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A phenomenological inquiry into the embodied nature of occupation at end-of-life

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A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy

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A PHENOMENOLOGICAL INQUIRY INTO THE EMBODIED NATURE OF OCCUPATION AT END-OF-LIFE

(Spine title: The Embodied Nature of Occupation at End-of-Life)

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by

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Graduate Program in Health & Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
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THE UNIVERSITY OF WESTERN ONTARIO
School of Graduate and Postdoctoral Studies

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The thesis by

Anna Park Lala

entitled:

A Phenomenological Inquiry into the Embodied Nature of Occupation at End-of-Life

is accepted in partial fulfillment of the
requirements for the degree of
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ABSTRACT

The current Canadian milieu depicts a rapidly growing demographic of aging Canadians in need of end-of-life support; however, limited funding and resources are available to provide access to these services. The question of how to foster quality end-of-life experiences for people who are terminally ill within this constrained context requires attention. Terminally ill individuals have articulated the inability to engage in activities that make life enjoyable as a factor influencing their decision to hasten their deaths. While occupational scientists and occupational therapists propose that occupation is a basic human need across the lifespan, there is limited understanding of the role of occupation at end-of-life, and its potential to facilitate meaningful end-of-life experiences.

The purpose of this work was to examine the embodied nature of occupation at end-of-life, from the perspectives of Canadians 60 years of age or older who are diagnosed with a terminal illness. A phenomenological approach, with a focus on embodiment, was adopted for this study. In-depth, semi-structured interviews were conducted with eight participants. Data collection also involved close, participative observation, embodied methods, and reflexive journaling. Data analysis involved a hermeneutic process utilizing processes of detailed, selective and holistic analysis.

This work is comprised of four integrated manuscripts. The first offers a systematic literature review that investigates what has been published about death and dying in the occupation-based literature. The second investigates phenomenology as a fruitful methodological approach for the study of human occupation. The third manuscript reports on an empirical study that examines the embodied nature of occupation at end-of-life, and presents the following six emergent findings; participants described orientations toward occupations that involved: living with death, reworking everyday life, being guided by the will of the body, focusing on relationships, attending to the small things, and engaging existential orientations. The final manuscript explores embodied phenomenological research as a methodological approach for qualitative research practices.

The thesis contributes to knowledge about human occupation at end-of-life and offers a starting point to guide care practices that are attentive to the lived dimensions of occupation in this life stage.

Key Words: human occupation, end-of-life, terminal illness, hospice palliative care, phenomenology, embodiment, occupational science, occupational therapy

CO-AUTHORSHIP STATEMENT

I, Anna Park Lala, acknowledge that this thesis includes four integrated manuscripts that evolved as a result of collaborative endeavors. In the four manuscripts, the primary intellectual contributions were made by the first author who: researched the methodology, designed the research, developed the ethics application, conducted the literature reviews, established relationships with gatekeepers, undertook the data collection, transcribed and coded the data, led the data analysis, and led the writing of the manuscripts. The contribution of the co-author, Dr. Elizabeth Anne Kinsella, was primarily through the supervision of the research, theoretical and methodological guidance, hermeneutic dialogue, and intellectual and editorial support in crafting the work for publication.

DEDICATION

This work is dedicated to my proud parents,
Yong-Gon and Bo-Wha Park.

This work could not have come to fruition
without their many lessons of sacrifice, patience and love,
all of which they shared through example.

ACKNOWLEDGMENTS

Although this work is penned and completed by a single author, it is an understatement to suggest that it reflects the words of just one. I have been blessed with an extraordinary supportive network, whose teachings and contributions are threaded throughout.

I must begin by expressing my immense gratitude to my supervisor, Dr. Elizabeth Anne Kinsella. There are no words to express how indebted I am to your brilliance and infinite patience. The culmination of this work and this entire process is as much your accomplishment as it is mine. Most importantly, I thank you for demonstrating that progress, excellence, creativity, and joy can only emerge from having the courage to work through the tough and messy, and from a whole-hearted love for what you do.

