key findings of Study 2, highlight their connections to the existing body of literature and address methodological aspects of this research.

11.1 Sample Characteristics

In Study 2, 12 semi-structured interviews with 17 participants were conducted. The eight patients interviewed were on average 75 years of age, two-thirds of them were male, and the majority presented with malignancies. In contrast, the nine carers in the study were on average 69 years old and about half of them were female. Patients and carers were most often each other's spouses. By the beginning of data analysis, all of the respective patients had died, which illustrates how close respondents were to the end of their life. The following sections will discuss preferences of patients and carers and how they were formed.

11.2 Preferences for Place of Care and Place of Death

All except for one patient expressed a preference to be cared for at home and all carers supported their patient's wish. Home had a strong emotional meaning for participants as it was described as representing family, memories, safety and familiarity. This supports the argument of Barclay and Arthur (2008) who suggested that home is often seen as the most natural place of death because it reflects who we are and what family means to us. With that said, Barclay and Arthur (2008) also pointed out that home deaths are not always associated with the presence of family members, strong support systems, or even sufficient symptom

control (see section 2.5.3). Similarly, in Study 2, there appeared to be a threshold at which the patient's needs exceeded the carer's abilities to provide the necessary care at home. At this point, home was no longer identified as the safest option and palliative care hospital wards or hospices were considered. As discussed in Chapter 1, Parkes (1978) concluded based on interviews with bereaved carers that "home can be the best place or the worst place to die" (p. 26). They found that inadequate pain management and exhausted carers were common issues in care at home (see section 1.1). Nonetheless, in their study, families often saw hospital admissions as a sign of failure and therefore delayed them until all resources were depleted.

At this point, it is worth noting that while most patients in Study 2 wanted to be *cared for* at home, many did not want to *die* there. This supports the findings of Agar et al. (2008), who suggested that preferences for place of care and place of death are two separate concepts (see section 2.6.1). The current study further offered reasons for these divergent choices. For instance, many patients preferred not to die at home out of fear that this would overburden the carer and ultimately "haunt" their family. Interestingly, some of the carers were also worried about being left with the memories of their loved one dying at home. They were concerned about having to stay in the same house, the same room, or sometimes even the same bed in which their loved one died. Nonetheless, carers' main focus was on providing the best care possible for the patient. Their preference for an institutional place of death was often based on the concern that they might not be able to adequately meet the patients' care needs during the time leading up to their loved one's death. Consequently, some felt that providing good care in the terminal phase would require a more professional setting and medical support.

These findings suggest that in most cases, participants were relatively accepting of institutional care. This acceptance, however, entirely excluded nursing homes, which were consistently reported to be the least preferred place of care and place of death in Study 2. People there were described as "abandoned", "drugged up" and even "locked up".

Consequently, respondents felt strongly about avoiding nursing homes at all cost. Participants often stated that they would rather die than go into a nursing home. However literally one may take these remarks, they illustrate the extremely poor reputation of these care settings, which were described in this study as "a waiting room for death". Similar concerns have also been found in previous end-of-life research, as discussed in Chapter 2. Lack of respect, communication and involvement in decision making, as well as untreated pain, were reported to be major problems of end-of-life care in nursing homes (Teno, 2003; Teno et al., 2004; Thompson et al., 2012; see section 2.5.2.3). Furthermore, Wilson (2006) highlighted that these facilities sometimes do not have enough space to provide privacy in the care of the dying. Adding to this, respondents in Study 2 described how they believed that nursing homes provided no stimulation, no dignity and poor quality of care. Participants even felt that people died there more quickly - and in some cases, these concerns might be warranted. For example, it was discussed in Chapter 2 that in a review of mortality rates in nursing homes, Mautner et al. (1993) found that 41% of residents died within the first six months after admission and, of those, the majority passed away in the first four weeks (see section 2.5.2.3). It is therefore not surprising that in Study 2 these concerns about nursing home care directly influenced respondents' preferences.

Overall, decision making at the end of life was described as very challenging in the interviews. Many participants stated that the choice where the patient would spend their last days was a hard one. The next section will now discuss how patients and carers formed preferences for place of care and place of death.

11.3 How are preferences for place of care and place of death formed?

In Study 2, the process of forming preferences at the end of life was described as personal, relational, contextual, conditional and flexible. It was personal in the sense that preferences were influenced by the unique history, attributes, emotions and thoughts of the

decision maker who had to consider the needs of the people around them and the demands of the situation. One key point is that while many participants had established a preference for place of care and place of death, these views were rarely absolute. Instead, they were expressed as conditional tendencies to favour one place over another. This can be compared to the findings of Thomas et al. (2004), who interviewed palliative care patients and carers, and described preferences for place of death as a "stronger or weaker leaning in one direction, qualified by speculation about how things might change" (p. 2436).

The current study adds that being flexible in their preferences allowed respondents to adjust their views if the situation required it. This supports the findings of Munday et al. (2009), who reported that, based on interviews with general practitioners and nurses, patients' preferences for place of death were often not clearly defined and hence, changed over time (see section 4.1.2). Instead, they described preferences as being co-created in discussions between patients, carers and doctors. Study 2 provided further evidence for this relational component of decision making at the end of life. For instance, patients' concerns for their families strongly shaped their preferences as they considered the carer's needs, health and other responsibilities, as well as the burden of the caregiving task itself. In the same way, Thomas et al. (2004) found that preferences for place of death were often influenced by informal care resources, such as patient's assessment of the carer's capacity to care and their concern for the welfare of their family.

The thematic analysis of the interviews in Study 2 emphasised that preferences were highly dependent on the context in which they were formed and this context was characterised by uncertainty. Furthermore, participants differed in how well they could tolerate this uncertainty and which strategies they used to deal with the unpredictable situation they found themselves in. These findings will now be discussed.

11.4 Decision Making in the Context of Uncertainty

Uncertainty was the most dominant theme reported by all participants. This was expressed in regard to the illness, the carer and the service provision. For example, participants were unsure what symptoms the patient might develop, how the carer would cope, and how much time they had left together. Structural concerns like the availability of support services were also important. In their interviews with terminally ill cancer patients about their preferences for place of death, Tang (2003) found that worries about being a burden, the overall quality of life and of care, as well as the availability and capacity of the carer were the major considerations in their decision-making process. The current study further adds to these findings by suggesting a connection between the different types of uncertainty and the care settings.

Specifically, illness- and carer-related uncertainty was strongest at home where the carers had to shoulder the majority of the work. The level of uncertainty depended on the carer's ability, conflicting responsibilities and the extent to which help was available. Conversely, in institutional settings, the caregiving task was handed over to professionals, which reduced some aspects of illness- and carer-related uncertainty. Of course, patients were still unsure when and how they would die, and carers nonetheless had to come to terms with the prospect of losing their loved one. Yet, the instant access to medical help offered some sense of security in regard to symptom control and lessened the burden on the carer. Finally, service-related uncertainty was equally present in all settings, but in different forms. At home, respondents were unsure what support services would be available and how to access them. In contrast, in institutional settings, there were more questions about the communication, structure and routine of the services.

These varying degrees and types of uncertainty influenced decision making. Study 2 suggested that for many participants too much uncertainty was anxiety provoking. Not knowing how the illness would progress, what they needed to do and how they would cope

triggered fears and concerns. In a discussion paper written at the end of the World War II, Zilboorg (1943) argued that the fear of death is based on the instinct of self-preservation, but it is often repressed to allow for normal day-to-day functioning. When faced with an actual threat to life, this fear surfaces and becomes conscious. Drawing from the findings of Study 2, it is reasonable to assume that the uncertainty at the end of life considerably contributes to this fear. This was supported, for example, in a survey of 60 adolescents with cancer by Neville (1998) who found that uncertainty was significantly associated with psychological distress, which included aspects of anxiety and depression.

It is therefore not surprising that in Study 2 many participants tried to reduce aspects of uncertainty. Specifically, patients and carers attempted to create some predictability by acquiring information, planning for the caregiving task and preparing for the end of life. Seeking certainty allowed them to achieve a sense of control, lessened the burden on the family and made them feel safer. As discussed in Chapter 2, this need to know has also been addressed in a qualitative study by Evans et al. (2009) who found that 87% of interviewed surrogates of incapacitated patients wanted physicians to discuss the prognosis, even if it was uncertain (see section 2.6.2).

One key finding of Study 2 is that individuals differed in how much they wanted to know. For many, there seemed to be a tipping point at which too much certainty caused more anxiety instead of less. Knowing every detail about the illness, and what was to come, or even knowing exactly when and how the patient would die was often not desirable. So, patients and carers found themselves on a spectrum between not knowing enough and knowing too much. In the current study, people used emotions, thoughts and actions to balance these two extremes.

At this point, I would like to highlight that in my initial review of the literature, decision making was often presented as a mainly cognitive process with clear behavioural outcomes. This was described, for example, in Chapter 3 in the Subjective Expected Utility

Theory and the Theory of Planned Behaviour (see sections 3.2 and 3.3.2). While evidence for this cognitive component of decision making has also been found in the current study, the role of emotions and uncertainty in decision making was much more noticeable and dominant than expected. In the literature, I encountered occasional remarks of authors about uncertainty in decision making but did not anticipate how strongly these concepts would feature in the interviews. After identifying this theme in the qualitative data, an additional scan of the literature was conducted to provide a framework for interpreting these findings.

11.5 A Theoretical Approach to Uncertainty in Illness

In 1988, Mishel proposed a theory of uncertainty in illness based on her previous clinical and empirical work. She suggested that people who are faced with a disease sometimes struggle to make sense of the situation. They may experience unexpected or fluctuating symptoms and other unfamiliar events, like sudden trips to the hospital. Mishel (1988) proposed that this somewhat unreliable and unstable situation or so-called "stimulus frame" can lead to uncertainty (p. 226). The theory defines uncertainty in illness as the inability of an individual to determine the meaning of illness-related events, assign definite values to events, and accurately predict outcomes. Uncertainty often arises when information is unavailable or incomplete, and when situations are complex, ambiguous and unpredictable. Based on this description, it can be inferred that the end of life may be a textbook example of an uncertainty trigger.

As illustrated in Figure 11.1, Mishel (1988) argued that a person's cognitive capacities can influence how they interpret their illness situation. When these capacities are exhausted due to information overload, people's ability to accurately assess the situation is limited. However, according to the theory, certain "structure providers", such as social support and credible authorities, can help to make sense of even complex events (p. 227). At this point, it is important to highlight that Mishel's theory sees uncertainty as an overall neutral cognitive

state that is neither good nor bad. The value placed upon it is solely determined by the individual's appraisal of the situation.

It is intuitively understandable that uncertainty in illness is often perceived as a significant stressor and only few individuals tolerate this well. If uncertainty is evaluated as a danger or threat, strategies to reduce this state of not knowing will be implemented. Mishel (1988) suggested that this can be done through "mobilizing", which may include direct actions, information seeking and affect management (p. 230).

Interestingly, Mishel (1988) further suggested that uncertainty can also be appraised as an opportunity. For example, in an unpredictable situation, when negative illness-related news is suspected and soon to be confirmed, maintaining uncertainty might be preferable for some. In these cases, not knowing is better than knowing. So-called "buffering" strategies can help to avoid threatening information and create illusions that protect uncertainty (p. 231). Similar responses have been observed in Study 2, which showed that participants dealt with uncertainty on a level of emotions, thoughts and actions. These aspects will now be discussed in more detail.

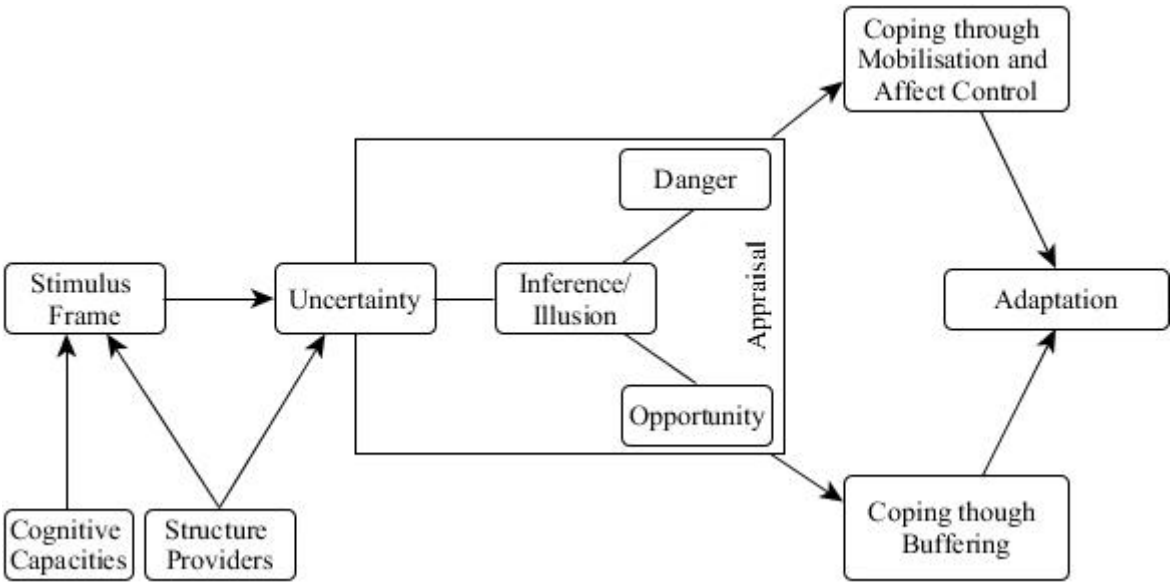

Figure 11.1. Schematic overview of the model of perceived uncertainty in illness by Mishel (1988, p. 226), permission obtained from publisher John Wiley and Sons.

11.6 Emotional Responses

In the present study, a wide range of emotional responses were discussed by participants in regard to the unpredictability of their situation. Challenging feelings ranged from fear, shock and helplessness, to sadness and guilt. Strengthening emotions included for example hope, trust, gratitude and contentment. In agreement with this, Mishel (1988) described affect control as one strategy to cope with uncertainty in illness, for instance, by staying positive and trying to redefine the situation. Going beyond this general theory, the present study found that different care settings were associated with varying levels of uncertainty and consequently evoked different emotional responses. Home was connected with strong positive feelings, whereas institutional care settings were more anxiety provoking. Especially the prospect of nursing home care triggered intense negative emotional reactions.

These findings can also be related to the Two-System View, which was presented in Chapter 3. The theory acknowledged that decisions are not only based on rational elaborations but also on emotional and intuitive processes, which are believed to be automatic, fast and habitual (Kahneman, 2003; see section 3.4). As the famous mathematician, Blaise Pascal, said: "The heart has its reasons, which reason does not know" (2006, p. 78). In the interviews of Study 2, respondents seemed to base their preferences often on cognitive and emotional aspects of the potential care setting. They discussed what they *thought* about different places of care but also how these places made them *feel*, and this influenced their choices.

Izard (1984) explored the origin of emotions in human development and argued that early forms of life adapted to the environment by using simple sensory-affect processes long before any complex cognitions emerged. Therefore, the rudimentary function of emotion was to motivate approach or avoidance. As demonstrated in Study 2, preferences for place of care and place of death were greatly influenced by emotions. Especially negative feelings such as

fear, helplessness and guilt seemed to be driving forces in the decision-making process. This is similar to what Kahneman and Tversky (1979) called loss aversion. As discussed in Chapter 3, Prospect Theory argued that losses, which can be any negative consequence of a certain behaviour, have more influence on choices than gains or positive consequences (see section 3.3.1). The present study found that negative feelings were strongly connected to decision making, whereas positive feelings served more as coping strategies. For instance, humour was frequently used by respondents to cope with the unpredictability of the situation.

