The lived experience of dying for hospitalized patients waiting to be transferred to a palliative care unit

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For my parents, Dimitra and George Bitzas
Thank you for recognizing the value of education and for supporting me in so many ways.

For my daughters, Dimitra and Georgia
Thank you for your patience and love.

For my husband, John
Thank you for always putting my dreams first. Now, it's your turn.

Abstract

Background:

Transitions in clinical care are often associated with changes in services and changes associated with care goals (Davidson, Dracup, Phillips, Padilla and Daly, 2007; Naylor, 2000). Although the transition from curative care to palliative care is recognized as a critical moment in the illness journey little is known about this potentially complicated transition (Schofield, Carey, Love, Nehill & Wein, 2006). More specifically, we understand little about the experience of hospitalized patients moving from acute care to palliative care. It is also not clear whether or not the notion of transition fully or accurately captures the lived experience of dying for individuals in this context. This interpretive phenomenology, influenced by the philosophy of Heidegger (1962) and the methodology of Benner (1984; 1994) sought to understand the lived experience of dying for hospitalized patients on acute care units waiting to be transferred to a palliative care ward for end of life care.

Methods:

An interpretive phenomenology was conducted in a tertiary care hospital situated in a multi-cultural urban center. Eleven participants were recruited and a total of 16 interviews were conducted. Participants were dying patients hospitalized on acute care wards waiting for a transfer to a palliative care unit within the same institution for end of life care. Data was collected through semi-structured interviews, observations captured in field notes and a reflexive journal. Data analysis was an iterative process in which interpretations occurred within the context of the hermeneutic circle and which emerged through frequent writing and immersion with the data. During the writing process and review of transcripts, development of summaries and phenomenological accounts, three parallel strategies were employed to guide the interpretive process: exemplars, paradigm cases and thematic analysis (Benner, Tanner & Chesla, 1996).

Findings:

The structure of the analysis was framed using the concepts of *thrownness* and *situatedness* (Withy, 2011) and are organized using the concepts of the situatedness of a contextual background, of a particular life and of the 'here and now'. The main findings of this inquiry are 1) participants transitioned to an awareness that they were dying prior to being told that they were by their health care providers. The impending transfer to the palliative care unit was not critical for this awareness; 2) participants' awareness of their own finitude was an experience imbued with a profound sense of aloneness; 3) the impending move to the palliative care unit was considered an opportunity for hope. At the same time, responses to the actual transfer to the palliative care unit were in part influenced by notions of control; 4) religious and spiritual beliefs offered hope and comfort but also had the potential to engender feelings of aloneness, and those participants who described themselves as non-religious found comfort in rationality and secular spirituality. Both religious and non-religious participants appear to find comfort in relinquishing control to a higher being; 5) an appreciation of embodiment is key to understanding the construct of dignity in the dying person.

Conclusions:

The findings of this inquiry offer a new way of understanding the lived experience of dying for hospitalized patients waiting to be transferred to a palliative care unit. These findings offer direction for future research and consideration for current theory. Clinical implications for nurses working with dying patients in acute care and palliative care settings are explored along with implications for nursing leaders and policy makers. Clinical implications for nurses could include supporting patients during the anticipated move to palliative care, creating a safe space to be with patients in their aloneness, and educating and supporting nurses to find ways of understanding and addressing the potential spiritual needs of patients.

Résumé

Même si la transition des soins curatifs aux soins palliatifs est reconnue comme étant un moment critique dans la trajectoire de soins, nous en savons très peu sur cette transition ayant pourtant un potentiel de complications important (Schofield, Carey, Love, Nehill & Wein, 2006). En effet, nous connaissons mal l'expérience vécue par les patients hospitalisés qui sont transférés des soins curatifs vers les soins palliatifs. De plus, la notion de transition ne saisit possiblement pas toute la globalité et la signification de l'expérience vécue. Cette analyse interprétative phénoménologique ou *interpretive phenomenology* cherchait à mieux comprendre l'expérience vécue par les patients en fin de vie, qui sont hospitalisés sur des unités de soins curatifs en attendant un transfert sur l'unité de soins palliatifs.

La recherche a été menée dans un centre hospitalier de soins tertiaires, situé en milieu multi-culturel urbain. Onze participants ont été recrutés et au total seize entrevues ont été effectuées. Les participants étaient des patients en fin de vie, hospitalisés sur des unités de soins curatifs et en attente d'un transfert sur l'unité des soins palliatifs. Les données ont été recueillies à l'aide d'entrevues semi-structurées, de notes de terrain ainsi qu'avec la tenue d'un journal de bord.

L'analyse des données a été effectuée par un processus itératif, dans un contexte de cercle herméneutique, duquel ont émergé des interprétations et ce, à travers une immersion fréquente avec les données recueillies. Trois stratégies ont été utilisées afin de guider le processus interprétatif : l'extraction des cas paradigmatiques, l'extraction des exemplaires ainsi que l'analyse thématique (Benner, Tanner & Chesla, 1996).

Résultats :

La structure de l'analyse a été basée sur les concepts d'intersubjectivité ou *thrownness* et de *situatedness* (Withy, 2011) en tenant compte du contexte particulier de l'expérience, tel qu'elle est vécue dans le ici et maintenant. Les principaux résultats de cette étude sont les suivants : 1) Les participants ont acquis une conscience de leur mort prochaine avant d'en être informés par leurs professionnels de la santé. Le fait d'être en attente d'un transfert aux soins palliatifs n'était pas essentiellement liée à cette conscience ; 2) cette conscience de leur propre finitude était une expérience empreinte d'un profond sentiment de solitude pour les participants ; 3) le transfert imminent aux soins palliatifs était perçu comme un espoir, alors que le transfert lui-même était influencé par des notions de contrôle ; 4) les croyances religieuses et spirituelles offraient un espoir et un réconfort aux participants, tout en ayant un certain potentiel de contribuer à un sentiment de solitude. Les participants qui se décrivaient comme non-religieux trouvaient du réconfort dans la spiritualité séculière et la rationalité. Autant les participants religieux que non-religieux semblaient trouver un réconfort avec le fait de remettre le contrôle des évènements entre les mains de « plus grand que soi » ; 5) le reconnaissance du concept d'intersubjectivité ou « d'être-dans-le-monde » est essentielle à la compréhension le concept de dignité, tels que définits par la personne en fin de vie.

Conclusion:

Les résultats de cette étude nous offrent des connaissances pertinentes dans la compréhension du phénomène à l'étude, ainsi que des perspectives intéressantes pour de futures recherches. Les implications pour la pratique clinique sont explorées et de plus, cette étude offre des avenues pertinentes autant pour les gestionnaires de soins que pour les leaders en sciences infirmières.

Les implications cliniques pour les infirmières incluent par exemple de soutenir le patient durant la période précédant le transfert aux soins palliatifs, d'offrir une présence ou de créer un espace afin d' « être avec » le patient, de l'accompagner dans sa solitude et finalement, de soutenir les infirmières et de leur fournir l'enseignement nécessaire à l'évaluation des besoins spirituels de leurs patients.

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Preface

This thesis is the original work of the author. As such, the author was engaged in the conceptualization and the conduct of all aspects of this research inquiry, including the identification of the topic of interest, the paradigmatic framework guiding the inquiry, the study design, the recruitment of participants, the collection of data, the transcribing of interviews, the analysis and interpretation of the results and the writing of the thesis. Dr. Robin Cohen acted as supervisor for this thesis and for the author's research training. In this capacity Dr. Cohen provided essential conceptual and methodological support throughout the conduct of the research study. Dr. Cohen and the author met regularly, and the author was supported along each step of this research project including the development of the study protocol, reviewing the main products of data collection, and several drafts of thesis chapters.

Dr. Franco Carnevale and Dr. Catherine Thibeault served as members of the thesis committee with an expertise in nursing and in interpretive phenomenology. Dr. Carnevale was involved in the early phases of data interpretation and met with the author several times to discuss the initial interpretations of the data and offer guidance with the analytic process. Dr. Thibeault was involved in the later phase of the inquiry and provided conceptual support. Dr. Thibeault was implicated in reading several drafts of both the Results and Discussion chapter as well as providing feedback on the entire thesis. Additional members of the thesis committee included Dr. Mary Ellen Macdonald and Dr. Helene Ezer. Both provided conceptual support for the research study and read drafts of the entire thesis. The author, her supervisor and all members of the thesis committee chose to present this thesis in the traditional style.

This inquiry was situated within a qualitative constructivist paradigm using interpretive phenomenology and it provides insight into the lived experience of dying for hospitalized patients waiting to be transferred to a palliative care unit.

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Chapter 1: Introduction

The social process and organization of dying and death within the modern hospital context in North America were first described in two US sociological studies: Glaser and Strauss's *Awareness of Dying* (1965) and Sudnow's *Passing On: The Social Organization of Dying* (1967). Shortly following these works Kubler-Ross (1969) documented the dying person's voice to the very end of life and dying came into its late-modern form as an experience that could be studied and inflected with value (Kaufman & Morgan, 2005). The dying individual became witness to and creator of his or her own identity (Armstrong, 1987). This concept of the dying patient as witness to their own dying experience is the essence of the philosophical and methodological foundation upon which this study is based. The purpose of this inquiry is to explore and understand the lived experience of dying for hospitalized patients waiting to be transferred to a palliative care unit. More specifically, the aim is to understand the experience of patients who are hospitalized on an acute care ward, having recently received curative treatments, but whose plan of care is no longer focused on life prolongation. Alongside this change in care goals, the patients are awaiting transfer to a palliative care unit. The chosen methodology to explore this issue is one of interpretive phenomenology, guided by the philosophy of Martin Heidegger and the methodological framework of Patricia Benner.

My clinical experience as a nurse working in palliative care for over 12 years has led me to believe that for many patients, preparing to transfer to a palliative care unit may be the first time, or at least the most salient indication, that they are dying. There are only a limited number of studies to date which focus on the patient's personal experience of transitioning from curative to palliative/end of life care.[1] This is despite the fact that in all of the studies about transition in the health literature reviewed by Kralik, Visentin and van Loon (2006), they found that it is only by understanding the transition processes that patients are living that health care professionals can provide the most appropriate and highest quality care. One of the goals of palliative care is to maintain a focus on the quality of life of patients up until the moment of their death and to do so by providing care in a holistic manner. In order to do so, we must first explore the patient's own understanding of their dying experience and the meanings which they assign to it. Clinicians should not purport to be providing optimal palliative/end of life care if this very significant transition for dying patients is ignored. This inquiry aims to uncover the meaning of the lived experience of dying for hospitalized patients who are waiting to be transferred to a palliative care unit in the hopes that a greater understanding will lead to the betterment of care.

I begin this inquiry with an exploration of my own personal narrative and orientation to the topic of interest. I uncover how and why I feel this to be an important question to explore. In addition, I expose my own preconceived ideas and beliefs which are relevant to the ensuing analysis.

Following my personal narrative, in Chapter 2: Background, I review the history and philosophy of palliative care and highlight some of the challenges inherent in defining concepts which have traditionally been used in inconsistent and unclear ways; namely "palliative care", "end of life care" and "terminal care". I identify the definitions and conceptualizations of these

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[1] "Palliative / end of life care" is used in this thesis in order to account for the fact that in many of the studies being referred to and reviewed, the distinction between these terms is either not made or is unclear. The terms "palliative care" and "end of life care" are often used interchangeably in the literature, although for the purposes of this thesis, they refer to two different concepts which will be defined on page 17.

terms as they are used throughout this work. The semantics and conceptual issues are in some ways born of two concepts which are also discussed, those of death denial and death awareness. As this is a study concerned with the transition to palliative care, there is a review of the literature on transition theories found in the nursing and other disciplinary literatures and more specifically transition studied in the context of palliative and end of life care.

According to Lopez and Willis (2004) choosing a research methodology without an examination of its philosophical basis can result in research which is ambiguous in its purpose, structure and findings. Therefore, also present in the Background chapter is a discussion of Heideggerian philosophy, particularly as it relates to concepts of Being, death and dying.

The primary aim of this study is to better understand the lived experience of dying for hospitalized patients as they await a transfer to a palliative care unit for end of life care. In Chapter 3: Methodology, I describe not only the methods used in the conduct of this study, but as well, there is an in depth exploration of interpretive phenomenology as a methodology which includes, but is not limited to, an explanation of the analytic process in which I engaged. Ethical considerations and steps taken to ensure methodological rigor are also discussed. In Chapter 4: Results, I present my interpretations of the data which were collected through interviewing the participants and noting relevant observations. Finally, in Chapter 5: Discussion, I link the key findings of the inquiry to existing literature and present implications for clinical practice, opportunities for future research, and considerations for theory. Limitations of the study are also addressed.

It is from the patients themselves that we learn what it is like to live this particular dying experience. In so doing we can hope to provide the best care possible to imminently dying hospitalized patients and to ensure that the care which we are providing is the most appropriate. What do these individuals think about when it becomes clear that they are imminently dying? How does the reality of their imminent death become clear? When does it not? What things are important to them, laden with meaning? Uncertainty is inherent in the dying process. There is uncertainty about prognosis, care requirements, and financial implications. There is also existential uncertainty about the meaning and purpose of the experience for the patient. Through this inquiry I contend that their previous experiences, beliefs, thoughts and expectations have a direct impact on the meanings which they ascribe to their dying experience. I suggest that the themes of awareness of personal finitude, aloneness in dying, relinquishing control and embodied dignity are key elements in helping to understand this experience for dying patients.

A Phenomenological Inquiry

In order to explore and uncover the essence of the lived experience of dying for patients waiting for a transfer to a palliative care unit from an acute care ward, I engaged in a phenomenological inquiry. Although Heidegger's key notion of fore-structure of understanding will be explored in more detail in coming chapters, it is important to introduce this concept here, as it played a key role in my decision to engage in this work using interpretive phenomenology. According to Heidegger (1962), the fore-structure of understanding exists in all of us, and it is our innate ability to intuit the meaning of being. More clearly, this idea of fore-structure of understanding implies that our every encounter, our every experience, is grounded and guided by something which already exists: an already determined way of thinking about that which we are interested in. As a result, there can never be a pre-suppositionless stance in any act of interpretation (McManus

Holroyd, 2007). It is only through an acute awareness of this often ignored or unacknowledged aspect of our existence that we are able to let go of our attachments to how we currently know, and how we currently understand the world and its phenomena. This then allows us to be open to new ways of understanding.

My own fore-structures of understanding are born of my history, my ethnicity, my personal and professional upbringing, as well as my work-related and personal experiences. All of these make up the familiar horizons of my life world. In order to situate myself as the researcher in this inquiry, it was vital to identify and find meaning in events which led me to ask questions about the dying patient's experience and to further describe and explore what I already believed about this phenomenon. It was only by uncovering and making explicit, to the extent possible, my own pre-understandings that I could be available to uncover new meanings and new understandings through my engagement with the participants in this study.

My Fore-structures of Understanding

The decision to embark on a study of this nature, with participants who are considered to be some of the most difficult to recruit and engage with due to their fragile medical state and limited life expectancy (Addington-Hall, 2002; Grande & Todd, 2000; McWhinney, Bass & Donner, 1994), was made after careful consideration. I will describe experiences which first led me to question what hospitalized patients waiting to be transferred to the palliative care ward for end of life care from acute care units were experiencing, and why I believed this to be a phenomenon worthy of study.

I obtained a Masters' Degree in Nursing and subsequently accepted a position as a bedside nurse on a hospital ward which admitted many dying patients. Although not technically a palliative care unit at the time, the medical and nursing staff had grown accustomed to working with the dying, as most terminally ill patients were being grouped together on this one ward. I worked there as a bedside nurse for just over a year, learning not only the basic nursing skills which would prove invaluable to my career, but beginning to develop my own understanding of what it was to be a dying patient. At the time, I remember feeling ill-equipped to engage in much more than very superficial conversations with these dying patients and their families. I was worried about being asked a question which I could not answer, or being in a situation where I would have to console a grieving family. I remember wondering at the time, largely thanks to re-reading the personal journals which I have always kept, how these patients who were so ill could manage to so often find the energy and strength to smile, to talk, to carry on.

In part, this wonderment was the result of growing up in a household in which death was never discussed, especially not with children. When our pet canary died, my siblings and I were told that it had flown away, discovering the truth only years later. When a family member died, as children we were excluded from funeral services, in order to protect us from distress. Dying was never considered an opportunity for growth or reconciliation; it was tragedy in its truest form. Serious illness too was cause for severe anguish; it was not something to cope with or rally against, it was something to fear and lament. The word *cancer* was never used in my family lest its mere utterance bring about ill fate. In fact, if cancer needed to be discussed, it was referred to instead as the *paleo arostia* or *the bad disease*. For the first several years of my career in palliative care, the older generation of my family would react to any discussion of my work with a sympathetic sigh, a shake of the head, and suggestions for other nursing areas I should specialize in. It took years for them to acknowledge that perhaps being exposed to death and dying regularly could provide opportunities for enrichment and appreciation of life.

During the past 14 years working in palliative care I have met thousands of patients who have died on the palliative care unit. I can still remember patients that I met when I first started working as a bedside nurse. One of the first patients that I worked with was Stephania. [2] She was a woman in her forties who had been diagnosed with metastatic colon cancer and was admitted with a complete bowel obstruction. Stephania was married and had a daughter in her twenties who was having such a difficult time coping with her mother's illness that she could barely muster the courage to visit her in hospital. I remember that Stephania, despite her bowel obstruction and the recommendation that she not take any food by mouth as it caused severe nausea and vomiting, enjoyed eating lobster that her husband brought her from home. She adored eating and found her dramatic weight loss due to her disease almost unbearable. Usually, she would eat the lobster, and then vomit. Occasionally, she would simply chew her food and then spit it out, taking pleasure in its taste and texture. What still strikes me about Stephania was that she always appeared very calm and peaceful, with no display of self-pity, despite a seemingly clear understanding that this would likely be the way she would live until she died.

One evening Stephania spoke to me as I was helping her settle in for the night. She shared that she was afraid and had concerns about dying. I immediately assumed that she was afraid of suffering and potential pain and of death in general but quickly realized that I was wrong. What caused her the most distress was her fear that her husband would remarry soon after her death, as his father had done following the deaths of two of his

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[2] All names that appear throughout the thesis are pseudonyms

wives. Unfortunately, I was ill-equipped to explore this further with Stephania. As a newly graduated nurse, all I felt capable of doing was to pat her hand and tell her that I was sure that this would not happen. I remember her smiling kindly at me, recognizing my limitations and understanding that I was being as helpful as I could be at the time, resigned to not being understood.

Raymond was a patient that I met approximately 6 years ago. A man in his sixties, he had been the picture of health his entire life. He was an avid runner and enjoyed racing with his wife of several years. Raymond had several visitors and his room was always full of activity, laughter and friendship. A spinal cord compression meant that Raymond was paralyzed from below the waist and would die never walking again. For a runner, I imagined that this would be the worst fate possible.

One day Raymond asked me if he could somehow be connected to the internet while in his room. His running club had a race the coming weekend and the members were dedicating their run to him. He wished to be able to connect with them online in order to cheer them on, and to feel part of the race that he had helped his friends train for. A few calls to the Information Technology department of the hospital made this possible and on the day of the run Raymond was able to video-conference with his running group. When I went into his room that afternoon to make sure that everything was set up correctly, I found Raymond and his wife laughing into the computer. He had placed a temporary tattoo on his chemo-therapy induced bald head – a huge tattoo of a scantily clad woman in sneakers striking a running pose. There was uproarious laughter on both sides of the computer, with Raymond and his wife enjoying the shocked faces of the running club members. I remember leaving the room feeling pleasantly unsettled – this is what dying looks like?

This was certainly not the first, nor the last time, that I had seen laughter, joy and life in the room of a dying patient. Yet, the memory of it still manages to give me pause, and I believe that this is due, in large part, to my own upbringing, my history. What both of these stories represent for me is a dichotomy between what I expected dying to look like, and what I was witness to. The ability to find joy, whether it was by eating, or by engaging with friends in new ways, while knowing that you are terminally ill was a concept which was foreign to me and very intriguing. In addition, to be afraid and distressed by things other than the mere fact of dying was surprising. It led me to question what other misconceptions I might have in relation to death and dying and what meanings people found in the everyday during that last phase of their lives.

Having worked in palliative care for close to 10 years at the start of my doctoral studies, I faced many clinical and administrative situations which had me query whether or not we were providing the best care, the most appropriate interventions, and the most adequate comfort to our imminently dying patients. Amidst all of these questions, what I noticed time and again was that the move from an acute care setting to the palliative care unit was largely treated as an inconsequential event by the health care team. Specifically, I found it strange that two nurses could have a discussion about a patient, prior to that patient being transferred to the palliative care unit, without exhibiting much emotion, nor commenting on the life altering impact that this move was surely (in my opinion at least) having on this one patient, on this one family. That such a move could be organized and executed without an overt sense of awe and wonderment for its significance, an appreciation of the possible sadness and anxiety, was distressing to me.

Tell Me About the Patient

When a hospitalized patient moves from one hospital department to another, nurses in the institution where this study took place communicate all facts deemed relevant to the admitting nurse. This *giving of report,* over the telephone, tends to focus on the medical status of the patient, the medical treatment plan (e.g., the patient has an intravenous running at 80 cc / hour) and any significant physical symptoms (e.g., the patient tends to get very short of breath on exertion). There is occasionally a discussion about social issues, such as whether or not the patient has family involved, and any glaring psychosocial concerns (e.g., the patient is dealing with feelings of regret or is hoping to reconcile with an estranged family member). Along with the giving of report, there are many tasks associated with transferring and admitting a patient from one unit to another. Rooms must be cleaned and prepared, room switches occasionally need to be made for patients already on the ward, charts must be organized, and the proper documentation needs to be in order. Finally, when the patient arrives on the palliative care unit, there are additional documents which need to be completed. All of these tasks are important and it is necessary to ensure that they are done thoroughly and thoughtfully. However, what seems to be lost in the midst of all of this work is that patients being transferred for terminal care will likely die on the unit to which they have just arrived. They are dying, and it has always impressed me that this monumental event seems to happen in a very matter-of-fact way, with the patient's experience being lost amongst all of the paperwork.

The most striking example of this occurred several years ago. In the middle of a very busy day, with several deaths, admissions and symptomatic patients, we were transferring a young man from an acute care ward onto our palliative care unit. In order to assist the staff nurses I called the acute care ward and spoke to the nurse caring for this young man. The only thing I knew about him was his name, age and diagnosis. The nurse proceeded to tell me that he was suffering from a lot of pain which they were having a hard time relieving with the narcotics that had been prescribed. She continued to give me information related to his diet, his skin integrity, and his bowel movements. I asked her how he was coping and she paused and told me that she felt he was fine. The word *fine* rang in my ears; it seemed incommensurate with what I imagined he was experiencing, and yet I did not pursue the issue further. We were busy, and I decided that we would get to know him when he arrived.

Approximately 45 minutes later an orderly brought the patient to the palliative care unit by bed. I remember seeing him laying there, his bed piled high with bags containing his belongings. He was alone and clutching a stuffed blue bear which he used to wipe away his tears. I went to help the orderly with the transfer and as I looked at our new patient I felt overwhelmed by the aloneness in which I perceived he was engulfed. How could anyone have considered this man to be *fine?* How could I have accepted that benign description of his being? I still feel that we cheated him; that we didn't take the time or find the opportunity to know him, to understand his experience, and to offer him the care that he needed, particularly during the time that he was transitioning to, or waiting to be transferred to, the palliative care unit. I imagined what the conversation was like, the one in which he was told that he was dying. Who was with him? How did he sleep that night?

How was he feeling? Did he have questions? Was he surprised, or did he know that this was his fate? What meaning did this have for him? Since that moment, I have been reminded time and time again, with similar situations, that we do not really have a sense of what the dying patient is living while waiting to be transferred from an acute care environment to a palliative care unit for end of life care, nor what this experience means for them.

I clearly held my own preconceived ideas, or fore-structures of understanding, regarding what impact a transition or move to a palliative care service from an acute care environment has for individuals living this experience. I imagined what the feelings, fears, and expectations were in patient's minds. I was almost paralyzed trying to empathize with the fear of the unknown, the slew of existential questions that I assumed patients must surely be living with. I pictured the enormity of the great unknown and the huge burden of "what if", and, particularly for younger patients, the "why me". Keeping a reflexive journal throughout the course of this study allowed me to not only acknowledge my own fore-structure of understanding but to ensure that I did come to the point of understanding which went beyond what I simply assumed to be true.

Why then is it important to explore this issue? Why must we try and understand what the experience of being a dying patient is? Could an inquiry such as this bridge the gap between the way health care professionals know dying and the way individuals understand and experience their own dying? How could an interpretive phenomenology conducted with terminally ill hospitalized individuals waiting to transfer to a palliative care unit meaningfully contribute to our understanding of the dying experience? This is the focus of my inquiry.

Chapter 2: Background

History of Hospice and Palliative Care

Verderber and Refuerzo (2006) trace the history of hospice to Our Lady's Hospice at Harold's Cross in Dublin, Ireland which opened in 1879. The founding of St. Christopher's Hospice in Sydenham England in 1967 however is generally recognized as one of the first social responses to the medicalization of dying. Dame Cicely Saunders, founder of St. Christopher's, had the goal of recreating a home experience for death, building a community of support and providing access to specialist skills and knowledge (Saunders, 2000).

Influenced by St. Christopher's, the first palliative care service in Canada opened in November 1974 at St. Boniface Hospital in Winnipeg, Manitoba. This was then closely followed in January of 1975 by the official opening of the palliative care unit at the Royal Victoria Hospital in Montreal, Quebec (Canadian Hospice Palliative Care Association, 2010). It was with the opening of the Royal Victoria Hospital unit that Dr. Balfour Mount, considered by most to be the pioneer of palliative care in Canada, coined the term *palliative care* in response to the negative connotations of the word *hospice*[3] in French (MacDonald, 2006). In the United States the first hospice facility opened in New Haven, Connecticut during the same time.

Although present in the province of Quebec since the 1970s, palliative care was only officially recognized as a health care service in the province in 1998 when it became one element of the *Programme Québecoise de Lutte Contre le Cancer* (PQLC) (Lambert & Lecomte, 2000). Unfortunately, this recognition and official inclusion as a public service

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[3] In French, the word "hospice" from the early history of Lower Canada commonly referred to a place of last resort for the poor and derelict. The word "palliative" however has its roots in Latin and means "to cover or cloak"

has not guaranteed the availability of well-organized care, in particular for patients with diseases other than cancer. A Canadian report suggests that only 16% to 30% of Canadians have access to palliative care services (CIHI, 2007). This is not surprising given the fact that although all regions of Quebec offer palliative care services, few regions made these services a priority in their 2002 regional organization plan, despite their programs not being up to the standards set forth by the PQLC (MSSS, 2004).[4] A recent analysis of the evolution of palliative care in Canada finds that palliative care resides at the margins of a bio-medical health care system which is focused on curing the ill and denying death (Williams et al., 2010).

Philosophy of Palliative Care

Palliative care was developed in an attempt to meet the needs of people living with incurable and life-limiting disease, particularly cancer. Palliative care follows a particular care philosophy which offers whole person care to patients and their families. As the term implies, whole person care, also referred to as holistic care, aims to address the whole person, by attending to spiritual, biological, psychological, social and existential aspects of the individual, not in isolation of one another but in recognition that all of these are interconnected and need to be attended to and valued as they are all potentially important and carry equal weight (Clark & Seymour, 1999). This philosophy is espoused by the World Health Organization (2009) which asserts that the goal of palliative care is to improve the quality of life of individuals affected by terminal illness by providing symptom relief, spiritual and psychosocial support from diagnosis to the end of life and then continuing on into bereavement (WHO, 2009). Similarly, the Canadian Hospice Palliative Care

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[4] The Quebec End-of-Life Palliative Care Policy has not been updated since the 2004 version (MSSS, 2004).

Association defines palliative care as whole person care which is aimed at relieving suffering and improving the quality of living and dying. This approach to care is believed to be appropriate for any patient and/or family living with, or at risk of developing, a life limiting illness due to any diagnosis, with any prognosis, of any age and at any time that they present with unmet needs and are open to accepting care (CHPCA, 2010)

Palliative care may complement and enhance disease-modifying therapies or it can be the sole focus of care. It is most effectively delivered by an interdisciplinary team of health care professionals and volunteers, with equal importance given to all members of the team, although it has been argued that much of palliative care is nursing care (Jeffrey, 1995). There is a focus on the family[5] as the unit of care and an understanding that death is a natural event with an inherent potential for growth and should not be considered a failure (Clark & Seymour, 1999; Clark, 2006).

Palliative Care in Hospital Settings

The majority of deaths in Canada occur in hospital (CIHI, 2007; Statistics Canada, 2011) and 80% of these occur on acute care medical units (Heyland et al., 2010). The reasons for this are multiple and include but are not limited to patients not having a living will or a Do Not Resuscitate order (Guo, Palmer, Bianty, Konze, Shin, & Bruera, 2010), not having end of life discussions and that most of these patients receive aggressive treatments right up until their death (Tobler et al., 2011). This situation is not unique to Canada. In the United Kingdom predictions estimate that only one in ten people will die at home by 2030, which will require a significant injection of resources into an already stretched health care system (Gomes, Cohen, Deliens, & Higginson, 2011).

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[5] For the purposes of this study and in the philosophy of palliative care, family is not limited to biological kin or family by marriage; family is comprised of whoever the patient identifies as important to him/her.

Palliative care has historically focused on caring for the cancer patient and his or her family. Data from Statistics Canada estimates that there will be 48,700 new cases of cancer diagnosed in Quebec in the year 2013 and that there will be 20,200 deaths due to cancer. In Quebec palliative care is mainly provided in 4 settings: the home, residential and long term care settings, free standing palliative care hospices, and in hospitals. Virtually all hospitals offer palliative care services of some sort however the accessibility, intensity and types of programs vary considerably from one institution to another (MSSS, 2004). Certain hospitals have dedicated palliative care units or beds and others have ambulatory palliative care consultation services. In certain cases, hospitals are equipped with both dedicated beds and consultation teams. Regardless of the way in which hospital services are structured it is clear that there is a lack of palliative care beds, both in hospital and in the community, in the province of Quebec. Currently in Quebec there exist 659 palliative care beds, 196 of which are found in hospitals. Based upon the recommended ratio of 1 palliative care bed for every 10 000 people, and a population in 2013 of just over 806 000 people, the province is lacking 147 beds (B. Lapointe, personal communication, April 8, 2014).

The limited number and high demand for dedicated palliative care beds in Quebec, considering the number of cancer deaths which occur annually in the province, results in the majority of hospital palliative care units admitting patients with a prognosis of less than one month, with some institutions admitting patients with a prognosis of up to three months (ASSSM, 2008); in other words, those patients who are in the stage commonly referred to as “end of life”. A recent Western Canadian report suggests that of all people dying in hospital, it is those in the “terminal illness” group, where death is expected within a few days, who were more likely to receive palliative care services (CIHI, 2007). People in this terminal illness group are typically cancer patients but also include patients with end-stage renal disease and AIDS (CIHI, 2007, p. 27).

Clarification of Terminology

Semantics are important, yet unfortunately the palliative care literature and palliative care clinicians have been inconsistent in the use of terms such as *palliative care*, *end of life care* and *terminal care*, using these interchangeably and variably (Davis, Walsh, LeGrand, & Lagman, 2002). As illustrated by its philosophy, palliative care is not time-defined but rather goal-oriented (Davis et al., 2002). It can, and should, be provided at any point along the disease trajectory, including at the time of diagnosis if appropriate. A palliative care approach should be offered, as required, alongside curative treatment, to support individuals (and their families) with chronic and progressive illness (Murray, Kendall, Boyd & Sheikh, 2005).

I contend that end of life care is not synonymous with palliative care, although the terms have been used interchangeably in the palliative care literature, leading to confusion and debate (Davis et al., 2002). Some authors (Davis et al., 2002) oppose to the use of the term end-of-life care in the palliative care literature entirely. This resistance to the term seems to stem from the assumption in the literature that end of life care is tantamount to palliative care or conversely, that it is not defined (Egan & Labyak, 2006; Reinke, et al., 2008). This ambiguity is felt to misrepresent the field of palliative care in part by implying that it is limited to those who are imminently dying thereby minimizing or ignoring the value of providing palliative care early on in the disease trajectory (Davis et al., 2002). Finally, terminal care, which falls within the end of life care experience, has been described as care which is provided when the patient's condition leaves no doubt that death is likely to occur within a matter of days (Twycross & Lichter, 2003).

For the purposes of this study, end of life care is seen as the latter part of palliative care, recognizing that palliative care itself ideally begins much earlier in the disease trajectory than end of life care does. The goal of this study is to understand the experience of dying of patients as they transition to end of life care in the context of being transferred from an acute care unit to a palliative care unit. Although some authors argue that end of life care is time-defined care, I am choosing to move away from the standard 3 – 6 month life expectancy criterion often used to define end of life due to challenges inherent in prognostication (Finucane, 1999; Murray et al., 2005). Instead, end of life care is defined as that care which no longer has life prolongation as its primary goal. In other words where curative and life prolonging measures are either deemed medically futile or declined by the patient to prevent interference with quality of life.[6]

Death Denial

In his 1915 paper "Thoughts for the Time on War and Death," Freud stated that it was "impossible to imagine our own death" and that our subconscious perceives itself as immortal because it cannot conceive of anything which is negative. For that reason the subconscious cannot know of its own death because to "death" we "can only give negative content" (Freud, 1915/1957, p. 289).

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[6] The only exception to this would be cases where life prolongation is attempted for a short duration in order to meet the dying wishes of the patient. An example of this could be an attempt to prolong life using intravenous fluid therapy in order to keep the patient alive long enough for the visit of an out of town family member.

The contemplation of our own finitude is almost universally and inherently disconcerting. However, as Zimmermann (2007) points out, although discussions related to the terror of death have been recorded since antiquity, it is only in the past 4 decades that Western societies have come to regard themselves as inherently death-denying (Aries, 1974). This conceptualization of our society as death-denying was advanced in the social science and medical literature between the years 1955 – 1985 (Zimmermann & Rodin, 2004). Somewhat ironically, it was during this same time that the hospice and palliative care movements were developing in the Western world with an ideology that was in part directed against this perceived denial of death.

In the early 1950's taboos obstructed the inquiries of many pioneering psychologists interested in the study of death (Kastenbaum & Costa, 1977). Despite the obstacles, one notable contribution made by Feifel (1956) was that although physicians, families and others may attempt to protect the dying person from awareness of his or her situation, patients themselves are often grateful for the opportunity to talk about their impending death (Feifel, 1956). In addition, in Feifel's classic work The Meaning of Death (1959), he expanded and opened the dialogue about death and cited a number of reasons for the denial of death seen to pervade North America after the 1900's. First he noted that at the time that he wrote the book there had been no wars on American soil, medical science had conquered infectious diseases that once increased childhood and infant mortality, the average life span had increased significantly, and families were scattered around the country, which made the care of the dying the responsibility of the health care system and not of the immediate family.

Regardless of the considerable evolution in the field of palliative care over the last four decades, the general, taken for granted opinion that western society remains death-denying is prominent not only amongst the lay public but also amongst clinicians (Emanuel & Emanuel, 1998). Conversely, in the sociological literature this idea is being challenged and the argument has been made that the perpetuation of the denial of death thesis is harmful to palliative care. It is believed that the focus of palliative care should be on the relief of suffering and not on extinguishing the inclination of society to deny death (Zimmerman, 2007; Zimmerman & Rodin, 2004).

One can argue that the medical system, despite the development of palliative care, is still grappling with its own death denying practices. Death is still often seen as a failure, and the acknowledgement that a patient's illness is progressing to a terminal phase is deemed unacceptable. This is particularly evident in cases where patients are referred to palliative care services late in their disease trajectory, often only a few weeks or even days, before death. In a study comparing physician service use by people with less than six months to live versus those who live longer, it has been shown that in Quebec, physicians take a very active approach to diagnostic exams and life-prolonging treatments up until the very end of life (Latimer, Verrilli, & Welch, 1999).