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Lastly, to my eight participants: wherever you are, I hope that there is peace. I cannot thank you enough for teaching me how to live.

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CHAPTER ONE: INTRODUCTION

AN INQUIRY INTO HUMAN OCCUPATION AND END-OF-LIFE

Introduction

The purpose of this doctoral research is to examine the embodied nature of occupation at end-of-life, from the perspectives of Canadians 60 years of age or older who are living with a terminal illness. The work presented in this dissertation is analytical, conceptual and empirical in that it: (a) reviews, analyzes and thematically synthesizes current literature on occupation at end-of-life, (b) investigates and composes an argument for phenomenological methodology and its application to the study of human occupation, (c) undertakes empirical work into the embodied nature of occupation at end-of-life, and (d) explores the potential of phenomenological work as an embodied approach to research.

This chapter begins with a brief introduction of myself as researcher, and sets the stage for this work as a situated investigation into occupation at end-of-life. Terms that are frequently drawn upon throughout this work are defined. In addition, readers are introduced to the study of human occupation as it is conceptualized in this dissertation, and to the occupation-based disciplines of occupational science and occupational therapy. At the end of this chapter, the plan of presentation of the dissertation is outlined.

Situating the Research

Truth as Situated

There are many kinds of eyes.
(Nietzsche, 1967, p. 291)

In writing this introduction to my dissertation, I am overwhelmed by the philosophical and methodological journey in which I have engaged. While there are immense changes I see in myself as a researcher and scholar, this process has also permeated who I am as a human being. One striking realization that I have made is a recognition that all notions of truth are situated. Everything I have blindly accepted with certainty can be questioned, weakened, destabilized, and overturned. What a frightening and yet liberating realization.

One change that I cannot overlook is a new recognition of the importance of situating myself as a researcher in relation to my work. In this spirit I offer a brief reflection on my situated perspective. At times throughout this work, I speak from a first-person perspective and draw on the pronouns ‘we’ and ‘our’ to refer broadly to humanity as a whole.

At this moment (fall, 2010), I am a 29-year-old doctoral candidate in the Occupational Science Program at the University of Western Ontario, in London, Ontario, Canada. I began this program in September 2006, following the completion of a Masters of Science degree in Occupational Therapy at the same Canadian university. I identify myself as both an occupational scientist and an occupational therapist. I am Korean-Canadian. My parents immigrated from South Korea in the late 1970s and a few years later, I was born, followed soon after by twin sisters. I married during the second year of my doctoral studies and am currently pregnant with my first child.

I am deeply humbled by recognition of my naiveté and inexperience. What stands before you is the work of a scholar in progress, one who has persevered through constructive and self-deprecating critique, tears of pride and despair, and the occasional, albeit passionate threat to wave the white flag in defeat. This work is a testament not to an end point, but to a process, a journey. I am not ignorant to the glaring certainty that there is so much more I need to learn…in time.

What Brought Me Here

> *There is no such thing as a natural death: nothing that happens to a man is ever natural, since his presence calls the world into question. All men must die: but for every man his death is an accident and, even if he knows it and consents to it, an unjustifiable violation.*
>
> *(De Beauvoir, 1964, p. 123)*

At times I find myself surprised to be undertaking a doctoral degree on the end-of-life experience. In the past, my university career had always centered on the goal of working with children. Meeting a seven-year-old boy, Brian, on a school health placement in my occupational therapy program led me to re-evaluate this plan. Brian was born healthy and had a typical childhood. Several months before I met him, he woke up with slurred speech, disorientation and he was unable to control his limbs. He had experienced a brain aneurysm that significantly impaired his gross motor abilities. One day, Brian and I walked together through the school and several of the students greeted him as they passed. 'It seems like you're quite a popular boy!' I noted. Brian looked at me with eyes beyond his years. 'They say hi to me now,' he said, 'but they won't when we're older.' I had to look away so he wouldn't see my face, as my eyes filled with tears. I was struck by his poignant observation, and disturbed by the gut feeling that he might be right. Day after day I met with children with a range of disabilities, and I found it more difficult than I had imagined. Every diagnosis, at such a young age, felt like a tragedy.