Many participants made humorous comments and everyone laughed at least once during the interview. Similar findings were presented by Olver and Eliott (2014), who asked 51 cancer patients about their views on resuscitation, and found that respondents often told amusing anecdotes or used colloquialisms for sensitive concepts like death in order to normalise the topic and reduce stress. In their study, some of the subjects most associated with patients' laughter included euthanasia, religion and funerals (especially their own).

Reciprocity was another strengthening emotion observed in Study 2. Carers often expressed a belief that their patients would provide the same support for them if the roles were reversed. They talked about battling it out together for as long as possible and this commitment was a source of great strength. This supports the findings of Grbich, Parker, and Maddocks (2001) who interviewed 20 caregivers over several months as they moved from the diagnosis of their loved one with terminal cancer, through to the stages of caregiving and bereavement. While carers in their study discussed a range of difficult feelings, not everything was negative. For example, many of their participants indicated that the opportunity to care for their family member allowed them to express their love through care.

In summary, Study 2 affirmed that emotions strongly influenced decision making and further served as coping mechanisms to deal with the demands of the context. However, the uncertainty of the situation did not only trigger a wide range of feelings, but also different cognitive responses, which will now be discussed.

11.7 Cognitive Responses

On the level of thoughts, patients and carers in Study 2 often tried to reduce uncertainty by referring to past experiences and constructing hypothetical scenarios about the future. These cognitive responses were similar to what Mishel (1988) called "inferences" (p. 226). According to her theory of uncertainty in illness, people make decisions based on situation-related examples, such as general experiences, knowledge, personality and contextual cues. These inferences influence whether the situation is appraised as a danger or an opportunity. In the present study, participants' often talked about their past experiences with different places of care to illustrate and rationalise their preferences in the interviews. These personal stories had a strong emotional basis and included first- and second-hand experiences, as well as stories they had heard from others and in the media.

Study 2 found that drawing from past experiences was one way of reducing uncertainty about what to expect from a care setting. Chapter 4 discussed the role of experiences in decision making and suggested that preferences are shaped by the amount and quality of previous encounters with certain treatment sites (see section 4.2.3). For instance, Thomas et al. (2004) identified experiences with services as one of the main themes that influenced preferences for place of death. In their interviews with patients and carers, they found that good experiences of community-based palliative care services strengthened the preference for a home death. Also, encounters with hospice services often positively affected participants' views about this care setting. Many of their respondents acknowledged that they had held negative pre-conceptions about hospices prior to visiting one. This was further supported in the current study, where patients and carers had only vague or incomplete understanding of hospices, believing they were "one-way streets" where you go to die. However, once they actually had been to a hospice, most participants spoke very highly about their experiences, which ultimately influenced their choices.

A similar observation was made for hospitals. Participants were generally accepting of hospital care if they had good experiences with it. In contrast, Thomas et al. (2004) found that their patients and carers avoided hospital care because many aspects of this setting were reported as problematic and distressing. Thomas et al. (2004) further encountered very negative ideas about nursing homes, which seemed to be independent of whether or not participants had personal experiences with these institutions. This was also found in the interviews of Study 2. Those who had been to a nursing home often saw their negative views confirmed. And those who had no personal experiences referred to reports from friends, neighbours or the media to inform and support their pre-existing attitudes.

While respondents used past experiences to inform their preferences, they also constructed hypothetical "if... then..." scenarios to reduce uncertainty about the future. Participants considered what they would do, for example, if the patient deteriorated, if the symptoms worsened, if the carer could not cope, or if no additional support was found. This deliberation process can be compared to the cognitive component of the Two-System View, which uses rule-based reasoning and logical weighing of pros and cons to find the best possible solution for a decisional problem. As discussed in Chapter 3, this is believed to be a slow, serial and controlled process (see section 3.4), which has been conceptualised in many rational decision-making models like the Subjective Expected Utility Theory or the Theory of Planned Behaviour (see sections 3.2 and 3.3.2). These models attempt to predict behavioural outcomes based on perceived values, attitudes and beliefs, and are useful for many intellect-based choices. However, as previously addressed, these rational theories generally underestimate the importance of emotions in decision making.

The present study found that constructing hypothetical scenarios was strongly connected to emotional responses. Participants considered different options, good and bad, which caused feelings of hope and fear. Many had established preliminary action plans ("If this happens, then I will do that."). This mental preparation was sometimes helpful to reduce

uncertainty. However, there was a tipping point at which too much thinking caused more uncertainty instead of less. Consequently, worrying was a frequently observed cognitive response. At home, worries often concerned the patient's pain and symptom management, as well as the burden on the carer. In institutional settings, people worried more about privacy, dignity, independence and personal care.

In conclusion, the uncertainty of the situation was associated with a range of cognitive and emotional responses, which were strongly interconnected. These thoughts and feelings influenced decision making as well as actual end-of-life preparations.

11.8 Behavioural Responses

Many participants in Study 2 reported that they had been actively preparing for the end of life. Carers' focus was often on the caregiving task and their main form of preparation was learning. They gathered information about the illness, the treatment and possible support; they learned medical jargon and set up the home for care. In contrast, patients prepared themselves by discussing their wishes, giving personal belongings away and making their own funeral arrangements. While these tasks were certainly confronting, respondents also felt that they provided a sense of control. Therefore, active preparations were for many a way to ease the burden on the family and reduce the overall uncertainty.

This is similar to what Mishel (1988) called coping through "mobilizing", which can include direct actions, information seeking and vigilance as suggested strategies (p. 230). In clinical practice, active preparation is often seen as an indicator that the patient is aware of the terminal state of their illness and has, at least to some extent, accepted their fate. Consequently, clinicians and policy-makers strongly encourage patients to prepare for the end of life by making living will arrangements, appointing a power of attorney and completing CPR orders. While Study 2 suggested that active preparations helped some participants to reduce the uncertainty of their situation, for others, dealing with the prospect of dying was

just too confronting. For this group, active avoidance was the favoured strategy to cope with uncertainty. These respondents preferred not to receive too much information about the illness and focused on more hopeful reports instead. This is comparable to what Mishel (1988) called buffering through "illusions", which are constructed beliefs that allow a person to see a situation in a favourable light (p. 231). While there has been some controversy regarding denial as a coping mechanism, American psychologist Richard Lazarus (1998) argued that avoidance can protect the individual in the initial stages of threat and when they need to come to terms with challenging information. Mishel (1988) added that once a situation is clear or certain, it is difficult to redefine it again. They concluded that "the maintenance of hope depends on the existence of uncertainty" (p. 229).

Thus, avoidance can be seen as a form of self-protection and Study 2 suggested it can also be a strategy to protect others. Both patients and carers sometimes chose to not discuss certain end-of-life issues or actively concealed information that would cause conflict or emotional disturbance. A similar approach has been noticed in a qualitative analysis of Cohen (1993), who examined the views of parents with terminally and chronically ill children. She described how families developed strategies to deal with conditions of sustained uncertainty. This, for example, meant that parents manipulated "the known, the unknown, and the unknowable" (p. 85), and limited or modified information received from health professionals. Similarly, Study 2 found patients and carers sometimes avoided or postponed end-of-life discussions when they believed them to be too upsetting for their loved one.

Cohen (1993) further noted that parents became more present-day-oriented because long-range plans for the future were too frightening to consider. This day-by-day mentality was also observed in the current study, where thinking too far ahead was not possible due to the unpredictability of the context. Many felt unsure about what tomorrow would bring, but focussing on the now helped them to create a sense of certainty. As previously discussed, this flexibility also allowed respondents to change their minds if they wanted or had to. Further

evidence for this day-by-day approach in end-of-life decision making was provided by Neville (2003) in an integrative review of uncertainty in illness. Referring to her own unpublished doctoral dissertation, Neville (2003) presented findings from interviews with adolescents who had recently been diagnosed with cancer. She reported that over time participants began to accept the uncertainty of their situation, instead of holding on to their pre-illness mode of prediction and control. Many developed a one-day-at-a-time approach and learned to appreciate the now rather than worry about long-term existential issues.

In summary, on a behavioural level, active preparation and avoidance were strategies used to cope with a highly unpredictable context. These behavioural responses were strongly connected with emotional and cognitive aspects of decision making. The use of these strategies was flexible, depending on the needs of the individual and the demands of the situation. People often went from challenging end-of-life preparations back to normal, day-to-day tasks such as reading the newspaper or doing crossword puzzles, and vice versa. It appeared that even those who were very accepting of their situation sometimes needed a break from thinking about death and dying. This created a balance and provided a sense of normality between the ordinary and the extraordinary. Correspondingly, those who preferred not to think about end-of-life topics could pause their avoidance and make necessary choices if the situation demanded it. This flexibility seemed to be essential in order to deal with the highly unpredictable and ever-changing circumstances at the end of life.

11.9 Connections between Responses

Participants' responses to uncertainty appeared to be strongly interconnected. Emotions triggered thoughts and actions, thoughts created emotions and behaviours, and in turn, actions caused feelings and thoughts. The responses described were so tightly linked that it was impossible to determine what was there first: emotions, thoughts or actions. As discussed in Chapter 3, Kahneman (2003) suggested that behaviour can be based on reasoning as well as

intuition, and according to the Two-System View, emotions and cognitions are distinct components of decision making (see section 3.4). However, there is evidence that they also share neural pathways, brain structures and neurotransmitters and, hence, are strongly linked (Bechara, 2005; Izard, 1984; Starcke & Brand, 2012).

It is important to emphasise that in Study 2 the responses observed frequently changed whenever new information or events occurred or when a previous response proved to be ineffective. This created an iterative loop in the response system. To illustrate this, a carer might have established a preference to support the patient at home and had even actively prepared for that by setting up the house, learning new skills and arranging extra support. However, sudden changes in the patient's health or the carer's ability to cope could alter the entire system. If the patient, for instance, developed considerable pain that needed to be managed, new uncertainty would arise. This could cause emotional responses such as fear, which, in turn, increased the need for safety and security. The carer would then make new plans and even take actions, for example, by discussing possible pain treatments with the nurses or by moving the patient to an institutional care setting for better symptom management. At this point the previously established "if... then..." conditions could come into action. Based on this, behavioural responses can be seen as externalised expressions of internal processes such as emotions and cognitions.

11.10 Challenges and Limitations

At this point, it is important to consider some methodological aspects of Study 2 as well as the influence of potential biases. To explain these concerns, the preference for home care found in the interviews will be used as an example. It must be noted that in Study 2, the overall wish to be cared for at home was somewhat stronger than expected with all but one patient and carer pair wanting to be at home. There are three potential reasons for this finding.

Firstly, it is possible that participants responded in a socially desirable way when asked about their preferences in face-to-face interviews. The tendency to report inaccurately on sensitive topics in order to appear in the best possible light has been frequently observed in quantitative and qualitative studies (Fisher, 1993). This social desirability bias could particularly explain the high home care preference in carers. All participants knew that their responses would be audio-recorded and five patient-caregiver pairs also chose to be interviewed together. Some carers might have been reluctant to openly disagree with their patient during these combined interviews. Future studies need to consider this potential response bias when interviewing patients and carers at the same time. The present study, however, deliberately chose this flexible approach, which encouraged patients and carers to decide if they wanted to be interviewed together or alone. This ensured privacy in the individual interviews and allowed for potential discussions to develop in the paired sessions. On the one hand, some authors have specifically highlighted the strengths of joint interviews as they provide particularly rich data concerning the relationship and the interpersonal dynamics of respondents (Bennett & McAvity, 1985; Bjørnholt & Farstad, 2014; Valentine, 1999). On the other hand, it is possible that participants might have influenced each other's answers and increased the need to respond in a socially desirable way.

Secondly, it is acknowledged that face-to-face interviews are susceptible to interviewer biases (Hughes, 2008). In Study 2, a semi-structured interview guide was used in order to avoid any leading questions that could potentially alter patients' and carers' answers. However, it is possible that unscripted prompts or comments of the interviewer have influenced participants' responses. In this regard, it can be highlighted that a portion of the interview transcripts has been reviewed by one of the thesis supervisors for quality assurance purposes. No leading interviewer statements have been identified in this process. Despite these precautions, interviewer biases can rarely be entirely ruled out in qualitative research.

Finally, the strong preference for home care might simply reflect the true views of this particular sample. Yet, it is worth noting that seven out of eight patients (87.50%) were being cared for at home when the interview took place. Similarly, six out of the nine carers (66.67%) currently supported their patient at home. As discussed in Chapter 4, Munday et al. (2009) found that patients often replace their initial preference to die in a specific place with a desire to remain at their current care setting (see section 4.2.4). This could explain the strong preference for home care in the interviewed sample. Future studies, therefore, need to consider the effect of the current place of care on patients' and carers' preferences.

11.11 Chapter Summary

Study 2 provided valuable insights into the reasoning behind place of care and place of death preferences. This chapter discussed how uncertainty regarding illness-, carer-, and service-related aspects influenced participants' emotional, cognitive and behavioural responses. Individuals differed in how well they could tolerate uncertainty. Many wanted to know what to expect to be able to prepare for the future but for some, maintaining a degree of uncertainty was important as it allowed them to hope.

Decision making itself appeared to be a continuous, iterative process that was negotiated with significant others and could change whenever new information, thoughts or emotions surfaced. Consequently, preferences strongly depended on the context in which they were formed and often remained conditional tendencies to favour one place over the other rather than definite choices. This flexibility was necessary due to the unpredictable nature of the end of life. The next chapter will discuss how these findings relate to the questionnaire results of Study 1 and draw final conclusions from this research.

12

General Discussion

CHAPTER TWELVE

The empirical research undertaken for this thesis examined the preferences for place of care and place of death in terminally ill patients and their family caregivers. Study 1 used multiple-choice questionnaires collected from 17 patients and 40 carers to describe their location preferences, identify factors that influence them, explore the relationship between preferred and actual place of death, and examine end-of-life agreement in patient-carer dyads. Study 2 included semi-structured interviews with eight patients and nine carers to gain an in-depth understanding of the underlying processes that govern the decision making. The findings of these studies have already been discussed separately in Chapters 8 and 11. This final chapter will now integrate key aspects from Study 1 and Study 2 to highlight the similarities and differences between the two sets of results. Specifically, this chapter will address the importance of location choices and summarise the influence of illness-related, personal, interpersonal and structural factors on patients' and carers' preferences. It will further discuss the challenges of talking about dying, draw connections to previously described decision-making theories and highlight the implications of these findings for clinical practice. Finally, the strengths and limitations of this research will be presented before providing possible directions for future studies.

12.1 Location Choices – Do they matter?

As outlined in Chapter 2, some researchers have questioned the importance of choices regarding place of care and place of death (see section 2.5). For example, Steinhauser et al. (2000) presented seriously ill patients, bereaved carers and formal care providers with a forced-choice selection of nine end-of-life attributes, of which dying at home was ranked as least important when compared to aspects like freedom of pain, presence of family and resolved conflicts. Steinhauser et al. (2000) pointed out that the responses to dying at home varied greatly, with some participants finding it very important, whereas others neither agreed

nor disagreed. The National Council for Palliative Care (2014) used a similar forced-choice format to survey British adults and found that only 10% rated being cared for and dying in the place of their choice as the most important aspect of end-of-life care.