Terror Management Theory. As humans have pondered the meaning of mortality and developed elaborate defense mechanisms to counter the terror of death, there has been a significant literature which has emerged on death denial and terror management. Since the late 1980's, Terror Management Theory (TMT), which is based on a global assumption that human beings are conditioned to deny the awareness of their own mortality, proposes that exposure to death reminders activates two psychological mechanisms aimed at mitigating mortality concerns – cultural worldview motivation and self-esteem enhancement (Solomon, Greenberg & Pyszczynski, 1991). The basic premises of TMT are that humans, like other living beings, are driven by an instinct to self-preservation, but that unlike other living things, humans have the capacity to understand that they are alive and that they must ultimately die. The theory claims that the combination of these two assertions creates an irresolvable paradox that has the potential to generate paralyzing terror. Thus, in order to be able to live and function and escape the overwhelming feeling of terror resulting from acknowledging the inevitability of our mortality, humans have devised elaborate psychological mechanisms to remove the awareness of death from our conscious thought.

Denial of death is ultimately a repression of death awareness although it is unlikely to be able to suppress the anxiety related to the acknowledgement of one's own finitude and is often considered doomed for failure (Wong & Tomer, 2011). This is because we can never fully insulate ourselves from the reality of death in general, nor from the understanding that we are all mortal and will one day die. As such, there has been an equally important focus on the process of death acceptance by academics, laypeople and health care professionals.

Death Awareness

In *Awareness of Dying,* Glaser and Strauss (1965) presented what has become a classic four point typology when they described four points of death awareness, with most of their analysis focusing on what transpires during the interactions between patients and staff. At one end of the spectrum they described open awareness which refers to situations where both the dying person and relatives know that the patient is dying, and at the other end closed awareness where knowledge of dying is hidden from the dying person. Between these two extremes is suspicion, where the dying person suspects they are dying, and pretence where one or both parties pretend that they do not know the person is dying. Derived from participant observation in hospital settings, much of their analysis focuses on movement from one situation or context to another. In particular, where dying trajectories are lengthy and death is predictable, people may move from one state of awareness to the next. For instance, a patient with incurable cancer may move from a state of closed awareness, through suspicion and pretence into open awareness as their disease progresses and impending death becomes evident.

In an analysis of 3696 relatives, friends and others who knew people who had died in 1990 in the United Kingdom, Seale, Addington-Hall and McCarthy (1997) found that people with cancer were more likely to have died in full open awareness compared to patients with other diagnoses. They describe "full open awareness" as differing from "open awareness" by indicators of ideological commitment to openness and by frank discussions about dying (Seale et al., 1997). They also found that these patients were reported by their family and friends to be more likely to have expressed a desire to die sooner and to have requested euthanasia.

Elisabeth Kubler-Ross (1969) was largely responsible for making death a legitimate topic for research and for discussion amongst health care professionals working with the dying. She describes the phases that patients move through as they approach death. She writes about the "stages" of denial: anger at anyone or anything; bargaining, which is expressed as making deals with fate; depression; and the movement towards eventual acceptance. She further emphasizes the persistence of various forms of hope throughout all stages.

Although the work of Kubler-Ross has probably been the most influential in the encouragement of concern for the psychological needs of the dying person, there has been much uncritical and simplistic application of her contributions (Kastenbaum & Costa, 1977). Furthermore, her “stages of dying” have been criticized for being very narrow, highly subjective, and presented with exaggerated salience. Additionally, they do not account for context, either cultural or otherwise (Bonanno, 2009; Kastenbaum & Costa, 1977). Her work is often considered to represent a prescriptive notion of how one *should* move through the dying process.

Just as palliative care and curative treatment can co-exist, death denial and death awareness can co-exist within a person, as can be seen in the work of Kubler-Ross (1977). Indeed, observations have shown that death awareness in people with advanced disease may coexist with a strong will to live, that is, awareness does not necessarily mean acceptance (Rodin, et al., 2007). Early observations have postulated that awareness of death most often represents a “middle knowledge” in which states of awareness and denial may fluctuate, alternate, and co-exist (Weisman & Hackett, 1961; Weisman, 1972). Rodin and Zimmerman (2008) contend that the capacity to simultaneously hold the ideas of death awareness and denial may be a very valuable psychological task for those who are facing the end of life. Movement from one state of awareness to another can be considered a transition; a movement from one place or state to another. Much has been written about transitions in general and in health care in particular, as individual patients move through different stages of health and illness. What follows is an examination of the literature discussing transitions generally and then transitions to the end of life more specifically.

Transitions

Transition theory has a long history in disciplines outside of health-related ones, particularly in anthropology. The work of Swiss ethnographer Arnold Van Gennep (1960) early in the 20th century, further developed by Turner (1969), highlighted the way that 'rites of passage' throughout the stages of human life are marked by socio-cultural rituals.

Van Gennep's theory (1960) describes the way that individuals move through life in three distinct phases characterized by particular rites. First, pre-liminal rites (rites of separation) are characterized by the removal of the individual from their 'normal' social life, which may occur through the use of customs or taboos. Liminal rites (rites of transition) refer to customs and rituals of the individual when they are between two states, perhaps feeling confused or isolated, in a state of 'limbo' or what Draper (2003) has referred to as being 'in no man's land'. (p. 63). Finally, post-liminal rites (rites of incorporation) occur when the person is brought back into society and takes up their new status (re-incorporation). In the context of this proposal we can consider that patients transitioning to end of life care who are awaiting a bed on the palliative care unit are in a period of separation or segregation as they detach from their former position as a patient receiving acute, curative care; there is a detachment from a previously stipulated social position. The period of reincorporation or aggregation begins with the patient's arrival to the palliative care unit as he/she assumes the new social position of someone who is publicly acknowledged to be dying and whose goal of care is no longer primarily life prolongation; an induction into a new social position. The liminal stage then would be what is held in the space between these two – the waiting for something, or what Kofoed (2008) has described as a dichotomy which is a “both-and *and* neither-nor position” (p. 201). In Tolstoy’s *Death of Ivan Ilyich* (1886/1960) this moving from one place to another is eloquently described: “From the very beginning of his illness, ever since he had first been to see the doctor, Ivan Ilych’s life had been divided between two contrary and alternating moods: now it was despair and the expectation of this uncomprehended and terrible death, and now hope and an intently interested observation of the functioning of his organs.” (p. 140)

Van Gennep’s (1960) tripartite sequence in ritual observation continues to influence current transition thinking in the social and health literature. Bridges (2004) for example, has also proposed a three phase approach to transitions which consist of an ending, a beginning and an important “empty or fallow time in between” (p. 17). He defines the latter as a period of confusion and distress necessary to move through prior to entering the phase of new beginnings.

Liminality. Turner (1969) has subsequently elaborated on Van Gennep’s structure and process of the transitional stages of rites of passage, illustrating how “liminal entities are neither here nor there; they are betwixt and between” (p. 96). Turner argues that liminality is an “interstructural state; that the structural invisibility of liminal subjects is twofold: they are at once no longer classified and yet not classified” (1969, p. 236). The state of liminality has been broadly defined by Kofoed (2008) as a stage of transition between different social positions. Furthermore, because liminal subjects fall between structurally acknowledged and clear states, they can be considered to be in a state of limbo (Kofoed, 2008). More specifically, liminality refers to the intermediate stage between recognized social categories and to the indeterminacy of the in-between state (Kofoed, 2008).

The segregation of the seriously ill from mainstream society has been documented with particular clarity (Kleinman, 1988) and it has been pointed out that "being ill is, above all, alienation from the world" (Buytendijk, 1974, p. 62). It is an experience which can perhaps be illustrated in the realization of a terrible metamorphosis, similar to the one imagined by Franz Kafka. In his novella *The Metamorphosis* Kafka (1915/1972) describes the plight of Gregor Samsa, a traveling salesman who wakes one morning to find himself transformed into an insect. Although initially supported and cared for by his family he is slowly and definitively ostracized, taking up residence in his room where he ultimately dies after succumbing to a wound. Although the plight of the seriously ill is not to be directly compared to that of being transformed into an insect, I use this story as an extreme metaphor to gain insight into the experiences of patients who, like Gregor Samsa, are transforming from healthy people to beings with conditions and illnesses which may alienate them from their former selves.

Inherent in the concept of liminality is the subtle sense of living in-between two realities; being in limbo which includes a sense of loss (Kelly, 2008). This state of living loss accounts for the phenomenological experiences of an individual and their social world (Kelly, 2008) and has been explored in numerous bodies of work, from academia and the arts. For example the anticipation of death and the condition of "betweenness" – the liminal state of being not dead - has been explored by Desjarlais (2003) in a phenomenological ethnography of two elderly Yolmo Buddhists as they prepare for death. It can also be argued that in *Waiting for Godot* (Beckett, 1954) Vladimir and Estragon (the two protagonists) are in a state of liminality, a period of limbo, as they spend two uneventful days waiting for a figure they can neither explain nor fully comprehend. Liminality has been referred to as well by Gordon (1994) in her account of the ambiguity and concealment about cancer in a community in Italy. She describes the notion of "living in the in-between spaces" in which patients know and do not know about their diagnosis and prognosis. For patients, a hospital room or unit can represent a liminal space that is at once physical and personal in that it can symbolize a stage of transition between independence and dependence, illness and health, life and death.

As noted by Little, Jordens, Paul, Montgomery and Philipson (1998), many existentialists, including Kierkegaard, Heidegger, Sartre and Merleau-Ponty, view liminality as the mode of life in which we must live. The certainty of death, according to Heidegger, is the fundamental confirmation of our existence in the world (Heidegger, 1985). For writers like Italo Svevo in *Confessions of Zeno* (1923/2001), the contemplation of human mortality leads to an understanding of personal identity and provides for an immanent meaning in life**.** Pattison (1977) has described living in the face of death as the living-dying interval, a personal trajectory through three clinical phases: 1) the acute phase when one first recognizes that death is likely or imminent; 2) the chronic living-dying phase during which an individual may cope in more or less adaptive ways with encounters whose duration and predictability may vary greatly; and 3) the terminal phase in which death itself comes closer and eventually arrives.

The Nature of Transitions

There is a debate which exists around the notion of whether or not transitions are dynamic processes which have clear beginnings and ends, whether they are linear or cyclical. Papers which are framed by van Gennep's rites of passage theory (Froggatt, 1997; Martin-McDonald & Biernoff, 2002) tend to assume that transition is a linear process which is uni-directional. There is a further assumption that the three phases are somehow distinct and that they may be easily extricated from one another for close examination. Many authors propose transition has an inherent beginning and end (Fraser, 1999, Elmberger, Bolund, & Lutzen, 2002). The research of Kralik (2002) challenges these notions however, suggesting that transitions are more intricate and elaborate processes with much forward and backward movement. Unlike the conceptualizations of van Gennep (1960) and Bridges (2004) which follow a linear trajectory to transitions, Kralik (2002) proposes that transitions do not follow a chronological trajectory. Kralik and colleagues (2006) believe that transitions are processes of convoluted passage during which people redefine who they are and develop self agency. Similarly, Paterson (2001), who performed a metasynthesis of 292 qualitative research studies examining the model of chronic illness, proposes that learning to live with chronic disease is an ongoing process which involves movement in many directions.

Transitions in Nursing

The middle range theory of transitions described by Schumacher and Meleis (1994) and Meleis, Sawyer, Im, Hilfinger Messias and Schumacher (2000) presents a comprehensive framework which recognizes the significance of transitions for health and attempts to encapsulate characteristics and indicators of healthy transition processes in order to suggest appropriate nursing interventions. It was developed by examining the findings of empirical work looking at a range of transition experiences such as becoming a mother (Sawyer, 1999), experiencing the menopause (Im & Meleis, 1999) and taking on the role of family caregiver (Schumacher, 1996). This work is not concerned with a particular instance of transition but rather focuses on transitions more conceptually.

In their comprehensive literature review exploring how the term 'transition' has been used in the health literature, Kralik, Visentin and van Loon (2006) found that most authors describe transition as not only a passage or movement, but also as a time of inner re-orientation and / or transformation. Transitions often require that people take on a new definition of self as they incorporate new knowledge, alter their behavior and take on new social roles (Wilson, 1997; Meleis et al., 2000). Transitions have also been defined as "the passage or movement from one state, condition or place to another" (Chick & Meleis 1986 p. 237).

Assisting patients to manage transitions is a key function of nursing (Schumacher & Meleis, 1994; Meleis, et al., 2000). People who are undergoing transitions are often seen as being more vulnerable, as evidenced by the fact that they are more susceptible to the risks which could negatively affect their health and well-being (Davies, 2005). Nursing's challenge is to ensure that the transition process is understood and that interventions are developed which are effective in helping patients regain a sense of equilibrium and well-being (Schumacher & Meleis, 1994).

In a review and synthesis of the nursing literature related to transitions (between the years 1986 – 1992), Schumacher and Meleis (1994) found that nurses think of many diverse situations as transitions, including the traditional types characterized as developmental, situational and health-illness (Chick & Meleis, 1986) and including organizational transitions. What is telling, however, is that while there are different types of transitions, there are commonalities manifested in all types. Firstly, they occur over a period of time (Schumacher & Meleis, 1994). Also, the process involves development or flow or movement from one state or another (Chick & Meleis, 1986). Sometimes this movement has been considered by dividing the process into stages or phases (Reimer, Davies, & Martens, 1991; Wong, 1991). Another theme common to all transitions is the notion of change. This can be changes in identities, roles, or relationships or changes in the structure and composition of an organization (Walker & DeVooght, 1989).

Transitions in Palliative Care/End of Life Care

The transition to palliative care, per se, can be very difficult to identify, with patients ideally receiving palliative care services and curative treatments simultaneously, with a shifting balance between the two treatment modalities depending on the circumstances of the patient and family. Hui and colleagues (2014) conducted a systematic review of published literature, medical dictionaries, textbooks, and organization Web sites for concepts and definitions of commonly used palliative care terms, including *transition of care* as it related to dying, between 1948 and September 2012. They identified 4 articles which aimed to conceptualize *transition of care* as it relates to palliative care. In a broader scoping review Marsella (2009) found 28 articles relevant to transition and palliative care published. These articles identified 3 broad areas complicating the transition to palliative care: the fact that the transition generally signifies that death is near, the timing of the transition and the lack of information surrounding the transition. The 2 qualitative papers included in this scoping review highlight that these 3 areas are most distressing for patients (Larkin, Dierckx de Casterle & Schotsmans, 2007a; Ronaldson & Devery, 2001). Marsella (2009) goes on to state that none of the remaining 26 papers, all quantitative, highlight which areas are most difficult for patients (Marsella, 2009). Unfortunately however, the author does not give a comprehensive reference list for these quantitative papers.

Transitions in clinical care are often associated with changes in services as well as changes associated with care goals (Davidson et. al., 2007; Naylor, 2000). The transition from curative care to palliative care is recognized as a critical moment in the illness journey and yet little is known about this potentially complicated transition (Schofield et. al., 2006). It has been reported that transitions often trigger fears of helplessness and abandonment by the health care system and there is a recognized paucity of research relating directly to managing the transition to palliative care (Schofield et al., 2006). It has been proposed that there are two fundamental facts which ensure that the transition to end of life will be difficult. First is the inherent desire for most people not to be dead and the second is medicine’s inability to predict the future and to give patients a precise and definite prognosis about when death is going to occur (Finucane, 1999).

Attempts have been made to easily divide the care of patients with life limiting disease into 3 distinct phases, each being determined by the primary aim of treatment and care: curative, palliative, and terminal (Ashby & Stofell, 1991). This model, although straightforward, has been challenged; indeed the boundaries between these phases have been found to be quite blurred and the clinical impression is that the divisions between these phases are artificial (Jeffrey, 1995). This is particularly relevant today, when even illnesses like cancer, which historically followed a very predictable course toward patient death, have a disease trajectory which is more unpredictable and variable. In many instances cancer can now be considered a chronic illness, with advances in therapy enabling patients to live for many months or even several years, even when complete remission is not possible (Schofield et al., 2006). For diseases such as congestive heart failure and renal disorders, this has traditionally been the case. In this regard, the traditional sharp transition point from a curative to palliative approach is blurred with the transition to palliative care taking on a much more gradual manifestation.

Patients with life limiting illness undergo numerous transitions as their illness progresses (Reinke et al., 2008). In a grounded theory study exploring transitions as defined by patients with advanced cancer or chronic obstructive pulmonary disease, their family members and clinicians, the transition theme of "no more treatment" was identified in all groups, although the meaning was different for patients and families compared with clinicians. Patients and families felt that this transition signified a state where there was nothing else to be done, whereas clinicians felt that this transition represented the time to shift from curative to palliative care (Reinke et al, 2008). Back (2005) reports that in a 1998 American Society of Clinical Oncology survey conversations with patients about transitions from curative treatment to palliative care appear more likely to trigger concerns about dying, loss, grief, and abandonment than those experienced at the time of diagnosis. This is in contrast to the work of Weisman and Worden (1976/1977), which drew our attention to the crucial period from diagnosis of cancer and continuing on for about 3 months during which time patients experienced what the authors labeled "the existential plight in cancer". This shift could be explained by current advances in medicine which have offered many patients a realistic hope for cure.

In the transition from curative care to end of life care, communication is extremely important in order to clearly establish an individual's goals, understandings and expectations (Friedrichsen, Strang, & Carlsson, 2000). Despite its importance however, this can still be a difficult task for health care providers (Morita et al., 2004). Unfortunately , when important discussions such as unfavorable prognoses and treatment failure are avoided or poorly managed, the quality of remaining life for the patient can be seriously jeopardized (Larson & Tobin, 2000). Health care professionals may avoid end of life conversations because they (1) fear causing pain and bearing bad news, (2) lack knowledge of advance directives laws and training in breaking bad news, (3) view death as the enemy to be defeated, (4) anticipate disagreement with the patient and family and (5) feel threatened by such discussions (Morrison, 1998). Although many analyses of failed communication at the end of life tend to attribute these failures exclusively to the health care professionals, there are findings which emphasize the role of the patient, who manages to keep conversations away from certain difficult and distressing topics (Heaven & Maguire, 1997; Hinton, 1998; Jarrett & Payne, 1995). Family members can also block or complicate certain conversations when they are unable to acknowledge that the patient is dying (Larson & Tobin, 2000). Family members express ambivalence about what they want to know and often have difficulty comprehending and accepting “bad news” regardless of how it is delivered (Cherlin et al., 2005). Despite these challenges, research shows that patients and families tend to value clear communication about the patient’s condition (Hanson, Danis & Garrett, 1997) and negative communication experiences, such as exchanges which have left at least one party feeling confused, frightened or distrustful, have been found to remain as indicators of poor quality of care for bereaved family members (Hanson et al., 1997; Morita et al., 2004; Spichiger, 2008).

Ronaldson and Devery (2001) studied patients and nurses to investigate the experience of patients undergoing transition to palliative care services across a large inner metropolitan health service setting. The patients who were interviewed for the study were in-patients being referred to palliative care services. Although not explicitly stated, it can be inferred by some of the patients' comments that they were being referred for a variety of reasons and not simply for end of life care. The study found that a lack of forewarning about palliative care referral leads to shock and distress for patients, particularly when they were unsure of what palliative care entailed. These findings imply that in clinical practice, providing patients with palliative care information early on may help ease the transition.

In their 2007 study, Larkin et al (2007a) describe a variety of intense emotional reactions felt by patients faced with the challenge of transitioning into palliative care. These were advanced cancer patients from six European countries (United Kingdom, Ireland, Italy, Spain, Switzerland and the Netherlands). The attributes of the patients and their experiences which they found reflected in their data included fragility, suddenness, powerlessness, impermanence, time, space, uncertainty, separation and homelessness. Clinically, these findings are extremely important as they can help direct interventions aimed at providing the best care possible to patients at the end of life. For instance, the notions of suddenness and uncertainty may indicate the challenges of the communication which occur between patients and their health care providers. On the other hand, even with excellent communication, patients may be experiencing a certain level of ambivalence with regards to the state of their health, which will invariably lead to a sense of shock when a concrete transition occurs. Larkin et al's (2007a) phenomenological study, however, included patients already admitted into palliative care units or free-standing hospices and is an account of their experience at that moment. It does not touch upon the experience of waiting for and perhaps anticipating the transfer, nor does it capture the experience of the actual transition.

Transience. Larkin and colleagues (2007b) make the argument that the concept which should actually be discussed in the palliative care literature is not transition, but transience. They argue that although the transition literature often focuses on overtly positive outcomes such as resilience, reconstruction, life purpose and transformation for patients, they found that patients reported having limited knowledge with regards to the purpose and time of the transfer to the hospice or palliative care unit, uncertainty about who initiated the transfer, rapidly increasing symptom burden leading to a poor involvement in decision making and, once transferred, patients reported experiencing a sense of waiting for something to happen (Larkin et al., 2007a; Larkin et al., 2007b). As a result of the fact that patients were experiencing more of a state of stasis versus living through a process, the validity of transition as a descriptor of the totality of their experience was questioned by the authors and the concept of transience was introduced.

Although empirical literature which addresses transience in a health context is relatively sparse there are two psychoanalytical papers which offer a concrete description of transience: one historical and one current. Freud's (1916/2006) seminal treatise, "On Transience" describes it as an ephemeral state of existence where things once considered permanent change. In the more current work, Kitayama (1998) further delineates between transition and transience. He describes transition as "a phenomenological description of movement" and transience as an emotional state often associated with sadness and painful feelings (p. 937). The transient state then is associated with a dual sense of impermanence and irreversibility; a sense of wanting to hold onto something when it is not possible to do so. The experience of patients who are transitioning into end of life care may in some ways be representative of this duality.

Heidegger and Death

When deciding to explore death and the experience of dying, it is appropriate to consider philosophical ideas related to this experience. Existentialists tend to consider extreme experience the best starting point for philosophical thinking, and Heidegger was an existentialist who focused much of his work on the experience of death (Kaufmann, 1959). Heidegger was a student of the German philosopher Husserl, who was the founder of phenomenology as a philosophy and the descriptive approach to inquiry. Over time, Heidegger critiqued and modified Husserl's work and in particular sought to answer the question of the meaning of Being. Ontology, in the widest possible sense, was Heidegger's main concern throughout his life and the question which fascinated him was "What is the meaning of being?" (Frede, 1993).

With regards to death, Heidegger has noted that if there is anything which is entirely and undoubtedly private and one's own, it is one's own death (1985). As a result, claiming to understand what a dying person is experiencing without actually gaining insight from them directly claims a false superiority of external insight (Okon, 2006). In discussing death in *Being and Time*, Heidegger (1962) does not refer to the empirical fact of a person's death, but rather to a fundamental ontological-existential structure. He does not consider death to be an experience, an event (or a non-event); instead he develops a new method of existential analysis which is purported to provide a concept of death by the analysis of the lived experience of *Dasein*.

Dasein, or Being-in-the-world (Dostal, 1993; Heidegger, 1962), refers to a specific way or mode of being, accessible only through a lived, individual experience. *Dasein* is always in the world with others, among various possibilities, most importantly *Dasein'*s own possibility. Death is an existential condition of *Dasein* in so far as *Dasein* is being-towards-death. Heidegger does not offer advice on how to prepare ourselves for death, but rather invites us to examine what Being is.

When Heidegger, in *Being and Time* (1962), seeks to link *Dasein's* possibility to the world as a whole, he begins the articulation of the *authenticity* of *Dasein.* Authentic modes of existence are those in which *Dasein* stands in a directly first-person relation to itself, as opposed to the second or third-person relations in which it stands to others. Authenticity consists in our understanding of the ontological structure of the first person, or what Heidegger (1962) calls "*Dasein's* mineness". Dying individualizes *Dasein* as dying is *Dasein*'s ownmost possibility, so that "death is in every case mine, in so far as it 'is' at all" (Heidegger, 1962, p.239) Heidegger refers to the "is" to point out that death can only be understood as a possibility, a not-yet which precedes the ontic "is". Furthermore, the *authenticity* of *Dasein* cannot be determined until the moment of death itself because, up until then, *Dasein* has the possibility of revision and reinterpretation. He goes on further to claim that death is not an event; it is a phenomenon to be understood existentially (Heidegger, 1962).

In our everyday lives we know death; we understand, in a very hypothetical sort of way, that one day it will come, however it is considered to belong to no-one in particular. Death is a mishap constantly occurring to someone else. This is clearly illustrated in

Tolstoy's *The Death of Ivan Ilych*, to which Heidegger (1962) refers[7], as Tolstoy describes the reactions of Ilych's acquaintances to the news of his death: "Besides considerations as to the possible transfers and promotions likely to result from Ivan Ilych's death, the mere fact of the death of a near acquaintance aroused, as usual, in all who heard of it the complacent feeling that, it is he who is dead and not I." (Tolstoy, 1886/1960, p. 2) Heidegger asserts that although this constant, and at the same time subtle, solicitude about dying may console us, its "constant tranquilization about death" (Heidegger, 1962 p. 298) does not allow courage in the face of death.

It is important to note that Heidegger's philosophy, including his most important work, *Being and Time* (Heidegger, 1962), are not without their critiques. Heidegger's writing has been criticized for being unnecessarily complex, and Heideggerian scholars themselves have not come to a universal consensus about the translation of and meaning of key Heideggerian words (Johnson, 2000). Stronger critics have considered his work to be obscure, indulgent, impossible to read, and to contribute nothing to philosophy (Davidson, 1989). His works after *Being and Time* have been considered obtuse and less technical in nature (Laverty, 2003).

These criticisms are augmented by Heidegger's involvement with National Socialism and Nazism, and his remarks and pronouncements after World War II were, and remain, horrifying (Davidson, 1989). Likely because of Heidegger's complex personal journey related primarily to his political and social affiliations, Scruton (1995) describes Heidegger's work not only as being incomprehensible, but also questions how much of it was about Heidegger's personal spiritual journey rather than philosophy.

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[7] Kaufmann (1959) goes so far as to say that Heidegger's discussion of death is nothing more than an unacknowledged commentary of Tolstoy's *The Death of Ivan Ilych*.

Beyond his writing style and troubling political and social affiliations, Heidegger has also been criticized for the incompleteness of his work. His opus, *Being and Time* (Heidegger, 1962) contains two sections, the first bearing the title, “The preparatory fundamental analysis of Being-there”, with *Being-in-the-world* (Dasein) referring to Heidegger’s term for human existence. The second section is entitled “The possible Being-Whole of Being-there and Being-toward-death”. In the lengthy introductory chapter we are told that the projected work has two parts, each of which consists of three long sections. The published work, however, subtitled “First Half”, contains only the first two sections of Part One. The “Second Half” never appeared (Heidegger, 1962).

Despite the complex nature of Heidegger’s work and the controversy that often surrounds it, it is undeniable that many nurse scholars have relied upon his philosophy in order to guide an interpretive form of inquiry, with some scholars going so far as to argue that the importance of Heidegger to nursing practice and theory cannot be overestimated (Horrocks, 2000). An exploration of Heidegger’s interpretive phenomenological philosophy allows for an understanding and appreciation of the interpretive phenomenology mode of inquiry which will be discussed in Chapter 3: Mode of Inquiry, and which guides the analysis of the data in this inquiry.

Summary and Study Purpose

In many ways the field of palliative and end of life care has grown and developed since its introduction to Canada nearly 40 years ago. For example, those working in the field now recognize that they must address the needs of patients living with diseases other than cancer and that palliative care should be introduced early on in the disease trajectory. Challenges however continue to exist. There are issues related to semantics which are at once both confusing and detrimental and there are societal factors which continue to influence, whether positively or negatively, the way in which we think about and discuss death. Discourse about death awareness and death denial is abundant in the literature, however much of this is based upon theoretical musing and conceptualizations or research done recruiting those other than the dying, such as health care providers and family members. Heidegger's seminal work, *Being and Time* (1962), is devoted to the notion of *Dasein* and contemplates the significance of an individual's own-most death. These are very important foundations on which to build an understanding of the lived experience of dying of patients waiting to be transferred to, or transitioning to, palliative care for the end of their lives.

Although there is much written about the concept of transition in the social science and health literatures, there is limited literature which explores the experience of patients as they transition to end of life care, and in particular the experience of hospitalized patients moving from acute to palliative care. It is important that we further the understanding and meaning of the experience of these patients in the hope of informing the care which is provided to them as it is clear that assisting patients to manage all forms of transitions is a key function of nursing (Schumacher & Meleis, 1994; Meleis, et al., 2000).

As noted by Marsella (2009), although the transition from curative to palliative/end of life care can be plagued with difficulty, fear and misunderstanding, it is one of the most understudied transitions in health care. A better understanding of the patient's lived experience would add to the discourse currently available. The purpose of this study is to better understand the lived experience of dying for patients waiting to be transferred from an acute care unit to a palliative care unit. Although I began this inquiry with my original research question focused exclusively on the transition process, it became evident through the process of data analysis that what was ultimately being uncovered went beyond transitions alone. Participants were sharing with me their experience of dying. The research question then is: What is the lived experience of dying for hospitalized patients who are waiting to be transferred to a palliative care unit for end of life care?

Chapter 3: Mode of Inquiry

The focus of this inquiry is to help uncover the meanings of the lived experience of dying for patients as they wait to transfer from an acute care unit to a palliative care ward for end of life care. This inquiry was situated within a qualitative constructivist paradigm using interpretive phenomenology. Lincoln and Guba (1985) reflect upon ontology, epistemology and methodology and consider them essential in conducting research. The constructivist paradigm which guides this study supports the ontological perspective that there exists more than one reality and that this reality is built and can be altered by the knower. In this paradigm, reality is something that is local and specifically constructed (Laverty, 2003) and realities are not judged by how "true" they are, but by how they are informed (Denzin & Lincoln, 2000). Knowledge is seen as the best understanding we have been able to produce so far; it is not a reflection of what is ultimately "real" or "true".

Epistemologically, within the constructivist paradigm there exists a relationship between the knower and the known; attempts to attain value-free research findings or conclusions are seen not only as misguided but impossible (Cotterill & Letherby, 1993; Laverty, 2003). Denzin and Lincoln (2000) go further in stating that the investigator and the investigated are interactively linked in the creation of knowledge and that the investigator's role is actually one of participant.

Methodologically, the perspective of the interpreter may evolve and change over time, for instance, in the process of interpretation and interaction between the investigator and the research participant (Laverty, 2003). Interpretive phenomenology fits very nicely within the constructivist paradigm as it is critical of objectivism; it holds that meaning independent of mind or being is inconceivable: “meaning cannot inhere in an object independently of any subject” (McNamara, 2005, p. 696).

Phenomenology

As a philosophical perspective, phenomenology has shed light on phenomena of the human experience, reformulated philosophical questions, and influenced many fields of scholarship (Tymieniecka, 2003). At the core of phenomenology as a mode of research inquiry is an attempt to describe and understand phenomena as experienced by the individuals who have lived them (Wojnar & Swanson, 2007). As noted by Lopez and Willis (2004), phenomenology offers nurse scholars and clinicians an inquiry approach which is commensurate with nursing philosophy and nursing art.

Two phenomenological approaches frequently seen in the nursing literature include descriptive phenomenology based upon the philosophy of Husserl and interpretive (hermeneutic) phenomenology which has as its foundation the philosophy of Heidegger (Cohen & Omery, 1994). Although many researchers do not articulate which of these approaches guides their study (Lopez and Willis, 2004) there are fundamental differences between the two based upon their philosophical values, knowledge claims and the types of research findings which result.

Heidegger’s philosophical focus was fundamentally different to that of Husserl, whose focus was epistemological; Husserl’s aim was to reveal knowledge which transcended human experience. Conversely, Heidegger’s philosophical concerns were ontological; he aimed for a better understanding of ‘Being’ itself (Mackey, 2005). In *Being and Time*, Heidegger sought to expand the influence of phenomenological philosophy from epistemological questions into the realm of *Dasein* or the ontological nature of existence

(Heidegger, 1962). Although it is not within the scope of this thesis to fully discuss the differences between descriptive and interpretive phenomenology, I will describe the fundamental tenets of interpretive phenomenology while addressing the rationale for choosing this method.

Interpretive Phenomenology

Interpretive, or hermeneutic, phenomenology is the study of lived experience which places emphasis on the world as lived by a person; the stance of phenomenology does not consider someone's world or reality as something separate from the person (Valle, King and Halling, 1989). The word hermeneutic is derived from the name Hermes, a Greek god who was responsible for making clear, or interpreting, messages between gods (Thompson, 1990). In this form of inquiry, the questions are "What is this experience like?" while attempting to unfold meanings as they are lived in everyday existence (Laverty, 2003). Interpretive phenomenology increases sensitivity to humans' ways of Being-in-the-world (Dreyfus, 1991) rather than providing theory for generalization or prediction of phenomena (Crist & Tanner, 2003). As this research inquiry concerns itself with exploring the hospitalized patient's lived experience of dying as they wait to be transferred to a palliative care unit for end of life care, an interpretative phenomenological approach to advance the knowledge surrounding this phenomenon was employed.

In the 1990s there were a number of salient and occasionally damaging critiques of how phenomenological research had been handled, particularly in nursing (Crotty, 1997; Paley, 1998). One of the strongest criticisms levied against nursing researchers who conduct phenomenology is that the philosophy, upon which the methodology is based, has been introduced into the discipline typically through secondary sources (Horrocks, 2000).

This makes an already challenging feat, understanding the philosophical underpinnings of phenomenological research, even more difficult. Benner (1984; 1994), arguably the most well known nursing academic who engages in interpretive phenomenology, introduces Heidegger into nursing through the interpretation of Dreyfus (1991).[8] Although this approach has been criticized for potentially obscuring initial ideas and concepts through the many layers of interpretation (Horrocks, 2000), it is also true that by so doing, it makes the work of Heidegger accessible to a wider and more diverse audience. In order to address the criticisms often levied against nursing scholars who use interpretive phenomenology, within this inquiry, the philosophy and methodology of interpretive phenomenology are intertwined. This is purposefully done in order to link methodological approaches to philosophical ideas where appropriate and to remind the reader that the attempt was made to marry the philosophy with the analytic approach throughout the thesis.

Heidegger sought to answer questions of the meaning of beings. He believed that humans are hermeneutic (interpretive) and therefore capable of finding significance and meaning in their own lives (Draucker, 1999) and this is where the major difference lies between descriptive (or Husserlian) and interpretive phenomenology. For Husserl, context was of peripheral importance, whereas, for Heidegger, context was of utmost importance (Wojnar & Swanson, 2007). Heidegerrian phenomenology, then, is based on the belief that the understanding of people cannot occur in isolation of their cultural, social and temporal context (Campbell, 2001; Draucker, 1999; Geanellos, 1998). To this end, Heidegger introduces the concept of *Dasein,* or the human way of Being-in-the-world, to emphasize

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[8] Benner references the Dreyfus' book in her papers stating that it is "to be published". The book was ultimately published several years later, in 1991.

that individuals cannot abstract themselves from various contexts that influence their choices and give meanings to their lived experiences (Wojnar & Swanson, 2007). Mackey (2005) states that by choosing to use a Heideggerian or interpretive method for research, the researcher commits to an ontological approach. Heidegger's philosophy requires the researcher to search for understanding of the meaning of Being, rather than for what can be known.

The assumptions of *Dasein* and *situatedness,* which will be defined later, form the basis for pre-understanding or, as Heidegger (1962) called it, a fore-structure of understanding. This fore-structure of understanding includes fore-having (all individuals come to a situation with practical familiarity or background practices from their own world that make interpretation possible); fore-sight (the sociocultural background which gives a point of view from which to make an interpretation); and fore-conception (the sociocultural background which provides a basis for anticipation of what might be found in an investigation) (Benner, 1994; Wojnar & Swanson, 2007).