My remaining fieldwork placements were adult based, and I realized that I was more comfortable with illness and death at old age than at young. In my time working with older people, I found that I enjoyed their stories, their humor, and their candidness. I attributed this comfort to the rationalization that these individuals had lived full and long lives, as compared to children facing advanced or terminal diagnoses. In the final year of my masters program, I was involved in two assignments concerning end-of-life that introduced me to some of the tensions in this area of occupational therapy service in Canada. These assignments triggered my interest in making a broad contribution to the profession through research and led me to embark on a doctoral degree focusing on the end-of-life experience of persons over the age of 60.

On a personal level, I have experienced the death of family and friends. My first funeral, at the age of 14, was that of my grandmother who died of a heart attack. I remember seeing my grandfather's back shaking as he cried over her casket. I remember hearing my aunt wailing for her mother, as the casket was lowered into the ground. Only a week earlier, my grandmother had mentioned to her husband that they needed to begin looking into funeral arrangements and planning for this eventuality. My grandfather had assured her they had plenty of time. I wondered how she knew. At every funeral that I have attended but one, I wore solemn black (in a traditional Hindu funeral, mourners wear white). I stood in line to pay my respects, sang hymns, expressed condolences to the loved ones left behind, and refrained from showing any emotion other than grief and sorrow. For me, death was a dark and uncomfortable experience.

Funeral services I have attended have ranged from hysterical and traumatic to poignant and beautiful, often with moments of both spectrums in each. In my experience, the most difficult end-of-life experiences involved sudden loss and/or death at a young age. Recent deaths have included close friends' fathers, one father only a year older than my own. It is difficult to imagine being in the shoes of my friends, and difficult to see their faces streaked with tears instead of youthful laughter. Losing their fathers changed them, and I can see it in their eyes now. How strange to realize that I had always unknowingly thought of my family as exempt from death. Even now, the thought of actively facing this inevitable moment still feels forever away.

One funeral stands out from the rest as truly beautiful, a service held for a friend's father, fittingly arranged on father's day. For the first time, instead of a religious sermon, different people in his life were asked to share stories that celebrated his life, his friendships, and his accomplishments. His college roommate recalled a night of debauchery, which ended with a couch being thrown out a window! My friend's father? I had never before considered his life prior to the man I knew. I remember feeling so much love in one room, a connection between strangers through this one life. The room felt yellow and warm, speckled with ambient candles. I remember chuckling at the stories shared throughout the entire gathering, until his youngest son spoke. At this point, the floodgates opened and the entire room released their grief. I will never forget, choking back tears, as he ended, '*And on this father's day, I have never been more proud to be my father's son.*' I remember telling my husband on the ride home that I wanted my funeral to be exactly like that, a celebration of life, a room filled with love. It was the first time it had occurred to me that a funeral could be something other than sad.

These anecdotes shed light on how I have come to this point, how I came to study death and how I have come to understand what death means to me. Looking back, I can see that my direct experiences with death have mainly been from a pew-perspective, characterized by rules and rituals about what to do, what to wear, how to behave. I have never been deeply involved as part of the lived experience of dying as a process. I do not know what it is like to simply 'be' with someone who is facing his or her final days, nor can I imagine dying myself. De Beauvoir's (1964) words that open this section, that death is an “unjustifiable violation” (p. 123), resonate to the core – in my world, while death happens every second of the day, it happens to other people. The notion of my own death violates everything I know and my very sense of personhood. It is difficult to imagine a world without me in it.

This work is never separate from my perspective, nor is it separate from my understandings about death, both explicit and implicit. These kinds of experiences have informed my interpretive lens. I share them with the hope of offering a glimpse into the perspective that shaped my engagement with the central phenomenon in this study, the embodied nature of occupation at end-of-life. I next present a clarification of the language repeatedly drawn upon throughout this work, to further elucidate the viewpoint from which I am situated.