While the question of where to spend one's last days may be subordinate to freedom from pain or the presence of family, the current research suggests that it is, in and of itself, perceived as highly important by patients, informal family carers and formal care providers. During the recruitment and data collection phase, it was noted that decisions concerning place of care and place of death were a central topic in nearly every staff and client review meeting at the participating sites. Additionally, in the questionnaires of Study 1, both patients and carers rated it as quite to very important: to achieve their first location preference; to avoid their last preference; and to participate in the decision making. This supports the work of Tang (2003) who found that dying in a place of one's choice was ranked as highly important by terminally ill cancer patients. Similarly, Patrick et al. (2001) found that dying in a place of one's choice was reported to be one of the central domains of a quality death for AIDS patients. To explain this further, Mezey et al. (2002) argued that the care setting has a palpable, direct and immediate impact on the quality of life of a dying person because it affects the philosophy of care, the types and intensity of services, the relationship between the care provider and care recipient, as well as the level of skill and availability of medical staff. In the interviews of Study 2, participants frequently reported that the decision where the patient would spend their last days was an important but also a very hard one. To summarise, the findings of the current research provide quantitative as well as qualitative evidence that choices concerning place of care and place of death do matter to people facing the end of their lives and the ones that care for them.

12.2 Preferences for Place of Care and Place of Death in Patients and Caregivers

Since location choices have been found to be an important part of end-of-life care, we need to address where people want to spend their last days. As discussed in Chapter 2, previous studies suggest that the answer is most often: home. Foreman et al. (2006) found that 70% of South Australians in the general public wanted to die at home. However, the current research highlights that respondents who are close to the end of life have somewhat different preferences.

In Study 1, 58.5% of terminally ill patients reported that they wanted to be cared for at home and only 40% of family carers favoured this option. This trend persisted even when respondents were asked about their preferences for place of death. In fact, just over half of the patients wanted to die at home (52.9%), while only 37.5% of carers preferred this too. As outlined in Chapter 4, other end-of-life studies have also found comparably low preferences for home (see section 4.6.1). For instance, Tang et al. (2005) reported that 61.0% of terminally ill patients and 56.9% of family caregivers favoured death at home. Similarly, Stajduhar et al. (2008) found a preference for home in only 53.6% of seriously ill patients and 50.0% of carers.

These findings highlight another important point, which is that patients and carers may not always have the same preferences at the end of life. In the overall sample of Study 1, carers' preferences for care and death at home tended to be lower compared to patients'. A direct pair-wise comparison of the 15 dyads showed that patient-carer agreement was only fair for the question concerning place of care and dropped to a non-significant level when dyads were asked about place of death instead.

To identify underlying reasons for these discrepancies, the current research used a mixed-methods approach that allowed going beyond the mere numeric description of respondents' views. In the interviews of Study 2, participants explained that home had a strong emotional meaning as it represented family, memories, safety and familiarity. Yet,

staying at home was also connected with high levels of illness-, carer-, and service-related uncertainty. Respondents were unsure what symptoms the patient might develop, how the carer would cope, and what support services would be available. Home care strongly depended on the involvement of the primary informal caregiver. In the interviews, almost all of the family carers expressed a desire to support their patient at home; however, these preferences were rarely absolute. While carers were very committed to fulfilling the patient's wishes, their main focus was on providing the best possible care. In some cases, that meant relocating to an institutional setting, such as a hospital or hospice. Respondents in Study 2 explained that the instant access to medical help offered a sense of security in regard to symptom control and lessened the burden on the caregiver. Consequently, this reduced illness- and carer-related uncertainty. Yet, institutional support also meant that care was provided by strangers in an unfamiliar setting with an unfamiliar routine. Participants reported being unsure about several matters, including: how to communicate with staff, who to approach regarding important decisions, how the day and the care were going to be structured, and how long they could or had to stay. They also described concerns about privacy and personal care. This service-related uncertainty was a noticeable trade-off that weighed considerably on the decision-making process.

Based on these findings, it was concluded that the answer to the question about place of care and place of death was in many cases: "It depends." And the factors that respondents' preferences depended on were illness-related, personal, interpersonal and structural in nature.

12.3 Illness-related Factors

Chapter 4 discussed that terminal illnesses are often associated with certain co-morbidities, symptom patterns and illness trajectories that vary depending on the diagnosis and the stage of the disease (see section 4.1). Previous studies have suggested that patients and carers frequently change their preferences over time. Specifically, the desire to die at home decreases as the illness progresses, while the acceptance of institutional care rises (Gerrard et al., 2011; Hinton, 1994; Townsend et al., 1990). There was evidence for this in Study 1, which found that patients who preferred an institutional place of care had been ill for significantly longer than those who preferred home care. Furthermore, the number and type of symptoms played a considerable role in shaping respondents' preferences. Caregivers who preferred institutional care believed that their patients had significantly more physical symptoms than those who preferred home care. Especially distressing symptoms like pain and those relating to personal hygiene, such as constipation, were often associated with a preference for a more formal care setting. This offers quantitative support for the qualitative findings of Thomas et al. (2004) who interviewed terminally ill patients and their carers, and found that their concerns about the management of socially stigmatised symptoms, such as incontinence, made them consider institutional care. Thomas et al. (2004) concluded that preferences for place of death were strongly influenced by these "corporeal matters" (p. 2438), which included symptom management and the maintenance of personal dignity in the face of an increasingly unreliable body.

The current research further suggests that not only physical but also psychological symptoms influence respondents' choices. A pair-wise comparison of patient-carer dyads in Study 1 showed that caregivers significantly overestimated their patients' symptoms and this occurred more often for psychological problems than for physical ones. It was argued that less visible symptoms, such as worries or low mood, leave more room for interpretations of how the patient may or may not be feeling. Especially when symptoms are ambiguous and

not clearly observable, caregivers may project their own feelings onto the patient. Study 1 found that the carers' estimates of their patient's psychological well-being correlated more with the carers' own psychological symptoms than with the patients' self-reports. This indicates that carers' emotional distress can affect the accuracy of their assessments and highlights that carers have symptoms too. These may be from pre-existing conditions or newly acquired problems resulting from the demands of the caregiving task. In the questionnaires of Study 1, carers often reported that they felt tense, fearful, weak, tired, depressed and angry. Many had trouble sleeping or eating, and were worried about their loved ones and the future. This was further supported in the interviews of Study 2, in which carers discussed how exhausted and overwhelmed they felt at times. Many were not sure how much they could handle, especially at home, where they had to shoulder the majority of the work. Similar findings were reported by Stajduhar and Davies (2005), who interviewed current and bereaved caregivers about their end-of-life experiences. Carers often negated their own needs and focussed solely on meeting the wishes of the dying, which they described as their "final gift" to the patient (p. 26). Stajduhar and Davies (2005) suggested that caregivers may not even identify themselves as persons in legitimate need of help and may not be perceived as needing support by the healthcare system. In a qualitative review of 18 international studies, Woodman et al. (2015) found that family caregivers often wanted to care for the patient at home, but the overwhelming emotional and physical burden of home care led to admission into formal settings. These findings are further added to by the interviews of Study 2 as they include the perspectives of patients who expressed great concern regarding the needs and health of their carers. Many patients were worried that care at home would over-burden their family and this concern substantially influenced their location preferences. Some said that they had decided not to die at home as they felt that this experience would "haunt" their loved ones. This illustrates how crucial the well-being and support of informal caregivers is for end-of-life care, especially at home.

12.4 Personal Factors

The current research suggests that the complexity of decision making at the end of life goes beyond the illness itself and is further shaped by the personal attributes of the decision maker. These concern the demographic background, personality and experiences of patients and carers.

12.4.1 Demographic Factors

As discussed in Chapter 4, previous research has suggested that men are more likely than women to prefer to spend their last days at home and more likely to achieve this wish (see section 4.2.1). As an example, in a review of 45 international studies, Grande et al. (1998) argued that women are more efficient carers, making home care and home death, therefore, more achievable for their male spouses. However, in the questionnaires of Study 1, there was a non-significant trend in the opposite direction. Here, male patients tended to prefer institutional care over home care more often than female patients did. It was discussed in Chapter 8 that this could be an effect of the current place of care as almost two-thirds of the male patients had been recruited from an institutional setting, whereas only one-third of the female patients had (see section 8.3.2). It is reasonable to assume that those who required hospital or hospice care might have struggled with symptom management or lack of carer support at home, which influenced their preferences. It is also possible that patients' current experience with institutional care was perceived as positive and that they consequently preferred to stay there.

Grande et al. (1998) further reported that older patients were less likely to die at home than younger ones. While age may have affected people's actual place of death, according to Study 1, it did not influence preferences for place of care. Similarly, no effect of respondents' educational status on their preferences was found. However, there was a medium but non-significant trend in patients with an institutional preference to report a lower household

income than those with a home care preference. In the interviews of Study 2, some respondents also addressed financial factors such as needing governmental help in form of carer allowances to manage care at home, or being concerned about the cost of health insurance, inpatient beds and support services. Grande et al. (1998) argued that those with more favourable social conditions, such as high income might have better access to home care and support services, which would put low-income groups at a disadvantage. The current research indicates a trend that this might not only influence patients' actual place of death, but also extend to their preferences.

12.4.2 Personality and Preferences

The current research illustrates that the role of personality in location decision making is challenging to capture. In Study 1, only non-significant trends were found in regard to the Big Five traits of extraversion, agreeableness, conscientiousness, neuroticism and openness (McCrae & John, 1992). Openness tended to be higher in patients and carers with an institutional preference as opposed to those who favoured home care. The preference for institutional care also tended to be associated with lower agreeableness and extraversion in patients, and lower conscientiousness in carers. These findings have already been discussed in greater detail in Chapter 8 (see section 8.3.2). At this point, however, it is worth noting that personality aspects were rarely mentioned explicitly in the interviews of Study 2 and can only be inferred from participants' responses. For example, some patients and carers reported being very upfront in their end-of-life discussions, which could indicate higher extraversion, whereas others were actively avoiding these conversations, which might indicate higher introversion and agreeableness. Some carers talked about their role as coordinators who have to schedule, plan and arrange caregiving-related matters for their patient. This could point to high levels of conscientiousness. Furthermore, many participants reported being upset, fearful and worried, which may be signs of higher neuroticism (or simply a natural response to the

challenging end-of-life situation). It is therefore impossible to say whether these reports actually reflect respondent's underlying personality traits. Beresford and Sloper (2008) argued that personality influences how people perceive a situation and how they react to it. This includes, for instance, how much information they seek or to what extent they want to be involved in the decision making. However, based on the findings of the current research and the lack of other relevant studies in this area, further research is required.

12.4.3 The Role of Experiences at the End of Life

The current research provided compelling, quantitative and qualitative evidence for the association between respondents' experiences and their preferences. Specifically, past as well as current experiences with different treatment settings were often used as a basis to inform future decisions regarding place of care and place of death. In Study 1, higher satisfaction with experiences correlated with a higher preference for these locations. This was significant for hospice and nursing home preferences in carers, and marginally significant for hospice preferences in patients. For the other locations, home and hospital, non-significant trends showed an effect in the same direction. The amount of experience also played a role. More hospice experience correlated with a stronger preference for hospice care. This effect was significant for carers, and patients showed a non-significant trend in the same direction. As discussed in Chapter 3, according to the mere exposure effect, more experience should be associated with more liking (Zajonc, 1980). Yet, interestingly, for the other three settings, hospital, home and nursing homes, the trends went in an unexpected direction. In fact, more experience with these settings was associated with a lower preference for each place. While these trends did not reach significance in the quantitative analyses, there was further evidence for the role of experience in the interviews of Study 2.

Here, personal stories about past experiences were often volunteered unprompted by participants to explain their location preferences. These included: first-hand experiences of, for example, themselves being in a hospital; second-hand experiences of, for instance, a close relative dying in a hospice; and third-hand experiences of stories they had heard from others or in the media. The amount of experiences played a role in these reports as unfamiliar care settings such as hospices or hospital wards were often seen as frightening. In contrast, some respondents indicated that certain wards had become familiar to them over time and they were less uncertain about what to expect. Yet, the quality of the experiences was much more important than their quantity. Those who had reported positive encounters with certain care settings were more open to considering them as an option, as opposed to those with negative experiences. In particular, nursing home encounters had been portrayed as very grim and hence often avoided. In agreement with the findings from Study 1, respondents' views of hospice care in the interviews strongly depended on their exposure to these settings. Those without any hospice experience saw this as a place where you go to die, whereas those who had personally encountered hospice care spoke very positively about them, which ultimately influenced their preferences. Finally, reports about past experiences with hospital care had been mixed. Some said they had received great care in hospitals and considered them as an option for end-of-life care, while others had been put off by their past hospital encounters and consequently wanted to avoid them.

In regard to patients' and carers' current experiences, Study 1 showed that many participants preferred to stay in the place where they were presently receiving care. It was discussed that their current setting may have become familiar to them and that relocation to a different place of care would mean jeopardising this familiarity (see section 8.3.2). It might be the proverbial "devil you know that is better than the one you don't". As outlined in Chapter 3, Kahneman's Prospect Theory (1979) suggested that people make choices based on their current reference point and have a stronger tendency to avoid losses rather than seek

gains (see section 3.3.1). In connection with this, the existing place of care can be seen as the patient's or carer's point of reference and relocating to another place might be perceived as a loss that needs to be avoided. In the interviews of Study 2, respondents further indicated that relocating to new and unfamiliar settings increased the overall level of uncertainty, which, in many cases, was perceived as stressful and frightening. This negative emotional response to a potential change of setting could be explained by the impact bias discussed in Chapter 4. According to Wilson and Gilbert (2005), people tend to overestimate the intensity and duration of their emotional reactions to future events (such as moving to a new care site) and underestimate how quickly they will cope with it (see section 4.1.1). This attachment to the current surroundings could further explain why most population-based surveys find an overwhelming preference for home care. Respondents of these surveys are likely to be at home and, hence, prefer their existing setting. Because people have difficulties detaching themselves from their current feelings and emotions, they might also have trouble imagining how it would be in a new care environment and therefore prefer to stay where they are.

Taken together, it can be concluded that experiences are very subjective, individual and complex in nature, which may be why they have rarely been addressed in systematic research. Similarly, in clinical practice, there is often no time for medical professionals to explore patients' and carers' experiences, and staff might not even be aware of the considerable influence that these personal stories have on respondents' preferences. By trying to understand the experiences of care recipients, the healthcare team may be able to identify, for example, why a patient is reluctant or scared to go into formal care. This could help staff to address and potentially alleviate these concerns of the patient. The findings of this research, therefore, make a considerable contribution to the existing body of literature, as they highlight the importance of current and past experiences in the decision-making process.