Heidegger states that the fore-structure is closely linked to how one understands the world and consequently how one interprets it. As a result, researchers engaged in interpretive phenomenology understand that before conducting research, the researcher must reflect on his or her past experiences and preconceptions about the phenomena being studied, not in an attempt to bracket out all of this knowledge as Husserl advocated, but instead to more clearly access the fore-structure of understanding which in turn informs the interpretive process (Benner, 1994).

Interpretive phenomenology further differs from the descriptive approach in that the interpretive approach does not negate the use of a theoretical orientation or conceptual framework as a component of inquiry (Lopez & Willis, 2004). Theory, however, is not used in a formal way such as to generate hypotheses to be tested. Instead, a theoretical approach can be used to focus the inquiry where research is needed and to make decisions about samples, subjects and research questions which need to be addressed (Lopez & Willis, 2004). The use of an orienting framework is often considered a useful way for the researcher to make explicit any study assumptions and to make clear the researcher's own frame of reference. The topics chosen to be reviewed in the Background chapter and the articulation of my own fore-structures of understanding are representative of the orienting framework which I employed during the conduct of this inquiry.

According to Heidegger (1962), the interpretive process is circular, moving back and forth between the whole and its parts (e.g. what happens within an instant and what occurs during the course of an entire conversation or what happens during the conversation with one participant and what transpires across several encounters), and between the researcher's fore-structure of understanding and what was learned through the research process. This process of entering into a hermeneutic circle of understanding reveals a blending of meanings as articulated by the researcher and the participants and has been referred to as co-constitutionality (Koch, 1995). Co-constitutionality indicates that the meanings that the researcher arrives at in interpretive phenomenology are a blend of the meanings articulated by the research participant and the researcher. Gadamer (1976) refers to the 'fusion of horizons' to explain this act of inter-subjectivity, understanding and interpretation. It is this fusion of horizons which allows for there to be more than one interpretation of narratives and which implies that there will be no one true meaning produced by any interpretive study, but that the meanings ultimately stated are logical and plausible within the study framework, and they must reflect the realities of the study participants (Annells, 1996).

Another philosophical assumption underlying the interpretive phenomenological approach is that presuppositions or expert knowledge on the part of the researcher are valuable guides to inquiry and in fact make the inquiry a meaningful undertaking (Lopez & Willis, 2004). Heidegger (1962) was clear in his belief that it is impossible to rid the mind of a background of understanding that has led to the posing of a particular question and that this pre-understanding (or fore-structure) should be considered of value (Koch, 1995).

Methods

Setting. This study took place in a 637 bed university affiliated tertiary care hospital situated within a cosmopolitan urban setting. Within this institution is a 17 bed palliative care unit, of which I have been the nurse manager since the year 2000. For a significant part of this inquiry, including data collection, I was on a part-time study leave of absence and my professional duties at the time were focused primarily on administrative responsibilities, staff development and policy reform; I had to suspend much of the clinical work I typically did with patients and families due to time constraints. These responsibilities were taken over by other professional nurses during the time of my leave.

The palliative care unit in this institution annually admits an average of 375 patients. Approximately 75% of the patients admitted die on the unit while 25% are transferred either to palliative care settings outside of the hospital or are discharged home. Of the 375 patients admitted to the unit, approximately 40% are admitted specifically for terminal care (meaning that at the time of transfer it is clear to the patient, family and health care providers that the palliative care unit will be the place of death). Other reasons for admission include, but are not limited to, pain and symptom management, palliative radiotherapy and respite for family caregivers. Pain and symptom management represent the second largest reason for admission and many of these patients also end up dying on the ward.[9]

Patients arrive onto the palliative care unit from a variety of places. Approximately 40% of admissions are either direct admission from home, from an out-patient clinic or from the emergency department. The remaining 60% of patients are transferred from other acute care units within the hospital. The majority of these transfers are from acute care medical units and more recently, acute care surgical units.

The Division of Palliative Care within this institution is sub-divided into 2 complementary services: the 17 bed in-patient palliative care unit with a dedicated interdisciplinary team which includes volunteers, and the supportive care team. The supportive care team is comprised of a full-time nurse consultant in palliative care along with 7 part-time family physicians. The role of this team is to respond to consults for palliative care from other health care providers (namely physicians and nurses) within the institution and also to be involved in the care of the approximately 500 home care patients known to the service. The Division of Palliative Care has a policy that no patient should be transferred to the palliative care unit without a consult first being made to the supportive care team. This ensures that being transferred to the palliative care unit is in the patient's best interest, and that while waiting for a bed, they will be cared for with the added expertise of palliative care specialists. Although statistics are not officially kept on the length of time that hospitalized patients are waiting for a bed for the palliative care unit, it

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[9] These statistics are based upon a review of data for the years 2009 – 2012.

is not typical that they be transferred the same day that they are placed on the waiting list. Beds do not become available every day and when they do patients from the Emergency Department or who are at home are given priority for admission. The typical range of time that a patient admitted in the hospital on an acute care ward is waiting for a bed on the palliative care unit is between 3 days and 2 weeks.

Participants. Given the aims of interpretive phenomenological research, sample selection for this inquiry was governed by considerations other than those used in empirical statistical approaches (Dukes, 1984). Participant selection was based on inclusion and exclusion criteria carefully chosen in an attempt to ensure that the research question was addressed in the best manner possible and in keeping with the phenomenological framework. Because this inquiry was concerned with the lived experience of dying, the participants were selected to include patients waiting for transfer to the palliative care unit specifically for end of life care. This specification was important because certain patients admitted to the palliative care unit are admitted for symptom management, medical treatments and occasionally temporary respite for the family caregiver. It is not unusual for patients within these categories to have a relatively long prognosis (over 6 months) and to be ultimately discharged home or to another institution. Including this subset of individuals into this study would not allow for an exploration of the experience of imminent dying.

Interpretive phenomenology goes in the opposite direction of traditional purposive sampling by finding a more narrowly defined group for whom the research question will be significant. According to Smith and Osborn (2009), the basic logic of this is that if one is interviewing a limited number of participants, which is expected to be the case in interpretive phenomenology, then it is not very helpful to think in terms of random or representative sampling. Sample size selection will be considered in more detailed in a later section.

Inclusion criteria

- Patients hospitalized on an acute care unit and who were on the waiting list for transfer to the palliative care unit.
- Patients for whom life prolongation was no longer the primary goal and in whom life prolonging measures were either deemed medically futile or declined by the patient to prevent interference with quality of life.
- Patients with a cancer diagnosis. The vast majority of patients waiting to be admitted onto the palliative care unit have a cancer diagnosis, and it is recognized that patients dying of other diseases may have a different trajectory of decline at the end of life.
- Patients who are able to communicate in English or French.

Exclusion criteria

- Physically and / or mentally incapable of providing informed consent and / or participating in the study (as determined by the supportive care team physician who evaluated the patient for transfer).

The sample in this study was homogenous by virtue of the fact that all participants were being cared for in one institution, were awaiting transfer to the same palliative care unit, were assessed by the supportive care team prior to the transfer and were patients with a diagnosis of cancer.[10] Prior to being placed on the waiting list for transfer to the palliative care unit, all participants were seen by the nurse on the supportive care team and by one of the physicians on the team, all of whom share the same philosophy of care. These consultations are done in order to assess, amongst other things, readiness and appropriateness for transfer to the palliative care unit. All patients would have been seen by the supportive care team, which is an institutional requirement for transfer onto the palliative care unit. Furthermore all potential participants would have had discussions with the health care team about their wishes regarding resuscitation as it is an institutional policy that the patient has a *do not resuscitate* order documented prior to transfer to the palliative care unit. This is noteworthy because it supports the idea that the participants would have already had some discussions with their health care team regarding their prognosis and plan of care. Furthermore it addresses the ethical concern that participation in this inquiry would reveal information about their illness for the first time. Hospitalized patients admitted onto acute care units of the hospital, who were awaiting transfer to the palliative care unit, and who met the inclusion criteria and not the exclusion criteria, were asked to participate in this study.

Although it was clear that there would be many similarities among participants who are homogenous in the ways described above, it was equally important that the sample be as diverse within a narrowly defined population as possible in order to enhance the possibilities of obtaining rich and unique stories of the particular experiences (Polkinghorne, 1989; van Manen, 1997). In order to capture this diversity I collected demographic data (Appendix A) such as age, gender, ethnicity, socio-economic statuses and

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[10] The sample was purposefully limited to the diagnosis of cancer. The vast majority of patients (>97%) admitted to the palliative care unit have cancer.

primary cancer diagnoses. This information was collected through observation (for instance, gender) or by asking the participant (for example, age, primary cancer diagnosis), depending upon what was most appropriate. This information helped to elicit the nuances in meanings that the lived experience of dying had for individuals of different backgrounds. Heterogeneity in the sample allowed for the possibility of conducting a detailed examination of similarities and differences, areas of convergence and divergence, among participants (Patton, 2002). Given that the institution in which this study took place serves a very multi-cultural population, and the fact that the cancer center has both a young adult program and a program for geriatric oncology, at the outset of this inquiry I was confident that my sample would be diverse enough to provide rich accounts of the experience under investigation.

Sample size. The number of participants necessary for phenomenological studies varies depending upon the nature of the study and the data which is collected along the way (Laverty, 2003). Although there are no hard and fast rules related to sample size, interpretive phenomenology studies are generally conducted with a small number of participants, as the goal of these studies is to give a detailed account about the perceptions and understandings of a particular group, and not to make more general claims (Smith & Osborn, 2009). Typically, sample size ranges from 1 to10 individuals are recommended for phenomenological research (Starks & Brown Trinidad, 2007). Furthermore, as stated by Benner (1994), although sample size is projected at the beginning of the study, “it may be adjusted depending on the quality of the text and the way that the lines of inquiry are reshaped by the participants” (p. 107). For this reason, a range is appropriate and necessary; prior to the start of this study a range between 9 – 15 participants was considered. Based upon the quality and richness of data which was collected (analysis occurred concurrently with data collection), 11 participants were ultimately recruited (Appendix B).

The inclusion of 11 participants in this inquiry reflects the trend in the literature to use small sample sizes for interpretive phenomenological studies (de Witt, Ploeg & Black, 2010; O'Mahony, 2001; Scheckel & Hedrick-Erickson, 2009; Smith & Osborn, 2007; Touroni & Coyle, 2002). Although it is acknowledged that very diverse and larger samples might provide a broader range from which to distill the essence of the phenomena, data from only a few people who have experienced the phenomena, and who can provide a detailed account of their experience, enables the researcher to uncover its core elements (Starks & Brown Trinidad, 2007). According to Benner (1994), sample size is generally considered adequate when interpretations are visible and clear. The 11 participants in this inquiry afforded richness of data from a diverse population which allowed for rich and clear interpretations of the phenomenon.

Recruitment. Participants were recruited from the 4 acute care units from which most transfers to the palliative care unit occur. Although many patients are admitted to the palliative care unit from the emergency department, directly from home and occasionally from the intensive care unit, the choice to limit recruitment from acute care units only was made in order to ensure that I would have adequate time to meet with potential participants prior to transfer.

A presentation of the study was made to members of the supportive care team as well as to the interdisciplinary teams of the acute transferring wards, and of the palliative care unit. I attended weekly supportive care team rounds in which home care palliative patients are discussed and where the status of hospitalized patients seen by the consult service are reviewed and updated if necessary. Often, new consults are also distributed by the nurse consultant to the various physician members of the team during this meeting. As head nurse of the palliative care unit I would normally have access to this meeting. If there are empty beds on the palliative care unit at the time, the patients on the waiting list requiring transfer most urgently (for medical or psychosocial reasons) are also reviewed.

Prior to the start of this study I had already engaged in informal communications with the various members of the supportive care team as well as with the physician responsible for coordinating all admissions onto the palliative care unit. All were strongly supportive of this project and had agreed to help identify potential patients for participation and as well to then ask these patients if I could meet with them in order to fully explain the study.

Patients who met the inclusion/exclusion criteria were approached either by the member of the supportive care team involved in their care or by the medical admissions coordinator of the palliative care unit, depending upon who knew the patient best. This clinician then determined whether or not the patient was interested in talking to me about this study. At this point, the clinician explained to the patient that although this research was being conducted as part of my thesis to fulfill the requirement for my doctoral studies in nursing, I was also working part-time as the head nurse of the palliative care unit. Patients were informed that as the head nurse I had no authority over selecting which patients got transferred to the palliative care unit, nor would their participation or refusal to participate in this study have any influence on when they got transferred, or the quality of care they would receive on the palliative care unit. For patients who agreed to meet with me in order to learn more about the study, this information was repeated and re-emphasized by me.

Only those patients who agreed to meet with me were approached in order to fully explain the aims of the study and obtain informed consent (Appendix C).[11] I was frank but gentle in telling all potential participants that our conversations would likely touch upon sensitive issues and private experiences. I assured the patients, however, that their best interests would always override the research needs. Participants were informed that they could discontinue involvement in the study at any point in time by simply stating that they wished to stop participating, and that they were always free to refuse to answer any question, or to make their answers as long or as short as they wished. They were also told that they could take breaks during the interviews and that they could ask that we continue our conversation the following day or later in the same day.

Data collection. In phenomenology, data can include the researcher's personal reflections on the subject of inquiry, information gathered from research participants, and depictions of the experience from outside the context of the research project itself including the arts and literature (Polkinghorne, 1989). The latter category of data sources were referred to in order to help draw out particular aspects of the experience from participants and to aid in my own reflections. It was interesting to note that there were instances where the participants themselves referred to the arts in order to help draw parallels between what they themselves were experiencing and what had been previously represented in the arts.

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[11] The title on the consent form in Appendix C reads: "The experience of patients waiting to be transferred to a palliative care unit". This was to take into account that patients may have been in various stages of "death awareness" and the inclusion of the term "lived experience of dying" may have been unethical for certain patients.

My extensive clinical experience in the field of palliative care and clinical judgment enabled me to engage participants in a manner which was intimate while at the same time being very sensitive to difficulties which surfaced given the nature of our conversations. Data was collected using face to face semi-structured interviews, through the use of participant-observation, personal reflections and field notes.

Interviewing. The interview is considered to be the main method of data collection in phenomenological research as it allows for the participants' stories to be explored, illuminated and gently questioned (Kvale, 1996). Researchers using an interpretive phenomenological approach need to be able to get at the "lived experience" of the participants (Wimpenny & Gass, 2000) which requires that the interviewer possess certain skills such as appropriate "use of reflection, clarification, requests for examples and description and the conveyance of interest through listening techniques" (Jasper, 1994, p. 311). According to Smythe and colleagues (2008), to enter an interview with the mindset of "conducting" is "to freeze the phenomenological spirit" (p.1392). There must be an openness to the conversation during interviewing in that the questions must not be so structured that they follow a pre-organized plan nor so unstructured that there is no clear sense of why the researcher and participant have come together at all (Smythe et al, 2008).

Due to the very fragile medical condition and short life expectancy of the participants in this study, and the resultant short period of time during which they were able to participate, it was unrealistic to expect to engage in more than two interviews with each participant. When conceptualizing how the study would unfold prior to recruitment, I ideally imagined that participants who were on the waiting list for transfer to the palliative care unit would be interviewed prior to the physical transfer to the palliative care unit, and then again after the transfer had taken place. The value of the second interview was to elaborate and develop specific issues and events which appeared salient during the first interview, to get a sense of how the experience varied over time and place, and, when they were willing and when it was not upsetting to them, to allow the research participants to reflect on the interpretations derived from the initial narratives. In the end only 5 of the 11 participants were able to participate in a second interview. The remaining 6 individuals either died within a week of our first interview (in certain instances without ever being transferred to the palliative care unit) or were too confused or sedated to participate in a second exchange.

The rationale for having the first interview occur before and the second interview after the transfer to the palliative care unit was to best represent the process of transition, and to potentially highlight the stages or steps which patients experienced as they waited for a transfer to the palliative care unit. When the second interview did take place it did so at least 24 hours after the transfer occurred, in order to give patients the opportunity to acclimatize themselves somewhat to their new surroundings. This was important for ethical reasons (not to overburden the patients during what could be a stressful time) but also because it allowed the participants to better incorporate their surroundings into the meaning of their experiences. Ultimately however I uncovered that what participants were actually sharing was their lived experience of dying more globally. They were not exclusively commenting on the waiting for a transfer to the palliative care unit as a transition process.

All participants recruited into this study either died or were transferred to the palliative care unit within a week of our first interview. Knowing that there could occasionally be very lengthy delays for transfer to the palliative care unit, the study was designed so that any participant who had not yet been transferred to the palliative care unit a week after our first interview would be approached for a second interview while still on the acute care unit. This opportunity never presented itself as all participants were either transferred to the palliative care unit in less than a week, or, if they did not get transferred, died within a week of our first interview.

The goal of phenomenological interviewing is to attain first person descriptions of specified domains of experience with the course of dialogue largely set by the participant (Laverty, 2003). I aimed to have the interview process take place within an environment of safety and trust by maintaining privacy to the extent that it was feasible. For patients who were not in a private room, I ensured that curtains were pulled around the bed. None of the participants were well enough to be moved out of their rooms into a more private location. Whenever I was unable to ensure absolute privacy I told the participants that others would likely hear our conversation and I reminded them that they did not have to participate in the study. In situations where family was present, I suggested to the participants that it would be preferable to conduct the interview while we were alone. I tried to be open and accommodating and expressed a willingness to return to interview the participants at times which were convenient for them. In cases where the patient preferred to have the family present, the interview was conducted after ensuring that both the participant and the family member understood that it was only the patient being interviewed, and that the family should not contribute to the interview process. A total of 4 of the 11 participants had family and friends present during the actual interview, however in no instances did the family or friends participate actively in the interview process.

Although the interviews began with a few pre-specified questions concerning the phenomenon under inquiry, most of the questions flowed from the dialogue (Pollio, Henley, & Thompson, 1997). In phenomenology, openness is critical and the exchange between researcher and participant may be entirely open, with few direct questions asked by the interviewer (Koch, 1996). Examples of the kinds of interview questions used to help guide the conversations can be found in Appendix D. The rationale behind this kind of interview process is to stay as close to the lived experience as possible. My years of clinical experience made it possible for me to engage with the participants in a manner which intended that participants felt at ease and which was responsive to their needs, while at the same time, meeting the needs of the inquiry.

Interview questions, statements and summaries were used to evoke descriptions and not to confirm theoretical hypotheses (Pollio et al, 1997). It is typically recommended to avoid questions which start with "why" in phenomenological research as these questions tend to shift the dialogue away from describing an experience to a more abstract, theoretical discussion (Pollio et. al., 1997). Interviews were audio-recorded and transcribed verbatim for analysis. I transcribed the interviews. This was a conscious decision as listening to the audio-recordings and transcribing the words which were spoken was fundamental in allowing me to be even more deeply engaged with the data. In addition, only I knew the context around the words which were spoken. Hand gestures, pauses, looks and vocal tones were noted and considered when later analyzing the data. For the interviews which were conducted in French, I translated the direct quotes found in Chapter 4 from French to English.

Observation. Although openness in interviewing revealed much of what the participants were experiencing, it was also very important to capture all of what was being said *between the lines* during these conversations (Kvale, 1996). Silence, what was said with the absence of words, was also paid attention to (van Manen, 1997) as was the presence of tears, laughter, hesitations, and crying. As Virginia Woolf so eloquently put it, "The merest schoolgirl when she falls in love has Shakespeare or Keats to speak her mind for her, but let a sufferer try to describe a pain in his head to a doctor, and language at once runs dry" (2008). Throughout the interview process, vocal intonations, physical expressions and gestures that were not captured by the audio recordings were included in field notes and later incorporated into the transcribed narrative text. These observations were then analyzed simultaneously with interviews (Crist & Tanner, 2003). A guide to the types of things which were noted through observation is included in Appendix E.

Field notes and reflexive journal. Data was also collected through the use of field notes. Bernard (2002) describes three different types of field notes: methodological notes, descriptive notes and analytic notes. Methodological notes deal with the technique of data collection and with the growth of the researcher as an instrument of data collection (Bernard, 2002). Descriptive notes generally arise from watching and listening; in this study they are comprised of the observations made and information gleaned while interviewing participants. Analytic notes were also kept and these are interpretations of the data. They represent the outcome of my understanding of the phenomena being studied and came about through "organizing and working with descriptive and methodological notes over a period of time" (Bernard, 2002, p. 376). All field notes and my reflexive journal were written as soon as possible (typically within 24 hours) after interviewing the participants in order to best remember the observations and my reflections (Polit & Hungler, 1995). In fact, my reflexive journal served as the proverbial dumping ground into which I almost daily wrote about my feelings, fears, thoughts, misgivings, suspicions and hopes in relation to this inquiry. This developed into a useful tool during the research process and addressed a main tenet in interpretive phenomenology, that re-interpreting phenomena you already believed you understood is the key to understanding.

Data analysis. Analytic guidelines for interpretive phenomenology are not extant in the literature but those who do try to lay things out remind us that the process is iterative and not linear (Crist & Tanner, 2003). Interpretive phenomenology does not require that the researcher bracket out their own preconceptions or theories during the process – a belief held by Husserl and emphasized in descriptive phenomenology (Crist & Tanner, 2003; Lowes & Prowse, 2001). Instead, what is necessary is that there is an acknowledgement of any assumptions which could both influence the interviews and observations as well as their interpretations (Crist & Tanner, 2003). Recognizing the assumptions that could be made during the interpretive process has been referred to as the forward arc of the hermeneutic circle and the actual interpretation as the return arc (Crist & Tanner, 2003). For this reason the conceptual issues discussed in the Introduction, such as death awareness, death denial, transition and transcience, in addition to Heideggerian philosophy as it relates particularly to Being-in-the-world and death were drawn upon and referred to during the interpretive process.

As suggested by Crist and Tanner (2003), an interpretive team, which consisted of Dr. Robin Cohen, who was my supervisor, and Dr. Franco Carnevale, who was a committee member who is an expert in phenomenology,[12] and me, conducted the first phase of analysis which included a detailed evaluation of the interview and observation techniques evident in the transcripts. This initial analysis, which occurred early on in the data collection process, helped guide subsequent interviews and directed future sampling in order to provide a deeper, richer understanding of the lived experience of dying for hospitalized patients waiting to be transferred to a palliative care unit for end of life care.

In interpretive phenomenology, data analysis and interpretation begin as soon as data begins to be collected. Throughout the interpretive process and the analysis, I was writing and re-writing in order to develop my interpretations (Crist & Tanner, 2003). In interpretive phenomenology the actual transcribing of interviews, the writing of interpretations, going back to the interview transcripts and various forms of notes, and re-writing of interpretations are all part of the analytic process. Writing does not occur once the analysis is complete; the writing is the analysis. This interpretive writing began with summaries of the central concerns, or themes, found in the interviews, with salient excerpts for each participant's story. Each participant's story was re-written through my interpretive lens and a *phenomenological account* of every interaction was created. *Phenomenological account* was the term I used to describe the developing interpretations of my encounters with the participants and they served several purposes. First, they encouraged me to re-evaluate and re-interpret the participants' stories in a way which was in keeping with certain Heideggerian and phenomenological ideas. Second, they encouraged an act of interpretation versus simply a description of events. Lastly, they ultimately became an additional source of data and served as the vehicles which uncovered

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[12] Dr. Catherine Thibeault, also an expert in interpretive phenomenology joined the committee after the point of data collection and initial analysis.

common themes and differences amongst participants. They were integral parts of the hermeneutic circle, which was a back and forth movement of questioning and re-examining the text, and the interpretations being developed, which resulted in an ever-expanding circle of ideas about what things mean. The hermeneutic circle relies on the circular movement from the whole of the data to the parts (or emerging themes), incorporating the contributions of all, deconstructing and then reconstructing, resulting in an in depth understanding or interpretation which can be shared with others (McConnell-Henry, Chapman & Francis, 2009). This process brought the level of my analysis from the concrete to the abstract and led to an understanding of the possibilities of Being, as revealed by human language and human behaviour (Parse, Coyne and Smith, 1985). In other words, the participants offered their stories, and by looking and re-looking at the data, searching beneath the words at what was not immediately obvious, I aimed to end up with an ontological perspective of the participant's experience. By using the hermeneutic circle, I was able to read between the lines and uncover the essence of the experience.

As interpretations were created they were refined through my frequent written revisions. During the writing process and the review of transcripts, summaries, and phenomenological accounts, three parallel strategies were employed to guide the interpretive process: finding exemplars and paradigm cases and then conducting thematic analysis. Exemplars are salient excerpts that characterize specific common themes or meanings across study participants. They are parts of the stories, or instances which have similar meanings within informants' stories. Paradigm cases are vibrant stories, or case examples, that are particularly compelling, and to which I tended to return in order to examine them from new perspectives (Benner, Tanner & Chesla, 1996; Crist & Tanner, 2003). Thematic analysis means reading the whole text across cases for common themes (Benner, 1994).

As the research participants' central concerns became clear, I was able to observe shared meanings amongst participants. My written interpretive summaries show connections between meanings found within and across stories, or constitutive patterns (Diekelmann, 1993). One of the unique and interesting features of interpretive phenomenology is that the act of interpretation is an unending process; readers of this thesis will actually be making further interpretations and perhaps questioning those which are presented here (Crist & Tanner, 2003).

Throughout the analysis, I kept in mind that my position as the head nurse of palliative care potentially influenced the participants' degree of disclosure about their experiences during interviews. It is impossible to know whether or not an individual participant was more, or less, open about their experience because of my role as head nurse, or whether it had no bearing at all. In cases where I suspected that the participant was hesitant to be completely open with me because of my role, I again reassured them that our interviews were confidential and that information that they shared with me would not influence their care.

Ethical Considerations and Methodological Rigor

Ethical approval for the conduct of this study was granted by the Research Ethics Committee of the institution where this study took place. As with all clinical studies, clinical research in palliative care requires close attention to ethical issues. In this section I elaborate on some of the ethical considerations in designing and conducting this research. In addition, a study which is not conducted in a manner which is rigorous cannot be considered ethical, therefore I will go on to discuss issues of methodological rigor here as well.

In 2010, the Tri-Council Policy Statement was updated and now includes a chapter devoted to qualitative research (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). This amendment is recognition that qualitative research has a long history in many established disciplines, including nursing, and that its use is increasing. There is an understanding that qualitative research methodologies are inherently dynamic and that the assumptions which shape quantitative approaches may not apply. Despite the differences however, many of the research practices and methodological considerations which guide quantitative research also guide qualitative inquiries. In particular, questions regarding research quality are fundamentally an ethical concern. How can one purport that a study is ethical if it is conducted without integrity? It would be a waste of the participants' time and financial and institutional resources, such as the time taken by the research ethics committee to review the research protocol and health care professional's time in helping to identify possible research candidates, if a study was conducted in such a manner that the results could not be relied upon to advance knowledge. In order to describe how scientific integrity was maintained throughout the course of this inquiry I will describe the elements of methodological rigour, including balanced integration, trustworthiness, credibility, transferability, and confirmability which guided the conduct of this research.

In addition to questions of integrity of qualitative research in general, and interpretive phenomenology more specifically which will be discussed, this inquiry presents additional ethical concerns. The conduct of research with imminently dying patients has been the subject of much debate (Casarett & Karlawish, 2000; Duke & Bennett, 2009; Raudonis, 1992). I will build upon the cornerstones of informed consent, privacy and confidentiality in order to address the issues that are particularly germane to qualitative research with dying participants.

Methodological rigor. Discussions related to rigor in phenomenological nursing literature are replete with controversy, primarily due to issues related to philosophical interpretation and to the debate which exists in deciding which criteria fully express the rigor needing to be addressed (de Witt & Ploeg, 2006). Phenomenology began as a philosophy and as such did not involve discussions about the collection of data nor their analysis. It has been adapted for health sciences research however and identified as an important way to gain a deeper understanding of patient experiences.

In their analysis of empirical nursing studies purporting to use a phenomenological approach to research, Norlyk and Harder (2010) were surprised to find that Lincoln and Guba's (1985) criteria to evaluate generic qualitative research were used to justify and evaluate many of these studies. Their surprise stems from the fact that, according to them, the criteria put forth by Lincoln and Guba (1985) are dated, and that philosophical inconsistencies between interpretive phenomenology and the criteria of credibility and confirmability (Sandelowski, 1986) demonstrate their inappropriateness as expressions of rigor for this research methodology (de Witt & Ploeg, 2006). They argue that these criteria are incommensurate with the methodological underpinnings of interpretive phenomenology and that there should be specific criteria used to evaluate interpretive phenomenological studies. The use of generic criteria to establish rigor in interpretive phenomenological studies may “create obstacles to full expression of rigour” (deWitt & Ploeg, 2006, p. 223) and generic criteria may overlook the unique threats to rigor which are inherent in particular methodologies (Armour, Rivaux, & Bell, 2009). To frame their discussion of the inadequacies of appraisal for phenomenological inquiry, de Witt and Ploeg (2006) chose to focus on Sandelowski’s (1986) paper on rigor in qualitative research, a paper which the author herself has argued is no longer relevant these several years later given the changing climate of qualitative research (Sandelowski, 2006).

Amidst all of the debate, Patton (2002) has argued that the choice of criteria for assessing rigor in qualitative inquiry should be based upon the methodological and philosophical orientation of the researcher and the perspective of the expected audience. As there are no clear guidelines for establishing methodological rigor in interpretive phenomenology I chose to draw from the work of several authors as suggested by de Witt and Ploeg (2006). First, I refer to the framework of balanced integration described by de Witt & Ploeg (2006). I subsequently refer to Lincoln and Guba’s (1985) framework for establishing rigour, which Sandelowski (1986) interpreted for nursing research. This was done despite the fact that some authors contend that Lincoln and Guba’s (1985) framework is not appropriate for evaluating interpretive research (de Witt & Ploeg, 2006). A close examination of the literature indicates that there are other authors who feel that Lincoln and Guba’s framework (1985) is indeed an appropriate way of expressing the relationship between validity and interpretive inquiry (Beck, Keddy & Cohen, 1994; Creswell & Miller, 2000). Understanding the murky waters inherent in any decision related to establishing methodological rigor in interpretive phenomenology, I follow the lead of Thibeault (2010) in referring to the work of Shenton (2004) in order to enrich this discussion.

Balanced integration. The criterion of balanced integration is an attempt to address an issue which receives much criticism in phenomenological nursing research, namely the misrepresentation or absence of philosophy (Cohen & Omery, 1994; Crotty, 1996). In order to meet the criteria of balanced integration, I spent a semester auditing a philosophy course on Heideggerian phenomenology. This course, and the discussions that I had with Professor Philip Buckley, helped lay the foundation for my understanding the basics of interpretive phenomenology. In addition to this course I later participated in a phenomenology working group, led by Dr. Franco Carnevale and I participated in a two day symposium honoring and discussing the work of Charles Taylor. Taylor, a philosopher who developed influential accounts of embodied personhood and agency (Taylor, 1989), is strongly influenced by Heidegger and other phenomenologists. His major work, *Sources of the Self* (Taylor, 1989), is an extensive inquiry into the sources of modern selfhood. My submersion in the philosophy of interpretive phenomenology enabled me to include, throughout this thesis, an articulation of the general philosophical themes present in Heideggerian phenomenology along with an exploration of how these fit, or do not fit, with my research question. This mingling of philosophical tenets continued throughout the study's execution and the interpretation and presentation of the results.

Trustworthiness and credibility. It is the responsiveness and analytic ability of the researcher, who must attend to questions of rigor and trustworthiness during all stages of the inquiry, which ensures research integrity (Morse et al, 2002). Credibility, which is the believability or "truth value" (Carnevale, 2002, p. 126) of a study is a notion which is philosophically complex when coming from an interpretive phenomenological perspective. I never set out to establish an objective truth; in fact doing so would be incommensurate with my chosen methodology. Instead, the goal was to ensure that my interpretations made sense of the text and that the text "appeals to our understanding of the language of expression" (Taylor, 1985, p. 17). As described earlier in this chapter, the act of interpretation is never complete, and my presented interpretations are *true* in so far as they are representative of the meanings which I was able to uncover when examining the data. The credibility which I can claim is supported by criteria set forth by Shenton (2004), as described below.

Familiarity with the research context. From the very beginning, I considered my close familiarity with the setting, the patient population and the philosophy of palliative care to be a significant strength of this inquiry. My familiarity (and the fact that I was familiar to others) was instrumental in facilitating my access to potential participants. Furthermore, this familiarity allowed me to identify a research question which I knew would resonate as important to my fellow clinicians (who would be aiding me in recruitment) and which was feasible given the institutional organization and characteristics of the potential participants.

However, this familiarity was also appreciated for its potential hazards. Having a long and significant relationship with the research environment, the key players who would aid in recruitment and the various departments which I would be interacting with begged the questions: Will my work colleagues, who I am now relying upon to help identify potential participants, feel coerced and pressured into aiding my recruitment? Upon learning that I am the head nurse of the palliative care unit, will patients be more likely to agree to participate in the hopes that this would somehow influence their care? How will my preconceived biases and ideas influence my emerging interpretations?

I am confident that neither the individuals helping me recruit participants nor potential participants felt coerced or pressured into becoming involved in this study. There were several different members of the supportive care team who were helping me to recruit potential participants. As a group, the supportive care team members, via their willingness to help me recruit participants in this study, felt that this was a project which had value and which could be beneficial to future patients. In addition, I did not have to repeatedly remind people that this study was occurring. It was enough to simply be occasionally present at the weekly supportive care team rounds and wait for the referrals to come to me. As well, it is important to note that I do not hold any power over the members of the supportive care team in terms of their jobs. None of these health care professionals report to me, and they are not my employees. To answer the second question, although I can never know for certain what participants believed they may have benefited from by participating in this study (in particular, a quicker transfer to the palliative care unit), care was taken to ensure that they were informed that I had no influence over the admitting procedures.

The issue of how my preconceived biases and ideas may have influence over my emerging interpretations and how these could impact the credibility of the inquiry was addressed via Shenton's provision of the researcher's reflective commentary. Reflexivity has been linked to the quality and credibility of research, as it requires the researcher to be open to the many ways in which they themselves can influence findings (Clancy, 2013). It is commendable as it implies that the researcher is capable of introspection while as the same time being able to look at external forces such as culture, history, and politics which could shape the relationship between the researcher and the participant (Sandelowski &

Barroso, 2002). The goal of reflexivity is not to limit bias but instead to make it transparent in order to adapt interpretations to bring a more credible version of the participant's accounts to light (Kleinsasser, 2000; Underwood, Satterthwait, & Bartlett, 2010).

I was constantly mindful of my automatic reactions and responses to what participants had to say, and saw these as opportunities for further and deeper engagement with the data. In fact, prior to any interviews being conducted I wrote several lengthy entries in my reflexive journal in which I described what I expected I would uncover during my conversations with the participants. I also wrote an imaginary first person account of what I imagined this experience would mean for me, should I have been the one waiting to transfer from acute to palliative care. My entries in my reflexive journal continued throughout the entire process of data collection and analysis. It has become a compilation of thoughts, meanderings, assumptions, random ideas and questions which have helped focus my interpretation of the participants' stories and which has clarified my own perspective on my research experiences.

Sampling. Although random sampling is sometimes felt to contribute to the credibility of qualitative inquiry (Shenton, 2004), it is not an appropriate criterion for interpretive phenomenology. Randomness does nothing to further enrich or change individual experiences. In this study, participants were recruited using purposive sampling.