Clarification of Language

In the phenomenological tradition, and more broadly in interpretive work, language is considered a significant conveyer of lived meanings, a medium through which intersubjective meanings are shared and created (Taylor, 1985). Giddens (1993) quotes phenomenologist Hans Gadamer (1967) as stating, “‘Verstehen ist sprachgebunden’ (‘Understanding is tied to language’)” (p. 61). In fact, a single word can elicit multiple understandings and interpretations depending on the context in which it is spoken. As Russian philosopher Bakhtin (1981) states:

> No living word relates to its object in a *singular* way: between the word and its object, between the word and the speaking subject, there exists an elastic environment of other, alien words about the same object, the same theme, and this is an environment that is often difficult to penetrate. It is precisely in the process of living interaction with this specific environment that the world may be individualized and given stylistic shape. (p. 276)

As such, a brief clarification of two important constructs, death and human occupation, and related terms is necessary.

Death and dying are complex constructs. Death has been called the “muse of philosophy,” a topic of stimulating debate and contemplation amongst scholars since the time of Socrates (Becker, 1973, p. 12). According to Heidegger (1927/2008), “dying is not an event; it is a phenomenon to be understood existentially” (p. 284). In other words, death is not a problem to be solved, per se, but a mystery to be pondered; like being, truth, beauty and love, death is a phenomenon that might be described as “intrinsically wondrous” (Carman, 2008, p.7).

On the surface, notions of death and dying appear to be simple and straightforward; death is the moment when life ends and dying is the period leading up to that moment (Auger, 2007). Yet, as Heidegger (1927/2008) remarks, “As soon as man comes to life, he is at once old enough to die” (p. 288). While death and dying are typically referred to from physical or biological perspectives, in actuality, what these terms mean is quite complex. For example, one of the most important factors of defining death is how the diagnosis of death occurs. Surprisingly, there is a range of definitions that can be the determining factor as to when death occurs, according to the judgment of the physician (Kellehear, 2008). Physicians may diagnose a death due to the absence of a heartbeat, the absence of spontaneous breathing, unresponsive pupils, irreversible brain damage, persistent coma, or the absence of a response to painful stimuli (Auger, 2007; Howarth, 2007). There is no single, unanimous definition of when death occurs, whether it is neurological, cardiovascular, respiratory or so on. Complications can arise when one factor trumps other healthy bodily functions, such as in the ethically challenging, and highly publicized cases of persistent vegetative states, where individuals may have a functioning brainstem and organ systems, but have lost higher brain functions and are in a coma-like state of unawareness. Therefore, in some instances the death of one body system can be declared as sufficient for the call of death, whereas in others this is not the case.

Sociologists would further suggest that there are different types of death, beyond just the physical body. Auger (2007) differentiates between a biological or medical death (death secondary to the decline of the physical body), emotional/psychological death (death secondary to the loss of social relationships and intense emotional trauma), spiritual death (the loss of religious faith or belief), and social death (isolation and discrimination due to impending deaths, often from socially charged illnesses such as AIDS). Therefore, death and dying are complex phenomena requiring clarification.

While I approach this work with the understanding that death and dying is laden with social, political, and cultural values and practices, for the purposes of this study, death refers to its typical and everyday understanding; in other words, death is defined as biological or physical death, the cessation of life, and both dying and end-of-life refer to the period leading up to that moment and often follow the diagnosis of a terminal illness (Auger, 2007). Drawing on Kellehear (2007), dying in this work is not the process of bodily, tissue and cellular shut-downs, but rather the experience of living with the awareness of impending death, and the impact this awareness has on one’s own and others’ everyday living.

The terms hospice and palliative refer to approaches of care for people diagnosed with illnesses that cannot be cured; they focus on improving the quality of life for individuals and their loved ones (Auger, 2007). The Canadian Hospice Palliative Care Association (CHPCA) (2010) currently describes hospice palliative care as “whole-person health care that aims to relieve suffering and improve the quality of living and dying” (¶. 2). In line with the CHPCA (2010), who state that in Canada these two terms refer to the same approach to care, the terms hospice and palliative care are drawn upon interchangeably in this thesis.