12.5 Interpersonal Factors

The present research emphasised that home care strongly relies on the involvement of informal caregivers. Study 1 found that the quality rather than the length of the patient-carer relationship significantly correlated with a preference for home care in both patients and carers. Consistent with this, in the interviews of Study 2, end-of-life decision making was described as a highly relational process. Instead of considering only their own wants and needs, patients and carers also took the views of significant others into account when forming end-of-life preferences. As discussed in Chapter 4, previous studies have found that the presence of an informal caregiver increased the odds of dying at home (Gomes & Higginson, 2006; Grande et al., 1998; see section 4.3.1). The current research adds that beyond the mere availability of carers, the quality of the patient-carer relationship has a significant influence on patients' and carers' preferences. It is likely that those carers who do not have a positive relationship with their patient would be less willing to take on the caregiving task and this needs to be considered in future studies as well as in clinical practice.

12.6 Structural Factors

The current research focussed predominantly on the influence of illness-related, personal and interpersonal factors on location preferences. With that said, Chapter 2 further addressed the role of structural variables in end-of-life decision making (see section 2.5.3). Specifically, it was discussed that in some regions support services might be fragmented, involve waiting periods, or are limited to defined conditions or criteria. As outlined in the rationale, these structural aspects were not specifically included in the questionnaires of Study 1 because they were believed to be less relevant in major metropolitan cities with well-established healthcare networks, such as Melbourne, where the current research took place (see section 5.1). Nevertheless, a number of respondents in the interviews of Study 2 brought up structural factors without being prompted and discussed their influence on decision

making. To illustrate, some expressed concerns about the proximity of certain inpatient services and whether the distance would be manageable for their family. Many indicated that their decisions partly depended on what services would be available at the time, which was often connected to service-related uncertainty. Some respondents also discussed financial matters including the cost of carer support, inpatient beds and health insurance.

Participants frequently indicated a belief that the quality of institutional care somewhat depended on whether these formal settings were sufficiently funded. Nursing homes, in particular, were seen as underbudgeted, understaffed and overpriced, and hence often avoided. Previous studies have addressed these structural factors but only in regard to the actual place of death. As discussed in Chapter 2, Gomes and Higginson (2006) found that the use and intensity of home care services were associated with higher odds of actually dying there (see section 2.5.3). Similarly, in a large scale American study, Pritchard et al. (1998) found that the likelihood of dying in hospital was increased for residents of regions with greater hospital bed availability and decreased in areas with greater nursing home and hospice availability. A Swedish study by Axelsson and Christensen (1996) added that nursing home deaths were more likely for patients who lived more than 40 km away from the nearest hospital, or in regions with available nursing homes. However, if and how these structural factors influence patients' and carers' preferences was unclear. The findings from Study 2 suggest that proximity, cost and availability of care services had been taken into account by respondents when forming their preferences, and that these factors might even play a role in larger cities with sufficient care resources.

In summary, the findings outlined illustrate that preferences for place of care at the end of life are influenced by a range of interconnected factors within and outside of the individual. The present studies indicate that talking about these preferences is an important but difficult part of clinical practice and of research. Some of the challenges of end-of-life communication will now be discussed in light of the current findings.

12.7 Talking about Death and Dying

Chapter 2 highlighted that death is an emotional, confronting and complex topic, and talking about it is therefore challenging for everyone involved (see section 2.6). As the care of the dying has become increasingly medicalised and scientific, so have the conversations surrounding this subject. The following sections will address three of the main challenges in end-of-life communication identified in this research.

12.7.1 Ambiguity of Place of Care and Place of Death

The first challenge concerns the ambiguity of place of care and place of death. Agar et al. (2008) found that these terms are often used interchangeably even though they are likely to be two different concepts. The current research found evidence for this distinction. A within-subject comparison of the full sample in Study 1 showed that approximately 30% of participants changed at least one of their preference rankings when asked about place of death instead of place of care. While for the majority the answers remained the same, for just under one-third of them these seemed to be different questions. This was further supported in a between-subject comparison of 15 patient and carer dyads. Here, agreement between patients and carers decreased when respondents were asked about place of death instead of place of care. If those were the same questions, the level of agreement should have remained stable.

Agar et al. (2008) criticised that people often talk about place of care instead of place of death, arguably because it is less confronting. It is important to realize that this can lead to considerable misinterpretations of respondents' actual preferences. For example, in the interviews of Study 2, most participants preferred care at home but they did not want to die there. This was often chosen out of concern for the family and driven by worries about the quality of terminal care at home. Given these points, it is necessary and meaningful to assess preferences for place of care and place of death separately, and this recommendation applies to clinical practice as well as to research.

12.7.2 The Tension between Not Knowing Enough and Knowing Too Much

The reluctance to raise the topic of death is one of the inherent issues of end-of-life communication, as it requires a balancing act between open and clear discussions on the one side and having to deal with overwhelming and potentially upsetting information on the other. To illustrate this point, in both Studies 1 and 2, participants varied greatly in their knowledge of hospice and palliative care. During the completion of the questionnaires and the interviews, participants often asked for clarification of these terms and many were unsure what they meant. For example, palliative care was only vaguely understood as care that was targeted towards people who are dying and frequently associated with a special type of hospital treatment. Consistent with this, the National Journal and The Regence Foundation (2011) reported that 61% of the American respondents in their study were not at all familiar with palliative care. As discussed in Chapter 2, Zimmermann et al. (2016) added that the term was often associated with negative and frightening stigmas of death, hopelessness and dependency (see section 2.6). Since preferences are based on people's current understanding, this lack of knowledge can have a considerable influence on their views. If research and clinical practice require and expect informed decisions from patients and carers, it is essential that we first examine their understanding of their options and potentially clarify central terms before recording preferences for place of care and place of death.

In Study 1, respondents further expressed worries about not being given enough information. These concerns were significantly stronger amongst patients and carers with an institutional preference compared to those with a preference for home care. In Study 2, participants also frequently discussed their lack of knowledge in the interviews and many tried to reduce this uncertainty by actively seeking information and open discussions. The high need for information was described in Chapter 2, where the majority of studies suggested that patients and carers at the end of life *do want to know* about the illness, the treatment options and the prognosis (see section 2.6.2). For instance, according to

Jenkins et al. (2001) 87% of 2331 cancer patients reported that they wanted to receive all possible information, both good and bad news. While this may be true, Study 2 further added that some patients and carers actually *do not want to know*. The interviews showed that for a small group of respondents, receiving too much information was very confronting, because with the end of uncertainty came the certainty of the end - and that was described as being scary. In response to this, some participants actively avoided or postponed these discussions and focussed on more positive reports, which was a strategy used to maintain some level of hope. However, it is critical to recognize that this avoidance could be paused if important end-of-life decisions had to be made. This flexibility was often necessary as a practical way to cope with the unpredictability of the end of life.

In their report on death and dying in Australia, Swerissen and Duckett (2014) argued that people rarely have open and systematic conversations about what they want when they die. The authors suggested that more encouragement and even incentives might be needed for healthcare professionals to engage patients in end-of-life planning. In spite of this, it is still unclear whether open discussions actually help to achieve one's preferences. Study 1 found that more discussions about the carers' preferences were marginally associated with achieving them. This is intuitively understandable as open communication should foster better understanding and agreement in patients and carers. Yet, for patients, there was a non-significant trend for more discussions to be reported by those who did not die in their preferred place. This indicated that frequent discussions could also be a sign of arguments and disagreements. It can be concluded that the benefit of end-of-life conversations might depend on their quality, rather than their quantity, and this is likely to be influenced by patients' and carers' ability and readiness to engage in such discussions.

12.7.3 Decisions versus Preferences

The third challenge in end-of-life communication relates to the distinction between decisions and preferences. In the multiple-choice questionnaires of Study 1, responses concerning place of care and place of death appeared to be very clear and structured as participants identified their first preference, followed by their second preference, and so on. But the interviews of Study 2 painted a different picture. Instead of firm and stable decisions, respondents talked about preferences as tendencies to favour one place over another. These were rarely absolute and instead often phrased as flexible "if... then..." conditions that strongly depended on the context and the demands of the situation. The findings obtained through the mixed-methods approach of this research point to a meaningful difference between decisions and preferences that would have been masked had only the quantitative data been used.

As outlined in Chapter 3, on a theoretical level, a decision can be defined as the outcome of choosing between different alternatives or the conclusion of a consideration (see section 3.1). Based on the findings of Study 2, there are two important aspects to consider here: firstly, in regard to place of care and place of death, some people did not feel that they had several alternatives to choose from. And secondly, even if they felt that they had a choice in this matter, there was often no clear endpoint or final conclusion of the decision-making process as such. Study 2 showed that most respondents had considered their location options but only very few had actually made a firm decision as to where they wanted to spend their last days. And even those who had made a choice were still aware that their circumstances might change and that relocation to a different setting might be necessary. Hence, forming flexible preferences rather than making solid decisions was often more useful in order to deal with the unpredictable nature of the end of life.

In contrast to a decision, a preference can consequently be defined as "a greater liking for one alternative over another" (Oxford Dictionaries, 2012, p. 566). This does not imply a final conclusion or a fixed outcome but rather reflects a dynamic, evolving and iterative process. While people may differ in how strongly they are attached to their views, the tendency to form preferences instead of decisions is an adaptive response to the ever-changing demands of the end of life. This illustrates that preferences for place of care and place of death are more complex than accounted for by most decision-making models. The following section will therefore address the value and limitations of this theory-driven approach in the light of the current findings.

12.8 From Theory to Practice

In Chapter 3, four decision-making models were introduced to gain a theoretical understanding of how choices are made and what influences them. The Subjective Expected Utility Theory predicts behaviour on the basis of the perceived value of an outcome and the expected probability of its occurrence (Savage, 1954). Similarly, Prospect Theory assumes that decisions under risk are influenced by the anticipation of losses and gains, and strongly depend on an individual's reference point (Kahneman & Tversky, 1979). The interviews of Study 2 provided some support for these conceptual ideas. For example, respondents considered their options and the consequences of their choices based on their current situation as their point of reference. Many participants also talked about the value of staying at home or achieving better symptom control in an institutional setting. The Theory of Planned Behaviour proposed that intentions and subsequent behaviours are shaped by a person's attitudes, subjective norms and control beliefs (Ajzen, 1985). Accordingly, in Study 2, all respondents discussed their attitudes about different treatment settings, which were often informed by past experiences. Many also highlighted the influence of others on their views, which can be linked to the concept of subjective norms. Study 2 showed that decision making

was a highly relational process in which preferences were often negotiated between patients and carers. Finally, the Theory of Planned Behaviour argued that when people believe they have little control over a desired outcome, they are less likely to form strong intentions and take the necessary steps to achieve them. In connection with this, some respondents in Study 2 addressed concerns about not having enough control over the location choice and the actual outcome. This could explain why preferences were rarely expressed as firm decisions but more often as conditional and contextual tendencies to favour one place over another.

While the present research found some evidence for the factors suggested by these theoretical models, it also highlighted their limitations. In this regard, three central points need to be considered: firstly, most theoretical models present decision making as a mainly cognitive process with little to no regard for the influence of emotions. Yet, Study 2 revealed that different care settings evoked different emotional responses, which had a considerable influence on participants' preferences. Affective control was also used as a coping strategy to deal with the demands of the situation. While emotions have been included in the Two System View (see section 3.4) and the Theory of Uncertainty in Illness (see section 11.5), many theoretical decision-making models do not fully recognize the strong impact that feelings have on choices. Especially at the end of life, which is an intensely emotional time for many, this impact is magnified and therefore needs be acknowledged.

Secondly, many of the theoretical models heavily rely on the prerequisite that the decision maker is, to some extent, able to anticipate the outcomes of their actions and this is often simply not possible in the unpredictable context of the end of life. Mishel (1988) highlighted that uncertainty is an inherent part of illness (see section 11.5). Going beyond this theory, the current research showed that uncertainty not only relates to the illness itself, but also to the carer and the services. With this in mind, the role of the context in which preferences are formed has so far received only limited attention.

Connected to this point is the final observation that the outcome of many of the proposed theoretical models is a fixed decision or an observable behaviour. In conflict with this, the present research suggests that forming stable choices at the end of life was often neither possible nor useful. Patients and carers were very aware that symptoms, conditions and circumstances could change at any moment, requiring them to re-assess the situation and adjust their views accordingly. The process of forming location preferences was, therefore, characterised as flexible, conditional and contextual. Based on this, it can be concluded that most theoretical decision-making models might be too rigid and simplistic to fully capture malleable preferences formed in an extremely unstable situation. Following on from the findings presented, four central implications of this research for clinical practice will now be outlined.

12.9 Implications for Clinical Practice

The implications for clinical practice concern: the malleability of preferences; the recognition of cognitive as well as emotional needs; the ripple effect of experiences; and the role of informal carers in the decision making.

12.9.1 Valuing the Malleability of Preferences

The current research highlights the malleability of preferences and decision making under uncertainty. Acknowledging this uncertainty seems to be easier for patients and their families than for the professional healthcare system. In a discussion paper on tolerating uncertainty in clinical practice, Simpkin and Schwartzstein (2016) described how the need to find the right answer is deeply-rooted within the medical training and culture. They criticised that "too often, we focus on transforming a patient's gray-scale narrative into a black-and-white diagnosis that can be neatly categorized and labeled" (p.1713). The same applies to preference assessments that are recorded in a tick-box format in the patient's file. As an

unintended consequence, Simpkin and Schwartzstein (2016) believed that we are oversimplifying the richly iterative and evolutionary nature of reasoning and decision making. Especially the end of life is a highly unpredictable and emotional time in which circumstances, views and wishes can change from one moment to the next. As a consequence, the clinical system needs to be able to respect and cater to this instability of choices and respond to the client's needs at short notice.

In light of this malleability, one might question the usefulness and value of recording end-of-life preferences. While the current research confirmed that end-of-life views can indeed be challenging to capture, asking patients and carers about their preferences serves two essential functions that persist even if their views might change over time: firstly, as discussed in Chapter 2, every decision reinforces a sense of control and self-efficacy, and these benefits can exist even in the absence of true control (see section 2.4). When patients and carers are asked about their preferences it shows them that their views matter and that they are being heard. This is particularly important at the end of life, where the sense of control over their lives is often compromised by the illness. Secondly, preferences can be seen as a reflection of personal values and experiences. They offer important insights into what matters most to the respondent at this specific point in time. For example, a preference for hospital treatment might reflect a desire to keep fighting in an attempt to extend life, while hospice care might be perceived as a sign of giving up. In this sense, preferences can be seen as snapshots of the current situation taken through the lens of the patient or carer. If the care team is able to identify these underlying motives and concerns accurately they would consequently be able to address them. For these reasons, just as we ask patients about their current level of pain and know that this might change over time, we need to approach preferences with the understanding that they too might change later in the process. Furthermore, instead of asking only: "Where do you want to be cared for and die?", we also need to ask: "Why?". To identify under what circumstances preferences exist, persist and

change, there needs to be a continuous dialogue between patients, families and healthcare professionals about their wishes and the reasons behind them. Since the instability of location preferences is a reflection of the instability of the end-of-life situation, this makes communication all the more important. It is therefore essential to ensure that clinical staff is equipped with the necessary training, time, resources and skills to engage in meaningful end-of-life discussions rather than making preference assessments a tick-box exercise.