***Triangulation**.* Triangulation refers to the use of various methods of data collection or multiple sources of data (Shenton, 2004). As this inquiry concerned itself with the lived experience of dying for participants waiting to be transferred to a palliative care, only dying individuals were interviewed. Triangulation was still achieved however as a wide range of informants were recruited into the study. Shenton (2004) states that this is one way of triangulating via data sources as individual viewpoints and experiences can be compared against others and "ultimately, a rich picture of the attitudes, needs or behaviour of those under scrutiny may be constructed based on the contributions of a range of people" (p. 66). In part due to the very multi-cultural fabric of the institution in which this study took place and the wide range of ages being served in the oncology department, my participant pool was quite heterogenous. There were eight different ethnicities represented amongst the 11 participants and ages which ranged from mid-forties to eighties. In addition, I used interviews and participant observation to help me understand the participants' experiences. Over the course of the research I maintained an ongoing awareness of participants' accounts and my interpretation of those accounts, and used my developing understanding of the phenomena under study as a foundation for further inquiry. It is important to keep in mind that within this inquiry triangulation was not used as a means of "confirming existing data, but as a means of enlarging the landscape of the inquiry, offering a deeper and more comprehensive picture" (Tobin & Begley, 2004, p. 393).

Participant honesty. I certainly did not enter any encounter with participants expecting or anticipating that they would lie to me, however the risk that this could happen is greater in cases where the participant feels either that there is something to be gained by lying, or who feels that they were coerced into participating in a research project that they would have preferred not to be part of. Given my role as head nurse of the palliative care unit, I frequently reminded individuals that I had no influence over when they would be transferred. In addition, I often reminded individuals that their participation in the study could be stopped at any time and that I would not even require a reason from them for stopping – it would be enough for them to tell me that they no longer wanted to participate. I was also sensitive to signs of fatigue during the interview process and asked participants if they would like to stop the interview several times during our conversations. It is interesting to note that several participants thanked me for approaching them about the study – although they were not led to expect any personal and direct benefits, several of them did feel that being able to verbalize their emotions, fears and experiences was beneficial to them.

Additional provisions to ensuring credibility. Shenton (2004) offers other approaches to ensuring credibility, such as frequent debriefing sessions with colleagues and thick descriptions of the phenomenon under scrutiny. To this end I shared my research plan and research conduct with my supervisor and members of my thesis committee. Particularly valuable was the time which I spent debriefing and brainstorming with Dr. Franco Carnevale who is well versed in qualitative research and in particular in interpretive phenomenology. It was during these discussions, and in preparing for these meetings, that much of the work of developing my ideas and interpretations, and recognizing my biases and preferences, occurred.

Transferability. The hospital chosen for this study is situated in a part of the city which has the largest number of newly arrived immigrants. It has a renowned cancer center, and a Division of Palliative Care which is divided into two separate but inter-related arms: the supportive care consultation team and the in-patient palliative care unit. Despite the fact that this study took place in one setting, the focus of this inquiry is the lived experience of dying for patients waiting to transfer to a palliative care unit for end of life care; this experience is interpreted in the analysis chapter with theoretical constructs which are broadly relevant across settings. While findings generated with a constructivist paradigm are necessarily context-bound, the insights which these findings generate can and should resonate with others. As defined by Tracy (2010), resonance is the "research's ability to reverberate and affect an audience" (p. 844). I have provided thick descriptions of the participants' experiences as well as their context; that is, even small details were taken into account in order to paint as appropriate a picture of the patient and their experience as possible while at the same time maintaining confidentiality. The timing of when the data was collected (for instance, the time since they were put on the waiting list for the palliative care unit, the time since diagnosis and the time relative to death) and the circumstances surrounding its collection have also been elucidated. In so doing, the reader of my interpretations will be able to consider how the findings presented here may or may not overlap with their own realities. As pointed out by Wright (2012), the point is not for the fit between any two contexts to be perfect, but instead for the insights generated by this research to "have theoretical currency for a multitude of contexts" (p. 79).

Confirmability. According to Carnevale (2002), confirmability of study findings is supported through an audit trail, which refers to "the maintenance of detailed records of data collection and analysis process, whereby a reader could confirm that they would arrive at the same conclusions" (p. 126). Such a criterion for confirmability is problematic for the type of constructivist inquiry outlined in this thesis. Interpretations are dependant upon the interpreter and are shaped by his or her thoughts, feelings, and analytic orientation. It is this individuality of interpretation which paves the way towards deeper understanding (Wright, 2012). Confirmability is related to the concept of "freedom from bias" in qualitative research (Sandelwoski, 1986, p. 33; Shenton, 2004). The process of triangulation, described earlier, contributes to confirmability. Furthermore, a clear description of the process of research conduct is important in order to ensure that the interpretations which the researcher arrived at are plausible and not simply figments of the imagination (Koch & Harrington, 1998). Considering the extensive reflective material at the beginning of this thesis and the weaving of reflective commentary throughout the interpretations, this inquiry meets this aspect of the criterion of confirmability.

Research with Dying Patients

It is not uncommon for palliative care research to be unsettling to researchers outside of the field, clinicians and the lay public, primarily because of the concerns related to ensuring the protection of the safety and rights of people facing life limiting illnesses. Duke and Bennett (2010) identified the key debates which are raised in the literature with respect to the ethics inherent in palliative care research with ill adults. They identified 5 key areas of debate including: whether dying individuals constitute a vulnerable population; whether research with this group of participants is morally justified; whether it is possible to gain informed consent; if individuals with a life limiting illness have the right to participate in research, and lastly, if the research environment offers the support needed for the researcher who will be engaging in work which has the potential to be personally taxing. I will address each of these themes as they relate to my research study and demonstrate that care was taken to ensure that the conduct of this research was ethical.

The question of vulnerability. The early focus of this debate in the literature was on whether individuals with life-threatening illness constituted a vulnerable population (Duke & Bennett, 2010). Although there are strong opinions that research with this population is never justified; a position which is based upon the belief that there is a great likelihood that participants will feel coerced to participate and will be unlikely to benefit from the study (de Raeve, 1994), there are counter arguments which state that palliative care populations are not inherently vulnerable and that ethical principles for conducting research can be applied to them (Addington-Hall, 2005; Casarett & Karlawish, 2000). The Tri-council Policy Statement (2012), on which Research Ethics Committees in Canada rely, does not consider dying individuals to be a vulnerable population per se. It is when there are questions of mental competence with any group of people that concerns of vulnerability arise. In addition, I strongly support the position of Mount and colleagues (Mount, Cohen, MacDonald, Bruera, & Dudgeon, 1995) who point out that people with palliative care needs are not a homogeneous dying group. Labeling individuals as vulnerable simply because they are dying is disrespectful of their individuality and is paternalistic (Berry, 2004; Mount et al, 1995).

Much of the weight of the debate in the literature addressing vulnerability is closely linked to discussions regarding informed consent, which will be discussed later, since an individual is vulnerable to harm if they are unable to give informed consent and participate in a study (Duke and Bennett, 2009). Because of the nature of this study, participants who were recruited had to be assessed by the supportive care team as mentally capable of participating in a conversation about their lived experience. As such, potential participants were mentally competent and cognitively intact, thereby addressing the often mentioned concern related to dying individuals recruited into research (Kristjanson, Hanson & Balneaves, 1994; Roy & MacDonald, 1998).

Moral justification. Karlawish (2003) refers to a balance between risks and benefits and describes several issues which need to be satisfied in order to reach a balance which then makes the research study morally justified. One of these is to question whether or not the research itself can be justified as being necessary. As discussed in earlier chapters, there is a paucity of literature which explores the experience of patients transitioning from acute to palliative care within a hospital context. Although the goal of this inquiry is not to establish guidelines, nor to uncover the one universal truth which this experience represents, it is meant to create new knowledge and gain a deeper understanding of what this phenomenon can represent for people so that health care providers can provide more appropriate quality care. There is no other way to gain this insight; interviewing other individuals, such as health care professionals or family members would not be addressing the question being posed.

The second issue that Karlawish (2003) addresses is the definition and assessment of risk. The usual accepted definition is that of minimal risk: that individuals should not be exposed to harm or discomfort which is greater than what they would have been exposed to had they not been part of the study. In this study, I identified several potential risks and took step to ensure that they were avoided or addressed. The first foreseeable risk was that participants would experience emotional distress while talking about their current situation, their illness and their impending death. Another foreseeable risk was that participants would find their participation in this inquiry physically taxing. For this reason, as the researcher I was responsible for ensuring that when participants were visibly tiring or becoming weak, they were offered the opportunity to rest or stop the interview, as opposed to simply waiting for the participant to make this request themselves. In some cases the participants did in fact state that they wanted to stop our conversation after I verbalized this suggestion. In other instances however, the participants clearly stated that they wanted to continue, despite appearing tired and, in one case, vomiting during the interview.

Informed consent. Informed consent is based upon the ethical principle of autonomy and an individual's right to both self-determination and privacy (Raudonis, 1992). It depends upon a person being given enough information to be able to decide for themselves if participating in a given research study is the right decision for them, in part by weighing the risks and benefits.

My recruitment strategy for this study included having the palliative care professional who knew the patient best asking potential participants if they would be interested in learning more about the study. These health care professionals were aware that the study would involve the collection of data via interview and were asked not to refer any individuals whom they knew to be cognitively impaired. It was at this point that I met with interested patients to explain the study, including issues related to potential risks and benefits, voluntariness and confidentiality. Following a thorough explanation of the study, including an opportunity for them to ask any questions, the patients were free to decide whether or not they wanted to participate.

Confidentiality. As described in the consent form, the identities of participants have been kept strictly confidential; upon recruitment all participants were assigned a study identification number. This identification number is the only way in which data could be referred back to any participant. I did have a master list which included the list of patient unit numbers (found on the patient's hospital card), their names and study identification numbers. This master list was kept separate from where data was kept and was in a locked and secure cabinet. This data has since been anonymized since data collection is completed.

Potential participants were made aware that the interpretive team (namely my research supervisor and / or a member of my thesis committee) could hear a recording of our interview or read transcripts of the interview. In addition, the consent form was clear that some staff members (of the acute care and palliative care units) would potentially know that the patient had been recruited into the study. Although the details of the study were not made explicit to the unit staff, they may have deduced that the patient was participating in a study by virtue of the fact that I was interviewing them. However, participants were assured that in presentations and reports care would always be taken to present the results in such a way that individual patients could not be identified by the staff that cared for them. To this end, certain participant characteristics have been modified within this thesis in order to help prevent identification of participants via their stories. Care was taken however to make changes which did not alter the essence of who these people were.

All data collected, including interview transcripts and field notes has been kept in a locked cabinet, in a locked office, under my supervision. Electronic versions of data and notes have been kept on password protected computers and individual electronic files are also password protected, ensuring that there is a double layer of protection on all data and identifiable information. A copy of all data and analysis memos has been kept in a secure, locked location off-site in an electronic format. This off-site location is my locked home office, where there is a password protected computer to which only I have access, as well as a locked filing cabinet. The reasons for an off-site location are two-fold; first, to add an additional level of security should anything happen to the original data and second, because I was conducting some of my data analysis from my home office. This data was coded and there was no way to identify which participant the data referred to. This data will be kept for a period of five years after study completion.

The potential complications related to my dual role as researcher and head nurse of the palliative care unit were not to be ignored. Although the interviews were conducted to gain a better understanding of the experience of dying patients waiting to be transferred to the palliative care unit for end of life care and not to gain a commentary on the quality of care received, it was expected that during these conversations participants could share information about staff. This information was considered as research data that informed my understanding and interpretations of the phenomenon in question. In no way did the information gained from interviews about staff affect either staff evaluations or lead to disciplinary actions. Furthermore, I did not specifically ask participants for commentary on the way that the staff behaved. As added assurance, I informed participants that if they were going to refer to a staff member they should try to avoid using their name.

Prior to the start of this inquiry, aspects of this study and specific ethical concerns and questions (particularly as they related to my role as the head nurse of palliative care) had been discussed informally with both the Chair of the Research Ethics Committee and the Coordinator of the Research Ethics Office of the institution in which this study took place. The Chair of the Research Ethics Committee at that time was also the clinical ethicist in the hospital. Furthermore, as I was employed by the institution during the conduct of this study, feasibility issues were discussed with the Director of Nursing, who asserted that there would be strong support systems and resources in place in order to make the process of data collection feasible.

The right to participate in research. The issue of an individual's right to participate in a research study relates to the notion of gate-keeping, in which family members or health care professionals act as intermediaries between the researcher and the potential cognitively intact participant. This is a phenomenon often seen in palliative care research, where others decide for the patient what is in the latter's best interest, often without consulting them (Hudson, Aranda, Kristjanson & Quinn, 2005).

In this inquiry, the palliative care team which was identifying potential participants for me was very supportive of this project and saw the value of it. As well, because they have known me as a clinician and administrator for several years, I believe that they felt secure that I would not cause any undue harm or distress to the patients. Once the patient agreed to meet with me, I arranged to meet directly with them, avoiding having to discuss the project with family members first, although in several cases, the family was there as I was explaining the study. By communicating directly with the patients, they were given the opportunity to decide for themselves whether or not they wanted to participate.

A quality research environment. Of the papers reviewed by Duke and Bennett (2010), a small number raised the issue of the influence of the research environment on the quality of research. In particular they found some debate related to the dignity, safety and well being of researchers in general (Johnson & Macleod Clark, 2003) and in researchers engaging with the seriously ill more specifically (Clark, Ingleton & Seymour, 2000). The concern raised for palliative care researchers was that an exposure to suffering could jeopardize the well-being of the researcher. Consequently, there is a need for support and supervision for the researcher (Clark et al, 2000).

I was fortunate to be surrounded by a very supportive supervisor and thesis committee. In addition, I had the added benefit of having worked closely with dying individuals for several years. As a result of my over 12 years of experience working in palliative care I have established very strong support systems and effective coping strategies to deal with the difficulties inherent in working with those who are imminently dying. This allowed me to engage with the participants and with the data in a very intimate way, while at the same time, not putting myself at risk for emotional difficulties, which would, amongst other things, compromise the inquiry.

Approach to Analysis

In this inquiry, I explored the meanings which were uncovered from the accounts of participants living within the space of waiting for a transfer from an acute care setting to a palliative care unit within the same institution. Meaning was understood as something constructed by the world while at the same time, this world is being constructed by individual backgrounds and experiences. There is a transaction between the individual and the world as they constitute, and are constituted by, each other (Munhall, 1989).

A participant's experience was not considered to be an isolated experience which had meaning in and of itself, nor was it considered to be the culmination of a series of sequential events in the participant's life. Instead, this experience of waiting to be transferred to palliative care was regarded as part of a temporally unified whole that continued to shape and be shaped by the participant's *thrownness* and *situatedness*. Heidegger (1962) describes our Being-in-the-world, or Dasein, as a *thrown projection*, projecting itself onto the possibilities that lie before it or which may be hidden, and interpreting and understanding the world in terms of possibilities. To be human is to be both free and spontaneous, while at the same time being limited and constrained, and finite (Heidegger, 1962; Withy, 2011). For Heidegger, these ideas are at the heart of our sense-making. Heidegger goes on further to state that human beings are thrown into situations without prior knowledge or individual option, into a world that was there before and will remain there after they are gone (Heidegger, 1962). As Withy (2011) further elaborates, all of our understanding is essentially situated, and therefore limited by the context and tradition into which it is thrown. Our sense-making is always limited by the things which are made available to be made sense of, and of the particular ways of making sense of them that are available to us. For Withy (2011), this understanding takes Heidegger's notion of *throwness* and *thrown projection* to amount to what she refers to as *situatedness.*

These concepts of *thrownness* and *situatedness* helped frame the structure of the analysis which follows. As human beings, naturally inclined to make sense of things, we are born and thrown into particular situations in which we then find meaning. To be thrown is to have a starting point, somewhere we are located (Heidegger, 1962; Withy, 2011). Likewise, because of our circumstances, we are insulated from other circumstances and contexts. This situatedness can be specified at different levels or scopes, depending upon how broadly or how narrowly we characterize the situation into which we are thrown (Withy, 2011). Within this inquiry I considered that meanings associated with the lived experience of dying for patients waiting to be transferred to a palliative care unit were informed by a lifetime of previous experiences and ways of Being-in-the-world.

Heidegger states that pre-understanding is a structure for Being-in-the-world and states that nothing can be encountered without referring to a one's own background understanding (Heidegger, 1962). The situatedness of the participants in this inquiry, integral to their lived experience of dying as they waited to be transferred from acute care to palliative care, was considered at three different levels, as articulated by Withy (2011). The decision to present the analysis using Withy's (2011) articulated levels was not made a priori to data analysis. It was made during the process of developing and uncovering the interpretations which follow in this chapter. As the themes were identified, Withy's (2011) three levels served the purpose of having the central ideas presented and organized in a way which reflected my interpretations of the data and the phenomenological spirit.

I first acknowledged that all participants were situated within a particular contextual background which gave them specific ways of making sense of events in their lives and implied that phenomena either were, or were not, available to be made sense of. In this thesis I consider that one's contextual background, in part, furnishes the beliefs and values that give individuals a sense of identity (Cortis, 2003). Secondly, I noted the situatedness of each individual participant's particular life; in other words, how their unique and personalized previous life experiences influenced how they made sense of what they were currently experiencing. Lastly, I considered the situatedness of the "here and now", or what was present in the moment.

These three levels of situatedness tie in to Heidegger's notion of *historicality* (1962). Historicality is represented by a person's history or background and includes what is given to a person from birth and what is handed down from others, which then presents ways of understanding the world (Koch, 1995). All understanding, including that of the researcher, is connected to a given set of fore-structures of understanding, including one's historicality, which cannot be eliminated. As a result one needs to become as aware as possible of these pre-understandings and subsequently account for these interpretive influences (Heidegger, 1962). It is important to be reminded here that the interpretive work being done throughout this analysis was done by me, the researcher. The words spoken by the participants, the observations made and noted, were all interpreted through the lens of my own pre-understanding. The analysis which follows is but one possible account of the meanings embedded within the words of the participants. As already described earlier in this chapter, great care was taken to understand how my interpretive lens was influenced by my own preconceived ideas and what I expected I would uncover.

As I sought to explore and uncover the intricate meanings embedded within the conversations of the participants, I engaged in an act of interpretation which was influenced and shaped by the ideas of Heidegger (1962), Benner (1994) and Taylor (1985). Heidegger states that interpretation is grounded existentially in understanding and that meaning, in the ontological-existential sense, does not belong to someone or something, but becomes "intelligible as something" (Heidegger, 1962, p. 124). This idea is consistent with Taylor who says that interpretation is "an attempt to make clear, or make sense of, an object of study" (Taylor, 1985, p. 15). For Benner (1994), interpretive phenomenology necessitates a dwelling in a particular situation which then leads to questioning and comparing; it is in this way that meaning is created. Furthermore my ensuing interpretations are presented in the context of themes and sub-themes, thereby building upon the methodological ideas of Benner (1994). These themes and sub-themes represent patterns of commonalities and differences found within and between participants.

Additionally, I have identified "salient excerpts" which are meant to "characterize specific common themes or meanings across informants" (Christ & Tanner, 2003, p. 204). The use of direct quotes is meant to give the reader access to portions of the text in its own terms, a glimpse into the voices of the participants, a technique advised by Benner (1994). This exercise of identifying themes and then commenting on texts within themes, allowed me to better understand both the consistencies and incongruities which emerged from the worlds of the participants in this inquiry (Thibeault, 2010).

Summary of Methodological Considerations

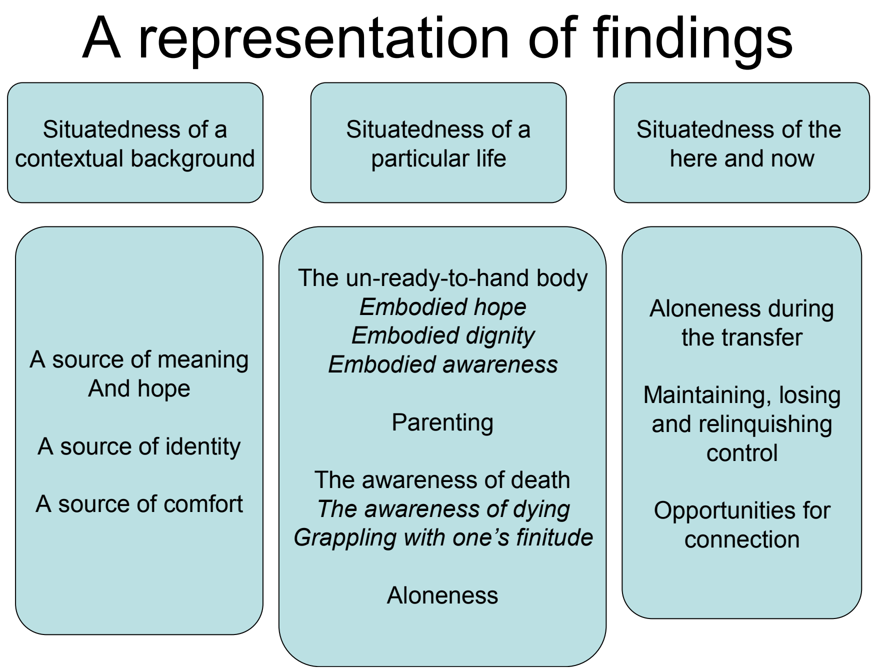
In this chapter I have outlined interpretive phenomenology as the methodology of choice to answer the question: *What is the lived experience of dying for hospitalized patients who are waiting to be transferred to a palliative care unit for end of life care?* I described my motivations and rationale for exploring the lived experience of dying from the patient perspective and made explicit my relativist ontological and constructivist epistemological orientations. I further suggested that such an approach to research requires a philosophical foundation, and have thus presented Heideggerian philosophy, particularly as it relates to Dasein, or Being-in-the-world. I shared with the reader the steps which were taken in operationalizing this inquiry, including describing the study setting, recruitment strategies, and modes of data analysis and the development of interpretations. In Chapter 4 the results of this data analysis and interpretation are presented.

Chapter 4: Results

In this inquiry I sought to understand that which dying individuals disclosed at a time when they were waiting to be transferred from an acute care unit to a palliative care ward for end of life care. I explored their lived experience and uncovered meanings which were implied in what they shared.

The pattern of themes uncovered in this inquiry is represented in Figure 1. The situatedness of a contextual background, of a particular life and of the 'here and now' are all equally valuable in helping to uncover the meaning of the dying experience for participants in this inquiry. In addition, by exploring each theme we note that there is overlap amongst these levels of situatedness and a realization that they are neither mutually exclusive, nor independent of one another.

Figure 1. A representation of the findings



I consider how each participant was situated within their contextual background and how this impacted the understanding of their experience. Individuals are born into particular contexts which may include, amongst other things, spiritual traditions and religious and secular worlds. These are subject to change and can have an important influence on how issues related to living and dying are experienced and understood. The situatedness of each individual's particular life takes into account their unique histories, experiences, strengths and limitations, within the larger contextual background. Within this framework I share the story of who these participants were, in an attempt to uncover the ways in which who they were influenced how they were. I explore how their individual lives shaped their lived experience of dying as they waited for a transfer from an acute care ward to a palliative care unit for end of life care and what meanings they ascribed to this experience. Both the contextual background and the situatedness of each particular life are a combined set of pre-understandings which are influential in considering the participants' situatedness of the 'here and now', or the present moment. While exploring the situatedness of the 'here and now', I describe how participants in this inquiry integrated what they were currently experiencing into their unfolding life story.

Situatedness of a Contextual Background

When we are born, we are thrown into a particular context. This occurs immediately, is unavoidable and is beyond our control; it is the essence of the world into which we are born. With time however our context, and as a result the identities that were formed based upon this contextual background, may change. Sometimes this change is beyond our control and in other instances it is precipitated by choices that we make. The themes of religion and spirituality as they relate to the situatedness of one's contextual background are explored in the analysis which follows because it is these concepts which appeared to be providing meaning and hope to participants, as well as being a source of identity and comfort.

Spirituality can be broadly defined as that which gives meaning and purpose in life whereas religion is one expression of spirituality (Puchalski, Dorff, & Hendi 2004). Religion is typically an easier phenomenon to conceptualize compared to spirituality. In many ways religion is more tangible, with concrete evidence and symbols of religiosity accessible and easily recognized, if not understood, by most. Spirituality, on the other hand, is a less clear and less certain phenomenon. Within this inquiry I explored the notions of religion and spirituality as discussed and presented by the participants.

Participants very easily identified themselves with particular religious beliefs, or non-beliefs, and with religious groups. They shared how their religion and spirituality brought them to a deeper understanding of their lives in general and how religion and spirituality influenced the meanings that were uncovered both before and during their illness. Discussions related to religion and spirituality were typically initiated by the participants themselves. Religion was a subject which was broached, to varying degrees, by almost all participants. At times it was simply to state that they were not religious, like Alan, who was raised in a religious Jewish household but who was not practicing. On other occasions it was to share how important religion was in their lives, like Myriam whose religion was incredibly important in shaping the meaning of her lived experience. Several individuals very eloquently and clearly described their religious discontent while others expressed the comfort provided by strong religious convictions. Other participants shared how religion and spirituality became important to them as they were seeking answers to existential questions related to their own finitude. Others were clear in their criticism of, and rebellion against, any form of organized religion, but at the same time found comfort in a strong sense of spirituality as they were approaching their death.

A source of hope and meaning. Blanche, a devout Catholic her entire life, worked for close to 40 years in the office of a church. She was born in a small town in Quebec, where everyone she knew was Catholic. Upon moving to Montreal as a young woman she initially found the diversity of beliefs and the diversity in religions into which she was thrown to be quite unsettling. Ultimately, however, she found this heterogeneity educational. She said, "This helped me a lot, brought me a lot with regards to culture, music, art and all of that. So, I was one of the fortunate ones of the era."

In situations where the participant was very religious, their beliefs not only brought them comfort, but also helped them to understand the world around them. Blanche ascribed the fact that she had a happy life to God. "With my husband, we were very happy. We were never apart, a beautiful life. God gave me a chance to be happy and He kept me in his arms."

In speaking about her death Blanche shared that her religion not only brought her great comfort ("[People are] always asking me if I am worried. I say no, because I had a very solid place in my religion") and hope, but she also assumed that her religion was allowing her the independence to make choices which would traditionally not be supported by mainstream Catholicism and Christianity. Blanche reframed basic religious tenets in order to have them to fit in with what she desired. In this way she relied on her religion to support her.

> Regarding my death, I am a believer. I am of the Christian faith, and I am expecting that Jesus will be waiting for me with absolution and this gives me support. I know that there are magnificent things that will be there, waiting for me, and because of that, I have a lot of hope. In being ill, my religion has let me be, because it is now that I need, I need to feel that the end is near, and that, since I have put it in my agenda since the time that I was operated on, because that was what would happen. (Blanche)

Contrary to Blanche who was a self-described devout Catholic, Myriam described herself in more liberal terms, as "inter-faith, but the Roman Catholic is my religion." Myriam was able to extend her religious dialogue, and described how her spirituality and belief system helped to shape her understanding of her world. During our first meeting, I asked Myriam about the idea of transition, and whether or not she felt that it was a good word to describe her current phase in life. She replied:

> It is! It is a very good word….transition. It is traveling, and I have already crossed the street, you know, you travel at night…that's why you "transit"…because you are moving and as you transit at night you see the beauty of nature, you see God is in nature everywhere. You tell, how beautiful, how beautiful, and then when you cross, you cross with that beauty, it's a marvel, a marvel, magnificent. It's only yesterday I stopped, last night, not even yesterday, it was last night, sort of stop, stop and I felt, why am I stopping? You just want to continue, the road is so beautiful, everything is fall, colors, that's the beauty of it. You don't see it only in one pattern, you see it in different colors, different forms, different beauty. The world makes the beauty, the

> life, the transition. So don't let, this is how I see it, I don't know how other people see it…so…so I will not question what other people see. I know what I see. (Myriam)

This sense of spirituality or religion, a power greater than individuals, was evident when Myriam described how she felt when she learned of her diagnosis of uterine sarcoma. She said "I didn't feel any shock. I just felt he (the doctor) failed me. But at the same time I felt that, that was what was written for me. That's how I was going to carry it."

For Eloise, religion and spirituality became important in her life as a result of her illness. She grappled with trying to understand some of what was happening around her and what would happen after her death. She was struggling with uncertainty and was searching for answers, and one of the places where she sought these answers was in religion. Eloise spoke about the new significance that religion had in her life as a result of her cancer.

> It's funny. I told you that my husband is not religious. Well, neither am I. I never have been a church-going, God-fearing person – at least not until I got sick. When I was diagnosed, I started praying – never telling my husband. I did it in secret, like I was having an affair with God (laughs). It is hypocritical I know – but I thought, what if? What if this makes a difference? How can I not try? (pause) And actually, it made a bit of a difference. I was happy to give something over to something bigger than me, bigger than the doctors, bigger than the universe. I felt protected. (pause – slight laughter as she moves her hands around the room) Mind you – it doesn't seem to have made a difference. (Eloise)

Similar to Myriam, we see that Eloise took comfort in being able to, as she put it, "give something over" to religion or God. Both women relinquished their need to control their situation and doing so appeared to provide them with some comfort and peace. What I also understood from Eloise's story was that despite the comfort that she found in praying, this had become something that she did alone, and which she felt the need to hide from her husband, worried about how he would react. I asked Eloise if she continued to pray, despite the fact that it had not helped cure her cancer. She said that she did still pray and that she had come to believe in Heaven.

> When I find it hard to breathe…when I start to panic, I close my eyes and imagine my Heaven. I am a good person, so I'm pretty sure I would go there. It is beautiful and magical, and there I can always still be with my daughter. I can see her, and she can sense me. She won't forget me. I'll be there somehow for her when she needs me. (Eloise)

Although Eloise began crying when she spoke these words, I understood that this way of thinking was helping her to incorporate the reality of her imminent death into her life in a way which was less threatening than it otherwise would have been. Eloise's belief in Heaven offered her hope that she could still, in some way, be connected to her daughter after her death. I asked Eloise if she had spoken to her young daughter about the Heaven which she had come to believe in, and where she felt she would be going to after her death. Although she had begun to weep, she was able to respond.

> I told her. She asked questions like "How do you really know?", "What if you're wrong?" I told her that I felt in my heart that this was true - and that she would just have to listen for signs of me (Eloise).

Eloise had developed the ability to respond to questions posed to her by her daughter about her new found beliefs and all that they implied. Her new beliefs served an existential and practical purpose. It was too difficult for Eloise to imagine that her death would cause a rupture in her relationship with her daughter and in her role as mother. Her heartfelt belief in Heaven and the hope for a continued connection with her daughter brought her a sense of peace and allowed her to find some meaning as she grappled with the fact that she would be dying and leaving her family behind.

Lillian shared similarities with both Blanche and Eloise. She was a Scottish woman who had grown up in a devout Catholic family, and, like Blanche, she referred to herself as someone who was very religious. However, despite her religiosity, like Eloise she had never really thought about death or Heaven, until she got ill. Prior to her illness, Lillian thought of Heaven in a very superficial way; as a nice place to go to after death. Since her diagnosis however, Lillian [13] found herself imagining what Heaven was actually like, what happened there, who she would be seeing. She called this wondering "a distraction", and that it was this sort of distraction which brought her the most peace. By engaging in this sort of distraction, Lillian said that she felt she was a little girl again, imagining "a place of magic and beauty where I will see my mother, my father and my husband again." Immediately after sharing this, Lillian informed me that she did not want to discuss Heaven with me anymore. When I asked her if I had done anything to upset her she replied that I had not, but that she did not want to have a discussion with anyone where her beliefs could potentially be challenged or called into question, because they were offering her so much support. I imagine that Lillian was still struggling with what she believed in and it was in

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[13] The audio-recording of Lillian's interview was damaged and, as a result, it was impossible to transcribe the interview. This was discovered within an hour after the interview ended. I immediately proceeded to write detailed notes about our conversation, complemented by some of the notes that I had taken during the actual interview. Any quotes ascribed to Lillian within the body of this inquiry are direct quotes in that they were phrases which she spoke and which I wrote down either from memory, or during our actual interview.

the context of this ambivalence that Lillian felt uncomfortable sharing what she was hoping for. As in the story of Eloise, Lillian had developed an idea of Heaven which was imbued with meaning. This meaning was extremely comforting for her and it offered her the opportunity to hope for something positive following her death. Although she had willingly shared her thoughts with me, she was in a way controlling my reaction and response to them because, I imagined, she did not feel secure enough in this newfound meaning to have it challenged.

A source of identity. There were participants who described themselves as religious, but for whom religion played a less significant role. Sabrina was an Italian Catholic, married to a man whom she also described as Catholic and religious. When I first met Sabrina she said, "Me, belief…I have always believed that there is a supreme being." At the time that I met Sabrina, her husband was undergoing treatment for cancer. Although Sabrina found some comfort in her beliefs she did not necessarily find answers in her religion. She spoke about how she was surprised when she discovered several years ago that she had breast cancer, and was even more surprised when she kept having recurrences. She described herself as someone in good health, who did not engage in bad lifestyle choices. She did not feel that religion helped her to accept what was, in her eyes, unacceptable. At the same time, she did not express any anger towards God or her faith for allowing her to be ill.

Similarly, Alan, a man born in the Jewish faith and raised in a religious household, was married to a woman of another faith. Alan had chosen not to practice any religion for most of his adult life. Interestingly, however, at the beginning of our initial conversation, I asked Alan to tell me a bit about himself, including anything that he might find important to share.

> Important? I'm not sure what is important but I will tell you that I am 62 years old. I …uh…I am Jewish but married to a woman who is not, so I'm not really all that Jewish. And…uh…what else? Ummmm….I don't know. I'm a business man. I am in the furniture business. (Alan)

What I found particularly meaningful about Alan's response is that even without any prompting, when presented with the opportunity to share anything about who he was, Alan chose to begin with who he was not (i.e. a religious man). I understood this to be an example of the pervasive influence that being thrown into a contextual background which includes religion has on an individual throughout their life, despite the fact that they choose to live in a different religious context, or in Alan's case, a secular world.

There were, as well, other participants for whom religion was simply absent, a non-entity. Mark and Karine did not define themselves by or identify with a religion or spirituality. Thomas, an 81 year old Chinese Canadian described his religiosity in the following manner:

> Thomas: Actually I don't have any religion. Chinese people, they are mainly Buddhist.
>
> Vasiliki: Yes, but do you follow…
>
> Thomas: Yeah, when I was young I go to church every week, and go there to sleep, so you can keep that one (laughing)

Like Alan, Javier too described himself in terms of who he was not with regards to religion. Javier was a 62 year old Chilean man who, as a young adult, had survived the Chilean revolution. When I asked him early on in our conversation to share a little bit about who he was he replied, "Well, I am 62 years old and I have no religion. I am not a believer. I come from Chile." As an adolescent in Chile, his dream had been to become a priest. Javier shared that at the age of 15, he changed his mind. I asked if he could explain what it was that had him change his plan. Javier explained:

> Nothing specific. No, I just didn't believe, that is all. I was in school. I was learning philosophy, culture, Marx, Lenin. This is more real than believing that there is a paradise after death. After death, we are dead. There is nothing that happens after that. (Javier)

Javier shared his beliefs very matter-of-factly, with no apparent regret and no longing. What is uncovered in the stories of both Thomas and Javier is that religion and spirituality, although not a source of meaning or great significance in their lives, shaped who they were as individuals by their mere absence. At this point in their lives, they were not turning to religion for solace and comfort, but they did refer to the role that religion used to play in their lives.

A source of comfort. Claude offered a very different perspective within this inquiry. Although raised in a Catholic family, he too, like Javier, renounced religion once he became more interested and educated in both philosophy and politics. Both men seemed to believe that education and religious beliefs where incommensurate. When I asked Claude if he was religious he answered, "I was, but that is lost." Claude not only believed that educated individuals could not ascribe to any religion, but he was, as well, very angry at religion. He was resentful of the fact that people put blind faith in religion and expected it to be the answer to the problems in the world. He appeared to consider this sort of approach complacency and an excuse for individuals not to take ownership of their own problems and the problems of the world around them. More importantly, I interpreted Claude's serious resentment of religion to be the result of the fact that he felt religion had a certain responsibility to the public, in light of its often powerful position in society, and that religious leaders had not taken that responsibility seriously nor had they dealt with it adequately. As a self-described revolutionary, Claude explained:

> Demographically, people no longer have work, people are suffering. Religion did not declare that the riches of the world are the property of all. They belong to the minority, the religious and the political. And so, this created a great need in the population. You have before you a field with a tree. On one side of the tree you see something revolutionary. On the other side, a gargoyle. A monster. (Claude)

I understood the monster that Claude described to be symbolic of religious organizations.