In this dissertation, the phrase ‘occupation-based disciplines’ refers to both occupational science and occupational therapy, two disciplines that share a focus on the construct of human occupation. While this work is situated in occupational science, the findings bear relevance for both occupational scientists and occupational therapists. The theoretical implications may have greater relevance for the former, due to the aim of occupational science to advance research into the science of occupation. The practical implications may have greater relevance for the latter, due to occupational therapy’s lengthier history and active therapeutic presence in end-of-life settings. Human occupation, and its location in the occupation-based disciplines, is discussed next.

The Study of Human Occupation

Human occupation is a central construct in this study, and is described as a “complex multidimensional phenomenon” (Yerxa et al., 1989, p. 6). Occupation is defined broadly as “all that people need, want, or are obliged to do” (Wilcock, 2006, p. 9). The term occupation is derived from the Latin word *occupatio*, which means to seize, to occupy, or to take possession (Christiansen & Townsend, 2004; Yerxa, 1993). Through engagement in occupations, humans seize and take control of both time and space and are bounded by social, cultural, and political forces (Molineux & Whiteford, 2006). Occupations are not simply ‘things we feel like doing’ or luxuries for a selected few; like food and water, occupations are a basic human need (Wilcock, 2006). Occupations inform the structure of our day, for instance when we brush our teeth, eat our meals, run our errands, and enjoy leisurely activities (Canadian Association of Occupational Therapists [CAOT], 2002). Human occupation is such an average and mundane part of our everyday lives that its significance is often overlooked (Hasselkus, 2006; Wilcock, 2006). However, studying what humans do and, consequently, how doing shapes and contributes to what it means to be human can offer profound insights into day-to-day existence. Engagement in occupation says a great deal about who we are; Heidegger (1927/2008) goes so far as to state, “‘one is’ what one does” (p. 283). Yerxa et al. (1989) state that, “individuals are most true to their humanity when engaged in occupation” (p. 7). What human occupation entails is not a rigid or static entity unanimously agreed upon by those involved in occupation-based scholarship and practice; occupation is, rather, an evolving construct (Hinojosa, Kramer, Brasic Royeen, & Luebben, 2003).

Occupational Science and Occupational Therapy

The study of human occupation occurs primarily in two disciplines: occupational science and occupational therapy. While this research is situated in the field of occupational science and focuses broadly on examining the nature of occupation at end-of-life, it also holds important implications for the therapeutic practice of occupational therapy in palliative settings.

Occupational Therapy

Occupational therapy is a rehabilitative profession, which can be defined as:

> The art and science of enabling engagement in everyday living, through occupation; of enabling people to perform the occupations that foster health and well-being; and of

> enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life. (Townsend & Polatajko, 2007, p. 372)

The profession of occupational therapy was founded by William Rush Dunton Jr., Eleanor Clarke Slagle, George Edward Barton, Susan Cox Johnson, and Thomas Bessel Kidner in 1917 in New York City (Schwartz, 2003a, 2003b). This group of individuals witnessed the power of meaningful engagement in occupation as a rehabilitative or therapeutic tool. In the early years, occupation mainly referred to handcrafts, graded physical exercise, habit training in the mental health sector, and to vocational skills training for soldiers returning from war (Schwartz, 2003a, 2003b). Over time, the discipline broadened its scope to work with people in a variety of settings, including pediatrics, hand therapy, ergonomics, palliative care, safe driving for older adults, long-term care, brain injury, and spinal cord injuries, among others (CAOT, 2002; Townsend & Polatajko, 2007). In 2008, there were 12,649 registered occupational therapists working in Canada (Canadian Institute for Health Information [CIHI], 2010). The Canadian Institute for Health Information (CIHI) reported a wide range of practice areas, with the majority of therapists working in general physical health, followed by neurological, musculoskeletal, and mental health. The majority of practitioners in 2008 were seen to work in general hospitals, rehabilitation facilities, and community health centers.