12.9.2 Addressing Cognitive and Emotional Needs

The current research underlines the role of cognition and emotions in end-of-life decision making. In regard to the cognitive needs of patients and carers, Chapter 11 discussed uncertainty as knowledge gaps that are either perceived as a threat or an opportunity. Those respondents who want to reduce uncertainty will seek and benefit from further information about the illness, the treatment and the services. Open discussions with medical staff about these topics can cater to patients' and carers' cognitive needs when they are in a state of active preparation. However, those who prefer to maintain some level of uncertainty (and perhaps hope) will be more likely to avoid too much information and force-feeding them medical facts that they are not ready or willing to hear may actually be more harmful than helpful. British poet T.S. Eliot wrote: "Human kind cannot bear very much reality. Time past and time future - What might have been and what has been - Point to one end, which is always present" (Eliot, 2014, p. 14). The immanence of death is a tremendously confronting reality and not everyone might be willing and able to accept this. As healthcare professionals, we cannot imply that preparation and acceptance are inherently "good" and avoidance and denial are consequently "bad". The current research suggests that both are valid strategies chosen in response to the uncertainty at the end of life. Noticing the difference between the states of active preparation and active avoidance is not a challenging task but it requires some level of sensitivity and time.

This research further emphasises that we need to go beyond the mere exchange of clinical information. The care of the dying has become a complex medical science and amongst the hectic attempts to identify the patient's preferences, extend their life, if at all possible, and deal with their symptoms, it is easy to overlook the emotional component of end-of-life decision making. While it is true that respondents in Study 2 often talked about medical facts such as treatment plans, medication and places of care, they also shared how different care options and settings made them *feel*. They discussed intense and conflicting emotions ranging from fear and guilt to gratitude and hope. This suggests that the emotional needs of patients and carers have a substantial and direct influence on their preferences and therefore, must be considered of equal importance to communicating medical knowledge and facts. Catering to both types of needs has to be a central part of high-quality end-of-life care.

12.9.3 The Ripple Effect of Experiences

The empirical studies undertaken as part of this thesis have highlighted the role of current and past experiences in end-of-life decision making. Patients and carers often referred to personal stories when rationalising their preferences. Some of these experiences had been recent ones whereas others had occurred several years or even decades ago. Based on this, it was concluded that experiences were used as an important source of information for decision making. It further seemed that experiences had a ripple effect as respondents talked about reports they had heard from family members, neighbours, communities, friends and the media, which strongly influenced their preferences and views. Attempts should, therefore, be made to improve the quality of palliative care in all settings and provide better experiences for patients and their families as these will be used to inform choices in the future. The same applies to the representation of care settings in the media. Home is often pervasively advocated as the most natural place of death, which is desired by the majority of people. Yet, the current research shows that only just over half of patients and approximately one-third of

carers who were actually faced with an imminent end-of-life situation preferred death at home. We must consider that those who do not prefer to die at home or are open to institutional care may be influenced by the idealistic portrayal of home care in the media. In contrast, death in hospital or nursing homes is often represented as an undesirable choice or even as a failure of the healthcare system. So if we want people to open-mindedly consider their options for place of care and place of death, we need to pay more attention to how we portray these settings publically.

12.9.4 Acknowledging and Supporting the Role of Informal Carers

The final clinical implication of this research concerns the role of family caregivers. Findings from Study 1 highlight that the physical and psychological state of the carer influences: (a) the carers' preferences and willingness to provide care; (b) the accuracy of carer predictions; and (c) the patients' preferences for place of care and place of death. It is, therefore, essential to acknowledge and carefully consider the health and well-being of informal carers because without them, end-of-life care (especially at home) would often simply not be possible. If the carers cannot cope because they are overburdened and under-supported then the entire care system at home is likely to collapse. Providing good care for the patient also means to provide the best possible support and training for the carers. Consequently, family caregivers need to experience that they are active participants in the decision making concerning the patient's place of care and place of death, rather than subordinating their needs and preferences to those of the dying person or the health professionals. The following sections will now summarise the strengths and limitations of the current research.

12.10 Strengths and Limitations

This research has a number of considerable strengths that can be acknowledged. Firstly, the studies presented chose the most appropriate methodological approach to elicit true end-of-life preferences, as discussed in Chapter 4 (see section 4.7). This involved: a) using a prospective design in order to avoid the influence of hindsight biases; b) recruiting terminally ill patients who were in their last 12 months of life instead of relying on long-range predictions of healthy, older participants; c) including the perspectives of the informal carers in order to directly compare their views to those of the patient; and d) clearly differentiating between preferences for place of care and place of death instead of assuming that they are the same.

Secondly, location preferences were assessed using the same methodology in different settings, namely hospital, hospice and home care. This substantially added to the strengths of this research as it allowed a comparison between these settings and highlighted the influence of current experiences on end-of-life preferences – a central aspect often overlooked in previous research.

Finally, the chosen mixed-methods design offered deeper insights into location preferences than either a quantitative or qualitative method alone could have. Specifically, Study 1 explored the influence of controversial and under-researched factors on location preferences. This included, for instance, the role of symptoms, the length of illness, demographic factors, personality traits, past and current experiences, as well as the length and quality of the patient-carer relationship. Study 1 further examined the association between the preferred and actual place of death, the role of discussions and patient-carer agreement at the end of life. Study 2 added depth and revealed the complexity of these findings by identifying three types of uncertainty that influenced end-of-life decision making, namely illness-, carer-, and service-related uncertainty. It further contributes evidence that forming preferences for place of care and place of death is a highly contextual, personal, relational, conditional and

flexible process. The studies combined provided a detailed, nuanced and well-rounded overview of the location preferences of terminally ill patients and their carers.

While this research offers valuable and unique insights into the views of terminally ill patients and their informal caregivers, a number of limitations also need to be acknowledged. Many of the study-specific challenges have already been discussed in Chapters 8 and 11. These included the limited generalisability of the quantitative results in Study 1 due to the small and unequal numbers of patients and carers in the sample, as well as the partly paired and partly unpaired composition of the data set (see section 8.6). In Study 2, the limitations related to the influence of social desirability and interviewer biases on the qualitative findings (see section 11.10). Three final remarks can be made regarding the limitations of the recruitment and sampling methods in both studies.

Firstly, the reliance on specialist palliative care staff for the recruitment of participants meant that there was an under-representation of patients and carers who had no contact with any of the selected palliative care services. Specifically, in the current studies, many patients reported that they had engaged in some end-of-life preparations in the form of discussions or actual arrangements. This is perhaps not surprising given that they were part of a palliative care system that strongly promotes formal planning. As a result, these findings might be different in a sample that is less connected to specialised palliative care support. Furthermore, nursing home residents were also not represented in this sample. It is possible that the low preference for nursing home care in both Studies 1 and 2 could be at least partly due to the absence of participants from these settings.

Secondly, some participants initially seemed to associate me with the respective recruitment sites, regardless of my best efforts to explain my role as an independent researcher and my connection to the University of Melbourne. As discussed in Chapter 4, Batchelor et al. (1994) pointed out that care recipients might be unwilling to criticise medical staff and directly express dissatisfaction with the care, for fear of antagonising the service

providers and experiencing even worse care in the future (see section 4.7.2). Consequently, if respondents believed that I was somehow connected to their current care team, this might have influenced their responses. It must be noted that all participants were assured that their answers are entirely confidential and no identifiable details would be passed on to the staff. Despite this, it cannot be entirely ruled out that some respondents might have avoided direct criticism of the care setting or the team if they believed me to be part of the treatment site.

Finally, this research used a purposive selection of participants according to pre-determined eligibility criteria. The research design excluded terminally ill patients who did not have an informal carer and those under the age of 18 years. It is possible and likely that their location preferences might differ from those found in the current sample. Hence, no inferences regarding the views of these groups can be made as they were outside the scope of this research. In addition, those who participated in the studies had to be aware of the terminal status of their illness and willing to talk about their experiences. With this in mind, different results may be found in a random sample that has not been pre-selected. However, this approach was specifically chosen for the ethical reasons discussed in Chapter 6 (see section 6.5). While Study 2 found that some participants reported avoiding thoughts and discussions about end-of-life topics, most respondents were very open in sharing their views. It must be acknowledged that those who used extreme avoidance as a coping strategy were unlikely to volunteer for an end-of-life study. In order to include and explore this particular group more, a random design would be needed. Further suggestions for future research will now be summarised.

12.11 Directions for Future Research

Throughout this thesis, it has been argued that in order to elicit true end-of-life preferences researchers need to focus on people who are actually close to the end of their life. In the current research, patients died, on average, less than three months after their own or their carers' participation in the studies. With only a few weeks left to live, their preferences for a home death were approximately 17% lower than suggested for healthy South Australians (Foreman et al., 2006). Hence, the timing of preference assessments is an essential factor to consider in future studies. Based on the findings presented, it is further recommended that patients are asked about their end-of-life views directly, whenever possible, instead of using the views of carers as a substitute. The current studies provided evidence that the views of patients and carers are not always the same, and for this reason, researchers need to acknowledge that they are, in fact, two separate entities with different backgrounds, perspectives and preferences. Future studies could explore if and how patients and their family caregivers differ in their decision-making strategies at the end of life.

Also, replication of some of the current findings with a larger sample is advised. Specifically, more research is required that compares participants from different care settings to address the effect of current experiences on respondents' preferences. Study 1 showed a tendency for respondents to prefer their current place of care over relocating to another setting. However, it is unclear whether this was because they had become more familiar with their current care environment or because they wanted to avoid the stress associated with another relocation. Furthermore, the role of personality in end-of-life decision making needs to receive more attention. The current research was, to my knowledge, the first to explore this potential association between Big Five traits and preferences for place of care. While only non-significant trends were found in Study 1, this is likely due to the small sample size. More research is urgently needed to address this gap.

As a suggestion for future quantitative studies, the location ranking developed for Study 1 provided more details than assessing only participants' first preferences. However, this forced-choice format also caused responses to appear more simplistic than they actually were. Hence, future studies could consider including open-ended questions in their surveys or adding a measure of certainty of these preferences, ranging for example on a spectrum from "no clear preference formed" to "firm decision made". In addition, it is recommended that surveys are kept much shorter than in Study 1 to minimise the burden on the respondents. Patients, in particular, often had difficulties concentrating over a longer period of time and would have benefited from an abbreviated version of the questionnaire. This contributed to the smaller than desired sample size.

Finally, the mixed-methods design used in the current research was found to be very useful in assessing preferences for place of care and place of death. This approach highlighted that certain hypothetical constructs, such as complex past and present experiences, are challenging to measure in a quantitative format. The differences between the views expressed in Study 1 and 2 suggest that a qualitative approach might be overall more suitable to detect fine nuances in patients' and carers' responses, and explore the multi-faceted question of where people would like to spend their last days.

12.12 Conclusions

The growth of our ageing population has increased the need for end-of-life care, which in turn has increased the demand for relevant research in this area. While studying the end of life is extremely important, it is also very challenging due to the sensitive subject matter and the vulnerability of its respondents. This prospective, mixed-methods research has highlighted the importance of choices concerning place of care and place of death for terminally ill patients and reinforced the role of informal caregivers as an essential and irreplaceable part of the palliative care system. Specifically, this research found that carers

tended to have a stronger preference for institutional care than patients themselves. Moreover, attention was drawn to carers' physical and psychological well-being, which had a direct influence on their own preferences and their ability to accurately assess the patient's current state. It also indirectly influenced the preferences of patients as they considered how much their care needs would burden their family. These findings emphasised the unique contribution of informal caregivers to end-of-life care and the process of decision making.

The current research further illustrated the complexity of location preferences and highlighted the differences between previously overlooked end-of-life concepts. This concerned, for example, the distinction between place of care and place of death, and the difference between preferences and decisions. This is a significant contribution to the current body of knowledge and suggests that that end-of-life researchers and clinicians need to be aware of the subtle nuances of these concepts. In regard to assessing location preferences, it became clear that where multiple-choice surveys tend to over-simplify end-of-life choices and the process of decision making, a supplementary qualitative approach adds considerable value to the findings. What appeared to be firm and clear-cut decisions in the questionnaires of Study 1 were shown to be conditional tendencies to favour one place over another in the open-ended interviews of Study 2. The process of forming end-of-life preferences may even be more complex than most other areas of choice, given the gravity of its consequences. This complexity appeared to go beyond the limits of any theory-driven model, in which decision making was often described as a mainly cognitive process with clear behavioural outcomes. In contrast, the current findings suggest that decision makers are not isolated in a bubble in which they analyse all available information in a rational manner and emerge with a well-defined and clearly established decision. Instead, the studies presented affirm that preferences strongly depended on a person's experiences, the uncertainty of the situation, and the views of significant others. Particularly the role of emotions in the decision-making process was emphasised. The process of forming preferences was therefore described as being highly

contextual, personal, relational, conditional and flexible. This makes capturing preferences for place of care and place of death a challenging task for healthcare professionals as well as for researchers. Notwithstanding this, it is important to remember that within the unpredictable and unstable context of the end of life, the dynamic nature of decision making is an adaptive strategy of patients and carers – one that allows them to adjust their views to their current circumstances.

We need to learn how to acknowledge and even embrace this uncertainty at the end of life, and the malleability of preferences that comes with it. Researchers, policy makers and clinicians need to manage their expectation that decision making ends with a clear and stable choice. This standardised approach might be applicable to other areas of life but it simply does not work in the physical, spiritual and emotional turmoil that people are confronted with when facing their own or their loved one's death. This means that we must accept that a lifetime of experiences and an array of emotions will not fit into a multiple-choice box.

Just as every birth and every life is unique, so is every death. Nuland (1994) wrote in his *Reflections on Life's Final Chapter*: "Every man will yield up the ghost in a manner that the heavens have never known before: every woman will go her final way in her own way" (p. 3). This uniqueness is expressed in end-of-life preferences that may evolve and change with the demands of the situation and the uncertainty that comes with it. So to support patients and families in this critical time of their life, we need to accept that there is no right or wrong place of death that applies to everyone and instead, allow patients and carers to choose freely what is right or wrong for them given their unique circumstances. This requires a care system that is accessible, receptive and flexible enough to respond to the ever-changing needs of those facing the end of their life.

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Appendices

Appendix 1 Study Flyer



Are you currently receiving palliative care and have a relative or friend who helps care for you?

Are you interested in supporting other families to better understand and prepare for this time of caregiving?

We are looking for patients and their caregivers to fill in a questionnaire about their experiences and wishes.

We want to better understand how you think about, and decide, where you would like to be cared for. To find out more about your views, we would like to visit you and your caregiver at a time of your convenience and ask you to complete a questionnaire. This should take less than an hour. You also have the option to talk to us more about your experiences in an interview.

We value your opinion and experiences.

Would you like to know more or make an appointment?

If you are interested in helping us by sharing your experiences or have any questions about the project, please contact Kate Gerber at any time:

Phone: [phone number]

E-mail: [e-mail address]

Appendix 2 Invitation Letter – Melbourne City Mission Example

[date]

Every year Melbourne City Mission supports a number of carefully selected research projects that aim to better understand important issues, experiences and views of our clients and their families. One of these projects is currently being undertaken by the University of Melbourne. It aims to find out more about certain decisions most clients and caregivers are faced with, such as where they would like to be cared for. We hope that this important research will gather information that can be used to support clients and their families in the future.

You have been contacted about this project because as a client of Melbourne City Mission Palliative Care your input and insight is highly valued. Please read the attached project flyer and contact Kate Gerber on [phone number] if you are interested in finding out more about the project.