Claude's willingness to speak openly and his willingness to share his opinions allowed me to explore with him what his thoughts were regarding the fact that, for certain individuals, religion became extremely important as they approached death, often more important than it had ever been when they were well. In response to this Claude said, "I think that this is an illusion. With everything that I have just said, if you still believe, or if people still believe, I feel I would never walk in their shoes. They are not my shoes." I offered that perhaps this is what brings people comfort and he replied, "What brings me comfort is to have arrived at a rational reflection. That the world is…that God does not exist."

Despite his anger towards the church, his criticism of religion and his cynicism about those who rely on religion for answers, peace and hope, what brought Claude the most comfort during the time that I met him was his belief that the woman who raised him, Rose, who had died several years previously, was still watching over him. One could argue that his belief that his dead mother figure was watching over him and offering protection and guidance was fundamentally religious in nature. However, I interpreted that Claude made the distinction between organized religion and religious belief and a more secular form of spirituality. He was able to internalize both seemingly polar opposite opinions and beliefs because, for him, they were unrelated and one did not pose any challenges to the other. Claude's account is an example of the divide which can exist between religion and spirituality, and how the two do not necessarily go hand in hand. Claude's attempt to gain a practical understanding of his world still made room for spiritual considerations and implications.

Claude attributed many of the positive events in his life to Rose's watchful protection. She was, in some ways, in control of his fate and well-being. Although Rose had died several years ago, Claude said that he had never stopped thinking about her, and so, his impending death did not make him think about her more. He felt strongly that she was the one who was helping him to prepare for his death. As a result, he denied being sad or scared, and spoke about the journey which he took in his reflection; a journey that he referred to as a spiritual process.

> She (*Rose*) is the one preparing me. What happens after death…no one returns. There are churches that speak of this. For me, there is no place. The sky is on the earth. It is not in the future. It is a grave error, a grave error of belief that religion, religions, replace reason. Marx stated that religion was opium. (Claude)

Along with helping to prepare him for his death, Claude credited Rose with the reunion that he had recently experienced with his son, from whom he had been estranged for 22 years. He shared that this reconciliation had happened a month prior to our meeting and crying, he said, "This, this is the work of Rose…of that I am sure." (Claude) Because he was not a religious man, Claude did not believe that he had relinquished control to God, the way that Eloise and Myriam had. Instead, I understood that Claude believed he had the fortune of having Rose take control, and care, of him and his dying.

Summary. The idea of being situated with a contextual background which helps give meaning to your experiences can encompass many facets of Being-in-the-world. For the participants in this inquiry, the theme which resonated amongst almost all of them was the influence and impact of religiosity, secularism and spirituality on hope, meaning, self identity and comfort in relation to their lived experience of dying. The participants in this inquiry represented a diverse range of beliefs. For those participants who were currently neither religious nor spiritual, their past situatedness within a context of religion and spirituality still had a role in shaping how they understood their current world. Other participants, like Blanche and Myriam, found that religion offered them hope and created meaning for their lives. Interestingly, although religious beliefs and spirituality could be sources of comfort, in some cases they fostered aloneness. Eloise was unable to share her reliance on prayer with her husband and Lillian was unwilling to share too much of her beliefs in Heaven with me, for fear that what she felt to be true would be challenged. Some of the comfort which was found in religion was related to the fact that participants felt that they could relinquish control over their circumstances, that something else, bigger than them, was dictating the way in which their lives would unfold. In all cases, religion and spirituality, in their simplest incarnation and their most complex manifestations were an important backdrop upon which to build further meaning and understanding.

The inherent mystery of life often triggers religious and spiritual questions and experiences for many people. As we can see from the analysis presented thus far, the participants in this inquiry who were waiting to be transferred to the palliative care unit for end of life care were finding meaning in their dying experience in part through their contextual backgrounds of spirituality and religion.

Situatedness of a Particular Life

Individuals are situated within a particular life, which is how we each find ourselves dealing with certain situations, and facing specific challenges. As Withy (2011) states, "In having a particular life, I have a definite history, a definite body and gender, a particular set of values and preferences, a specific personality, and so on" (p. 4). As such, finding meaning in things always takes place within the context of a particular life, and this determines not only what there is to make sense of, but also how this can be done. Each of the participants in this inquiry owned their own unique story, which was continuing to unfold. They graciously shared with me intimate and important details about their lives, details which shaped who they were as individuals. It was within this framework of appreciating the uniqueness of each individual participant that we can move towards understanding and finding meaning in their experiences.

Individuals' lives are filled with events, experiences, pre-understandings and pre-conceptions. In the previous section I illustrated how religion and spirituality, impacted by past events and experiences, helped form pre-understandings and allowed for the uncovering of identity and meaning, the fostering of hope, and the provision of comfort. In this section I will present what is known about the individual participants by exploring the stories which led to the awareness of illness, how they engaged with those closest to them and how they developed an awareness of death in general, and their own finitude in particular.

The un-ready-to-hand body. An individual's embodied interaction with its world, in its state of physical limitations due to a deteriorating and weakened condition is akin to Heidegger's analysis of the breakdown of *ready-to-hand* equipment and the subsequent revelation of the world through the phenomenon of the *un-ready-to-hand* (Heidegger, 1962). Just as when a tool or a piece of machinery functions properly and as it should, its authentic *readiness-to-hand* remains inconspicuous and unnoticed; it is only at the moment of breakdown that this tool's interaction with the world becomes obvious. Similarly, for the participants in this study, the awareness of their illness and their embodied interaction with their world became obvious only when their bodies displayed signs of breaking down, or of not being able to engage in the world the way that they used to.

Embodied hope. For Thomas, his *potentiality-for-Being*, that is, his striving to be more than what he was in the moment, meant that he was able to maintain the hope that he would one day regain his appetite in order to regain his strength thereby ensuring a better quality of life and better health. "When I lost my appetite, I actually, my strength is from there". When he mentioned the symptoms which brought him into hospital, Thomas related them back to his loss of appetite. This loss of appetite was a tangible indication that things were worsening. He strongly believed that with an improved appetite, he would be able to ensure that he ate enough healthy food to fight off future infections and challenges to his body, and to resist future health problems.

Thomas believed that a significant loss of weight indicated that his health was deteriorating and that death was near. “If a guy does not eat, how can he live?” His lack of appetite and inability to eat also appeared to represent a change in his relationship with others. He spoke with longing and some frustration about the fact that he had a friend with whom, for years, he shared meals on a weekly basis. They would use this time to catch up and socialize with one another. For Thomas, an important part of average everydayness was represented by his previous ability to engage in this social activity with his friend. His inability to eat was an isolating experience.

When Thomas first began to experience significant weight loss he was able to feel his tumor pressing against his ribcage and was convinced that he could feel it growing. Although he was vocal while speaking to me that he did not want to know many of the details related to his illness and the progression of his disease, it was difficult for him to ignore when the evidence of illness was so present. He was compelled to wonder what the changes in his body meant when they were so pronounced. At the time of our second interview, when he was transferred to the palliative care unit, Thomas felt like he was losing even more of his strength. He described a numbness in his leg, and alluded to the fact that one can reach a point where they would rather be dead, than live in such a weakened and debilitated state. I interpreted Thomas’ focus on the physical changes in his body to be his way of trying to communicate with me that he was dying, without actually having to say the words.

Myriam, a 60 year old Haitian woman dying of uterine sarcoma, was also very preoccupied with eating and with food. When we first met on an acute care ward, I asked what she hoped for. She laughed and said that she was extremely hungry. She spoke about her desire to eat and her need to address her hunger, while at the same time speaking about finding peace. Her cancer had resulted in Myriam having a partial bowel obstruction, a blockage of her gastro-intestinal tract, which resulted in nausea and vomiting, particularly after she ate. As a result, the treating team on the acute unit she was hospitalized on had advised her not to eat, in order to avoid these symptoms, and to prevent further complications.

Myriam had agreed to follow these recommendations but she expressed concern that her physical symptoms were likely not going to be addressed while she was on the acute care ward. When asked about her experiences with her hospitalization so far, Myriam said “This morning I nearly suffocated because I vomited and we called and called. If I don’t have somebody to be with me all around the clock…that’s it…you’re done.”

When she was transferred to the palliative care unit, Myriam was most pleased that she was finally able to eat. Following a medical exam, some adjustments to her medications, and a discussion about what would improve her quality of life, her palliative care physician told her that she could eat if she wanted to, but to keep the portions small. She explained, “Yesterday, for the first time, my friend cooked and I was able to eat what was cooked and that was, it was a mystery.” Myriam went on to share the meaning that her ability to eat this food had for her and the joy that it brought not only to her, but also to her friend. “And she (the friend) was so happy that I was able to eat that she cried because she attempted it before but I was not able to do it….but this time I was able to do it”.

Through the stories of Thomas and Myriam we can appreciate that hope is an embodied experience. The way that they lived with the changing nature of their bodies as their illness progressed was linked to the hope that they had, whether it was the hope to eat as was the case with Myriam or Thomas' hope to regain his appetite in order to be stronger. Thomas' loss of appetite most seriously affected both his quality of life and his understanding that he was, in fact, quite seriously ill. In Myriam's story we come to understand the importance of food in her social life. It becomes clear that her inability to eat had been both a sign of worsening illness and of less than optimal care. Furthermore, an inability to engage in an everyday, social activity such as eating, either because of a lack of appetite or because of a physiological cause which made eating inadvisable, was an isolating experience, as sharing meals with friends and loved ones had been such an important part of their social lives.

Embodied dignity. In this section I demonstrate that the notion of dignity was very closely linked to how the participants in this inquiry lived and interacted with the world around them, in ways that were often times changed due to their illness. For many individuals, their bodies had changed, and the ability of their bodies to function in ways that they had been accustomed to had disappeared. This had a significant impact on how they were experiencing the phenomenon of dying as they waited to be transferred to the palliative care unit.

Perhaps the clearest account of how an unfamiliar body impacts one's Being-in-the world came from Alan as he described his dependence on others to care for him because he was so weak that he needed help for his most basic bodily functions. After taking a break during our conversation to rest and replace his nasal prong oxygen supply with a mask which delivered more oxygen, he stated "You take the simple things for granted. Like breathing and going to the bathroom". He then went on to elaborate,

> Yeah, until it starts to become a problem. I had never thought about my bowel movements before this. Now, I know more than I want to know about laxatives and constipation and hemorrhoids, and legs that don't work so you have to do it in the diaper (crying). That may be the hardest part. (Alan)

For Alan, one of the most difficult things to cope with was the fact that he was struggling to maintain control over his bodily functions; he was finding himself incapable of doing so. He described his incontinence as the hardest thing to accept, and it was clearly not something that he ever imagined having to deal with before.

Due to his deteriorating physical condition and his reliance on others for his basic care needs, Alan did not feel that returning home either to die, or even to spend some time before dying in the hospital, was an option. Particularly difficult for him was the fact that his weakness made it impossible for him to toilet himself. He expressed that he felt humiliated by the fact that he was wearing a diaper and that others were responsible for cleaning and changing him. He described a time on the acute care ward when he needed to have his diaper changed, "One day they wouldn't come for such a long time, my wife almost did it. I yelled at her to leave. I would rather sit in my shit all day than have my wife wipe my ass." He continued,

> Well, that's part of why I want to stay in the hospital. So, if they move me to another unit that's fine. I just can't go home, where my wife will have to do all that stuff because there won't be someone there all the time. ....It would be hard for her but hard for me too. I don't want her having to do the dirty work. It's too much. There is no dignity in that. (Alan)

Blanche was an 87 year old woman whose need for a colostomy was a defining moment in her illness. For her it signaled the end of her "femininity" and was the impetus for her decision to no longer pursue life prolonging treatments. For Blanche, the changes in her body were undeniable and important factors in her decision making. Her place in her world, as a woman, was altered, and for Blanche, this was unacceptable. Although expressing no anger or self-pity, she was clearly comfortable with her decision to not prolong this altered engagement with her world. In referring to her operation and her decision to forego any chemotherapy Blanche stated, "I found that my entire femininity was lost with the colostomy and so I took the decision without anyone's help. In other words, to find myself with a colostomy and to feel as though I was half the person I used to be, I think that, it was very wise" (referring to her decision to not agree to chemotherapy treatments) . She further explained, "I feel as though I am only half way in this world and I suffer a lot, perhaps for nothing." It was with the physical changes in her body that Blanche first started to feel that she was no longer the person that she had always been. She went from being a healthy woman with a strong sense of who she was as a person in her world and, as a result of her illness she became someone she did not want to live as. What is interesting about Blanche's story is that unlike other participants who had obvious limitations and physical signs of illness, Blanche's colostomy could have been easily hidden from the rest of the world. For her, being able to conceal it was clearly not significant. In Blanche's mind it was her own perception of herself which was most important, and for this reason she took control of her health herself and made her own decisions.

Embodied awareness. Mark had been diagnosed with prostate cancer almost 10 years before I met with him. For many years following his diagnosis Mark had, for the most part, lived a life that was in keeping with his original conceptualization of who he was as a person before cancer. For most of these years Mark had been physically unlimited, able to work, and able to interact with his world in ways that were expected of him and by him. It was with this current hospitalization, 10 days before my meeting him, that this all began to change quite dramatically. Mark's embodied interaction with his world, in its state of physical limitations due to his deteriorating and weakened condition had altered. In describing the changes he experienced over the past 9 years he shared the following:

> Mark: Yeah, very slowly. I was exercising every day, I was eating well.
>
> Vasiliki: So, things were happening in your body that were not significant enough for you…

In this short exchange we see that Mark was realizing that even though he was getting sicker slowly over the course of the past few years, the changes which were likely happening in his body were not significant enough for him to notice. What was significant was that on the day that Mark came in to hospital, he was unable to lift himself up off of the toilet at home. This was what prompted the hospitalization. I inquired whether or not his current 10 day hospitalization had afforded Mark the opportunity to think about what could be happening, something that he stated he did not do prior to being admitted into the hospital. To this he replied, "I've got plenty of time (to think). I just don't want to. That's the difference." When I tried to probe a little further and asked Mark what it was that he thought about instead, he changed the subject and asked if he could bring in some weights in order to strengthen one of his arms. He continued, "I know I'm not going to get my vitality back, but I'm going to get some strength back and that will be a big help." Mark had already stated that he did not want to know much about his illness, nor about his prognosis. His new physical limitations however were impossible to ignore, and his focus was on improving his physical functioning enough so that his quality of life could be improved. Interestingly, when asked if his concept of what constituted quality of life had changed over the past little while, he replied that it had not, because "I had never given it any thought. I'm finding out the hard way." Mark was acutely aware of his illness and that it had progressed because he experienced the loss of control of his body. He was no longer able to function and interact with his world in the ways that he was used to. He struggled to regain at least some control of his body by exploring exercises and weights. Despite his deteriorating physical condition, what Mark could control however was how much he spoke about his illness, how much information he was given and how he internalized and processed that which was shared with him.

For Karine, who came into the hospital after falling at home and being found by her sister in a condition which Karine described as being inert, her moving towards death was uncovered by her inability to swallow and her lack of energy. Throughout our conversation Karine was coughing and trying to bring up secretions. The effort of this was clearly exhausting. She was, however, pleased because even small improvements in her condition were meaningful to her, as when she stated, "I have a pneumonia. I'm happy because today, this morning, I coughed something up. I cough, spit, and wake up." Despite the fact that Karine was so physically ill, her ability to take control over part of her bodily function, in this case, being able to cough up secretions, was very important.

For some participants the discovery of their illness happened over a long period of time. Months after Javier found lumps on his body and realized that he was bruising very frequently and inexplicably, his friend, who happened to be a physician, convinced him to go to the hospital, where he was ultimately diagnosed with chronic leukemia.

> I was told that it was not a fatal leukemia. It was a chronic leukemia and that people usually die of something other than their leukemia. That was 5 years ago. And so we continue the exams, and everything is under control. But then she (the doctor) told me that there were mutations in the blood and that it had become more aggressive. We continue just the same, but at a certain point, problems arise. A lump here, a lump there. Lump. Lump. And so I said, no, we will not simply continue this way. Is there chemotherapy? What is the treatment that we can do? They did give me chemotherapy but that didn't work 100%. So, another step with cortisone, this didn't work either. Then, you have a transplant. My sister is 100% compatible with me. It should work. But, my sister has a dormant condition, which my mother gave to her, and she, she has given it to her daughter….So, we do a second round of chemo, but that doesn't work either. And while waiting, not a long time, about 6 months, in the hospital I contracted c-difficile. (Javier)

In Javier's story we see that he had been successful in controlling his medical care plan. He made decisions based upon a hope for a cure, including when he learned that his brother was a match for a bone marrow transplant. When it became clear that he could not be a donor however, Javier experienced a loss of control; he had no control over his sister's dormant condition which made a transplant impossible and he had no control over the aspects of his hospital stay and illness which resulted in him contracting c-difficile.

Being unable to engage in the world as before was a challenge for several of the participants in this study. On the other hand, in stories where I initially believed that the breakdown of the body would have been the most challenging and distressing, it was not. Sabrina was an Italian woman who had made a very successful living in the food industry. While she was a stay-at-home mother with her only child Sabrina began a business in which she, and then people that she employed, catered for local businesses. Her business flourished and 20 years later she was serving hundreds of clients and employing several people.

Sabrina was diagnosed with breast cancer in the mid-nineties and was living through her second recurrence when I met her in 2011. Her cancer had caused her to have severe lymphedema in her left arm, in addition to a malignant wound over her left chest and shoulder area. As a result, she was severely limited in the mobility of her left arm and was unable to use her left hand for any fine motor activities. Even large movements caused her pain and difficulty. Although I assumed that this limitation would be very difficult for her, more so perhaps than for someone who had not spent a life working with their hands, she explained that there was no relationship between the two for her.

Vasiliki: So the pain is mainly in your hands?

Sabrina: Yes, in the chest, because I cannot…it pulls. The skin pulls. If I do this (tries to lift her arm up above her head) it pulls.

Vasiliki: I imagine that this must be especially hard for you since you spent your life working with your hands.

Sabrina: No, there is no relation…one has nothing to do with the other.

Vasiliki: Oh, I imagined it to be like a musician or an artist who could no longer use his hands. What is the most difficult thing?

Sabrina: To accept the pain.

Vasiliki: Accept the pain. Do you think that it can be controlled?

Sabrina: Mmmmm

Vasiliki: The pain is always there?

Sabrina: Always there. It has been a year that I cannot move my hand and that I have pain.

Although the pain and limited mobility were very difficult for Sabrina to accept, she shared that the pain and physical limitation were not made more unbearable because of the fact that she had spent a career working with her hands. Although I found this to be quite surprising, I interpreted this to mean that, because of the severe physical pain that she was constantly in, the loss of function in her hand and arm lost some significance by comparison.

Eloise was a young woman with end-stage ovarian cancer. She referred to her disease as a silent killer that crept up on her, despite the fact that she was someone who was very in touch with her physical Being-in-the-world. As a researcher herself, she naturally sought answers on her own and attempted to learn what she could about the disease that had devastated her life. She explained what she uncovered.

> I learned that I was screwed. I mean, my chances were quite small to survive this thing. I knew right from the beginning. Do you know that they call ovarian cancer "the silent killer"? Well, someone calls it that – I don't remember where I read it…but it is true. It is so silent. I had no idea what was going on in my body and I think that was a really hard thing to accept. I always thought that I knew my body really well. I ate well, I listened to symptoms. Like, when I felt a cold coming on I would do everything I could to keep it away. Garlic and honey and warm baths. I

> am really in tune with myself. And then, I started to feel bloated, so of course, I thought I was constipated or gaining weight. So, I started eating lots of bran, eating less. And the bloating would go away, and then come back. Until I had severe abdominal pain one day and I went in to see my gyno eventually, and she suspected…she sent me for tests…and there you go….ovarian cancer…what?! (Eloise)

For Eloise, who was so used to being in control of her own health and well-being, the surprising diagnosis of ovarian cancer affected her self-image of being someone who knew her body very well. During my conversation with Eloise I came to understand that her disease was somehow a sign of betrayal of all things that she knew, believed and relied upon. Her understanding of the way that her world functioned, her impact on it, was dramatically challenged.

Parenting. It is difficult to envision a circumstance in which a particular life exists in isolation, removed and uninfluenced by any interpersonal connections. All participants in this inquiry were married, divorced or widowed. In addition, many of the participants, except for Alan, Myriam and Karine, were parents. The youngest participant in this inquiry was Eloise at the age of 47. This information is important not for the sake of descriptive demographics, but because it reminds us that although this inquiry was solely focused on the participant’s experience, their experiences were all impacted in one way or another by the fact that the patients had, at some point at least, been spouses. They had all been the children of parents and several of them were mothers and fathers themselves. Although familial roles extend further (these participants were sisters, brothers, uncles, grandparents and so on), the relevance of these roles within this inquiry was not profound.

Parenthood is a bond which is potentially one of the strongest which humans can develop. Throughout this inquiry, the relationship that the individual participants shared with their children was at once unique to each situation, but also similar across all cases, as parenthood seemed to be a strong factor influencing how participants understood their current experience and found meaning in it. Looked at from a different perspective, all of the participants of course were also, once upon a time, children, with parents of their own. The way that they were parented seemed to greatly influence their current situatedness, be it via how they were taught about, and exposed to death, like Lillian who grew up on a farm, or by the impact that an absentee father had on a child's development, as in the case of Claude. These two roles, that of parent and that of child will be considered.

Blanche, who was 87 years old when I met her, was raised in a typically large French Canadian family. Born in the countryside, she was the youngest of several children. When the family moved to Montreal when Blanche was 14 years old she was able to attend school thanks to her older sisters, who went to work to help support the family.

With her spouse Blanche had 4 children, a daughter and 3 sons. In speaking about her death, Blanche did not appear to be particularly overcome by emotion in relation to her children and the fact that she was dying. As well, Blanche had not solicited, nor had she expected, any advice or input from her children in relation to her health and care plan. She had not consulted them when she was making the decision on whether or not to take the chemotherapy which was offered to her initially, and she stated that when she did finally inform her children of her decision they told her that it was "entirely her choice" . Blanche was looking forward to a transfer to the palliative care unit, as she felt that this meant she would be offered assisted suicide. She framed this desire not only in the context of ending her own suffering, but also as a means of protecting her children from experiencing unnecessary burden. Although not her primary motivation for desiring assisted suicide, Blanche did consider that by choosing to end her life she was protecting her children from distress and responsibility.

In contrast to Blanche's story, Thomas' children were very much involved in his care and he appeared not only to expect that, but to welcome it. Thomas had 3 adult children, a son and two daughters, all of whom were married. Near the end of our initial interview, Thomas' son called his father's room. When Thomas explained to his son that he was in the middle of being interviewed for a research project, he asked his son to stay on the phone and to listen to our conversation. He did not consult with this son on any of the questions that I asked, although I did consider how knowing that his son was listening may have influenced the responses Thomas gave, and the information he chose to share.

At the completion of our first interview, when I asked Thomas if it would be acceptable to him to have me meet with him again for the purpose of this research project, he immediately agreed and stated that his whole family would love to meet me. Although I did meet with Thomas a second time, after he was transferred to the palliative care unit, I did not meet his family. He did however proudly explain to me that his daughter-in-law had brought in a special foam mattress for him to put on his bed for added comfort. It seemed particularly important for Thomas, more so than for any other participant, to try and actively engage and include his family in all aspects of his care. He gave me the impression that he was attempting to do this in order to assuage his feelings of aloneness when he was by himself in the hospital.

Lillian had 4 adult children, 1 of whom was in the process of completing a university degree. She stated that because of her children she knew how important research was and therefore she was happy to participate in this inquiry. Although she did not speak at length about her own children, Lillian did acknowledge that it was very distressing to imagine that she would not be present with them for much longer. "It is a very sad thing, to know that your family will go on without you, to know that you will no longer be part of the world."

Not all individuals in this inquiry had harmonious relationships with their children. We learned that Claude had been estranged from his son for 18 years and had only reconciled with him a month before our interview (which happened to be 3 days prior to his death). Claude also had a daughter and he stated that "They both take good care of me". Claude described his relationship with, and his estrangement from, his son in more detail. He stated the following:

> It is like a consolation to see my son after being estranged for 18 years. Ultimately, he allowed me to think freely, he allowed me to act, and he left me the solitude to develop my thoughts. Eighteen years before we could reconcile. I am very happy about this. Very happy. (Claude)

Although not clearly stated, my impression is that Claude had also had limited contact with his daughter for several years. She was living with her mother, from whom Claude was divorced, up until the time of her mother's death.

> My daughter well, it was in Secondary 3 (grade 9) that she asked me to go to CEGEP [14], because she had more…I told her I was waiting for her. Her mother had died and

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[14] In Quebec, the highest grade in secondary school is grade 11. Following this, individuals who want to continue their education enroll in either a two or three year CEGEP program. The former are meant to prepare students for University, while the latter are often technical programs which allow graduates to work in a technical field.

> so she accepted. She came to the house and she did her CEGEP. She finished her high school and then she did her CEGEP. She came when she was 13 years old and she stayed and finished her high school and she did her CEGEP with me. (Claude)

As mentioned earlier, Claude truly believed that his reconciliation with his son was attributable to the divine work of Rose. Rose, who had been his savior in life, continued to be his savior after her death. Claude's biological mother had died when Claude was very young and Rose filled in the role of step-mother. Claude began to speak about Rose quite spontaneously, after discussing his favorite musical band which he found inspiring for its ability to use music and poetry to transmit political messages.

> It's that, very young, I established a relationship. I would say, it was privileged, on what basis? She (Rose) had 10 children, 3 miscarriages. My father was a truck driver. A good worker. But her…what a job, what devotion! (crying) That which is causing my tears, it's to see that it was unconditional. She raised 10 children. It amused me. It impressed me. It touches me still. She kept us free from misery. Because of her we were able to eat, go to school, be cared for, yes. (Claude points to a pot of flowers by his bedside). My sister brought me a vase with roses. It's her. A simple woman. Dead at 75 years of age.

By noting how impressed Claude was with Rose's ability to mother and raise 10 children during what appeared to be very difficult times, I interpreted that his own relationship with his children, particularly the estrangement with his son, was especially difficult for him. I understood that he felt in some way inadequate as a father, particularly as he was holding himself up to the standard of Rose, a woman whose parenting he was clearly awed by.

The awareness of death. As Heidegger (1962) acknowledges, our pre-understandings are shaped in part by the experiences we have previously been exposed to. The death of another does not typically make up part of our average everydayness, and so, even one previous experience with death and dying has the potential to impact the way that we understand the world and the meaning that we ascribe to our own finitude. In this section I share how the participants' previous experiences with death informed their general death awareness.

Lillian had experienced several important losses in her life and therefore, had many varied experiences with death, all of which influenced how she understood her own finitude. She lived through the death of her husband, both her parents, and a childhood being raised on a farm where death was an almost everyday reality and occurrence. When I met Lillian she had been a widow for 10 years. Her husband had died suddenly of a brain aneurysm. She described him as someone who had been in "tip top shape", athletic, careful with what he ate, exercised daily, and yet he still succumbed to an unexpected and premature death.

Lillian shared how one evening she had gone out for supper with some friends and when she returned home a few hours later she found her husband lying dead on the couch with the television on, and a can of beer on the floor beside him. Lillian understood her husband's sudden death to be a blessing for him. She took great comfort in being told by his doctors that her husband had likely died in his sleep, without even waking up. Although she was not convinced that this was true, she liked to believe that he did not experience any pain, fear or suffering. "If you ask me", she said, "that is the way to go." This experience clearly influenced Lillian's thoughts in relation to her own death awareness and her statement “that is the way to go” represents her thoughts related to an unexpected death.

The deaths of her father and then her mother were also significant for Lillian. She was living in Canada, the country she had moved to from Scotland as a married woman in her early twenties. She had returned to Scotland for a visit with her first child while he was still a baby. At that time her father was ill and he died a few months following her return to Canada. Her mother, who had acted as her father’s primary caregiver while he was ill, died a few years after that.

As Lillian shared her story I recognized that the meaning that Lillian ascribed to her mother’s caregiving experience was very significant to how she understood her own situation. Her father had died in the family home, with her mother caring for him until the very end. He had experienced a lot of pain, a lot of discomfort, and near the end of his life he was incontinent and “he was not himself”. Although her mother never stated that this was so, Lillian firmly believed that her father’s home death had been a great hardship for her mother. “How could it not be?” she wondered. Along with the physical burden of care, on an emotional level, Lillian wondered how anyone could possibly continue to live in a house where your spouse had died. This same discomfort had Lillian move out of her home a month following her husband’s death. What we can understand from Lillian’s story is that, for her, a good death is one which is quick and where the dying individual is not aware of his or her own imminent death.

I asked Lillian if she could remember the moment that she knew she herself was dying. Her response was presented in the context of her life experiences, namely, growing up on a farm. She responded that she had always known and accepted that she was dying;

that she would one day die. It was not a notion which was foreign to her, nor was it a fact that she tried to shield herself from. Being raised on a farm, Lillian was constantly confronted with death despite the fact that she was raised by parents who were very good at “protecting their children”.

Lillian shared the story of how, when animals on the farm died, her father would tell her and her siblings that the dead animals had simply run away. The children, having no reason to doubt their parents, always accepted with blind faith that this was the case. Lillian, being the youngest of her siblings, was the last one to realize that this was not true and that, in fact, the animals had died, often being killed for food. This discovery came when Lillian walked in on her father skinning a rabbit he had killed; a rabbit that he said had run away. Despite the fact that Lillian was only 9 or 10 years old at the time she was able to describe to me in great detail the colour of the fur on the ground and the look on her father’s face when she walked in on him. Not only was Lillian able to remember the visual details of that moment, but she was able to remember how she had felt at the time. I wondered if she had been upset, shocked, saddened. Lillian told me that in the moment she had felt very scared. It had been scary to see so much blood and it frightened her to know that it had been at the hands of her father. She denied ever feeling anger towards her parents however. She recognized even then that they were simply trying to protect her in the best way they knew how. Instead she had been angrier at herself for being “so stupid, so gullible”.

After this incident Lillian’s parents were very open about death and the cycle of life with her and all of her siblings. They no longer evaded conversations about death and dying. The death of Lillian’s grandparents was openly discussed in the family. As well, Lillian shared the story of a classmate she had when she was 10 years old. This boy had become quite ill and had died within a month. Although Lillian never knew what illness this boy had, she did remember that she was the only child in her class who understood that he would likely die, because her parents had told her so.

For Lillian the reality of her dying was not a shock for her. She acknowledged that she knew people who felt that they would live forever. "I think that living on a farm cures you of that kind of thinking." Through Lillian's story we see the important impact that previous experiences with death can have on understandings of our own mortality. Lillian's death awareness was intimately tied to her childhood experiences of living on a farm and her experiences of the deaths of individuals very close to her, namely her husband and her parents.

Blanche described the loss of her husband 2 years earlier. He had been ill for 2 to 3 years and had stayed at home with her for approximately 5 months during that time. The rest of the time he was too ill to remain at home and had been hospitalized in Montreal. Her husband's illness had been very difficult both for him and for Blanche.

> During the time that my husband was ill, it was a little bit difficult, because he was so ill that it was difficult to support him the way that he was. It was something very difficult. (…) It was a very punishing experience. Because it was very, in this moment, it is very difficult. (crying). And then, … we were still in certain moments quite happy. The children helped. (Blanche)

The fact that Blanche was still very emotionally upset regarding the death of her husband, and the fact that she viewed his illness and death as being very difficult, helps to provide context for her desire for assisted suicide and her desire not to subject her children to a similar experience with her dying. Blanche's experience of her husband's death meant that she was not only aware of what was happening, but she was also trying to exert control over her own dying experience – control that she did not have with her husband's death.

Javier had a different past experience with death and dying. As a young man Javier had lived through the political revolution in Chile during the early 1970's, under the dictatorship of Pinochet. When he was able to, Javier left his job in Chile and arranged to immigrate to Canada. "It was not fun," he stated, "but it was that or, or die. So, this is not the first time that I am facing death." Javier continued:

> I was in a concentration camp and well, they said that we could come and go, but this was not true. So, I have lived all sorts of things before this (…) I was 23 years old. Yes. 23. Something like that. I was in the concentration camp for about 3 weeks. (Javier)

Our conversation then continued with the following exchange:

> Vasiliki: During this time, did you lose a lot of friends?
>
> Javier: (very emphatically) Ah, yes, yes, yes. I had friends that simply vanished. We no longer know where they are. There were a lot of people that had been put on helicopters and they were flown towards the sea, which was not far. They would get thrown out of the helicopter and into the sea.
>
> Vasiliki: (long pause) Surely, an experience like that must change you?
>
> Javier: (gentle laughter) Ah yes, yes, yes.
>
> Vasiliki: I'm not sure what to say. I can't imagine what this was like.

> Javier: It gives you another perspective on life. (in a mimicking complaining voice) 'Oh, it's cold', 'Oh, it's warm', ah…This is not what is important. This has no importance.

Javier's experience during the revolution and his time in the concentration camp offered to him another perspective on dying and death. I returned to his experience during the Chilean revolution later on in our conversation and asked him what impact, if any, he thought that particular chapter in his past had on his life now. After some reflection, Javier offered the following:

> The resources that we have here, the hospitals, the techniques, the different techniques, but there (in Chile) I didn't have any choice. There, it was war, and it ends there. There were no choices to make. So, that's it. And there, they would cover the person's head with a drape, and the people…we would hear the screams. No, it's something, it's something else. (pause) And here, here at least, there is medication to control the pain. They will make this the most short, and the least painful possible. That is the difference. (Javier)

Clearly, living through this horror had changed who Javier was as an individual and had impacted how he made sense of his impending death. It offered a different perspective, with anxiety and fear being somehow replaced by gratitude and resignation. Javier had already lived through experiences which were more frightening and more traumatic than his own relatively controlled terminal illness. He recognized that at the time that I met him he had the luxury of some control; he was able to make certain decisions and choices, something which did not exist when he lived through the revolution.

The analysis related to the impact of previous death experiences on the participants within this inquiry helps us to understand that although each person truly experiences only his or her own death, the deaths of those around us leave permanent impressions. We are reminded of these when our own deaths are imminent and we must appreciate the influence that they have on our Being-in-the-world.

The awareness of dying. Key to this inquiry was acknowledging that participants were informed that they were being transferred to the palliative care unit and that this was an indication that they had engaged in a discussion about their prognosis and change in the approach to care. Minimally, all participants would have had a discussion with regards to level of intervention, and that the level of intervention (or code status)[15] was such that the patient was to receive primarily comfort care with no heroic attempts made to sustain or prolong life.

Within these participants' stories there were varying degrees of awareness related to their own imminent dying, some of which were explicit, and some of which were implicit. As well, there were different ways in which the participants coped with and experienced this awareness. Although not all participants readily engaged in discussions about their own finitude, none of the participants expressed an outright denial of their poor prognosis.

Myriam described what I identified as the decision making process she engaged in when she decided to transfer to the palliative care unit. She shared that initially she had

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[15] Level of intervention refers to the decision made in relation to interventions for resuscitation and other critical interventions should a patient have a cardiac arrest or another life threatening situation. This decision is made after discussion between the physician and patient or family (if the patient is unable to engage in a discussion). All participants in this inquiry had a Level of intervention which was either Level 3 or 4, meaning that in the case of cardiac arrest, no chest compressions or transfer to a critical care unit would be done.

been very ambivalent about this decision, even though the palliative care physician that she had been working with had broached the subject with her.