Occupational Science

The discipline of occupational science is a more recent development. Occupational science was named by Dr. Elizabeth Yerxa and emerged in the late 1980s at the University of Southern California (Zemke & Clark, 1996). The discipline was originally created to inform the profession of occupational therapy (Yerxa et al., 1989), although there has been much debate among scholars in the two fields regarding the nature of their relationship. For example, Clark (2006) proposes that the relationship between the two fields is nurturing, symbiotic, and even likened to a parent-child partnership. Others see the two fields as independent of each other and potentially detrimental to both disciplinary identities (Mosey, 1992, 1993). The goals of occupational science are diverse. In 2004, Molke, Laliberte-Rudman, and Polatajko systematically analyzed occupational science documents published between 1990 and 2000, and reported that the articulated goals and objectives of occupational science are varied, and at times, contradictory. The goals identified in their review included: exploring human occupation, providing a foundation for occupational therapy, describing the discipline as established on and fueling occupational therapy's epistemological foundations, and achieving social reform and social justice. Distinct from occupational therapy, occupational scientists are interested in studying occupation beyond the realms of health and well-being. Such research can potentially contribute to the knowledge base of other disciplines, such as those which Yerxa (2000) identifies as fitting with occupational science's epistemology, including: "biology, anthropology, developmental and social psychology, interdisciplinary cognitive science, management theory, social geography, sociology and philosophy" (p. 95), as well as services, professions, and agencies involved in socio-cultural-political dimensions of health planning and policies (Wilcock, 2005, 2006). Occupational science views itself as an interdisciplinary field of study, and aims to foster interdisciplinary collaborations (Clark et al., 1991; Yerxa et al., 1989). Today, occupational scholarship can be found in a number of countries, including Canada, Chile, Japan, Sweden, and the United States, to name a few (Larson, Wood, & Clark, 2003; Wicks, 2006).

The study of human occupation, without boundaries on its scope, such as health and well-being, mainly occurs within the discipline of occupational science. However, there is a blurry distinction between the two disciplines, as the majority of occupational scientists, at this time, are occupational therapists, and occupational therapy scholars are frequently engaged in studies on human occupation. While occupational therapists have controlled the study of occupation in the past (Molineux & Whiteford, 2006), occupational scientists are interested in developing multidisciplinary and international partnerships (Clark et al., 1991; Yerxa et al., 1989), which introduce a variety of cultural values, beliefs, and perspectives (Larson et al., 2003) into the field. With the growth and development of occupational science, the study of human occupation is becoming more collaborative both in terms of interdisciplinarity and in terms of international research partnerships. Both occupational scientists and occupational therapists contend that occupation is a basic human need and a source of meaning and fulfillment.

As mentioned earlier, human occupation is described as a “complex multidimensional phenomenon” (Yerxa et al., 1989, p. 6). As such, there are a number of ways to engage in the study of human occupation. For example, human occupation can be examined according to categorical perspectives, levels of analysis, and from a range of methodological standpoints. First, human occupation can be studied in and of itself from different categorical perspectives. For example, Larson, Wood and Clark (2003) state that occupational scientists can study human occupation according to its form, function and meaning. The form refers to the dimensions of occupation that are directly observable, such as who, what, and where related questions. The function refers to occupation as a means, its role of influencing or being a vehicle for adaptation, progress, and development. An example may be the impact of smoking on one's long-term health status, although it can also include the impact smoking has on one's relationships. The meaning of occupation refers to the personal and cultural significance that occupations can hold. For example, smoking can have personal meanings (i.e. relieving stress, succumbing to peer pressure, an act of rebellion) but also broader cultural meanings (i.e. smoking is banned in many public areas in Canada but these rules are not enacted in other countries, and smoking has different connotations today than it did in the past). Form, function and meaning are examples of ways in which occupation itself can be broken down for study. In 2000, Hocking examined the occupational science literature and identified three categories in which occupation itself has been examined: the essential elements of the phenomenon of occupation itself (i.e. its nature, structure, features, and its social, cultural, and personal meanings), occupational processes (i.e. its dynamic, interactive and experiential dimensions, such as tracing the course of occupational performance), and the significance of occupation and its relationship to other phenomena (i.e. health, well-being, identity, and social and political constructs). These categories are useful reminders that the study of human occupation is dynamic and complex, and that a single study is only able to capture partial understandings of human occupation at any one time.