The support offered to you by Melbourne City Mission Palliative Care will not be affected, regardless of whether or not you wish to be involved in this study. I am aware that this is a difficult time for you at the moment, so I am very grateful to you for considering this request.

Yours sincerely,

[signature of acting manager]

Manager of Palliative Care Services

Melbourne City Mission

Appendix 3 Plain Language Statement – Broadmeadows Example

PATIENT INFORMATION

Project Title: End-of-life preferences in terminally ill patients and their informal caregivers
Principal Researchers: Kate Gerber
Associate Researchers: Dr. Christina Bryant, Prof. Fiona Judd, Dr. Barbara Hayes
Location: Broadmeadows Health Service

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1 Introduction

You are invited to take part in a research project examining end-of-life preferences of patients with a life-limiting illness and their caregivers. You are receiving this information because as a patient of Broadmeadows Health Service, your input and insight is highly valued.

When we are talking about your caregiver, we mean the person, for example a family member, neighbour, or friend, who is most involved in your care and who provides physical, social, or psychological assistance to you.

This Patient Information and Consent Form explain what is involved in this research project to help you decide if you would like to take part. Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether or not to take part, we encourage you to talk about it with your caregiver. You may keep this Patient Information and Consent Form as a record.

By signing the Consent Form, you indicate that you

- understand what you have read
- give your consent to participate in the research project and
- consent to the use of your personal and health information as described.

2 What is the purpose of this research project?

When diagnosed with a life-limiting illness, patients and their caregivers are faced with a variety of decisions. One of these choices concerns where they would like to be cared for at the end of their life. The aim of this research is to better understand the factors that influence these preferences and evaluate the role of the caregiver in this decision making process. This research is part of the PhD project of the principal investigator Kate Gerber and the collected information will contribute to her thesis.

3 What will I be asked to do?

Should you agree to participate in this project, we would ask you to fill out two parts of a questionnaire. The first part gathers general information about you and your living situation, your personality and your relationship to your caregiver. This part will take about 15 minutes to complete. The second part contains questions about your and your caregiver's health, your preferences for where you would like to be cared for at the end of your life, and about your experiences with different treatment locations. You will also be asked questions about other general end-of-life arrangements and your caregiver's preferences and views. The second part will take about 30 minutes to complete.

If you agree to take part in this project, you would be asked to do the following four things:

1) After you read this Patient Information, feel free to ask questions about everything you want to know more about. We encourage you to talk to your caregiver about the project. If you feel that you understand enough about what this project involves, please sign the attached Consent Form. This indicates your agreement to take part in this research.
2) Then we would like you to complete the first part of the questionnaire. You can do this with a researcher present or alone at a time convenient to you.
3) When you are ready to fill out the second part of the questionnaire, a researcher would like to be with you to help you and answer your questions.
4) Finally, at the end of the second part of the questionnaire, we would like you to indicate whether you are interested in participating in an interview and whether you would like to receive a study summary after the projected is completed. With your permission, we will also collect some general information about you from your medical records, such as your primary diagnosis and the length your illness.

4 Do I have to take part in this research project?

Participation in this research is voluntary. You do not have to take part if you do not want to. Also, participating in the interview is optional. You may choose to complete the questionnaires, but not take part in an interview. Should you wish to withdraw from the project at any stage, you are free to do so.

5 What are the benefits of taking part?

There are no direct benefits to you, but the information you provide has important implications for future research in palliative care. You may also find that completing the questionnaire and potentially the interview encourages you to think about some of your wishes and preferences at the end of your life and fosters discussions with your caregiver about where you would like to be cared for.

6 Are there any risks to me if I take part?

We estimate that filling in the questionnaires will take approximately 45 minutes. You do not have to complete both parts of the questionnaire in one sitting, but can do so at your own pace with regular breaks when needed. If participation causes you any distress, you can talk with the principal researcher Kate Gerber or the study supervisor Dr. Christina Bryant on the telephone numbers given below (see Section 11 – Where can I get further information?).

7 How will my confidentiality be protected?

We will protect the confidentiality of your responses. The questionnaires you complete will receive a code. Only the principal researcher will have access to the coding system, which will be stored with your contact information in locked filling cabinets in a research unit of the University of Melbourne. This information will be kept separately from your questionnaires to ensure confidentiality and anonymity. Any electronic information or audio recordings will be stored with password protection. The data will be kept securely for five years from the date of publication, before being destroyed. If this or another researcher decides to use the collected information for a follow-up project, the same confidentiality standards will apply and approval from the Human Ethics Research Committee will be sought.

Any information obtained in connection with this research project that can identify you will remain confidential and will only be disclosed with your permission or if required by law. Information about you will be collected from your health records held at Broadmeadows Health Service. In any publications or at conference presentations, information will be provided in such a way that you cannot be identified. Results of the questionnaires will be reported based on overall group trends and do not involve reporting individual participant's information. Answers from the interview may be quoted verbatim but anonymously.

8 How can I access my information?

In accordance with the relevant Australian and/ or Victorian privacy and other relevant laws, you have the right access the information collected and stored by the researchers about you. You also have the right to request that any information, with which you disagree, will be corrected. Please contact the principal researcher Kate Gerber or the study supervisor Dr. Christina Bryant on the telephone numbers given below (see Section 11 – Where can I get further information?).

9 How will I be informed of the final results of this research project?

If you wish, a summary of the study findings can be sent to you or your family member at the completion of the study. It is anticipated that this summary will be available within 12 to 14 months after the start of the project. You may indicate your interest to receive this summary at the end of the second part of the questionnaire.

10 Is this research approved?

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

All research in Australia involving humans is reviewed by an independent group of people called Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of Broadmeadows Health Service and of the University of Melbourne.

11 Where can I get further information?

Should you require further information, or have any concerns, do not hesitate to contact the principal researcher Kate Gerber on [phone number] or the study supervisor Dr. Christina Bryant from the School of Psychological Sciences at the University of Melbourne on [phone number].

If you have complaints about any aspect of the project, the way it is being conducted or questions about being a research participant in general, then you may contact Cheryle Williams, Acting research of Governance Officer the Broadmeadows Health Service on [phone number].

THE UNIVERSITY OF MELBOURNE

Broadmeadows HEALTH SERVICE

Appendix 4 Patient Consent Form for Study 1 – Broadmeadows Example

PATIENT CONSENT FORM - QUESTIONNAIRE

Project Title: End-of-life preferences in terminally ill patients and their informal caregivers
Principal Researchers: Kate Gerber
Associate Researchers: Dr. Christina Bryant, Prof. Fiona Judd, Dr. Barbara Hayes
Location: Broadmeadows Health Service

I have read this Patient Information and I understand the purposes, procedures and risks of this research project as described within this document.

I freely agree to participate in this project, the details of which have been explained to me, and I have been provided with a written Patient Information and Consent Form to keep.

I understand that my participation will involve completing a questionnaire in two parts. I agree that the researchers may use the results as described in the Patient Information.

I acknowledge that:

(a) The project is for the purpose of research.
(b) The procedure and possible effect of filling in the questionnaires have been explained to my satisfaction.
(c) I give permission to my doctors or other medical staff of the Broadmeadows Health Service to give information to the researchers concerning my illness. I also give permission to the researcher to access my medical records and understand that such information remain confidential.
(d) I have been informed that participation in this research is voluntary, and I am free to withdraw from the project any time without explanation or prejudice and to withdraw any unprocessed data I have provided.
(e) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements.
(f) I have been informed that the completed questionnaires will be safely stored and destroyed after five years.
(g) I agree to be contacted by the researchers in regard to this project or potential follow-up research.

.....

Participant's Name (please print): ----------

Preferred Contact Number: ----------

Participant's Signature: Date:

Declaration by principal researcher
I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Signature: Date:

Appendix 5 Questionnaire Study 1 – Patient Version

Note: The questionnaire for patients and carers were almost identical with only minor differences in the wording. For instance, patients were asked: "For how long have you known your caregiver?" and congruently carers were asked: "For how long have you known the patients?" Given the overlap between the two versions, only the questionnaire for patients is included as an example in this appendix.

ID: _____ Diagnosis: _____

Group: _____ _____

Date: _____ Time since Diagnosis: _____

Patient Questionnaire Part 1
- GENERAL QUESTIONS -

We would like to ask you some basic questions about yourself and your current circumstances. Please tick the option that describes you best.

1	Your date of birth (dd/mm/yyyy)	____/____/_____
2	Your Gender	☐ Male ☐ Female
3	Which cultural background do you most identify with?	☐ Australian ☐ New Zealand/ Oceania ☐ Aboriginal / Torres Strait Islander ☐ Middle Eastern ☐ Asian ☐ African ☐ North American ☐ South American ☐ European: Please specify _____ ☐ Other: Please specify _____
4	How long have you lived in Australia?	☐ All my life ☐ Not all my life, but _____ years ☐ One year or less
5	What is the highest level of education that you have completed?	☐ Up to Year 10 ☐ Up to Year 12 ☐ Trade/ TAFE certificate ☐ University undergraduate degree ☐ University postgraduate degree ☐ Other: Please specify _____

6	What is your current employment status?	☐ Not employed ☐ Student ☐ Part-time employed ☐ Full-time employed ☐ Full-time house duties ☐ Disability/ Sickness benefits ☐ Aged pension
7	What is your gross annual household income?	☐ Under 25,000 AUD ☐ 25,000 – 50,000 AUD ☐ 50,001 – 75,000 AUD ☐ 75,001 – 100,000 AUD ☐ 100,001 – 150,000 AUD ☐ Over 150,000 AUD ☐ Prefer not to say ☐ Don't know
8	What is your current relationship status?	☐ Single/ Never married ☐ In a Relationship/ De facto partner ☐ Married ☐ Separated/ Divorced ☐ Widowed
9	How many children do you have?	_____ children
10	Which best describes your current living situation?	☐ Living alone ☐ Living with spouse/ partner (no child(ren) living in the household) ☐ Living with spouse/ partner and child(dren) ☐ Lone parent (yourself and child(dren)) ☐ Living with relatives ☐ Living with unrelated others ☐ Other: Please specify _____
11	What suburb or town do you currently live in?	_____
12	What is your religious affiliation?	☐ Protestant Christian ☐ Roman Catholic ☐ Jewish ☐ Hindu ☐ Muslim ☐ Buddhist ☐ Agnostic ☐ Atheist ☐ Other: Please specify _____
13	How important are your religious and spiritual beliefs to you?	☐ Not at all important ☐ Not very important ☐ Moderately important ☐ Quite important ☐ Very important

Now, we would like to ask you some questions about your main informal caregiver. This is the person, for example a family member, neighbour, or friend, who is most involved in your care and who provides physical, social, or psychological assistance to you. When we refer to your caregiver throughout this questionnaire, we mean the person you are thinking of right now.

14	Your caregiver is your ...	☐ Current partner/ Spouse ☐ Former partner/ Spouse ☐ Father/ Mother ☐ Brother/ Sister ☐ Son/ Daughter ☐ Other relative. Please specify: _____ ☐ Friend ☐ Unrelated other. Please specify: _____
15	For how long have you known your caregiver?	☐ All my life ☐ Not all my life, but _____ years ☐ One year or less
16	Taking everything into consideration, how close do you feel in the relationship between you and your caregiver?	☐ Not at all close ☐ Not very close ☐ Moderately close ☐ Quite close ☐ Very close
17	How well can you and your caregiver exchange ideas that really concern you?	☐ Not at all well ☐ Not very well ☐ Moderately well ☐ Quite well ☐ Very well
18	In general, how similar are your views about life to those of your caregiver?	☐ Not at all similar ☐ Not very similar ☐ Moderately well ☐ Quite similar ☐ Very similar
19	Generally, how well do you and your caregiver get along together?	☐ Not at all well ☐ Not very well ☐ Moderately well ☐ Quite well ☐ Very well

ID: _____ **PERSONALITY QUESTIONS** Date: _____

The following statements describe people's typical behaviours. Please use the rating scale below to describe how accurately each statement applies to ***you*** *generally*. Describe yourself as you honestly see yourself. There is no right or wrong answer. Please read each statement carefully, and then circle the corresponding answer that applies to **you**.

	Statement	Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
1	I often feel blue.	1	2	3	4	5
2	I feel comfortable around people.	1	2	3	4	5
3	I do not like art.	1	2	3	4	5
4	I have a good word for everyone.	1	2	3	4	5
5	I am always prepared.	1	2	3	4	5
6	I dislike myself.	1	2	3	4	5
7	I have a vivid imagination.	1	2	3	4	5
8	I believe that others have good intentions.	1	2	3	4	5
9	I am often down in the dumps.	1	2	3	4	5
10	I am skilled in handling social situations.	1	2	3	4	5
11	I have a rich vocabulary.	1	2	3	4	5
12	I insult people.	1	2	3	4	5
13	I get chores done right away.	1	2	3	4	5
14	I have frequent mood swings.	1	2	3	4	5
15	I would describe my experiences as somewhat dull.	1	2	3	4	5
16	I am the life of the party.	1	2	3	4	5
17	I accept people as they are.	1	2	3	4	5
18	I panic easily.	1	2	3	4	5

	Statement	Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
19	I know how to captivate people.	1	2	3	4	5
20	I carry out my plans.	1	2	3	4	5
21	I suspect hidden motives in others.	1	2	3	4	5
22	I keep in the background.	1	2	3	4	5
23	I make people feel at ease.	1	2	3	4	5
24	I make plans and stick to them.	1	2	3	4	5
25	I seldom feel blue.	1	2	3	4	5
26	I have little to say.	1	2	3	4	5
27	I am not interested in abstract ideas.	1	2	3	4	5
28	I have a sharp tongue.	1	2	3	4	5
29	I waste my time.	1	2	3	4	5
30	I enjoy wild flights of fantasy.	1	2	3	4	5
31	I cut others to pieces.	1	2	3	4	5
32	I find it difficult to get down to work.	1	2	3	4	5
33	I rarely get irritated.	1	2	3	4	5
34	I pay attention to details.	1	2	3	4	5
35	I avoid philosophical discussions.	1	2	3	4	5
36	I do just enough work to get by.	1	2	3	4	5
37	I enjoy hearing new ideas.	1	2	3	4	5
38	I am not easily bothered by things.	1	2	3	4	5
39	I don’t like to draw attention to myself.	1	2	3	4	5
40	I make friends easily.	1	2	3	4	5
41	I do not enjoy going to art museums.	1	2	3	4	5

	Statement	Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
42	I get back at others.	1	2	3	4	5
43	I carry the conversation to a higher level.	1	2	3	4	5
44	I don't see things through.	1	2	3	4	5
45	I am very pleased with myself.	1	2	3	4	5
46	I don't talk a lot.	1	2	3	4	5
47	I rarely look for a deeper meaning in things.	1	2	3	4	5
48	I respect others.	1	2	3	4	5
49	I shirk my duties.	1	2	3	4	5
50	I feel comfortable with myself.	1	2	3	4	5

Finally, we would like to ask you some questions about making choices. Please state how much you agree or disagree with each of the statements by circling your answer.

	Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1	I am the kind of person who likes to be offered choices rather than being told the best way forward.	1	2	3	4	5
2	I prefer to know what options are available for me.	1	2	3	4	5
3	It's not important to me to make my own health care decisions.	1	2	3	4	5
4	I like to know all possible ways in which I could be treated.	1	2	3	4	5
5	I am the kind of person who feels overwhelmed by choice and would rather it could be more simple.	1	2	3	4	5
6	I am not interested in finding out what all the options are for treating my problem.	1	2	3	4	5
7	I am happy for the doctor to make decisions for me.	1	2	3	4	5
8	I prefer to make my own mind up about what treatment I will have.	1	2	3	4	5

ID: _____ **Patient Questionnaire Part 2** Date: _____

- HEALTH QUESTIONS -

Before you fill in this questionnaire, please remember a few points:

1. Read each question carefully.
2. Make sure you answer all the questions.
3. There are no right or wrong answers – we are simply interested in your views.
4. Don't spend too long thinking about the answer. Often your fist reaction is the best.

The first questions will ask about **your** health. Please circle the number that best represents how **you** felt during the past week.

Over the past week, how much of a **problem** have the following been **for you**?		Not at all	A little	Moderately	Quite a bit	Very much
1	Pain	0	1	2	3	4
2	Feeling weak, tired or lacking energy	0	1	2	3	4
3	A change in your appetite and/ or weight	0	1	2	3	4
4	Feeling sick and/ or being sick	0	1	2	3	4
5	Constipation	0	1	2	3	4
6	Diarrhoea	0	1	2	3	4
7	Bladder/ urinary problems	0	1	2	3	4
8	Sleeping problems	0	1	2	3	4
9	Shortness of breath or a cough	0	1	2	3	4
10	Mouth/ taste problems (e.g. dry/ sore mouth)	0	1	2	3	4
11	Swallowing problems	0	1	2	3	4
12	Other symptoms (please specify) _____	0	1	2	3	4
13	Problems with concentrating or remembering things	0	1	2	3	4
14	Feeling low in mood or depressed	0	1	2	3	4
15	Feeling tense, worried or fearful	0	1	2	3	4
16	Feeling irritable or angry	0	1	2	3	4
17	Concerns about not being given enough information about your illness or treatment	0	1	2	3	4

Over the past week, how much of a **problem** have the following been **for you**?	Not at all	A little	Moderately	Quite a bit	Very much
18 Anything to do with your treatment (e.g. side effects) or care	0	1	2	3	4
19 Dissatisfaction with the way your doctor and nurses communicate with you	0	1	2	3	4
20 Not being able to do the things you usually do (e.g. social activities)	0	1	2	3	4
21 Caring for yourself	0	1	2	3	4
22 Not getting enough support from others	0	1	2	3	4
23 Your relationship with important people in your life (e.g. your partner, children, family members)	0	1	2	3	4
24 Worries or concerns about important people in your life now or in the future	0	1	2	3	4
25 Worries or concerns about your future	0	1	2	3	4
26 Worries or concerns about your appearance	0	1	2	3	4
27 Your intimate/ sexual relationships (leave blank if not applicable)	0	1	2	3	4
28 Your finances	0	1	2	3	4
29 Your work (leave blank if not applicable)	0	1	2	3	4
30 Spiritual/ religious concerns	0	1	2	3	4

31 Considering all parts of your life - physical, emotional, social, spiritual and financial - how would you rate <u>yourself</u> as feeling overall?	Very poor	Poor	Neutral	Good	Very good
	1	2	3	4	5
32 Considering all parts of your life, how much help and support from others do <u>you</u> have overall?	None	A little	A moderate amount	Quite a bit	A lot
	1	2	3	4	5

33 To what extent have you discussed <u>your</u> symptoms of the past week with your caregiver?	☐ Never ☐ Rarely ☐ Occasionally ☐ Often ☐ Very often
34 How satisfied are you with the discussions you have had with your caregiver regarding <u>your</u> symptoms?	☐ Very dissatisfied ☐ Quite dissatisfied ☐ Neither satisfied or dissatisfied ☐ Quite satisfied ☐ Very satisfied

Now we would like to ask you the same health related questions in regard to **your caregiver**. Please circle the number that best represents how you think **your caregiver** felt during the past week.

Over the past week, how much of a **problem** have the following been **for your caregiver**?		Not at all	A little	Moderately	Quite a bit	Very much	I don't know
1	Pain	0	1	2	3	4	☐
2	Feeling weak, tired or lacking energy	0	1	2	3	4	☐
3	A change in his/her appetite and/ or weight	0	1	2	3	4	☐
4	Feeling sick and/ or being sick	0	1	2	3	4	☐
5	Constipation	0	1	2	3	4	☐
6	Diarrhoea	0	1	2	3	4	☐
7	Bladder/ urinary problems	0	1	2	3	4	☐
8	Sleeping problems	0	1	2	3	4	☐
9	Shortness of breath or a cough	0	1	2	3	4	☐
10	Mouth/ taste problems (e.g. dry/ sore mouth)	0	1	2	3	4	☐
11	Swallowing problems	0	1	2	3	4	☐
12	Other symptoms (please specify) _____	0	1	2	3	4	☐
13	Problems with concentrating or remembering things	0	1	2	3	4	☐
14	Feeling low in mood or depressed	0	1	2	3	4	☐
15	Feeling tense, worried or fearful	0	1	2	3	4	☐
16	Feeling irritable or angry	0	1	2	3	4	☐
17	Concerns about not being given enough information about your illness or treatment	0	1	2	3	4	☐
18	Anything to do with your treatment (e.g. side effects) or care	0	1	2	3	4	☐
19	Dissatisfaction with the way the doctor and nurses communicate with him/her	0	1	2	3	4	☐
20	Not being able to do the things s/he usually does (e.g. social activities)	0	1	2	3	4	☐
21	Caring for him-/ herself	0	1	2	3	4	☐
22	Not getting enough support from others	0	1	2	3	4	☐

Over the past week, how much of a **problem** have the following been **for your caregiver**?	Not at all	A little	Moderately	Quite a bit	Very much	I don't know
23 His/her relationship with important people in his/her life (e.g. his/her partner, children, family members)	0	1	2	3	4	☐
24 Worries or concerns about important people in his/her life now or in the future	0	1	2	3	4	☐
25 Worries or concerns about his/her future	0	1	2	3	4	☐
26 Worries or concerns about his/her appearance	0	1	2	3	4	☐
27 His/her intimate/ sexual relationships (leave blank if not applicable)	0	1	2	3	4	☐
28 His/her finances	0	1	2	3	4	☐
29 His/her work (leave blank if not applicable)	0	1	2	3	4	☐
30 Spiritual/ religious concerns	0	1	2	3	4	☐

31 Considering all parts of <u>your caregiver's</u> life - physical, emotional, social, spiritual and financial - how would you rate <u>your caregiver</u> as feeling overall?	Very poor	Poor	Neutral	Good	Very good
	1	2	3	4	5
32 Considering all parts of <u>your caregiver's</u> life, how much help and support from others does <u>your caregiver</u> have overall?	None	A little	A moderate amount	Quite a bit	A lot
	1	2	3	4	5

33 To what extent has your caregiver discussed <u>his/her</u> symptoms of the past week with you?	☐ Never ☐ Rarely ☐ Occasionally ☐ Often ☐ Very often
34 How satisfied are you with the discussions you have had with your caregiver regarding <u>his/her</u> symptoms?	☐ Very dissatisfied ☐ Quite dissatisfied ☐ Neither satisfied or dissatisfied ☐ Quite satisfied ☐ Very satisfied

ID: _____ **PREFERENCE QUESTIONS** Date: _____

Now, we would like to ask you some questions regarding **your** views and preferences **for yourself**. Again, there are no right or wrong answers. We are simply interested in your perspective.

1	How satisfied are you overall with your current location of care?	☐ Very dissatisfied ☐ Quite dissatisfied ☐ Neither satisfied or dissatisfied ☐ Quite satisfied ☐ Very satisfied
2	Given your current circumstances, where would you like to be cared for in your last days? *Note:* Please rank the following options from 1 (most preferred) to 5 (least preferred place). Please use every number only once.	__ Hospital __ Nursing home __ Hospice __ My own or my caregiver's home __ Somebody else's home
3	Given your current circumstances, where would you like to be when you die? *Note:* This may or may not be the same place as in question 2. Please rank the following options from 1 (most preferred) to 5 (least preferred place). Use every number only once.	__ Hospital __ Nursing home __ Hospice __ My own or my caregiver's home __ Somebody else's home
4	How important is it to you to be cared for in the place you prefer most?	☐ Not at all important ☐ Not very important ☐ Moderately important ☐ Quite important ☐ Very important
5	How important is it to you to avoid being cared for in the place you prefer least?	☐ Not at all important ☐ Not very important ☐ Moderately important ☐ Quite important ☐ Very important
6	How important is it to you to participate in deciding where you spend your last days?	☐ Not all important ☐ Not very important ☐ Moderately important ☐ Quite important ☐ Very important
7	In your opinion, who will have the most influence on the decision where you will spend your last days? *Note*: Please rank the following options from 1 (person who makes this decision) to 5 (person with the least influence on this decision). Use every number only once.	__ My doctor __ My friends __ Myself __ My caregiver __ Other family members

8	In your opinion, how likely is it that you can influence where you spend your last days?	☐ Not at all likely ☐ Not very likely ☐ Moderately likely ☐ Quite likely ☐ Very likely
9	To what extent have you discussed your preferences with your caregiver regarding where you would like to stay at the end of your life?	☐ Never ☐ Rarely ☐ Occasionally ☐ Often ☐ Very often
10	How satisfied are you with the discussions you have had with your caregiver regarding your location preferences?	☐ Very dissatisfied ☐ Quite dissatisfied ☐ Neither satisfied or dissatisfied ☐ Quite satisfied ☐ Very satisfied

Now, we would like to find out more about what you think of **your caregiver's preferences for you**.

1	Where do you think your caregiver wants you to be cared for at the end of your life? *Note:* Please rank the following options from 1 (most preferred) to 5 (least preferred place). Please use every number only once.	__ Hospital __ Nursing home __ Hospice __ My own or my caregiver's home __ Somebody else's home
2	How important do you think is it to your caregiver to achieve this preference?	☐ Not at all important ☐ Not very important ☐ Moderately important ☐ Quite important ☐ Very important
3	How important do you think is it to your caregiver to participate in making this decision?	☐ Not at all important ☐ Not very important ☐ Moderately important ☐ Quite important ☐ Very important
4	How confident are you that your caregiver knows your preference in regard to where you would like to be cared for at the end of your life?	☐ Not at all confident ☐ Not very confident ☐ Moderately confident ☐ Quite confident ☐ Very confident

Finally, we would like to find out more about what you know of **your caregiver's preferences for him-/herself**. Please try to think about what your caregiver would want.

1	Where do you think your caregiver wants to be cared for at the end of his/her own life? *Note*: Please rank the following options from 1 (most preferred) to 5 (least preferred place). Use every number only once.	__ Hospital __ Nursing home __ Hospice __ My own or my caregiver's home __ Somebody else's home
2	How confident are you that you know your caregiver's preferences in regard to where s/he would like to be cared for at the end of his/her life?	☐ Not at all confident ☐ Not very confident ☐ Moderately confident ☐ Quite confident ☐ Very confident
3	To what extent have you discussed with your caregiver his/her preferences regarding where s/he would like to stay at the end of his/her life?	☐ Never ☐ Rarely ☐ Occasionally ☐ Often ☐ Very often
4	How satisfied are you with the discussions you have had with your caregiver regarding his/her location preferences?	☐ Very dissatisfied ☐ Quite dissatisfied ☐ Neither satisfied or dissatisfied ☐ Quite satisfied ☐ Very satisfied

We would now like to ask you some questions about **your experiences** with different treatment locations. Please think of all the experiences you have had with each location.

1	In general, how much experience have you had with hospitals?	☐ None ☐ Little ☐ A moderate amount ☐ Quite a bit ☐ A lot
2	When you look back, how would you rate your overall hospital experiences in your life?	☐ Very negative ☐ Quite negative ☐ Neither positive or negative ☐ Quite positive ☐ Very positive
3	In general, how much experience have you had with nursing homes?	☐ None ☐ Little ☐ A moderate amount ☐ Quite a bit ☐ A lot
4	When you look back, how would you rate your overall nursing home experiences in your life?	☐ Very negative ☐ Quite negative ☐ Neither positive or negative ☐ Quite positive ☐ Very positive
5	In general, how much experience have you had with home care?	☐ None ☐ Little ☐ A moderate amount ☐ Quite a bit ☐ A lot
6	When you look back, how would you rate your overall home care experiences in your life?	☐ Very negative ☐ Quite negative ☐ Neither positive or negative ☐ Quite positive ☐ Very positive
7	In general, how much experience have you had with hospices?	☐ None ☐ Little ☐ A moderate amount ☐ Quite a bit ☐ A lot
8	When you look back, how would you rate your overall hospice experiences in your life?	☐ Very negative ☐ Quite negative ☐ Neither positive or negative ☐ Quite positive ☐ Very positive
9	How much have your personal experiences with these treatment locations influenced where you would like to be cared for at the end of your life?	☐ Not at all ☐ A little ☐ To a moderate amount ☐ Quite a bit ☐ A lot

We would now like to ask you some general questions in regard to preparations and decisions **you** may or may not have made already.

1	Have you made a living will? *Note*: That is a document that specifies what treatment a person does and does not want in the case that s/he becomes too ill to express these choices. It also can be called advanced directives or health care directives.	☐ Yes ☐ No ☐ I don't know
2	Have you filled out a form that names your medical power of attorney? *Note*: That is a form that allows someone to designate another person to make medical decisions on his/her behalf in the case that this person becomes too ill to make these choices him-/herself.	☐ Yes ☐ No ☐ I don't know
3	If for some reason your heart would stop beating or you stop breathing, would you want CPR? *Note*: CPR (cardiopulmonary resuscitation) is a procedure which tries to get the heart beating again. It may involve chest compressions, electric shocks applied to the chest, mouth to mouth breathing or ventilation via a breathing bag or a tube that in inserted into the throat. *Please also note*: This question relates to this research only and does not affect your treatment.	☐ Yes ☐ No ☐ I don't know
4	How confident are you that your caregiver knows about your arrangements and wishes in regard to your living will, medical power of attorney and CPR?	☐ Not at all confident ☐ Not very confident ☐ Moderately confident ☐ Quite confident ☐ Very confident
5	To what extent have you discussed your arrangements and wishes with your caregiver regarding your living will, medical power of attorney and CPR orders?	☐ Never ☐ Rarely ☐ Occasionally ☐ Often ☐ Very often
6	How satisfied are you with the discussions you have had with your caregiver regarding your arrangements and wishes?	☐ Very dissatisfied ☐ Quite dissatisfied ☐ Neither satisfied or dissatisfied ☐ Quite satisfied ☐ Very satisfied

Now, please think about the preparations and decisions that **your caregiver** may or may not have made already.