> Myriam: I was to have another treatment, and uh, I was thinking that if there was any other flicker of hope left, let us use it. And when EVERYTHING fails, then we will consider the next step, so, that's it.
>
> Vasiliki: And so, what happened between that point and getting to the point where you are now?
>
> Myriam: Because, uh, now, the treatment does not work. It may work, but I find that it's not worth it. So I decided that, it's time, time has come.

Myriam was a woman who was at peace and fully aware that she was dying. Some of this peace came from the fact that she felt she had a certain control over her destiny, and was happy to exert this control in ways that she could. She did not believe that pursuing further treatments would be beneficial, or worth the sacrifice to her quality of life. Myriam quite eloquently described her experience living through chemotherapy, which was a 24 hour regimen. "Well, we did the chemo…it was 24 hour chemo, and I find that was too long. First that was extremely long and then I had a lot of vomiting which was extremely painful, lots of nausea, which was extremely painful, so why go through all these?" Myriam's questioning of why she should continue on with the treatment indicated to me that Myriam was in a position to make a choice about how she was going to face her illness and her life. She believed that subjecting herself to further pain and suffering was not worth it; this meant that she knew that despite everyone's best efforts, her nearing death was a reality. It was within her control to choose to discontinue any more potentially life-prolonging treatments. I understood her power and ability to choose to quite possibly be the reason why Myriam was so serene when contemplating her imminent death.

The day after Myriam was transferred to the palliative care unit she said, “Everything is complete, everything is complete. When they are complete, you’re a circle, it’s a whole. The circle becomes a whole.” She appeared to be commenting on the fact that she was satisfied with the choice that she made; that her life was playing out the way that it was supposed to. Similar to Myriam, Javier was able to understand that his own death was, to some degree, under his control. He described in great detail the numerous treatments that he had undergone, initially in an attempt to cure his leukemia, and then in an attempt to manage some of the more serious side effects of his disease. Javier spoke about the fact that metastases to the bones in his spine had caused serious fractures which had to be fused together. This had not been an easy experience and Javier realized at that time that each intervention would likely lead to another intervention, until either he or his physician decided that there was nothing more that would be done.

> It is too much suffering, so, I did the most, but, for me, it no longer made any sense. Yes, they may prolong my life a little bit, but, they will give me an extra six months of suffering. (…) And, my wife, me, my children, the boyfriend of my daughter, the whole world had plenty to say. It was not worth the pain. So, my doctor now has told me to live some time with no pain, and not to live longer in constant pain. (Javier)

Navigating through treatment options and weighing them against the expected outcomes and the burden of these treatments was not a situation unique to Javier. Alan, diagnosed with metastatic lung cancer, described his experience with cancer treatments.

> Yeah, I have lung cancer and a brain tumour. Bad. It has affected other parts of my body too. I don't know. When they found it, it was already too late to do anything really. Surgery wasn't an option. I had some radiation, then some chemotherapy…experimental. There really wasn't a hope to cure the thing, but you gotta try you know. (Alan)

Claude very clearly understood that he was dying. I asked him if he could explore with me what waiting to transfer to the palliative care unit was like.

Vasiliki: You are waiting to go….

Claude: To leave.

When I asked Claude if I could meet with him a second time, he said that would be fine, unless he was already dead. After speaking about his children, crying, he shared the following, "That is life. I am leaving happy. I lived free in thought, in speech and in action. I am a free man. That is what we should wish for, no?" Claude ended our conversation with the following:

> It is lucky that you came and that I shared my personal thoughts and reflections with you. The ideas that I do not know, that I will not uncover. I don't know what you will do with this information, but, do what you think is correct. Me, I said what I had to say. (Claude)

For some participants, the understanding that they were dying would be revealed very gently but would then, just as gently, be pushed down below the surface. For instance, during our second interview, while he was on the palliative care unit, Thomas shared that along with his increasing weakness, he was having thoughts about his future. He said,

> "Maybe make me more anxious to live, or whatever. And uh, sometimes, some sick people, then in this case I'd rather … gone…dead…better than to live. You understand my point?" (Thomas)

I got the sense that Thomas may have had a willingness to speak about his death but that he was not sure that it would be an appropriate thing to do. He was a gentleman who was so eager to please, constantly asking me throughout the interview if he was answering the questions correctly. I understood him to be a man who would not be happy having upset anyone, and he felt that difficult discussions or morbid topics like his death would be upsetting. Still, perhaps because he felt I was a safe person with whom he could test the waters, he did share the following:

> Thomas: I'm very glad I am staying here for now. I don't know what will happen in the future, but I hope… Let's put it that way, if I die, I'd rather die (motions around the room to indicate 'here')
>
> Vasiliki: You would rather die here?
>
> Thomas: Excuse me aye…
>
> Vasiliki: No, you don't have to excuse yourself.
>
> Thomas: No?

While Thomas seemed to be testing the waters to see what he could safely say regarding his death, Mark made a conscious effort to steer away from any difficult and emotionally charged conversation. By focusing on his physical mobility, Mark was able to consider how to fully re-engage in the world as he used to, and in a sense this provided him with a distraction to keep from thinking about things which were too difficult. He explained, "I find it easy not to think about anything I don't want to think about." When I commented that this seemed to be a good coping skill he replied, “You have to make adjustments…and I’m trying to make them the best that I can for me.”

For Mark, who had been diagnosed with prostate cancer 11 years prior to our meeting, it was a breaking down of his ability to mobilize which brought him to the hospital. For the years since his diagnosis and after initial treatment, he had been doing quite well.

Vasiliki: And prior to coming to the hospital this time, how were things at home?

Mark: Okay…ohhh..I’m getting heartburn…okay. They started getting bad that’s all. Really bad.

Vasiliki: How did they start going bad?

Mark: The last days, my legs, my arms.

Although Mark’s new limitations were impossible for him to ignore, as he was in a state where he could no longer walk or use his arms with any amount of strength, he tried to limit the information that he received from his physicians and nurses. When asked if he could explain to me what he understood about his meeting with the palliative care physician the day before, he said that he didn’t ask any questions. “I didn’t want to know. I wasn’t concentrating.” I interpreted this to mean that Mark did not want to hear the answers to any questions related to his illness, his prognosis or his treatment plan. He appeared to have an ability to effectively block out information which could potentially be too distressing and yet, he did admit that he could concentrate even on distressing topics when he wanted to. His purposeful attempts to stay on safe topics did not mean that Mark was unaware of what was happening, however. His story did not indicate to me that he was in denial. Mark was aware that he was dying, that the physical changes he was experiencing were indicative not only of his declining physical state, but of his approaching death. Near the end of our conversation he said,

> I have a lot to say, not sure what to say. How long it will be I don't know. I don't know how to feel sometimes. I don't know what to think …aaahh (deep sigh). (Mark)

This moment of deeper engagement led to an exchange during which Mark admitted to being nervous and high strung, just as he had been his entire life. When asked if he was scared however, Mark immediately responded by returning to a safer topic and replied that his leg was bothering him. He sat up in bed and asked if we could stop the interview, which we immediately did. Mark struggled with how to possibly reconcile the fact that he was in the throes of death while at the same time being a living and breathing human being.

Other participants discussed the awareness of their impending death much more explicitly. This did not mean however that they were at peace with it, or that they did not experience anxiety and angst when they thought about their death and the existential questions that their own finitude raised. When asked about her experience and what she understood about her illness, Lillian responded, "Oh dear, you don't have to tiptoe around it. What I know about my illness is that it is going to kill me – sooner rather than later. I am dying – it is as simple as that." Lillian was able to elaborate further and describe what this knowing was like for her; particularly in light of the fact that she had shared that a sudden death, like her husband's, was "the way to go." Lillian described knowing that you are dying to be "a funny sensation". She likened it to going for a root canal in that you are aware of what is going to happen, you plan for it the best way you know how, but you try not to think about it all the time. The difference, she said, was that with a root canal you know the exact time of the procedure, but with dying it was different. The only concept you had with regards to time was that it could be "soon." Lillian admitted to a deep and profound sadness some of the time. She said that it was a very sad thing, to know that the world and your family would go on without you.

Not thinking about her death all of the time was apparently easy for Lillian because, "life gets in the way." She was easily preoccupied with day to day events, such as who her assigned nurse would be, what she would be served for lunch, when her children would visit and what color she would ask her grand-daughter to paint her nails. When she did think about dying too much, she found herself unable to breathe, and felt as though she was drowning.

> I don't know if that is a panic attack because I have never had one before – but I get a pain in my stomach, an ache, and it is very hard to breathe. I try to catch my breath and then I try very hard to think about something else – my kids, my garden, something else. (Lillian)

Lillian then went on to say that it was being visited by the palliative care team doctor a few days prior to my meeting her which made her realize, without a doubt, that she was going to die. She asked the doctor directly if she was dying and, "after dancing around a bit, he admitted that yes, I was dying." She then went on to say that she had a suspicion, but that there was a glimmer of hope, maybe a chance, that she would recover at least for a while. She went on to say that in some ways it was a relief to know what the doctors knew, because in some way, the not knowing was the hardest part.

There was much about Lillian's story that was contradictory and incommensurate. On the one hand, she had a clear and articulate understanding that death was inevitable and something that all living things would one day face. Her understanding appeared logical and matter-of-fact. She had seemingly incorporated this reality into her everyday existence, acknowledged the universality of it, and yet, at the same time, she envied those who did not have to accept death as she had done, and was doing. In feeling that a sudden death was the preferred way to die, as opposed to an impending and prolonged dying, she was favoring a situation which did not afford the possibility of pondering one's own certain and impending finitude. Although she faced her death gracefully and somewhat humorously, Lillian still found it quite difficult.

What we learn by interpreting the stories of the participants in this inquiry is that they were all aware that they were dying, and although this was not entirely surprising given the nature of the inquiry and the inclusion criteria for the study, what was surprising was that this awareness did not appear to be fueled by an external confirmation. In other words, the participants did not need someone to tell them that they were dying in order to understand that they were. Furthermore what differed amongst the participants was how they reacted to this revelation of their own dying and how they shared their impressions about what they felt to be the reality.

Grappling with one's finitude. As indicated in the previous section on parenting, in most instances when the participants in this inquiry started to speak about their children, they expressed great sadness, and what I would argue, was akin to Heidegger's writings (1962) of angst, an emotion more profound than sadness. This occurred primarily when participants were contemplating their finitude and acknowledging that there would come a time when the world would exist without them. This was evident in the story of Javier, who, when he initially spoke about his children, made it clear how proud he was, not only of them, but how proud he was in knowing that he and his wife had done a good job in raising their children. He considered his young adult children to be his greatest accomplishment.

> I can't complain. Other people they say (in a mimicking voice) 'Ah, you are lucky. You have this, I wish I had that'. I know families that do not have children. We can't have everything. But me, I have my children. (Javier)

He went on to say:

> There was someone who came the other day and told me that I had done the most difficult task. It was to raise my children well. The principal task was well done. It's true, children, my children are very proper. They are never late, they always speak with respect. (Javier)

When I commented that he seemed very proud, Javier responded, "Well yes, I have to be. It is not easy to raise children"

This sort of devotion, pride and love for his children represented Javier's strong feelings towards them. In speaking about his limited life expectancy, Javier shared the following:

> Javier: It is strange, but I have an overwhelming feeling of sadness. For the children.
>
> Vasiliki: It's strange? You find that strange?
>
> Javier: (crying) Yes, a little. And I've been afraid, I'll say, for a long time, a long time. It's not that. My children work well, make money, are kind. They are not too…(pause)…but I have a great sadness for them. Then I think, you can't do more for them than what I have already done, in any case.

It appeared to me that Javier harbored some guilt at not being able to do more for his children, and perhaps this stemmed from the fact that when he was a young adult, his parents were not present in his life. He may have felt the weight of his parents' absence during his own upbringing and was therefore worried about subjecting his children to the same sense of loss and difficulty when he himself died. He wanted to protect them from harm and from experiencing distress upon his death.

Eloise was fully aware that she was dying, and that she was dying rather soon. She shared, "I don't think about being scared. I just am. I am actually a little less scared now. Now, I know what the future is. I am going to die. Soon. I will stay in the hospital and I will die here." As we spoke Eloise made several witty comments and small jokes and I commented that she often seemed to be using humor as a coping mechanism. She responded to my observation with the following:

> No. I mean, I cry, but I don't want to cry all the time. I want to laugh. I want to remember that this is ludicrous, because it is. I am not in denial, I am just trying to cope with this mess the best way that I can. It can be overwhelming, thinking about dying, about being dead. It is too much to think about almost. I know it on a logical level. I know that I am dying. I know that you (points to me) will one day die, that we all will, my daughter…but right now, it just seems impossible that I will…just not be here…anywhere. It stops my breath. (Eloise)

I consider Eloise's story to be the most poignant related to parenting and grappling one's own death, likely because she was a young patient with a young daughter, the only minor child of any of the participants in this inquiry. Having young daughters of my own, I had to make an especially concerted effort not to let my emotions and personal biases get in the way of the interviews and the analysis. Because Eloise's daughter was a child, being raised and cared for by her parents, we can assume that she was witness to many of the harsh realities which accompanied her mother's diagnosis. Eloise was able to share how her chemotherapy treatments were impacting her daughter.

> There was some hope. It was very hard to take though. The chemotherapy I mean. It made me very sick, very weak. I think that it scared my daughter. She was not used to seeing her mother like that, sick and ill and vomiting and scared. I think I was very scared. So scared and it showed. (Eloise)

Like Javier who felt great distress knowing that he would not be with his children for much longer, it was Eloise's daughter and the knowledge that she would be leaving her behind, without a mother, which caused Eloise the most angst. She compared her mother role to that of her role as a wife, and clearly described how for her, they were very different.

> This is what makes me the most sad. A sadness that I think only a mother can understand (smiles at me). My husband, he's a man. We met and married. He had a life before me, and he will have a life after me. It's different. He is a wonderful man. He loves me very much and I love him and he's a wonderful father, but it's different with your child. My daughter, she is my perfect joy. When I think about all of the things that I will not be there for…(deep sigh) (pause) It makes me more than sad. Part of me dies every time. That is dying for me. (long pause). You know, I sometimes wonder if you can miss people when you are dead. (laughs) How ridiculous is that? (Eloise)

We can understand through this piece of dialogue that for Eloise, dying is a multi-faceted experience. Although the absence of life is the final and absolute point of death, she believed that there were points within her life-world which held the qualities and significance of death even while she lived. As a parent, sharing difficult information with a child is never easy, but sharing the fact that you are dying with an adolescent girl, I imagined being tragic. I asked Eloise what her daughter understood about what was going on, and what she and her husband had told her. She shared the following:

> Well, she knows everything. I, we, have been very upfront with her. Not at the beginning, not until we knew what we were dealing with, but we have not sugar-coated anything. She is old enough to understand. And that way it is better, there is no shock like 'What!? Mom is dying?!' She has known that this is a possibility for a while. (Eloise)

I asked Eloise if she could describe what it was like for her to have this conversation with her daughter and to share this information.

> Mmmmmm…..well, of course, I would rather not have had to (small laugh). Of course. But, it was okay. It was awful. We cried a lot. A lot. There was a lot of hugging, a lot of crying, and then, a lot of silence. She didn't want to talk about it for a while. And that was good, because I couldn't any more either. (Eloise)

Even when Eloise's need for support was perhaps the greatest, after she had been transferred to the palliative care unit and was expressing to me her feelings of existential crisis, the knowledge that she would one day cease to exist, she was still primarily interested in protecting her family, and in particular, her daughter. I asked Eloise if she was able to share her fears and anxieties with her family.

> (Sigh) I could. But I can't. It's harder when it is someone you love. You are still protective of them, you want to care for them. Maybe this is a woman thing. My

> daughter especially, I want to protect her. I want her to be a better person because of what is happening to me. I want her to appreciate life, to not be scared of life. I want her to remember me and think of me as a strong role model, courageous (crying). And my husband too, I know how much pain he is in. I don't want to add to his pain, by sharing mine with him. I am still the comfort zone of the family. I always was. The person who fixes, who makes better. I'm still that person. (Eloise)

We are reminded in this excerpt that the role that Eloise played in her life prior to her illness and hospitalization did not automatically stop or change because she was dying. There persisted within her a maternal instinct, an impulse which seemed to drive her to act for the benefit of her child, despite resultant personal sacrifices. Even in her most vulnerable and fearful moments, Eloise's focus remained protecting her daughter.

We learn from both Javier and Eloise that while contemplating their own finitude, they simultaneously tried to find ways to protect their children. In contrast, in Alan's story the responsibility to protect his wife was met with resentment. Alan described how he felt when he had a perceived obligation to console his wife when they first had the discussion with the doctor about palliative care.

> Well, my wife, she started crying. And so, I tried to console her, and then, I don't know, I got annoyed. I got annoyed at her but I tried not to show it. I mean, I was telling her it was going to be okay. And it's like, what the hell, I'm the one dying! Shouldn't she be consoling me? (pause) I felt bad afterwards, even though I don't think she knew that she had upset me, but I felt so, I don't know…as if my dying was more difficult for her than it was for me. Who was consoling me? (Alan)

I interpreted Alan's anger and frustration to be the result of feeling unsupported in his experience. His questioning who was consoling him was a plea to have someone understand what he was experiencing and to help relieve some of the aloneness which he undoubtedly felt. One would expect a spouse to be the ideal person to fill this role, but Alan was resentful of the fact that his wife's needs seemed to supersede his own. I asked Alan what the hardest part of his illness experience was. He responded with the following:

> I think just knowing that the world is going to continue on without me. My wife will move on. My friends will eventually stop thinking about me too much. (pause) And then, I think I'm scared. (tears up)
>
> Vasiliki: What is the scariest part?
>
> Alan: I don't know. That's just it. I don't know. I don't know how it's going to be, I don't know how long it is, I don't know how much I will suffer. I am very scared.

The experience of grappling with one's own finitude is multifaceted and holds different meanings for different participants. The theme of aloneness, which appears to be inherent in many of the instances in which participants are grappling with their finitude is explored. I review how participants in this study felt alone even when surrounded by others.

Aloneness. In this section I uncover how feelings of aloneness while waiting to be transferred to a palliative care unit can exist even when the patient is surrounded by loving family. As will be described in the analysis which follows, the concept of aloneness is more profound that simply being isolated or lonely. It is a profound sense of being on one's own, even if surrounded by loving family and friends. This is represented by Mark's story. Despite the fact that Mark was married and his wife was often at his bedside, he impressed me as someone surrounded by aloneness. His room was littered with what I assumed were his wife's personal effects, by virtue of their femininity. Mark was surprisingly unkempt looking. His hospital gown was not on properly, his mouth and chin were dirty and his hair had not been combed. The sheets of the bed he was lying in appeared excessively crumpled. Mark's wife was present during the interview, however she sat behind me and, as such, was out of Mark's line of vision for the entire time that I was there. She did not interrupt and gave the impression that she was not listening to the conversation at all; I could hear her flipping through a magazine while Mark and I were engaged in our discussion.

Spousal relationships are often complex and can be further complicated by stressful situations such as serious illness. Although I initially attributed Mark's state of disarray to neglect, both from his wife and from hospital staff, I came to understand, through interpreting and re-interpreting my interaction with him, that perhaps it was not very easy to engage with Mark and to help care for him. To illustrate this point, I have included a portion of our interview. This segment of text is an example which is indicative of the larger exchange that I had with Mark. Our conversation was replete with his sarcasm, and I found him quite difficult to engage with.

Vasiliki: When were you diagnosed?

Mark: Eleven years ago.

Vasiliki: With what kind?

Mark: Prostate

Vasiliki: Can you tell me a little bit about what that was like?

Mark: Not very much. I just lived my life.

Later on, there was the following exchange.

Vasiliki: From what I understand you were at home, you were diagnosed several years ago, you were well. You were functioning well, you were feeling fine and then this, very suddenly it sounds like, things took a turn.

Mark: (sarcastically) Yeah, very suddenly over 9 years.

Vasiliki: okay

Mark: That's not very sudden.

Mark's sarcasm appeared to have its foundation in anger. I had the sense that he was a man who was impatient in life and with others. He was not one who tolerated inadequacy, and he found himself living his own life in an inadequate way. He was unable to mobilize and function the way that he was used to and this made him angry and frustrated. He did not have patience for his limitations and my feeling was that he did not expect anyone else to have patience for his limitations either.

Eloise played a role in her spousal relationship which was similar to the role that she played as a mother; she felt the need to protect her husband from bad news and sadness and her own angst. When describing how she was living with her fears and uncertainty, I asked if she was able to share this with her husband. She replied,

> My husband, I tried to tell him, but he just said, 'Don't talk like that, there is always hope, miracles'. That was very funny to hear him talk like that about miracles because he is the least religious person I know. (Eloise)

Eloise went on to say:

> My husband, of course he was there, but he is a man who has to fill the silence. He could not just let me be, could not just be there, with me, in my fear and sadness. He does his best. Everyone does their best. (Eloise)

In this passage it seemed as though Eloise was resigned to the fact that her dying was going to be a solitary process in many ways. She acknowledged that she was surrounded by love and yet she was unable to articulate what she felt she needed most. This may have been partially due to her need to protect her husband, the way that she felt she needed to protect her daughter. It could be surmised that when trying to protect others from her own pain, the result was that the fundamental aloneness of dying was highlighted. We ended our first conversation when Eloise told me that her husband would be coming to the hospital soon and that she wanted "to relax and change my mind before he does" and she needed to be alone to do this.

Eloise's husband was given the opportunity to take on the protector and supporter role as well. When I met with Eloise for the second time, after her transfer to the palliative care unit, she described the circumstances surrounding her transfer. "It was fast. My husband was here thank goodness, because I don't think they would have waited even if he wasn't. He was able to pack everything up." When she was admitted into her new room, Eloise noticed that the blind in her room was broken. This was very distressing to her and she described how her husband tried to fix the blind himself.

These acknowledgements of the efforts that Eloise's husband made to alleviate some of her distress and fear represent her willingness to be more open to giving up her own protector role during times of greater vulnerability. In describing her transfer to the palliative care unit the following exchange occurred.

Eloise: I tried to keep it together for my husband. He is having a hard time.

Vasiliki: Are you able to discuss how you are feeling with him?

> Eloise: You know, the thing is. The thing is…what is there to say? I don't want to die. I'm scared. I'm sad. I'm so upset. He knows that. He's all of those things too. But nobody can understand how I feel. Nobody can come into my body, into my soul and really understand how I am, how I am. Not only how I am 'feeling', but how I am. (Eloise)

Here too we are presented with a poignant account of Eloise's deep sense of aloneness. We can understand from this excerpt that what is being revealed through Eloise's attempts to protect her husband is that she, like Mark, fundamentally felt that she was alone in what she was experiencing. No matter how close she was to her spouse, no matter how able she was to discuss with him how she was feeling, it was clear that there were certain phenomena that she alone could experience. Her inability to discuss her emotions and thoughts with her husband did not cause her feelings of aloneness, it brought to the surface the aloneness which was present.

We can understand by these accounts that marriage, and the roles that the participants in this inquiry were thrown into within their spousal relationships, were important factors which helped shape their pre-understandings and their current understandings. Partners in life did not automatically translate into partners in death as dying proved to be a solitary experience for the participants in this inquiry.

Summary. Each of the participants in this inquiry had a unique, complex and rich life story. The importance of exploring how these individuals were situated within their particular lives is that, in so doing, similarities and differences across individuals are highlighted. These similarities and differences can then be appreciated for the influence they have on the meanings they help create for the participants. How individuals engage with their world, how they are embodied within their world and how they make sense of past experiences, like the deaths of others, all contribute to the lived experience of dying for these patients.

What is uncovered in this consideration of the situatedness of the participants' particular lives is that the ill and failing body is inseparable from the way in which individuals understand and ascribe meaning to their lived experience of dying. There is fluidity amongst the various themes presented in this section. For instance, familial relationships at once influence how one understands death in general, and how one grapples with their own individual mortality. The un-ready-to-hand body not only makes available the concept of embodiment, but as well illustrates how an embodied way of being in the world has relational implications. By revealing the ways in which relationships with others both supported and distressed the participants we can begin to appreciate the overwhelming sense of aloneness that the dying person faces.

Situatedness of the ''Here and Now''

The participants in this inquiry were situated in a particular ''here and now'', and each of them was thrown into a situation of waiting to be transferred to the palliative care unit. The meanings that they found in their experiences were constrained by what was before them and the 'here' held particular significance. I initially believed that I would encounter individuals in a state of limbo, as they were waiting for a transfer to the palliative care unit. Although this period of waiting was significant, it did not necessarily imply that which I expected it would. What was uncovered was that the ''here and now'' in which participants were living, was replete with a sense of aloneness on the one hand, and yet, on the other hand, a transfer to palliative care was an opportunity for hope and connection.

Aloneness during the transfer. When discussing the situatedness of the ‘‘here and now’’, it is important to address the ‘here’ in relation to the actual spaces and places that the participants found themselves in. All participants interviewed for this inquiry had family and friends involved in their care. Many had turned their immediate surroundings into places representative of home, with family photos, mementos, and personal effects all around them. However, what was seen across most stories was that despite the physical and emotional proximity of others, the dying person still felt fundamentally alone.

Eloise described how she was feeling when the staff of the medical ward came in to tell her that there was a bed available on the palliative care unit and that she would be transferred there. She went on to share how she experienced the actual move. “I almost felt like a prisoner condemned to death, walking down the corridor to the execution chamber. Although, of course, I didn’t walk, and I wasn’t getting a last meal.” (Eloise) She went on to say that she was entering the death ward. She stated that this was a very dramatic way to think about her transfer, but she really did feel as though she was walking towards her death. She continued:

> I have never really been a proponent of the death penalty, and now even less. That feeling of walking towards your death, you can’t breathe. I started to feel a panic attack coming on I think when I was being brought here. So, I tried really hard to think about something else. I was watching the walls go by as I was being wheeled here. The cracks, the paint chipping, anything. Just to try to forget what was happening. (Eloise)

Eloise was admitted into a large private room with a window which faced out onto an oratory. Unfortunately, the blind in her room was broken, which meant that she could not raise it up to look out her window or to let natural light in. This for her was incredibly distressing.

> The blind is broken. Apparently I have a great view, but I can't see it. I can't see it at all because the blind is broken and won't go up. I have been asking since I got here for this to be fixed, but apparently things like this are not fixed immediately. They are not an emergency. (Eloise)

Eloise's account of her transfer to the palliative care unit illustrates how alone she felt. She was overwhelmed with aloneness while she was being transferred, overcome with a feeling of anxiety and likening herself to a prisoner. Furthermore, her description of the broken blind in her room, which did not enable her to look out into the world, was metaphorically and practically another layer of isolation. Her window was a means of accessing the outside world and she was, at least temporarily, denied that opportunity.

For Alan, the day that he had the discussion about transferring to the palliative care unit was a pivotal one for him. He described it this way:

> Yeah, I think I lost my patience. I think that the reality really hit me. This was it. Everyone knew it and this was it for me. I wanted it to be all about me then. But it wasn't…it isn't. I want to tell everyone that I see that I am dying, that this is it for me. When the meals are delivered, I want to tell the guy, 'Did you know that I'm dying?' Part of me wishes that everyone knew even though they would have nothing to say. At least they would know. (long pause, eyes well up with tears) I think that I want people to feel sorry for me. (Alan)

Alan was quite articulate about why he wanted people to know about his condition.

> My mother died when I was twelve in a car accident. She used to say something like "share the happiness, share the pain." I wasn't sure what that really meant until now. I want people to feel my pain, maybe then it would take some away from me. (Alan)

Alan felt intense aloneness in his dying and was desperate to share not only how he was feeling, but some of his pain as well. He felt misunderstood by those around him to the point where he was willing to share his feelings with strangers delivering meal trays, simply to be heard. In realizing that he was unable to do this, that his struggles were truly his alone, his desperation and sense of aloneness grew greater and greater.

Although a sense of aloneness permeated many of the encounters that I had with the participants, several of them shared that the nighttime, with its accompanying darkness, made them feel especially alone. The nighttime posed particular challenges for several of the participants. When Alan discussed with me his wishes upon transferring to the palliative care unit, he mentioned that he primarily wanted to have a private room. However, when I met with him again after his transfer into a two-bedded room on the palliative care unit, he had the following to say:

> I'm still scared. At night here, last night it was very quiet. I had a hard time sleeping. I felt very alone. I think maybe that it is not bad that I am not in a private room. At least I have someone else here too. My wife, she can't sleep here. It is too hard for her. (Alan)

A semi-private room was a way to keep some of the aloneness, which was particularly troubling at night, at bay. Simply being in the presence of another human being was enough to help make Alan feel somewhat better.

When I met with Lillian on the acute care ward she described the feeling of panic that she found particularly present at night. Although she tended to fall asleep quite easily at bedtime, she was easily woken during the night either by staff, noises or pain. Once this happened, she had a difficult time falling back asleep. For Lillian, the nighttime was the most difficult part of the day. With the quiet, not much circulation in the hallways, and no visitors, she felt very alone. This feeling of aloneness represented a vulnerability which permeated every moment.

Maintaining, losing and relinquishing control. On the acute care unit, Myriam's room was likely one of the largest and brightest, with windows along an entire wall, and plenty of room for family and friends when they came to visit or stayed overnight. She was a woman who was often surrounded by people. In fact, it was quite challenging to find a time to conduct my interviews with her, as she constantly had company.

Her room was in a quiet corner of the unit, far from the nursing station, and almost isolated from the hustle and bustle of the unit. Although she was aware that she was going to be transferred to the palliative care unit when a bed became available, she did not consider herself to be someone who was waiting.

> I'm not really waiting, it's only that we are waiting for that bed, that place, and then you want also reassurance that everything will be okay, that everything will be alright. Not that, it's not uh…everything will be alright not in a physical sense, but in

> a, in a, in a, what sense can I say? In a care sense. In, in getting the proper, the proper care, that's what I meant. (Myriam)

When the time came for Myriam to be transferred to the palliative care unit, she sent her sister to assess the room before agreeing to be moved. This is significant in that it implies that Myriam felt that she was in a position to refuse the transfer should the room not have been to her liking. It also meant that the physical accommodations that she was moving into were important.

> I told my sister to go and check the room first, whether I like it or not, before I decide to take it. 'Cuz I really wanted a room on my own, where I feel at peace. So, she decided to go and do an evaluation and when she came back up she said it's a nice room. So we said, we take it. (Myriam)

When I met Myriam for the second time, the day after she was transferred to the palliative care unit, I commented that it appeared that the physical environment was important to her, particularly because she was coming from a large private room. She agreed and said, "I was in a private room yeah. But I also wanted now, to continue in the same process." For Myriam, having enough space and place for family and friends to visit, and to accommodate them as they wanted to be ever present, was meaningful to her. She worried that if she shared a room with another patient then by doing what was important to her, she would be disturbing the other person.

The feeling that place gave to participants was as important as the look and size of it. When Myriam was first transferred to the palliative care unit, she described her feelings as being ones of uncertainty, of not knowing what to expect, and the unsettling nature of change. When I met with her after the transfer, she was not exhibiting any outward signs of sadness, distress or fear. While on the palliative care unit Myriam said, "I feel good to be here. I feel good to be at peace. I feel really comforted here. I feel in good care here. That's what is important. That is what is important…to be able to feel at peace." This was despite the fact that her room on the palliative care unit, although private, was significantly smaller than the one she had been in on the acute care ward.

Although Myriam felt very much in control of her environment and orchestrated her movements to suit her needs, Eloise felt controlled by her environment. In addition to the fact that the broken blind in her room represented a deep layer of isolation, it also indicated that there were things which were happening to her, and around her, that she could not control. Like a prisoner, Eloise was trapped in a place from which she could not escape. The broken blind was a stark reminder of that and a metaphor for everything else she could not control.

> I thought I was always in control. But now…what control? I don't even know what is really happening. I mean, I know. I get it. I am dying of advanced, metastatic ovarian cancer. I get it. I know that. But I don't know what is happening. I don't understand the medicine, or the anatomy, whatever it is, of it all. This bowel obstruction – why is it there? Why won't it just go away with treatment? (looks over to the window). And this blind. If I was in my home I would have ripped that blind right off the wall so that I could see out the window. But I can't do that here. It's not my blind (long pause), and I don't even have the strength to get up and try to pull it down. I'm sorry, I am in a bit of a foul mood today. (Eloise)

For Lillian, death was seen as a natural and inescapable fact of life, which should not be too closely linked to life. She did not believe that death should happen in the home, and when it did, she considered this to be a hardship. When Lillian's husband died suddenly in the family home, she needed to move. In addition, when her father died in his home, she perceived this as a great difficulty for her mother. It was not surprising then to learn that the hospital was her chosen place to die, and it was fitting that her hospital environment had no semblance of home. Despite the fact that she described what appeared to be a close-knit and large family, there were no signs of family in her room; no photos, no mementos, no cards, no drawings from grand-children. The starkness and impersonal nature of the hospital space in which she was living was telling. Death was a part of life, but life and death did not mix.

Opportunities for connection. In some instances, the phenomenon of waiting to be transferred to the palliative care unit was a confirmation of what participants already felt to be true; that they were dying. Sometimes, this transfer was a confirmation for the family more so than for the patient, as in the case of Eloise. Eloise spent some time discussing her young daughter with me, and sharing how she and her husband had explained Eloise's illness to her, and at what point they told her that there was no longer a hope for a cure. Eloise spoke about how difficult it had been for her to share her emotions, thoughts and fears when she knew that she was dying, when everyone around her told her to wait and pray for a miracle.

When Eloise was told that there would be a transfer to the palliative care unit, she said that this was very helpful in allowing her to communicate with her family. "It is now official" she said. "I have the seal of approval to die. Seriously though, now my family, my husband, can't say 'don't talk like that', I'm not the only one talking like that…the experts are." The potential transfer to the palliative care unit represented an important opportunity for Eloise to connect with her family. It was the ice-breaker she needed to start the difficult discussion about her death and it provided her with the security to broach the subject, knowing that she could not easily be dismissed.

Eloise continued to share the following regarding her transfer to the palliative care unit:

> For me, it means, hopefully, a better place. I hear it is quiet and clean and the staff are experts in caring for people who are dying. I am hoping for a better quality to my last days, or weeks, or whatever I have. But for my husband, and other people, this was really 'Oh shit, she is really dying'. Thankfully this has happened or else I would still be listening to how miracles happen. (Eloise)

Her actual transfer to the palliative care unit was for Eloise very meaningful. On the one hand, it was liberating in that it allowed her the opportunity, like opening the door to a discussion, to speak about what was happening with her family. On the other hand, as we saw earlier it exacerbated a feeling of aloneness and loss of control.

Summary. When considering the situatedness of the ‘‘here and now’’, we see that there are several meanings embedded within the theme of space and place. Participants within this inquiry found themselves feeling aloneness, even when surrounded by others. Several participants struggled with control, some maintaining it, others losing it and still others giving it up. This impacted the meaning that the actual transfer to the palliative care unit has for these participants. At the same time, the transfer to the palliative care unit had the potential to provide an opportunity for establishing deeper connections between the dying person and their family.

Summary of Findings

My interpretations of what the participants shared with me during the conduct of this inquiry revealed the unifying themes of awareness of dying, of embodiment, of grappling with one's own finitude, and of aloneness which are woven throughout the lived experience of dying for these individuals. We can recall for instance that the concept of embodiment is represented in several of the participants' stories, like Alan who described his loss of independent toileting ability as painfully undignified, and Myriam who hoped above all else that she would be able to eat again. In the midst of the aloneness precipitated by the transfer to the palliative care unit we recall that Eloise also described the transfer as a blessing because it represented an opportunity to now open the door to discussing her death with her family. An ability to control, a struggle to control and a relinquishment of control were found in all three levels of situatedness which guided this inquiry. Whether it was Myriam who felt that her destiny was being controlled by God, or Blanche who felt that it was her right to control when and how she died, each participant understood their lived experience of dying as they waited to transfer to the palliative care unit in terms of what they could control, how they could control it, and what it meant when they were unable to be in control. These above mentioned themes all contributed to the meanings which were ascribed to these individuals' Being-in-the-world and help us to understand the lived experience of dying for hospitalized patients waiting to be transferred to a palliative care unit.