Second, according to Molineux and Whiteford (2006), human occupation can also be explored according to its unit or level of analysis. The level of the individual, they suggest, has been a significant focus in the work conducted on human occupation thus far. They suggest that the reasons for this may be attributed to the influences of both biomedicine and the Western values of individualism on occupational therapy's development. These authors state that less work has been conducted on three other levels of study, the family, the community/society, and the population. Nonetheless, they point to a growing interest in these latter levels of study, which they suggest are due to technological and communicative advances that are shrinking our global geographies, expanding accessibility beyond those of our immediate vicinity, and changing the way we engage in everyday occupation.

Finally, a variety of methodological approaches have been utilized to attend to the complexity of human occupation. However, recently, a growing trend toward qualitative studies in occupational science research has been documented (Molke et al., 2004). Wilcock (2003) notes that researchers have begun to stray away from quantitative research in the study of occupation, suggesting that this may be due to the richness and depth that can emerge from qualitative research in this area. Recently, a number of scholars have been articulating the need for methodological pluralism to enable disciplinary growth (Clark, 2006; Kinsella, in press; Kinsella & Whiteford, 2009; Molineux & Whiteford, 2006; Rudman et al., 2008; Wilcock, 2003). While small-scale, individualized studies are recognized as important contributions necessary for the study of human occupation to thrive, Clark (2006) and Wilcock (2003) remind occupation-based scholars of the value and communicative power of quantitative methods, particularly in the global research context that hails the latter as a 'gold standard.' They suggest that these should not be overlooked in the quest for methodological pluralism.

Summary and Methodological Considerations

In summary, human occupation is studied from perspectives that can be addressed through different categorical perspectives, levels of analysis, and methodological approaches. The purpose of the current study was to examine the embodied nature of occupation at end-of-life as lived and directly experienced by people who are living with terminal illness. Taking into consideration the controversy and debates concerning how to study human occupation, the challenge of how to engage this research question required thought and necessitated further investigation.

For the purposes of this study I judged that the methodology of phenomenology offered the best means through which to address the question at hand. Phenomenological approaches contain important epistemological assumptions regarding what it means to know and how to engage in knowledge generation. These are elaborated in chapter three, though a few relevant assumptions are introduced here. Briefly, in regard to the study of human occupation in terms of categorical perspectives, phenomenological approaches to investigating phenomena are not restricted to categorical assignments but begin from a standpoint of wonder (van Manen, 1997); in other words, they allow interpretive understandings about the phenomenon, in this case occupation at end-of-life, to emerge from the data. As such, in an effort to allow the data to speak freely, I did not strive to begin my study situated within a single categorical perspective. While the study was not designed to attend to any specific categorical perspective, the findings may subsequently address and contribute to some or several of the aforementioned categories (i.e. different forms of occupation at end-of-life, the meanings behind engaging in certain occupations, etc.).

Second, while the significance of each level of study (individual, family, community) is acknowledged, I contend that these levels of analysis are not distinct but exist along an interrelated continuum. Research that focuses on the individual experience of phenomena can also shed light on broader issues of significance to family, community/society and populations. While my study investigates individual experiences of occupation at end-of-life, it also has potential to elicit relevant insights beyond the individual. This is a point that I elaborate in manuscript two, which alludes to the potential for phenomenological approaches to challenge social, political and cultural assumptions about the phenomenon through an articulation of individual, first-hand perspectives and experiences with the phenomenon.

Lastly, given the controversy and debate concerning appropriate methodologies for the study of human occupation, I undertook a detailed methodological investigation into the rationale for using, and the potential contributions of, phenomenology as a rigorous methodology for the study of human occupation. This investigation is introduced in chapter three, and presented in more detail in manuscript two, entitled *Phenomenology and the study of human occupation*; it is therefore not elaborated here.

Plan of Presentation

The scholarship of this integrated manuscript style dissertation involves analytic, conceptual and empirical contributions to the study of human occupation.