7	Has your caregiver made a living will?	☐ Yes ☐ No ☐ I don't know
8	Has your caregiver filled out a form that names his/ her medical power of attorney?	☐ Yes ☐ No ☐ I don't know
9	If for some reason your caregiver's heart would stop beating or s/he would stop breathing, do you think s/he wants CPR (cardiopulmonary resuscitation)? *Please note*: This question relates to this research only and does not affect your caregiver's potential treatment.	☐ Yes ☐ No ☐ I don't know
10	How confident are you that you know about your caregiver's arrangements and wishes in regard to his/her living will, medical power of attorney and CPR?	☐ Not at all confident ☐ Not very confident ☐ Moderately confident ☐ Quite confident ☐ Very confident
11	To what extent have you discussed your caregiver's arrangements and wishes with him/her regarding his/her living will, medical power of attorney or CPR orders?	☐ Never ☐ Rarely ☐ Occasionally ☐ Often ☐ Very often
12	How satisfied are you with the discussions you have had with your caregiver regarding his/her arrangements?	☐ Very dissatisfied ☐ Quite dissatisfied ☐ Neither satisfied or dissatisfied ☐ Quite satisfied ☐ Very satisfied

Finally, is there anything else you would like to tell us?

_____

_____

_____

_____

_____

_____

_____

Thank You

Thank you for taking the time to complete this questionnaire. We hope you have found the survey interesting. Your responses are very valuable to us. Would you be willing to talk to us in person about your preferences? This would involve an audio-taped interview at your convenience. If it is OK to contact you for this, please write your phone number below:

Phone number: _____
Preferred time to call:

- ☐ Morning
- ☐ Afternoon
- ☐ Evening
- ☐ Specify if desired: _____
- ☐ Doesn't matter

Feedback

If you or your caregiver wish to receive a summary of the findings after the project is completed, please provide an address to which the summary will be mailed to in 12 to 14 months:

Name: _____

Street: _____

Post Code/ Suburb/ State: _____

Note: This page will be stored separately from your completed questionnaire to protect the confidentiality of your responses.

Appendix 6 Formulae for *r*, Odds Ratios and Confidence Intervals

- Effect size *r* used for Mann-Whitney U and Wilcoxon signed-rank tests (Field, 2009, pp. 550, 558):

  $$r = \frac{z}{\sqrt{N}}$$

  where *N* is the number of observations

- Odds ratio (Bowers, 2002, p. 92):

  $$\text{OR} = \frac{a/b}{c/d}$$

  where $\frac{a}{b}$ are the odds of the event occurring in group 1

  and $\frac{c}{d}$ are the odds of the event occurring in group 2

- 95% confidence interval for odds ratios (Szumilas, 2010, p. 229):

  $$95\%\ \text{CI} = e^{[\ln(\text{OR}) \pm 1.96 \times (\frac{1}{a}+\frac{1}{b}+\frac{1}{c}+\frac{1}{d})]}$$

Appendix 7 Patient Information and Consent Form for Study 2 - Royal Melbourne Hospital Example

PATIENT INFORMATION - INTERVIEW

Project Title: End-of-life preferences in terminally ill patients and their informal caregivers
Principal Researchers: Kate Gerber
Associate Researchers: Dr. Christina Bryant, Prof. Fiona Judd, Dr. Barbara Hayes
Location: Department of Supportive and Palliative Care of the Royal Melbourne Hospital

You have completed a questionnaire on end-of-life preferences and we would like to find out more about your wishes. Therefore, we invite you to participate in an interview in which you may share as much or as little information as you feel comfortable with.

For the questionnaire, it was important that you and your caregiver both took part. However for the interview, this is not as essential. If you would like to talk more about your views in person, but your caregiver prefers not to, we are happy to interview only you. It is also up to you whether you would like your caregiver with you in the room or rather do the interview alone. Answers from the interview will not be shared with your caregiver. The interview will be audio recorded and transcribed. If we use information from your interview in future publications, we may quote you verbatim but always anonymously.

Please feel free to ask any questions you may have and talk to your caregiver. If you feel that you understand enough about what this interview involves, please sign the Consent Form below. This indicates your agreement to take part in this interview.

PATIENT CONSENT FORM - INTERVIEW

I understand that:

(a) The interview is for the purpose of research, and will be audio taped and transcribed.
(b) I have been informed that participation in this interview is voluntary, and I am free to withdraw from it any time without explanation or prejudice and to withdraw any unprocessed data I have provided.
(c) I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements.
(d) I am aware that any audio material and transcribed interviews will be safely stored and destroyed after five years.

Participant's Name (please print): ----------

Participant's Signature: Date:

Declaration by principal researcher
I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Signature: Date:

Appendix 8 Interview Guide for Study 2

(Feedback questionnaire)

- overall impression
- length
- questions that stood out

First Preference:

- The questionnaire asked about where you [patient] would like to be cared for. Can you tell me more about that?
- What does **[most preferred location]** mean to you?

- What do you need in order to achieve this preference?
- What do you think might prevent this preference?

Second Preference:

- If **[the first preference]** wasn't possible. What would be the next best option?
- What does that place mean to you?

Last Preference:

- You said you would prefer not to be at/ in **[least preferred location]**. Can you tell me more about that?
- What does **[least preferred location]** mean to you?
- What would have to happen for you to be okay with being in **[least preferred location]**?

Other Options:

- Would **somebody else's home** be an option?
- What do you know about **palliative care**?
- Have you heard of **hospice care**?

Importance:

- How **important** is this decision for you?

Place of care versus Place of death

- Do you think where you want to be cared for and where you want to die are two different questions? Or is it the same? Can you explain why you think that?

Discussion:

- Have you discussed this with each other?

End:

- Is there anything else you would like to add?

Appendix 9 Thank You Note and Study Summary – Royal Melbourne Example

THE UNIVERSITY OF MELBOURNE

The Royal Melbourne Hospital

You have recently participated in our palliative care decision making study and we would like to say:

Thank you!

Your views and insights are extremely valuable to us and we very much appreciate the time you gave to participate in this study. Please know that this important project would not be possible without you.

If you have further questions or comments, please do not hesitate to contact me. Kind regards,

---

Kate Gerber - Melbourne School of Psychological Sciences - University of Melbourne
Phone: [phone number] - E-Mail: [e-mail address]

Note: The grey text was only included in letters to carers whose patient had died during the study.

Kate Gerber
c/o A/Prof Christina Bryant
Redmond Barry Building
School of Psychological Sciences
University of Melbourne
E-mail: kgerber@student.unimelb.edu.au

[date]

Dear [name],

I hope this letter finds you well. You may remember that in [month and year], you took part in a study on end-of-life decision making. For this, you completed a questionnaire at the Royal Melbourne Hospital that asked about your wishes and views on palliative care. At the end of the survey, you indicated that you would like to receive a study summary of the final results. This research has now been completed and as requested, I have attached a brief outline of the central findings for you.

At this point, I would like to express my heartfelt gratitude for your participation. Your insights and the time you invested are sincerely appreciated and deeply valued. This important study would not have been possible without you.

Finally, please accept my sincere condolences for your loss. I have heard [patient's name] died in [month and year]. This must have been an extremely difficult time for you and my thoughts go out to you and your family.

If you have further questions about the study, you may reach me through my supervisor A/Prof Christina Bryant (phone: 03 9035 5921) or please feel free to e-mail me directly (kgerber@student.unimelb.edu.au).

Kind regards,

Kate Gerber – c/o A/Prof Christina Bryant – Redmond Barry Building - School of Psychological Sciences - University of Melbourne 3010 VIC - kgerber@student.unimelb.edu.au

STUDY SUMMARY

End-of-life preferences of terminally ill patients and their family caregivers

Advances in healthcare, treatment and technology have changed how and where people face the end of their lives. While caring for family members at home as they approached death was once the norm, dying has now become an increasingly complex medical science that often requires formal care in institutional settings. With these developments in mind, decisions concerning place of care and place of death have received considerable attention in the medical field. Given the choice, the majority of people want to stay at home; however, the reality is that most die in hospitals. This research explored decision making concerning place of care and place of death, using multiple-choice questionnaires and open-ended interviews, and this is what we found:

- Firstly, in the questionnaires, 59% of patients wanted to be cared for at home, whereas only 40% of family carers preferred this option. Carers often favoured a more formal setting for their patient, most often hospice or hospital. The interviews revealed reasons for this discrepancy. Institutions were seen to offer 24-hour professional support, which eased the burden on the carer. However, here, care was provided by strangers in an unfamiliar setting with unfamiliar routines and that was a trade-off that needed to be considered.

- Secondly, we found that for just under one third of participants there was a difference between the question "Where do you want to be cared for?" and "Where do you want to die?" Specifically, many respondents preferred care at home but they didn't want to die there. This was often chosen out of concern for the family. The problem is that in clinical reality these two questions are used interchangeably and people talk about place of care when they are reluctant to raise the topic of death.

- Finally, this research highlighted that preferences are not the same as clear-cut decisions. Particularly in the interviews, preferences were expressed as conditional tendencies to favour one place over another rather than absolute choices. Responses were flexible and depended on patients' and carers' current situation. The context in which preferences were formed was strongly characterised by uncertainty. This meant that respondents were often unsure what symptoms the patient might develop, how much the carer could handle and how much time they had left together. Many tried to reduce this uncertainty by gathering information about the illness and the prognosis. However, too much certainty was often not desirable either. Receiving details about the illness and the future was sometimes perceived as confronting and scary. So respondents had to balance on a spectrum between not knowing enough and knowing too much. And in this turmoil of emotions and thoughts it was often not possible or feasible to form clear and stable choices.

In summary, these findings suggest that to support people in this challenging time of their lives, we must be aware that patients and their families might not always have the same preferences and find ways to reconcile potentially conflicting views. We must be clear in the way we communicate with patients and carers by using language that does not confuse place of care with place of death. And finally, we must acknowledge that preferences can change over time and create a care system that is flexible enough to respond to the ever-changing needs of those facing the end of their life.

Appendix 10 Ethics Approval from Northern Health, Melbourne Health and the University of Melbourne

Northern Health

May 14, 2014

Dr. Christina Bryant
Senior Lecturer
Melbourne School of Psychological Sciences
University of Melbourne
VIC 3010 Australia

Dear Dr Bryant,

RE : P02/14 – END OF LIFE PREFERENCES AND PATIENT CAREGIVER AGREEMENT

The Northern Health HREC at its meeting on April 15, 2014 considered the subject study

The Committee has ratified this study until 2015.

To enable the Committee to fulfill its obligations in relation to monitoring the program, you are asked to provide a report within 12 months (due July 1 annually), or on completion of your project whichever is earlier.

You must also inform The Northern Hospital Human Research and Ethics Committee immediately of any matter, which arises that, may affect the nature of the approved program. Should you require any further assistance please do not hesitate to contact Cheryle Williams, Secretary HREC on 8405 2918.

Yours sincerely,

Prof. Peter Brooks AM MD FRACP FAFRM FAFPHM FRCP (Glas,Edin)
MD Hon Causa (Lund)
Executive Director Research
NORTHERN HEALTH

02/14 April 2014

The Northern Hospital
Panch Health Service
Craigieburn Health Service
Broadmeadows Health Service
Bundoora Extended Care Centre

Northern Health
The Northern Hospital
185 Cooper Street
Epping Victoria 3076
Phone: 8405 2918
Fax: 8405 2930

PO Royal Melbourne Hospital
Parkville Victoria 3050
Telephone 61 3 9342 8530
Facsimile 61 3 9342 8548
Email: research@mh.org.au
Website: http://research.mh.org.au
ABN 73 802 706 972

OFFICE FOR RESEARCH

MELBOURNE HEALTH

SITE SPECIFIC ASSESSMENT (SSA) AUTHORISATION

APPROVAL TO CONDUCT A RESEARCH PROJECT AT MELBOURNE HEALTH

Ms Katrin Gerber
University of Melbourne
Melbourne School of Psychological Sciences
12th Floor Redmond Barry Building (115)
MELBOURNE VIC 3010

28th January 2014

Dear Ms Gerber

Local Project Number: 2013.260

Study Title: End-of-Life Preferences and Agreement in Terminally Ill patients and their Primary Informal Caregivers

SSA Authorisation Date: 28th January 2014

HREC Approval Date: 28th January 2014

I am pleased to advise that the above project is approved to be conducted at Melbourne Health. This approval is subject to compliance with any conditions imposed by the reviewing HREC.

SSA Approved Documents:

- Melbourne Health HREC Approval Letter dated 28th January 2014 and approved documents therein
- Study Protocol Version 2 dated 14th November 2013
- Royal Melbourne Hospital Participant Information and Consent Form dated 23rd December 2013
- Royal Melbourne Hospital Patient Information – Interview dated 23rd December 2013
- Royal Melbourne Hospital Participant Information and Consent Form – Caregiver Information dated 23rd December 2013
- Royal Melbourne Hospital Caregiver Information – Interview dated 23rd December 2013

Research governance

You are required to notify the Office for Research of:

1. The actual start date of the project at Melbourne Health.
2. Any amendments to the project after these have been approved by the reviewing HREC
3. Any adverse events involving patients of Melbourne Health, in accordance with the Melbourne Health Guidelines for Monitoring and Reporting of Safety in Clinical Trials Involving Therapeutic Products and Other Clinical Research, July 2009.
4. Any unforeseen events.

5. Any changes to the indemnity, insurance arrangements or Clinical Trial Research Agreement for this project. This includes changes to the project budget or other changes which may have financial or other resource implications for Melbourne Health.
6. Your inability to continue as Principal Investigator or any other change in research personnel involved in the project.
7. Any other matters which may impact the conduct of the project at Melbourne Health.

You are also required to submit to the Office for Research:

8. A copy of the TGA acknowledgement letter in respect of the CTN notification (if applicable).
9. An Annual Progress Report every 12 months (or more frequently as requested by the reviewing HREC) for the duration of the project. This report is due on the anniversary of HREC approval. Continued SSA and HREC approval are contingent on receipt of an annual report by the reviewing HREC and the Research Governance Office.
10. A comprehensive Final Report upon completion of the project.

The Office for Research may conduct an audit of the project at any time.

Please refer to the Office for Research website to access forms such as the Amendment Form, Annual Report/Final Report Form, Guidelines for Monitoring and Reporting of Safety in Clinical Trials Guidelines and Adverse Event Report Forms, and other information and news concerning research at Melbourne Health:
http://www.mh.org.au/www/342/1001127/displayarticle/1001352.html

Please Note: Template forms for reporting Amendments, Adverse Events, Annual Report/Final Reports, etc. can be accessed from: www.health.vic.gov.au/cchre.

Yours sincerely,

Dr Angela Watt
Director Research Governance and Ethics

Ethics Record Overview

Ethics ID	1441564
Last Date Record Updated	06-Jan-2016
Last Update By	Bryant, A/Prof Christina
Status	Inactive
Status Reason	Completed
Status Date	13-Dec-2016
Application Type:	Registration
Approval Category:	HESC
Responsible HEAG:	Psychological Sciences
HESC:	Psychology Health and Applied Sciences
Approval Date:	29-Jan-2015
Annual Expiry Date:	31-Dec-2016
Maximum Expiry Date:	29-Jan-2020
Administering Department:	5120 - Melbourne School Of Psychological Sciences

Related Documents

Version Name	1441564.1
System Status	Finalised
Operational Status	Ratified HESC
Status Set By	Callahan, Mr Anthony
Last Update	2016-01-06 14:33:58.0
Last Updated By	Bryant, A/Prof Christina

Annual Reports

Number	1	2
Year	2015	2016
System Status	Finalised	Finalised
Operational Status	Approved (set at submission)	Approved (set at submission)
Status Set By	Bryant, A/Prof Christina	Katrin Gerber
Last Update	06-Jan-2016	13-Dec-2016
Last Updated By	Bryant, A/Prof Christina	Katrin Gerber