What I came to understand from the analysis of this inquiry was that the meaning of the lived experience of dying for these hospitalized patients had been shaped by circumstances and experiences throughout their entire lives. We can recall that the three forms of situatedness used in this inquiry were meant to help frame the themes which would be revealed through an interpretation of the participants' stories. These forms of situatedness allowed me to represent themes in a meaningful way, and in a way which ties in nicely with Heidegger's notion of historicality (1962). The pre-understandings possessed by each dying person in this inquiry laid the foundation for the understanding of their own finitude and the meanings embedded within it. Heidegger (1962) further states that temporality is an important factor in considering how one lives in the world. The participants in this inquiry created meaning based upon what their pasts revealed, what they were currently living and what their anticipations were for the future.

The decision to represent my interpretation of the analysis in this inquiry using the constructs of the situatedness of a contextual background, of a particular life and of the "here and now" must not be viewed as a way of clearly delineating into which category the various themes fit. Instead, this representation is meant to portray the many levels of fore-structure of understanding which are available to draw upon in trying to find meaning and understanding in an experience, in this instance, the lived experience of dying. A close examination of the interpretations as they are represented in this chapter indicates that there is potential overlap amongst these levels and they are in many ways dependant upon one another. So, for instance, the overarching concept of the situatedness of a particular life is dependant upon, and influenced by the individual's contextual background. Furthermore, these levels of situatedness must not be considered as static. There is potential fluidity between these levels through the various themes which have been presented. For example, the theme of aloneness is represented in both the situatedness of a particular life and the "here and now". This fluidity and interdependence will become more evident in the upcoming Discussion chapter, where I move towards a more overarching discussion of key findings.

Reflections on this Analysis

Eleven terminally ill cancer patients allowed me the privilege of sharing some of their last moments with me. They were gracious in their honesty, thoughtfulness and insightfulness. As much as I learned and grew from this experience, I do feel that they too benefited from our interaction. Several participants echoed the comment made by Claude when he thanked me for meeting with him.

> "It was lucky that you came and saw me and that I shared some of my personal thoughts and reflections, my final thoughts. The ideas that I did not know, that I would not see. I don't know what you are going to do with this interview, but, do with it what you like. Me, I said what I had to say." (Claude)

Although the interpretations presented in this chapter are my own, I believe that the participants' conversations with me created new meanings for them. In other words, even though I acted as the interpretive researcher, by engaging in conversations with me for the purposes of this study, the participants were potentially able to uncover new meanings related to their experiences for themselves.

Chapter 5: Discussion

The research question guiding this inquiry was: *What is the lived experience of dying for hospitalized patients who are waiting to be transferred to a palliative care unit for end of life care?* I addressed this question through an interpretive phenomenological lens as this research approach seeks to uncover meanings of phenomena experienced by individuals through the analysis and interpretation of their stories (Benner, 1984; 1994). The individuals whose experiences were being explored in this study were terminally ill hospitalized cancer patients admitted to acute care wards who were on the waiting list for transfer to the palliative care unit within the same institution. The reason for transfer was for specialized end of life care.

In Chapter 4 I presented the key findings of this study. In this chapter I now present the salient themes which appear to me to characterize the findings of the inquiry are highlighted and comparisons are made with knowledge derived from existing literature. In essence, this chapter represents an additional layer of interpretation based upon those presented in Chapter 4. Links are made to a wider clinical practice and research context by analyzing the diverse and many faceted realities which are characteristic of the patient's experience of the phenomena of interest. This approach is characteristic of the constructivist paradigm, which ascertains that single explanations for complex phenomena are neither possible nor desirable. Instead, by developing multiple interpretations, and exploring various themes related to the phenomena being questioned, seemingly contradictory ideas are brought forth and provide for a more realistic, relevant, and potentially useful portrayal of what is being examined (Appleton & King, 1997; Wright, 2012). At the same time, multiple interpretations do not imply the absence of cohesion or commonalities.

The following key findings will be linked to existing literature and implications for practice and research will be discussed:

- Participants transitioned to an awareness that they were dying prior to being told that they were by their health care providers. The impending transfer to the palliative care unit was not critical for this awareness.
- Participants' awareness of their own finitude was an experience imbued with a profound sense of aloneness.
- Participants saw the impending move to the palliative care unit as an opportunity for hope. At the same time, responses to the actual transfer to the palliative care unit were in part influenced by notions of control.
- Religion and the belief in an afterlife offered hope and comfort, and had the potential to engender feelings of aloneness.
- Participants who stated that they were not religious found comfort in rationality and a secular spirituality.
- Both religious and non-religious participants appeared to find comfort in relinquishing control to a higher being.
- An appreciation of embodiment is key to understanding the construct of dignity in the dying person.

Transitioning to an Awareness of Dying

I began this inquiry expecting that participants would share with me experiences of being in a state of liminality, as they found themselves living between two realities, an in-between living-dying phase which coincided with the confirmation that they were now officially moving to palliative care. I anticipated that everything that participants would share with me would be in relation to this transition to end of life care. As a clinician and hospital administrator I understood the moment at which a patient is labeled a candidate for the palliative care unit to be a pivotal and transitional point in their illness trajectory. I expected that it would be at this point that patients would be transitioning from a state of suspicion or pretence of death to one of open awareness (Glaser & Strauss, 1965). Instead what was uncovered was that the process of transitioning to an awareness of dying was not hinged to that one event or moment in time, but that it had, in fact, happened earlier. Participants in this inquiry transitioned to an awareness that they were dying prior to having the discussion with the palliative care team about a transfer to the palliative care unit for end of life care. The knowledge that there was an impending transfer to palliative care was not critical for this awareness of dying.

In health care literature not specific to palliative care, many authors describe transition as a time of inner re-orientation and change (Kralik, Vistentin & van Loon, 2006) as individuals process new knowledge, change their behavior and often take on new social roles (Wilson, 1997; Meleis et al., 2000). Transitions often trigger fears of helplessness and abandonment by the health care system (Shofield et al., 2006). The term transition is often used to describe change processes through which patients move, and although many authors have tried to come to an understanding of the theme of transition at the end of life, it is a term not well conceptualized in the palliative care literature (Hui et al, 2012). Renz and colleagues (2012) attempted to understand the process of transition of hospitalized dying patients in Switzerland by conducting interpretive phenomenological analysis of the psychotherapy records of deceased cancer patients. Their research suggests that transition, which they conceptualized as a transformation of perception, has three stages, pre-transition, transition itself and post-transition. The step-like conceptualization they describe is reminiscent of van Gennep's (1960) theory of rites of passage. The stage of pre-transition occurs before an inner transformation of perception when the patient feels his or her needs, such as thirst, pain, and emotions. The transition itself is seen as a phenomenon which implies losing ego consciousness, with patients typically showing signs of anxiety and physical struggling. Finally, they describe post-transition / spiritual opening where patients are in a serene state, beyond anxiety, pain or powerlessness. The authors described patients in this phase as being "unable to speak but still hearing" and "communicating by gestures, uttering, or single words" (Renz et al., 2012, p. 286). Although not clearly articulated in the paper, the post-transition phase described appears to be referring to the terminal phase. The transition itself then is seen as occurring over the course of a few hours, and when individuals are entering a state of unconsciousness prior to death.

Although attractive in its straightforwardness, Renz and colleagues' (2012) model of transition seems to be referring to a narrower, more specific experience in the overall experience of dying than the one uncovered in my inquiry. The participants I met who had transitioned to death awareness did so earlier than a few hours before death. They had come to some awareness of their own dying by the time I met with them, at a point where they were still conscious, oriented and able to converse. Indeed, several participants, like Lillian, shared that they somehow knew they were dying before being told so by their physician. Although there was an element of anxiety expressed by many of the participants in my study, it is unclear if the transition to an awareness of dying itself was characterized by the extreme anxiety and physical struggling suggested by Renz and colleagues (2012). Since this transition to death awareness had occurred prior to my meeting the participants, I was not privy to witnessing their reactions and emotions during that time. What was evident however during my conversations with them was that there appeared to be a sense of resignation and peace amongst those who openly discussed the awareness of their impending death with me.

Being aware of one's terminal illness and accepting death are two different phenomena, even though they are often conflated one with the other (Thompson et al, 2009). I learned that the participants in this inquiry were all aware that they were dying, and that this awareness had occurred prior to the discussion they had with their health care providers about being transferred to the palliative care unit. Contrary to my presumption that an event external to the patients themselves (i.e. a label of "waiting for transfer to palliative care") would be critical to their death awareness, it was instead something internal to the person which informed them that that their death was imminent. When Eloise was asked if it was the conversation which she had with the doctor about a transfer to palliative care that made her realize she was imminently dying, she said the following: "I knew even before the doctors told me. I have known that I was dying for a while now…maybe a month or so". Eloise was aware that she was dying, despite the fact that no one else was talking about it. Her illness was being discussed, and she had discussions with her health care team about the futility of any future curative treatments, but her actual dying was something that she came to understand on her own.

Heidegger (1962) asserts that human beings have the capacity to know and understand that they are always, already at the possibility of their own death. For this reason, he states that death is the ultimate and most fundamental meaning-giving possibility and consequently, it is his fundamental ontology. With this understanding however, people can choose how they want to live their lives. People can choose to live either inauthentically (by denying their finitude of existence) or they can choose to live authentically, by choosing one's existence in accordance with one's limited possibilities (Heidegger, 1962). It appears that several of the participants in this inquiry had chosen, at least temporarily, to live in the latter. By acknowledging that they were dying, participants like Eloise, were able to experience their Being-in-the-world in a way which was different, and, Heidegger (1962) would state, more authentic, than if they denied their impending deaths. My intention is not to present this as a value judgment (i.e. that an authentic existence is superior to an inauthentic one) but rather as an indication that individuals with life limiting illness have the capacity and, more importantly, may have the propensity to face their future and interact with their world while acknowledging their imminent demise.

The Aloneness of Dying

The theme of aloneness in facing one's death has been explored in the palliative care literature, and what I have labeled as aloneness in this inquiry appears to be akin to existential loneliness. The term existential loneliness has been used to refer to an intrinsic aspect of being human (Booth, 1997, p. 24) and "an ever present feeling of aloneness, against which one defends oneself for much of the time but for which there is no permanent remedy" (Mayers, Naples, & Nilsen, 2005, pp 95 – 96). Therefore, although one may distract oneself with work and vacations and everyday tasks, when faced with disruptive events such as impending death, these distractions may prove to be inadequate (Ettema et al., 2010). Consequently, it is when faced with life threatening situations that we realize we are ultimately alone in our reflective consciousness (Ettema et al, 2010). For the participants in this inquiry, the awareness of their dying, of their finitude, was an experience which was imbued with a profound sense of aloneness.

In a study conducted by Zack (1991) the theme of loneliness was conceptualized and seen to be an unpleasant feeling of separateness, aloneness and emptiness. Loneliness was found to be related to 3 associated conditions: (1) deficits in relationships that provide a sense of attachment and the opportunity for nurturance, (2) the absence of a spiritual belief system, and (3) a pattern of living-dying characterized by fear and uncertainty. There are instances of similarities between the interpretations in my inquiry and the findings in Zack's (1991) study. Alan's sense of aloneness, represented in part by his angst that, although he was supporting his wife during his dying, there was no one available to support him, speaks to the perceived deficit in relationships which could be associated with loneliness. Furthermore, like the participants in the Zack (1991) study who experienced loneliness, Alan was without a clear spiritual belief system, and when I met with him he was fearful and uncertain about his future and his dying. Contrarily Eloise, who eloquently described her feeling of aloneness in contemplating her finitude, was in a seemingly loving and committed marital relationship, had turned to a spiritual belief system, and was experiencing an illness trajectory which did not appear to be filled with much uncertainty. Despite all of this, Eloise was not immune to or protected from a sense of aloneness when faced with acknowledging her finitude. We can understand from these two exemplars that the phenomenon of aloneness when facing one's own death is more complex and nuanced than the conditions described by Zack (1991).

In a study of end stage hemodialysis patients one of the main themes identified as representative of the patients' inner thoughts and feelings about death and dying was being alone with existential thoughts (Axelsson et al., 2012). As with Eloise who didn't feel she could talk to her husband, participants in the Axelsson (2012) study found it difficult to talk about death and dying and did not want to burden their families with their existential questions and preoccupations. When these participants did try to talk about death with their family, they felt that they were being pushed away. This desire to protect family by not speaking about worries and fears related to death and dying, leaves patients facing these existential questions alone. This phenomenon has also been described in patients with other diseases approaching the end of life (Sand & Strang, 2006; Ek & Ternestedt, 2008).

The essence of aloneness which was present in several of the participants' experiences of facing their own finitude is best exemplified by the following statement by Eloise: "But nobody can understand how I feel. Nobody can come into my body, into my soul and really understand how I am, how I am. Not only how I am 'feeling', but how I am." (Eloise). The experiences of the participants in this inquiry resonate with the literature which states that existential loneliness or aloneness and death are intertwined (Mayers et al, 2002). Heidegger (1962) viewed aloneness as an essential aspect of human existence. The existential loneliness which is experienced when grappling with one's finitude cannot be relieved by the presence of others; in the anticipation of death one remains fundamentally alone (Mayers, Khoo, & Svartberg, 2002). As was uncovered within my inquiry, even the presence of a loving marital relationship or a close parent-child relationship cannot mitigate the experience of aloneness when dying. This echoes Heidegger's (1962) contention that death is ultimately one's own unique experience and that *Dasein* always faces death alone.

The Anticipated Transfer: Hope and Aloneness

There is literature which reports that for some patients, a transition to palliative care has meant a shifting of the focus of hope. Patients move away from hoping for a cure to hoping for a better quality of life, being able to live life to the fullest, not suffering, and experiencing a peaceful death (Benzein, Norberg & Saveman, 2001; Duggleby & Wright, 2004; Herth, 1990; McKechnie, Macleod, & Keeling, 2007). Criteria which have been reported to be important to the experience of transition to palliative care include the place of care, the qualifications and experience of care professionals providing the care, and goals of care (Burge, Lawson, Critchley & Maxwell, 2005; Rayson, & MacIntyre, 2007; Reinke et al., 2008). Similarly, the participants in my inquiry considered a transfer to the palliative care unit to be primarily a positive event. They felt that they would be cared for by professionals who were better able to meet their needs, that their quality of life would improve and that the physical environment would be more comfortable and welcoming to family and friends. It is important to note that all of the participants who were recruited into this inquiry had already engaged in at least one conversation with a palliative care specialist prior to being placed on the list for a transfer to the palliative care unit. During this encounter they would have had the opportunity to ask questions and to engage in the decision making process related to the transfer which may have been critical to their perceptions of palliative care, expectations and hopes.

In addition, for the participants who participated in this inquiry, waiting to be transferred to the palliative care unit for end of life care implied that they were not expecting to return home to die. There is much discussion in the literature about patients' overwhelming desire to die at home (Fischer, Min, Cervantes, & Kutner, 2013; McGrath, 2007). Although being hospitalized has also been described as a huge relief for hospice patients, these patients have considered that they were guests of necessity, being confronted with unfamiliar worlds and faces (Spichiger, 2009). In Spichiger's (2009) study, several of the hospitalized hospice patients interviewed hoped to return home as soon as the care at home was organized. This study reflected the patient's experience with the hospital as their temporary and final place of residence. Within my inquiry, discussions about returning home, as a hope or concrete plan, were absent from the stories of the participants. Even Mark who was perhaps the most hopeful about improving his physical functioning did not mention a return home as either a goal or a desire. Indeed, no one that I interviewed stated that they wanted to return home, or that they hoped to die at home. The only time that home was mentioned was by Alan, who said that he knew he would not be able to return home as he could not bear the thought of his wife having to provide basic care for him.

Along with the hopes which participants had while anticipating a transfer to the palliative care unit, the actual move there from the acute care ward appeared to amplify the participants' existential aloneness, in particular if there was a perceived loss of control. Conversations with patients about transitions from curative treatment to palliative care have been known to trigger concerns about dying, loss, grief, and abandonment (Back, 2005) and uncertainty (McKechnie et al., 2007). In part this is because patients have reported having limited knowledge with regards to the purpose and timing of a transfer to a hospice or palliative care unit. They may be uncertain about who initiated the transfer, experiencing increasing symptom burden, may not be involved in decision making, and once transferred to palliative care, may experience a sense of waiting for something to happen (Larkin et al., 2007a; Larkin et al., 2007b, McKechnie et al., 2007). Misunderstanding what palliative care can do has been shown to result in a reluctance to accept palliative care services (Ronaldson & Devery, 2001).

In the study by Ronaldson and Devery (2001), participants equated palliative care with death rather than an opportunity to optimize quality of life and this led to feelings of fear. Rayson and McIntyre (2007) state that discussions of transitioning to palliative care often involve a shifting of care goals and strategies with palliative treatment, which implies accepting that a situation is hopeless, or that hope for a cure is futile. The move to palliative care is often considered a confirmation that the end of life may be near and this confirmation brings with it an awareness of temporariness which in turn creates a sense of having very little time left to life (Ellingsen et al., 2012). Because the participants in this inquiry were very close to death, only 5 were transferred to the palliative care unit before they died. Despite the almost overwhelming sentiment that a transfer to the palliative care unit was going to be a positive event, those who shared their experience of the move highlighted that these were extremely difficult moments, during which they felt panic and an overwhelming sense of aloneness. Eloise likened the actual transfer to being a prisoner who was approaching death row. Even though she had been looking forward to a move to the palliative care unit, in the hopes that it would provide her with opportunities for a better death, she still found the experience of moving difficult. Through Alan's narrative of the transfer I interpret that he felt panic and was distraught, in part because those around him, namely staff, did not seem to appreciate or even notice how he was feeling. A commonality shared between Alan and Eloise was that during the move to the palliative care unit and shortly thereafter, there was a perceived loss of control. Eloise described how she was unable to fix the broken blind in her room and how the timing of the transfer was beyond her control. Likewise, Alan shared how afraid he was of the unknown; he was afraid of not knowing how it would be, how long he would suffer, and how he would experience his dying. Myriam on the other hand who was not distressed by the actual move itself felt that she had a very strong sense of control over her situation. She described how she sent her sister to first see the room before agreeing to be moved, implying that the transfer was not something that was being done to her, but something that she was in control of. Issues of making choices, patient autonomy and involvement in decision making have been shown to be important to dying people (McKechnie et al., 2007).

Although I was unable to find any literature which specifically focuses on the patient's experience of the transfer from an acute care unit to a palliative care unit or hospice, there is literature which examines the impact of relocation stress for patients moving from a palliative care unit to a nursing home (Porock, Martin, Oldham, & Underwood, 1997). Relocation stress is defined as a "state in which an individual experiences physiological and / or psychological disturbances as a result of transfer from one environment to another" (Carpenito, 1993, p. 224). As well, McGrath (2006) has researched the experience of Aboriginal people relocating for treatment during end-of-life care. This literature can provide some insights into the distress that certain participants in this inquiry experienced during the move to the palliative care unit. Relocation stress is characterized by feelings of loneliness, apprehension, depression and anxiety (Carpenito, 1993). In studies exploring relocation stress in the elderly population, the most severe stress has been found to occur during the time of entering a new institution (Brooke, 1989; Tobin & Leiberman, 1976) and the most profound effects of relocation can be observed during an individual's first month in a facility (Brooke, 1989). Relocation has been identified as being a frightening experience (McGrath, 2006). For Aboriginal people required to leave their communities and family ties, the experience of relocation has been described as one of fear, including fear of travel, fear of loneliness, fear of communication barriers and financial worries (McGrath, 2006).

It is unclear whether or not the participants in this inquiry were experiencing relocation stress as it has been defined in the literature. Additionally, although the circumstances of palliative Aboriginal patients are unique, and their specific context was not represented by the participants in my inquiry, we can still draw similarities between McGrath's (2006) findings and the findings here, particularly the notions of fear and aloneness. The risk factors for relocation stress described by Manion and Rantz (1995) which include, but are not limited to, past losses and poor physical health can often be found in patients who are at the end of life and who are waiting to be transferred to palliative care. The participants in this inquiry were in poor physical health and had experienced, and were continuing to experience, profound losses which would ultimately lead to the loss of life. Although they were all prepared for the transfer to the palliative care unit, and many had participated in the decision to move, the timing of the move still occurred without any warning, another risk factor identified by Manion and Rantz (1995). Furthermore, none of the participants had themselves visited the palliative care unit, nor had they met any of the staff members who would be providing direct care to them once admitted. It can be noted however that when a family member visited the palliative care unit and was able to provide the participant information and reassurance it appeared to be helpful.

Religion and Spirituality

In the next section I discuss religion, the belief in an afterlife, non-religion or atheism, and spirituality in relation to how they help us to understand the lived experience of dying. This inquiry helps us to understand the many layers of complexity which can be uncovered when we being to consider the influence of religion, atheism or non-religion and spirituality on the experience of dying. Within this study we begin to see that religion can, within the same person, be a source of comfort and hope while at the same time, the very thing that offers comfort and hope can make manifest the aloneness which is inherent in dying. Spirituality is considered in a secular way, and this extended conceptualization allows us to understand how spiritual beliefs can impact the lived experience of dying for individuals who we may not have otherwise considered as spiritual.

Religion and belief in an afterlife. Religious beliefs can be powerful and significant to some people facing terminal illness (McGrath & Newell, 2001) and there is a need to understand the difference between religion and the more generalized notion of spirituality, which will be elaborated on later in this chapter. Religion can be defined as an organized system of faith, beliefs, worships and practices which nurture a relationship with a superior being or divine force (Dombeck & Karl, 1987; Emblen, 1992; Murray & Zentner, 1985; O'Connor et al., 1997). A religion is a group, and religious people are those who identify with the group and adhere to its normative practices and beliefs (Hogg, Adelman, &

Blagg, 2010). The participants in this inquiry came from a diverse set of backgrounds with regards to religious beliefs. At the time of the interviews, six of the eleven participants claimed no religion, despite the fact that most had been raised in religious households. For the remaining five, religion played an important role in their lives. For some participants in this inquiry religion, the belief in an afterlife offered hope and comfort, and had the potential to engender feelings of aloneness.

Empirical studies of religion at the end of one's life generally suggest that religious belief is beneficial and provides comfort as death approaches (Idler, Kasl, & Hays, 2001). For several of the participants in this inquiry, religion and a belief in God and an afterlife provided them with a sense of comfort and a way to help find meaning and purpose in their lives. What I uncovered, however, is that a reliance on religion, although comforting, did not mitigate feelings of aloneness and possibly vulnerability. Regardless of whether the person was religious or spiritual, the comfort and hope, however fleeting, which most individuals in this inquiry were able to attain from their beliefs was linked to the notion of control, and the feeling that participants were able to securely let go, and give in, to something greater than themselves.

Belief in the afterlife: hope and comfort. Finding comfort in the belief of an afterlife has been explored in the literature. Pevey, Jones and Yarber (2008) interviewed 38 hospice patients with the express objective of determining whether or not religion was a source of comfort for them, and if so, how. They found that when religion did offer comfort it did so, in part, by giving individuals the hope of an afterlife. Similarly, in a survey of patients with end stage congestive heart failure, the belief in an afterlife was linked to how often individuals felt the presence of God, found strength or comfort in their religion or spirituality, and felt God's love either directly or through others. Individuals who felt secure in their religious beliefs and who were comforted by them held strong hopes with regards to an afterlife (Edmonson, Park, Chaudoir and Wortmann, 2008).

Certain participants in this inquiry shared with me their belief in an afterlife and, more specifically, in Heaven. This belief appeared to offer them comfort. For Lillian, eternal existence by way of Heaven meant that she would be reunited with her deceased husband and parents. For Eloise, Heaven offered hope that she would remain connected with those who would be left behind, particularly her daughter. In trying to come to terms with the fact that she would be dying and leaving her child without a mother, Eloise relied on her belief that she would go to Heaven and the idea that she would, in some way, remain connected with her child was comforting to her.

The comfort and hope that the belief in an afterlife offered was not limited to the idea that it would offer connections to loved ones. Blanche expressed her belief that when she died she would attain a closer connection with a higher being. For her, comfort was wrapped in the idea that she would be met in Heaven by Jesus. "I am expecting that Jesus will be waiting for me with absolution, and this gives me support. I know that there will be magnificent things waiting for me, and because of that, I have a lot of hope". (Blanche)

Still another way in which religion and the belief in Heaven offered support was that it had the potential to provide a distraction from what was occurring in the patient's body and in the world around them. Lillian, when describing how she imagined Heaven and the afterlife to be, stated that because she was not certain of what she would encounter and experience after death, she was kept wondering. This wondering was a welcome distraction, and it was this distraction which offered her comfort. Imagining Heaven brought her back to feeling like a child. This idea of the afterlife as an interesting distraction for terminally ill patients, and as something that is unknowable, has been commented upon before (McGrath, 2003).

Contrary to being a source of comfort, other individuals experience religious struggle as they approach death and this can lead to increased anxiety, depression and functional disability (Burker, Evon, Sedway & Egan, 2004). Religious struggle is defined as the breakdown of religious worldviews, when individuals perceive that they are being abandoned or punished by God in the course of stressful life events. During religious struggle, God continues to exist and maintains control but does not provide the individual with care and comfort (Edmonson, Park, Chaudoir, & Wortmann, 2008). Religious struggle was not a theme which was uncovered within the stories of the participants in this inquiry. Only Sabrina expressed difficulty understanding why she was confronted with her illness, however she did not appear to be angry at God, nor did she challenge why this was being done to her.

The aloneness of religious beliefs. Although belief in an afterlife, representing an eternal existence in Heaven, was reassuring and comforting to those who ascribed to it, it appeared to me that these beliefs also encouraged aloneness and possibly vulnerability. Imbued perhaps with more hope than certainty, there was an apparent concern that a belief in Heaven, and everything that it represented, could be challenged by outsiders. It was recognized by some participants that the implications of having their beliefs questioned would be unsettling, and therefore strategies were put into place to ensure that this did not happen.

When Lillian, a devout Catholic, initiated a discussion of the afterlife and described how she imagined Heaven would be, she immediately concluded by saying that she wanted to change the subject. I understood her need to change the topic to imply that for her, sharing religious beliefs and hopes placed her in a position of vulnerability. By sharing her beliefs with me, she was opening herself up to having the very thing which offered her comfort being questioned and challenged. For Lillian, engaging in thoughts about Heaven may have been something which was best done alone.

Eloise offered a unique perspective as she was the one participant in this inquiry who had turned to religion because of her illness. Despite the fact that religion had played no role in her life previously, since her cancer diagnosis Eloise has begun to think about God as a reality, and of an afterlife. She described how, perhaps because her reliance on religion as a source of comfort was new and outside of her previous way of Being-in-the-world, she was uncomfortable sharing with her husband that she had begun praying. She described her husband as someone who was not religious, and therefore, it is possible that she felt that the comfort she was now getting from religion would be challenged or questioned by him. Eloise shared that when she began praying she did so secretly, and felt that she was perhaps being somewhat hypocritical. We are reminded of Eloise's comment about praying, "I did it in secret, like I was having an affair with God. It is hypocritical I know – but I thought, what if?" (Eloise) Despite being married and having a family, Eloise's relationship with God was one which she engaged in alone.

Eloise is certainly not unique in turning to religion when faced with stressful life circumstances. It has been reported that there can be little interest in religion or spirituality when things are going well, but that new questions may be asked when illness strikes (Swinton & Pattison, 2010). In a study of 108 women undergoing treatment for various stages of gynecological cancer, 49% reported becoming more religious after their diagnosis and no women stated that their illness had caused them to be less religious (Roberts et al., 1997). This information was gathered using a self-administered questionnaire and did not define religiosity nor did the authors differentiate between religion and spirituality.

Facing illness and one's mortality can be an opportunity for opening up to new experiences, self-awareness and enhancing meaning in life. In this inquiry we see this phenomenon occurring with Eloise, who turned to prayer and asked herself questions about an afterlife and Heaven as she approached death. This is contrary to the findings in a previous study, which found that when ill individuals turned towards religion, it was a strengthening of previous beliefs, and not an embracing of new ideas (McGrath, 2003).

The absence of religion. In my inquiry, non-religious individuals facing their deaths found comfort in rationality and a secular spirituality. Collin (2012) collected information on six hospice patients who declared themselves as non-religious but were at the time of the study, questioning the place of a transcendent power in their current and future circumstances. Despite declaring themselves as non-religious, the respondents nevertheless wrestled with religious concepts and demonstrated a need to talk about religious and spiritual issues. Two broad themes emerged, one of which was anger at God, who was blamed for their current condition. The second was the concept of God as someone who could provide a supportive role and a form of afterlife. There was also fear, both of being parted from loved ones and of physical suffering as death approached. These fears were paralleled by the hope that they would move on to a better place, and that those who were left would cope well with their loss.

All 6 of the 11 participants in my inquiry who stated that they were not religious had been raised in religious households. Although none of these participants referred to themselves as atheists, they did fit the definition of what an atheist is; i.e. one who has a disbelief or lack of belief in the existence of God or gods ("Atheist", n.d.). As adults, even in the face of death, belief in God did not occupy an important place in their lives and it was neither a source of hope nor of comfort. Of these 6 individuals, Javier and Claude were most emphatic about their disbelief in God and an afterlife, and Claude went further to question the rationality of others who would find comfort in religion. Both of these men were well educated and well read in philosophy and politics. They felt that to believe in religion was incommensurate with being an educated and rational human being. Unlike the participants who found comfort in religion, and specifically in the belief in an afterlife, Claude found comfort in what he referred to as rational thinking. We are reminded of Claude's statement that "what brings me comfort is to have arrived at a rational reflection. That the world is…that God does not exist".

In the Collin (2012) study individuals were found to blame God for the ills of the world and for their own personal plight. Although we can see some similarities between the findings of this study and Claude's account, Claude did not appear to blame religion per se, but instead he blamed religious leaders for what he claimed were injustices in the world. Despite the fact that one can theoretically denounce a corrupt organization but still believe in the core values and foundation that preceded the corruption, it appears that for Claude religion and belief in God could not be comforting nor a source of hope.

Previous studies of hospice patients have found that participants with atheist beliefs have an angry rejection of religiosity (McGrath, 2002). The experience of hardship, or witnessing the injustices of life has been noted as a significant obstacle to entertaining religious beliefs (McGrath, 2002). This idea that disillusionment with the way that the world functions makes it difficult to rely on religion is evidenced in the story of Javier. When Javier was a young man of 15, he had planned on becoming a priest. He explained that he changed his worldview for reasons which he couldn't clearly articulate. He did share, however, the following: "No, I just didn't believe, that is all. I was in school. I was learning philosophy, culture, Marx, Lenin. This is more real than believing that there is a paradise after death. After death, we are dead. There is nothing that happens after that." (Javier)

A quote from a paper published by McGrath (2003) which explored religiosity at the end of life for hospice patients being cared for at home resonated with me, as it held similarities with Javier's life story. In this paper there is a participant's account of why he was no longer able to gain comfort from religion: "No, no, I haven't got the religious faith there….I saw so much death in my life and man-made. When I lost my son in an accident with a tractor it cut me right off [from religion]" (p. 887). This quote reminds me of Javier's experience of living through the Chilean revolution when he was a young man, and hearing his story of being imprisoned and his friends being dropped into the ocean by a helicopter, never to be seen again. We are left to wonder then, what the implications are for people who do not believe in God when they are dying. What do they have to turn to? Where – if anywhere – do they turn to for comfort, for hope?

Smith-Stoner (2007) attempted to answer some of these questions via a pilot study in which she aimed to uncover the end of life care preferences for atheists, but as with many of the studies done on similar topics, the information was gleaned from healthy individuals. Still, her findings are significant in that they shed some light on what the unique needs of atheists might be. First, respondents shared that components of a good death would include a respect for their non-belief and the withholding of prayer or any other references to God. This fear of being inundated with external religious forces was not raised as in issue or a concern by the participants in my inquiry.

Another central theme from participants in the Smith-Stoner (2007) study was a strong preference for physician-assisted suicide. Contrary to that finding, in this inquiry, only Blanche, a devout Catholic, alluded to the fact that she was hoping for, and possibly expecting, palliative care to provide her with a hastened and deliberate death. None of the 6 participants who identified themselves as being non-religious seemed to hope for, or expect physician assisted suicide, although it should be noted that this question was not asked directly. Furthermore, none of these individuals alluded to the fact that they were tired of living and looking forward to dying. I find this to be particularly important in light of the fact that during the time of these interviews, Quebec was in the midst of great public and professional debate concerning changing legislation to make physician assisted suicide and euthanasia legal in the province for people with end stage disease. As this was already a discussion which was happening in the media and amongst the public, I assume that participants would have been more prone to broach the subject if it were a preoccupation for them.

Except for Eloise, the non-religious participants in my study did not suddenly turn to religion when faced with a terminal illness. This is supported by other research as well. When McGrath (2003) interviewed 14 hospice patients, being cared for at home, with a prognosis of less than six months to live, she found that most did not seek explicit comfort through religion in response to their illness. However, what is important is that although these participants were not actively seeking religion as a result of their illness, they did hold spiritual perspectives which were important to them.

Secular spirituality. Even though there is a growing body of literature on spirituality, there is no consensus on a definition for this concept (Tanyi, 2002). Spirituality can be considered as a sense or meaning that each person is making from life or interprets from events and experiences (Frankl, 1977). Spirituality has also been defined as a personal pursuit of existential understanding and an approach to the divine and sacred which typically revolves around self-transcendence (Helminiak, 2006; Miller & Thoresen, 2003). In our secular society (Taylor, 2007) however, explicit or implicit religious connotations associated with the term spirituality have been changed so that many definitions do not mention the word God or any higher power (Chochinov, 2006). It is not uncommon for people who are not religious to still have a place in their lives for spirituality. In fact, in a study involving hospice patients, it was noted that patients acknowledged spirituality as part of their total existence as they got closer to death, whereas they initially related spirituality directly with religion (Hermann, 2001).

Amongst all of the participants in this study Claude was the most vocal about his disbelief in an afterlife and resentment of religion. At the same time he was the individual who spoke so emotionally and with conviction about his belief that the woman who had fulfilled the role of mother in his life, and who had died several years previously, was the one who was helping him to make this journey towards death, and who had helped him to reconcile with his children. Although Claude did not identify himself as a spiritual person I understood this belief to be a secular spirituality.

Although the definition of spirituality is variable, with one comprehensive review of the health literature identifying 92 separate definitions (Unruh, Versnel & Kerr, 2002), there have been some attempts to define spirituality from the perspective of those who are dying (Chao, Chen, & Yen, 2002). Ten themes, in 4 broad categories have emerged: communion with self (self-identity, wholeness, inner peace); communion with others (love, reconciliation); communion with nature (inspiration, creativity); and communion with a higher being (faithfulness, hope, gratitude) (Chao et al, 2002). An attempt has also been made to apply a three-fold model of spiritual care to those individuals who identify as being atheists. This model is very similar to the themes described above in that it includes the realms of the intrapersonal (self-acceptance), interpersonal (relationships with family and friends), and connections to nature (animals and environment) (Smith-Stoner, 2007). The only theme which is missing is the one which has to do with communion with a higher being. The goal of this model is to use it as a guide to assess the appropriateness of potential end-of-life interventions (Smith-Stoner, 2007). Although these 3 dimensions were consistently identified as being important to respondents, the findings in that study also indicated that the term *spirituality* was rejected by several individuals. It is important to note however that not only were the respondents in this study not ill, but they belonged to atheist organizations. Their views may represent the more extreme views of individuals who do not believe in God or an afterlife as compared to those individuals for whom religion is simply absent from their lives.

Within my inquiry, we see examples of each of the 3 themes identified by Smith-Stoner (2007). In the realm of the intrapersonal we remember that Claude spoke about doing his "last reflection", a process of reflecting on his life and obtaining some closure. Javier shares his belief that when one dies, there is only nothingness afterwards. In the realm of the interpersonal, we remember that Thomas spoke about his need to retain relationships with friends and family. Javier shared his love for his children, how they were his greatest accomplishment and how full of sorrow he was at the knowledge that he would not be part of their lives when he died. For Claude, it was the reconciliation with his son and daughter which was most important to him. Lastly, in the realm of the connectedness with nature, which through its themes of inspiration and creativity can be taken to include relationships with the arts, we recall Claude sharing the meaningfulness of certain music in his life.

Relinquishing control, mitigating anxiety. Within this inquiry both religious and non-religious participants who believed in a higher power appeared to find comfort in relinquishing control to a higher being. Although the objective of this inquiry was not to look specifically at religion in the context of dying, and more particularly, at the impact that religion has on individuals' feelings of death anxiety, it is important to note that there did not appear to be a direct relationship between religiosity and anxiety amongst the individual participants in this study. This is important in light of the literature which tries to establish a clear link between degree of religiosity and level of death anxiety (Feifel, 1974; Franks, Templar, Cappellety, & Kaufman, 1990; Pevey et al., 2008).

As noted by Pevey and collegues (2008), although there are studies and seminal works to date which examine the relationship between death anxiety and religion, most of these are conducted with individuals who are not actively dying (Dezutter, et al, 2009). In actuality, we know very little about the role of religion as it related to anxiety in those who are nearing death. Furthermore, non-religious individuals or atheists, individuals who do not believe in afterlife or in God, represent a unique and understudied group in the palliative care literature (Smith-Stoner, 2007).

One way in which the link between religious views and death anxiety has been attempted to be understood is with TMT (Terror Management Theory) (Solomon, Greenberg & Pyszczynski, 1998). TMT builds upon Becker's claim (1973) that concerns about mortality play a pervasive role in human affairs. TMT suggests that people create cultural worldviews in order to manage the terror which comes with the human awareness of death. According to TMT, cultural worldviews, including religiosity, provide important ways to achieve meaning in one's life. The theory assumes that religion may ease the terror which comes with acknowledging one's own finitude by providing answers to existential questions about death and dying and by providing hope of immortality (Solomon et al., 1998). This immortality can be either symbolic as in the leaving behind of a legacy, or literal through religious beliefs of an afterlife and Heaven (Solomon et al., 1998). Much like Jung (1965) and Frankl (1977), TMT argues that religion may help minimize death anxiety and be protective against existential despair.

For individuals in the present inquiry who relied on religion or some notion of spirituality to protect them against existential despair there was a sense that it was in part the allocating of control to a higher being which helped them find some peace. Myriam for example, described that she was not shocked when she learned about her diagnosis, and simply accepted that this was what was written for her; it was her fate. Eloise, described how she felt relieved to be able to turn to prayer to try to find help and support "I was happy to give something over to something bigger than me, bigger than the doctors, bigger than the universe" (Eloise). At the same time, just as those participants who were religious found some comfort in giving control over to religion and to God, Claude too found comfort in the belief that Rose was taking control of his well-being. Although he argued that it is a grave mistake to replace reason with religion, Claude credited Rose with helping him face his death and allowing for the reconciliation between himself and his children.

In his exploration of how religion can assist people in coping, Pargament (1997) suggests that religion can assist people who are faced with life-threatening illnesses by enabling surrender to something sacred, or superior in some ways, to the individual. Although Pargament (1997) was referring to a more typical surrender to a religious supreme being, such as God, Claude's experience shows us how individuals who are not religious still have the capacity to rely upon something that they view as sacred, and that this can be beneficial in providing the dying individual with hope and comfort.

Dignity as Embodied

The phenomenological notion of the person includes a view of the body that is fundamentally different from the Cartesian notion of the body as an object of possession (Leonard, 1989). An individual does not inhabit an unchanging body but is subjectively embodied in a changing, developing and negotiated process of being (Waskul & van der Riet, 2002). Merleau-Ponty (1968) highlights that we are embodied Being-in-the-world, and that we realize ourselves through our body. He postulates that the body is a subjective experience of the world it inhabits as opposed to an objective experience, and it is the perceived experience of the world which determines human experience (1968). Heidegger (1962) develops an analysis of the breakdown of "ready-to-hand" equipment and the subsequent revelation of the "world" through the phenomenon of the "un-ready-to-hand". It is only at the moment of breakdown that the tool's interaction with the world becomes obvious. Likewise, it is with the breakdown of the physical body, as is experienced by the participants in this inquiry, that embodiment becomes most evident.

The way that our world is shaped by our being bodily agents, that is, our embodiment, is a particular aspect of engagement, or how we interact with and understand our world. Our experiences are shaped by our bodily constitutions and our bodily constitution, in turn, impacts the meanings we ascribe to these experiences. As dying individuals, the participants in this study not only had their sense of embodiment awakened and challenged, but they understood and ascribed meanings to their experience based upon how they were connected physically to their world.

Dignity has been described as a subjective belief (Franklin, Ternestedt & Mordenfelt, 2006) which exists when individuals are capable of having control over their behavior, their environment and the way in which they are treated by others (Mains, 1994). This understanding has been broadened to include an understanding of dignity as being embodied and socially constructed over time (Street & Kissane, 2001).

The participants in this inquiry experienced the phenomenon of dignity in embodied ways. Within this inquiry, the notion of dignity as embodied is linked to the illness itself, and in particular the patient's level of independence and functional capacity. Alan describes his experience of having his toileting needs attended to. For him, this was an issue which was very emotional (he started crying when he discussed having to use a diaper) and represented a loss of dignity. For Blanche the changes in her independence and functional capacity did not cause her dignity to be threatened. Rather it was the bodily changes which she had undergone as a result of her illness. She described her colostomy as a pivotal moment in her life; the point at which she no longer felt like a woman and her identity was threatened.

The term basic dignity has been described as a universal moral quality which is internal to the person and inseparable from life itself (Pullman, 1996; 2002). In contrast, personal dignity is often used to refer to phenomena related to experiences of death and dying (Chochinov, 2002; Pullman, 1996; 2002). Chochinov (2006) has stated that personal dignity is individualistic, transient and often tied to personal goals and circumstances. The Dignity Model, an empirically based model of dignity in the terminally ill in part provides insight into what influences a patient's wish to go on living in the face of their impeding death (Chochinov, 2002; 2006; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002).

Study Limitations

It is important to include within this thesis an acknowledgement of the limitations related to this inquiry. In the section on Methodological Rigor in Chapter 3, I describe the steps which I took to engage in this inquiry competently and with integrity. I did come to it however with subjectivity, which, although expected and appropriate in interpretive phenomenology, still needs to be addressed. My identity as a palliative care specialist with years of clinical and administrative experience impacted not only the way in which I conducted the inquiry, but also how I interpreted the findings. Additionally, my experience as a palliative care nurse is only one dimension of who I am as a researcher. My religious upbringing and current religious beliefs, along with my identity as a mother of two young girls, are other facets of who I am as a person and as a researcher. Several approaches were used to counterbalance subjectivity related to myself as researcher. First, as described in the Methods section of Chapter 3, I kept reflexive journals throughout the entire study period. These personal journals allowed me to step away from the data and work through what I expected to uncover in order to be open to new perspectives and check that the interpretations presented in this thesis are not simply iterations of my own presupposed findings.

Along with my use of reflexive journals, my research supervisor and committee members challenged my analytic accounts as they were unfolding. This led to several re-workings of initial analysis and compelled me to delve deeper into the stories of these participants. Still, the interpretations presented in this thesis are limited by my own ability to uncover what I could from the participants' accounts. It is expected that another researcher, engaging in the same research process, would come up with different interpretations. In fact, readers of this thesis will themselves be able to expand on what is presented, and re-interpret it in ways which make sense to them and for their particular context.

Although discussed in detail in Chapter 3, the issue of transferability bears repeating here, as it is often misconstrued as a limitation in interpretive phenomenological research. Sandelowski (1986) argues that generalizability, to which transferability in qualitative inquiry is related, is something of an illusion, as "every research situation is ultimately about a particular researcher in interaction with a particular subject in a particular context" (p. 31). I feel that this is particularly relevant in interpretive phenomenology. In response to what some might consider a limitation, i.e. that the findings cannot be automatically applied to different contexts, I attempted to make explicit the context of the participants' stories, the stories themselves and the interpretive process. In so doing, my hope is that clinicians and researchers will recognize the findings uncovered in this inquiry as potential themes in their own work, and that they may, as a consequence, reconsider what they have previously assumed to be true.

There is another limitation which is specific to me as the researcher. I cannot be certain that the ways in which participants engaged with me, and chose what they shared, was not influenced by the fact that some of them knew of my position as the Head Nurse of the palliative care unit to which they were waiting to be transferred. Although it is possible that this knowledge played a role in what the participants chose to share, I do not believe that it had an important impact. First, participants were reminded that I had no control over admission processes and that I was on a partial study leave during the time of the data collection and therefore not present on the palliative care unit every day. In addition, interview questions did not focus on evaluating care; had they, it may have been more problematic in terms of my position as a hospital administrator.

Implications for Practice

As first introduced in Chapter 4, the interpretations in this inquiry were structured using the concepts of situatedness and throwness as articulated by Withy (2011). The decision to structure the results as such was made after I reflected on the data and came to understand that although people may die existentially alone, a concept written about by Heidegger (1962), no one dies void of a past or backdrop of experience (Moon, 2009). Heidegger reminds us that meaning is always situated in the context of something – one's humanity, one's personal history, or one's anticipated future (Heidegger, 1962). Being situated then, in this inquiry, is to make sense of, and to find meaning in the lived experience of dying, in the context of a particular past, and present life. Throwness implies that we are entities that encounter (particular) things, lead (particular) lives and have (particular) backgrounds to make sense of (Withy, 2011). Being-in-the-world reminds us that our lives are unified and connected within the whole of our significances and involvements (Heidegger, 1962; Johnson, 2000). As such, the participants' experiences and the meaning of these experiences cannot be separated from the whole of that person's world. I understood the participants in this inquiry to be shaped by their pasts, living in their present, and anticipating their futures.

The constructs of situatedness and throwness, although grounded in philosophy, espouse ideas which resonate clinically as well. Buckman's (1998) three stage model of the process of dying is an example of this. Although Buckman's model is based upon clinical experience and wisdom as opposed to empirical data, its impact is potentially quite significant, particularly with clinicians and the general public. In addition to having authored a chapter on communication in the second edition of the widely referenced Oxford Textbook of Palliative Medicine (Buckman, 1998), Buckman, a medical oncologist and a prolific author, published several books and articles for health care professionals on how to communicate with cancer patients and on breaking bad news. According to Buckman's theory (1998) the stages of dying are divided into the initial stage, the chronic stage and the final stage. The initial stage is marked by the moment when the person first faces the possibility that they may die from their disease, not as an abstract possibility, but as a concrete probability. Buckman asserts that people emotionally face their impending death in many of the same ways that they faced other circumstances in their lives; an individual who generally reacts to stress with anger, will experience anger. Someone who has relied on denial in order to cope with stressors will likely rely on denial when in the initial stage of dying. The second or chronic stage occurs when the patient resolves those elements of their initial reactions which are resolvable and that although the intensity of the initial emotional responses may diminish, the nature of the feelings generally does not. The third stage is defined by acceptance even though Buckman (1998) points out that many palliative care clinicians do not consider this as something which will definitely occur.

Buckman's model of dying is based upon two central concepts: 1) that patients facing death exhibit a variety of reactions which are in keeping with their own characteristics and not of the diagnosis or the stage of the dying process and 2) that movement through the process of dying is marked not by a change in emotions, but by resolving what can be resolved of these emotions. Like Withy (2011), Buckman (1998) states that when people are confronted with the threat of impending death they respond in ways which are consistent with who they are and how they have experienced difficult events in their past. Individuals' reactions are not a product of the stage that they may find themselves in (as might be expected in Kubler-Ross's (1969) stage theory of dying for example), or the details of their particular illness. Instead, the meaning that individuals ascribe to their dying experience is reliant upon who they are as individuals and no experience is separate from its context of involvements. By considering the constructs of *situatedness* and *throwness*, and by referring to Buckman's model, clinicians should consider that the person for whom they are caring is much more than just a patient.

Getting to know the human being in front of them, learning about their history, discovering their previous ways of coping, and searching for their strengths and weaknesses will help clinicians accompany patients who are dying in ways which are meaningful for them.

This inquiry suggests that patients who are waiting to be transferred to a palliative care unit for end of life care are already, prior to this, aware to some degree that they are dying. This knowledge is imbued with a sense of aloneness as patients struggle with existential questions internally and by themselves. As revealed in this inquiry, the experience of dying is fundamentally one which we all face alone (Heidegger, 1962), but this does not mean that patients would not benefit from presence and acknowledgement. Nurses on the acute care wards are in a unique position to offer their presence and support to these patients, by demonstrating a willingness and ability to share the space of this existential loneliness. Although patients could benefit from all clinicians adopting this approach, it is nurses who are available to be with the patients at all hours of the day and night, at times when the feeling of aloneness may be overwhelming. Nurses must be educated, encouraged and supported to enter into these relationships, despite the abyss of uncertainty that they may be falling into.

This inquiry also suggests that the actual move from an acute care ward to the palliative care unit is a very stressful situation for patients, and again, a time in which feelings of aloneness may pervade. There is a potential for some degree of relocation stress which can perhaps be minimized if the predictability of the new environment is maximized (Schulz, 1987). As much as possible, nurses and the entire clinical team should encourage patients to ask questions about where they are going, who will be caring for them, and what they can expect. Patients may not think to ask, or may not be comfortable asking these questions. Nurses should be aware of this and be willing to broach the subject with their patients. In order for this to be effective however, nurses themselves must have a good understanding of what palliative care can provide and what its philosophy is. Whenever possible, it could be helpful to have the patient, or minimally the family, visit the palliative care unit prior to the move. This could address some of the distress caused by entering a strange and unpredictable environment.

Clover and colleagues (2004) found that palliative care patients often adopt passive roles and tend not to engage in decision making for a variety of reasons, including adopting a wait and see attitude, opting for quiet acceptance of whatever the health care team and their families decided for them and tolerating what they perceived to be the bossiness of others in making decisions. Within this inquiry there were exemplars of participants maintaining a sense of control over their situations, and others who relinquished control either to their health care team, to God or to their families. Nurses must be aware that even though some dying patients may not wish to be involved or have control of all decisions, this does not imply that they are entirely disinterested in engaging with the health care team about their care. It is important to be sensitive to this in order to facilitate open, trusting relationships with patients and to ensure that important discussions are had. Furthermore, understanding a patient's right not to participate in decision making must also be respected, if that is what the patient desires.

The way that nurses engage with patients can either assist or impede patient autonomy. Studies of elderly patients moving into nursing homes have shown that the adjustment to a move is easier if the decision to relocate was the patient's (Noelker & Harel, 1978). This should always be remembered and nurses should act as patient advocates in situations where a transfer to the palliative care unit is a decision that the patient is still ambivalent or concerned about. As advocates nurses must first recognize the added difficulty to adjustment which will occur in patients who have fears and questions about being transferred, and bring this to the attention of the entire health care team. Armed with their knowledge of the patient and the research literature, nurses must be supported in advocating either for more time for the patient to adjust to the move or for more information to be given to the patient. Unfortunately, organizational and administrative factors can sometimes impede even the best intentions of the nurse advocate. In such cases, nurses should inform their colleagues in palliative care that the patient they have just been transferred may have a greater degree of difficulty adjusting to the move.

The main sentiment related to the transfer to the palliative care unit of the participants in this inquiry was that the anticipated move represented hope. They hoped for specialized care, they hoped to meet their personal goals which would coincide with a better quality of life and they hoped for a better physical environment. Nurses must be mindful that awaiting a move to a palliative care unit does have the ability to foster hope. An awareness and openness to these hopes is first needed for nurses to then be able to discuss these hopes with their patients. What may be uncovered is that some of these hopes are tangible possibilities which nurses can help support. Furthermore, nursing administrators must provide their staff with the resources, tools and education needed to ensure that the best quality care is available to patients, including care which is appropriate for those who are dying.

We learned through this inquiry that the physical space participants found themselves in was important in shaping meaning for their experiences and thus nurses need to be mindful of these lived spaces. The world of the imminently dying hospitalized patient ultimately gets reduced to the hospital bed and what lies around it. Nurses must be conscious of the fact that they have a role to play in ensuring that this space is clean, comfortable and as therapeutic as possible. Nurses must take care to not treat the patient room as their space, but as a shared space between the health care team and the patient and his or her family. As members of a larger interdisciplinary team, nurses are in a position to remind all of their colleagues that the physical space the patient finds himself or herself in has an important impact on their well-being. Nursing leaders and administrators, along with hospital executives must pay attention to the fact that this is important, and take it into account when designing hospital spaces. Potential financial donors should be guided and informed that this is a way in which their money can make a positive difference for patients and families. Beyond physical space, ultimately what is important to bear in mind is that the hopes of patients, when acknowledged and explored, are often attainable, at least in part, and nurses can be instrumental in enabling and encouraging this to occur.

Nurses must also acknowledge and recognize that they have a role to play in providing a safe space for religious and spiritual discussions related to the end of life. As suggested by McClement and Chochinov (2010) terminally ill patients and those with life-threatening illnesses want health care providers to be attuned to their spiritual needs. This inquiry suggests several things; first, some patients may be apprehensive about sharing their religious beliefs with others, lest they be challenged. Asking close ended questions about religion, belief in God and spirituality may be a disservice to patients who may have existential questions and concerns which require more of an exploratory approach. In engaging in discussions about religion and spirituality nurses must be careful not to be judgmental, critical or dismissive of what the patient is sharing. As well, nurses must step beyond simply asking their patients if they are religious, but should additionally ask open ended questions which touch upon the realms of self acceptance, relationships with friends and family and connections to nature and the arts.

Lastly, nurses must realize that all patients, including those who are dying, experience their world in an embodied way, and that changes and breakdown of their body can impact the way in which they interact with others and the way in which they perceive themselves. It is generally agreed in the nursing literature that the maintenance of patient dignity is not only highly valued by patients, but also an important element of nursing care (Walsh & Kowanko, 2002). The notion of dignity is closely linked to the body, and nurses, being directly implicated in the care of the body, need to provide care in ways which help to preserve dignity, right up until the moment of death, and even afterwards. During busy days, when certain aspects of patients' care become more rote than thoughtful, nurses should remember that the body they are caring for is inextricably linked to the person who is before them and as such, they must provide care which is always competent and dignified.

Implications for Research

I understood the ease of recruitment for this study to represent a willingness and ability for patients at the end of life to engage in research which explored their lived experience of dying. It is interesting to question whether or not recruitment was facilitated by the fact that I am the head nurse of the palliative care unit to which these patients were waiting to be transferred. I do think that my professional role likely helped with the initial identification of participants by the supportive care team. All patients who were first approached to learn more about the study consented to participate. Of those who consented, only one participant, at the time of the interview, decided that it would be too difficult for her to carry on a conversation in her very weakened stated. I do not believe however that my professional role was significant enough to these participants to cause them to agree to participate solely because of that reason. Instead, I am reminded of Claude, who thanked me for providing him with an opportunity to conduct his last reflection on life, and of Javier's sister, who approached me in the corridor after the interview and thanked me for giving her brother a space to talk about what he was living, as he had not been able to do this with anyone else. I mention these two anecdotes as a way of encouraging future research with imminently dying patients. It is imperative to include the voices of the terminally ill in discourses on death and dying and there should not be a reluctance to approach them or an assumption that they will be impossible to recruit.

The themes which emerged from this inquiry suggest many areas for future research. This inquiry suggests that although religion can be a source of comfort and hope for the dying, there is the possibility that it is also imbued with a sense of aloneness. How do patients who turn to religion in response to life threatening situations experience aloneness? How is aloneness experienced by those who describe themselves as non-religious or atheist? How does this impact their dying experience and their quality of life?

How does the context of care affect aloneness? How can nurses help patients uncover meaning in their current situation?

This inquiry suggests that there is much we do not know about how religious belief, non-belief and spirituality impact the experience of dying and more specifically, the lived experience of waiting to be transferred to a palliative care unit for end of life care. Although there is evidence which suggests that religion may not be important to the dying (Pevey et al., 2008), it is undeniable that atheism, or the needs of the non-religious, is a little explored phenomenon in the palliative care literature. This is irresponsible given the prevalence of individuals who identify themselves as being non-religious in our secular society. The voices of these individuals must be better represented in the literature on death and dying.

From a methodological perspective, this inquiry provides insight into some of the challenges inherent in embarking upon a methodology which has few guiding principles available in the literature. The difficulty that many people have in carrying out an interpretive phenomenological research study is the lack of examples within the literature which guide analysis. As a result investigators must exercise caution and resist seeking out concrete examples for ways of conducting interpretive phenomenology. When concrete examples are conveniently offered, there is a risk of creating a fixed standpoint and a solitary horizon of meaning (McManus Holroyd, 2007). For a new researcher, this can be particularly problematic as there is tendency to search for a method which is clear, reliable and accessible. Despite the personal challenges and hurdles that I struggled with during the conduct of this study I believe that this inquiry can add to the methodological discourse which exists on conducting an interpretive phenomenological study. In addition the study of and reference to Heideggerian philosophy proved to be an important element in ensuring that the focus of the inquiry and the interpretations which were uncovered herein were in keeping with the mission at the outset. The task of this analysis was to uncover the meanings of the lived experience of dying for these participants in a way which does not de-contextualize, trivialize or sentimentalize them. My job as a researcher was to provide a meaningful account of the experience of the participants and to be transparent in how I did so. The development of phenomenological accounts, which weaved together the interview data, participant observations and reflexive notes and thoughts, helped uncover the initial interpretations of each participants lived experience.

Theoretical Considerations

The goal of interpretive phenomenology is not to develop or to test theory. However, given what has been uncovered within this inquiry, we have the opportunity to examine how various existing theories can be further elucidated to take into consideration some of the interpretations found herein. The results of this inquiry can provide a new way to consider TMT (Terror Management Theory), from the perspective of people who are facing their own finitude. TMT proposes that knowledge of the inevitability of death gives rise to potentially paralyzing terror which in turn makes goal directed behavior unlikely (Solomon, Greenberg, & Pyszczynski, 1991). However, the findings of my inquiry raise the same concern about TMT that other authors have raised (Leary & Schreindorfer, 1997). Namely, since people who are facing their own death are able to find meaning in their experiences and continue to have hope and goals, how can we theorize that human beings inherently do all that they can to avoid thoughts of their own mortality, as suggested by TMT (Solomon, Greenberg, & Pyszczynski, 1991)? Few theorists have devoted as much effort to testing their theories and, when necessary, revising them as Solomon and his colleagues have (Leary & Schreindorfer, 1997). The questions about TMT which are possibly raised by this inquiry make it interesting to contemplate if and how the theory would be adapted when applied to those who are imminently dying.

In palliative care, transition theory has not been very well developed, however transition theory has been a central concept in nursing (Meleis, et al., 2000). The middle-range theory of transitions developed by Meleis and colleagues (2000) provides a broad view of transitions, framed by 3 components. These are comprised of the nature of transitions, conditions for transitions and patterns of response. The nature of transitions refers to the types and nature of the transition as well as the properties of the experience. These transitions can be developmental, situational, organizational and related to health / illness (Geary & Schumacher, 2012; Meleis et al., 2000; Schumacher & Meleis, 1994). Transition conditions within each of these levels include the meaning associated with the transition and its' resultant outcome. Patterns of response refer to the process and outcome indicators and denote healthy movement through the transition. Within this pattern of response, location and being situated is considered and could refer to the movement of the person from one place to another. The transfer from an acute care unit to a palliative care unit for end of life care fits within the concept of the health / illness nature of transition and could help inform the transition conditions with regards to the meanings associated with the transition. The findings of this inquiry suggest that there may be aspects of the lived experience of dying for patients waiting to be transferred to a palliative care unit for end of life care which could further elucidate Meleis' mid-range theory of transitions, or which could be informed by this theory.

End Note

The conduct of this study has been an intellectual and emotional journey for which I am profoundly grateful and forever changed. My hope is that readers of this thesis will be able to better understand the lived experience of dying for hospitalized patients waiting to be transferred to a palliative care unit for end of life care and that this understanding will translate into the provision of better care. I hope that the implications outlined earlier in this chapter will inspire those who are directly, and indirectly, involved in the care of the dying, and that they will examine their current practices and beliefs in an attempt to support the dying patients in their care as best as possible. At the same time I imagine that readers will be left with a sense of wonder as they acknowledge that we can never fully understand this experience. I believe however that this should serve as an impetus to further exploration and research.

I would imagine that readers of this thesis will draw their own conclusions and interpretations through the data which is presented. My inquiry and my interpretations provide a way to consider the Being-in-the-world of dying patients by listening to the voices and stories of those who matter most. I hope that readers will find their pre-existing notions of what it is like to die in hospital challenged, the way that mine were, while at the same time identifying with moments which they recognize from their own practice, research or other work. My hope is that readers of this thesis will remember some of its key findings as they engage in work with their patients, and that patients will benefit from having attentive ears listening to their own individual experiences, waiting to hear the uniqueness of what might be learned.

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Appendix A: Demographic information sheet

Gender Male ______ Female_______ Other________

Age ____________________________

Mother tongue ____________________________

Language of interview____________________________

Religious / ethnic background ____

Highest level of schooling ____

Primary diagnosis ____________________________

Date of diagnosis ____

Length of time in hospital (current hospitalization) __________________________________

Acute care unit where patient is hospitalized _______________________________________

Reason for transfer to palliative care unit ____

Date when patient was placed on the waiting list ____________________________________

Date when patient was transferred to the palliative care unit ____________________________

Appendix B: Participant Table

Name	First interview on acute care ward	Second interview on palliative care unit	Number of days between last interview and death	English or French speaking	Cultural / Ethnic identity
Thomas	Yes	Yes	6	English	Chinese
Myriam	Yes	Yes	9	English	Haitian
Claude	Yes	No	3	French	French Canadian
Lillian	Yes	No	5	English	Scottish
Sabrina	Yes	Yes	11	French	Italian
Mark	Yes	No	4	English	Jewish
Javier	Yes	No	15	French	Chilean
Blanche	Yes	No	12	French	French Canadian
Karine	Yes	No	9	French	French Canadian
Eloise	Yes	Yes	12	English	English Canadian
Alan	Yes	Yes	8	English	Jewish

In the context of this inquiry "Cultural / Ethnic identity" was identified based upon what the participants themselves stated.

Appendix C: Informed Consent Form

The experience of patients waiting to be transferred to a palliative care unit

Introduction

You are being invited to participate in a research study which is designed to understand the experience of patients who are waiting to be transferred from an acute care ward to a palliative care unit. You have the right to know about the purpose and procedures that are to be used in this research study, and to be informed about the potential benefits, risks, compensation, and discomfort of this research.

Before you give your consent to be a participant, it is important that you read the following information and ask as many questions as is necessary in order to understand what you will be asked to do, should you decide to participate. It is also important that you understand that you do not have to take part in this study.

1. Purpose of study:

Currently, there is almost no research available which examines what it is like for patients to make the move from an acute care unit to a palliative care unit. By taking part in this study you will be able to help develop an understanding of what this is like from the patient's perspective, by sharing your own feelings, thoughts and experiences. Health care professionals may be able to use the findings of this research to better care for patients.

This study is being conducted in partial fulfillment of the researcher's doctoral studies. In addition to her studies, the researcher is also the Head Nurse of the Palliative Care Unit at the Jewish General Hospital.

2. Procedures:

If you agree to participate, you will be asked to participate in an interview. If you are interested, then you may be asked to participate in additional interviews, for a maximum of three. The first will be while you are still on the floor you are now on and the second will be once you have been transferred to the palliative care unit (but not within the first 24 hours). If after a week you are still waiting to be transferred, a second interview may take place on the floor you are now on. A third interview will then be conducted upon transfer to the palliative care unit.

Prior to starting the first interview some basic information will be collected. This will include things such as your date of birth, the date of your diagnosis, the type of cancer that you have, your highest level of education. This information will be used to see if there are similarities or differences between participants and whether or not these influence your experience.

Each interview will last between 30 minutes to one hour, but this is largely dependant on you. The interview is a "semi-structured interview" which means that there is some flexibility in how it is conducted and the questions are open-ended. It will feel more like a conversation than an actual interview. There are no right or wrong answers.

The interviews will be audio-recorded in order to ensure the accuracy of the information collected. The transcripts and notes of the interviews will be read by the researcher and other members of the research team in order to try and understand your experience and what you have in common with other people waiting to be transferred to a palliative care unit. Before starting other interviews, you may be asked to comment on some of the initial interpretations made to your first interview, to make sure that they are representing what it was you meant to say.

3. Risks, Discomforts and Side-Effects:

All interviews will be conducted in a safe and respectful manner, and time will be given to deal with any difficult thoughts and emotions. Some of the issues which may come up during the interviews may be emotionally difficult to discuss. If you experience any distress during the interview then, with your consent, this is will be discussed with your nurse or doctor in order to provide you with the most appropriate care.

It is also important to know that at any time you are free to stop the interview. You may also choose not to answer specific questions.

4. Benefits:

Agreeing to participate in this study will, in no way, influence when you are transferred to the Palliative Care Unit.

You may benefit directly by participating in this study because you will be given the opportunity to discuss your experience, your feelings and thoughts in a safe and confidential manner.

In addition, by agreeing to participate in this study, other patients in situations similar to yours may benefit from the knowledge which is gained. Health care professionals may be more aware of what issues are important to people like you and this may help them to provide more sensitive and appropriate care.

5. Voluntary participation/withdrawal:

Your participation in this study is voluntary. You may choose to participate now and decide to stop your participation at any time. Your future medical care and relationship with the health care team will not be affected in any way.

You may decide to withdraw your participation in this study at any time or it may be stopped with or without your consent at any time for any of the following reasons:

- You decide to withdraw from the study

- The study researcher feels that the risks and discomforts you are experiencing as a result of participating are not worth the potential benefits.
- Your plan of care has changed

6. Confidentiality:

All information obtained about you during this research will be treated confidentially within the limits of the law. The identity of study participants will be kept strictly confidential when reporting results and all participants will be assigned a study identification number. This identification number will be the only way in which data is referred back to any participant. I will keep a master list which will include the list of patient unit numbers (found on the patient's hospital card), name and study identification number. This master list will be kept separate from where data is kept and will be in a locked and secure cabinet in the Palliative Care Research offices. This will be destroyed once data collection is complete for the study and at this point all data will be anonymized.

The interpretive team (which includes the student researcher, the student's supervisor and up to three other members of the student's thesis committee) may hear recordings of the interviews or read transcripts of the interviews but they will not have access to your identifying information. In addition, there may someone who is involved in helping to transcribe interviews (listening to the audio-recordings and typing out the content). This person will not have access to your identifying information.

All data collected, including interview transcripts and field notes will be kept in a locked cabinet, in a locked office, under my supervision. Any electronic versions of data or notes will be kept on a password protected computer to which only I have access. This data will be kept for five years after study completion.

Some staff members (of the acute care and palliative care units) may realize that you have been recruited into the study. Although it will not be made explicit to the hospital staff, if they already know the details of this study design, they may figure out that you are a participant. In presentations and written reports/publications, care will be taken to present the results in a way that individual patients cannot be identified by the staff that cared for them.

For monitoring purposes a representative from the Jewish General Hospital's Research Ethics Committee may look at medical and research records identifying you.

This consent form will not be placed in your medical records.

The results of this research may be published or communicated in other ways; however, your identity or any other identifying information will not be disclosed in any reports or publications.

If you withdraw (or are withdrawn) from this study, any information collected up to the point of withdrawal for the purpose of this research may still be used in order to protect the scientific integrity of the study.

7. Costs and compensation:

You will not be paid for your participation in this study.

8. Compensation in case of injury:

If you suffer an injury as a result of participating in the study, necessary medical treatment will be available at no additional cost to you. Unless required by law, compensation for such things as lost wages, disability or discomfort due to such an injury will not be offered. However, by signing this consent form you do not give up any of your legal rights (including the right to seek compensation for an injury resulting from your participation in the study) nor relieve the sponsor, institution and investigator from their professional and legal responsibilities.

9. Investigator Compensation

The researcher has received funds from FRESIQ (Fondation de recherche en sciences infirmieres du Quebec) in order to pursue her doctoral studies in Nursing. This research study is in partial fulfillment for this doctoral degree.

10. Contact information or questions:

If you have any questions about the research now or later, you should call Vasiliki (Bessy) Bitzas at 514-340-8222 ext. 5685. If you have questions about your rights as a research participant, you may call the Jewish General Hospital Local Commissioner of Complaints & Quality of Services, Rosemary Steinberg, at (514) 340-8222 ext. 5833.

STATEMENT OF CONSENT

The experience of patients waiting to be transferred to a palliative care unit

I have read the above information and my questions were answered to my satisfaction. A copy of this signed consent form will be given to me. My participation is voluntary and I can withdraw from the study at any time without giving reasons, without it affecting my medical care now or later. I do not give up any of my legal rights by signing this consent form. I agree to participate in this study.

Signature: ____Date:_______________

Name of Participant: _______________________________________

Consent form administered and explained in person by:

Signature: ____Date:_______________

Name of Investigator (or delegate)

____

Appendix D: Interview guide

Examples of questions meant to guide the conversation with participants

<u>Initial interviews with participants while they are on the acute care unit</u>

<u>Central questions</u>:

Tell me about your illness experience so far (date of diagnosis, prognosis given ect…)

Tell me about when you were being placed on the waiting list for the palliative care unit?

- Who initiated this discussion of transfer? How was this conversation started? What was this like for you? Was anyone else present (family member, friend)?

- What was your involvement in making this decision (to be put on the waiting list)?

What does it mean to you to be on the waiting list for the palliative care unit?

Why do you think you are waiting for a bed on the palliative care unit?

Probes:

Has anything changed for you now that you are waiting for a bed on the palliative care unit?

Describe what this waiting feels like to you?

Describe how you feel about being on a unit where most patients are not waiting for a bed on a palliative care unit?

- How are other people (staff, family, friends) interacting with you now that you are on the waiting list to move to a palliative care bed?

How do you feel about yourself now that you are waiting for a bed on the palliative care unit?

Follow up interviews with participants who have been transferred to the palliative care unit

Central questions:

How were you told that there was a bed for you on the palliative care unit?

What was your immediate reaction to being told that you were going to be transferred to the palliative care unit?

Probes:

What does it mean to you now that you are on the palliative care unit?

Can you describe how you feel to be admitted onto the palliative care unit?

What has changed for you now that you are on the palliative care unit? What has stayed the same?

Compare your feelings now with what you thought they would be when you came to the palliative care unit.

How do you feel that other people (staff, family, friends) interact with you now that you are on the palliative care unit?

How do you feel about yourself now that you have been transferred to the palliative care unit?

Appendix E: Observation guide (during interviews)

Observe the setting where the interview is taking place

Describe the physical space
Describe how people are positioned in the setting
Describe auditory, olfactory and sensory stimuli
Note the date, day of the week and time

Observe the people in the setting

Describe who is present
Describe their roles / behaviors / actions
Describe how they are situated in the setting

Observations during interviews between the investigator and participant:

These observations will be recorded in the field notes that will be written following the interviews (Morse, 1995)

Location of interview
People present during the interview
Description of the setting
Description of the patient (i.e. using oxygen, intravenous installed, physical appearance)
Description of all auditory, olfactory and sensory stimuli
Non-verbal behaviors (ex. Tone of voice, posture, gestures, forcefulness of speech, facial expressions)
Anything that is said or occurs which is not captured on tape