To set the stage of the research, this chapter offered an introduction to the study that: situated myself as a researcher, clarified terms used throughout this work, and introduced the study of human occupation and the two occupation-based disciplines (occupational science and occupational therapy). It also considered different means of studying human occupation including categorical perspectives, levels of analysis, and methodological approaches, and discussed some of the reasoning behind the methodological choices adopted for this study, which are elaborated later in the dissertation.

In chapter two, I paint a picture of the end-of-life context in Canada by presenting an overview of changing social and cultural attitudes towards death over time. Four components of the good death, as proposed by the Quality End-of-Life Care Coalition (2010) and the Canadian Association of Occupational Therapists (2010) are presented to illuminate their ambiguous nature. The background to this study and the findings of the systematic literature review (manuscript one) illuminate a number of emergent tensions and key issues. These inform the importance of studying end-of-life occupation at this point in history, and the purpose and questions of the study, which are presented at the end of chapter two.

Chapter three focuses on the methodological grounding for this dissertation. Phenomenology was chosen as an appropriate methodology to study the lived experience of human occupation at end-of-life. This chapter introduces phenomenology's interpretive underpinnings, provides an overview of the phenomenological tradition, and introduces three important philosophers that informed this work, Husserl, Heidegger and Merleau-Ponty. Two theoretical perspectives that guide this work, an occupational and an embodied phenomenological perspective, are discussed. This chapter is somewhat brief in light of the extended discussion of methodology that occurs in manuscript two. A detailed outline of the study design and methods are presented in Appendix A.

The next four chapters present integrated manuscripts that make contributions to the field of occupational science. In particular, the papers contribute to analytic conceptual, and empirical work that include: (a) a systematic review of the literature on the current state of knowledge on occupation at end-of-life, (b) the use of phenomenological methodology in the study of human occupation, (c) phenomenological understandings about occupation at end-of-life and (d) the use of embodied phenomenological perspectives in research.

Chapter four, entitled *Occupation and end-of-life: A review of the literature*, details a systematic review of the literature regarding occupation and occupational therapy at end-of-life. This article presents an analysis of the literature to date, situates occupation and end-of-life in the current context and illuminates areas that require further research. Six themes are identified from the literature regarding occupation at end-of-life: the role of occupational therapy, evaluating occupational therapy, the experience of occupational therapists, the impact on the 'Other,' personal reflections, and the nature of occupation at end-of-life.

Chapter five is entitled *Phenomenology and the study of human occupation*. This article has been accepted for publication in the Journal of Occupational Science. The purpose of this conceptual paper was to propose that phenomenology is a useful, though overlooked, methodological approach for the study of human occupation. Five phenomenological dimensions and their generative possibilities for the study of human occupation are presented: a reconceptualization of knowledge generation, intentionality and the lifeworld, the notion of being, the lived body and phenomenology as first critique.

Chapter six is entitled *A phenomenological inquiry into the embodied nature of occupation at end-of-life*, and has been accepted for publication in the Canadian Journal of Occupational Therapy. This article presents the findings of the study at the centre of this dissertation, an examination of the embodied nature of occupation at end-of-life. The article presents six thematic findings that emerged from analysis of the empirical research. Participants described orientations towards occupations that involved: living with death, reworking everyday life, being guided by the will of the body, focusing on relationships, attending to the small things, and engaging existential orientations.

Chapter seven is entitled *Embodiment in research practices: The body in qualitative research.* This manuscript has been accepted for publication as a chapter in the book, *Creative spaces for qualitative researching...Living research*, edited by J. Higgs, A. Titchen, D. Horsfall and D. Bridges. This chapter inquires into what embodied phenomenological perspectives can offer to research practices, and emerges out of ongoing reflection on phenomenological methodology and future possibilities for such work. Three dimensions of embodied research are examined: the lived body as a path of access to the world, the body's skillful intelligence, and the body's intercorporeality. These three dimensions are enhanced by examples from the literature, as well as examples from this doctoral research. This chapter inquires into what it might mean to think of qualitative research practices from an embodied phenomenological perspective.

Together, these four manuscripts address several important gaps in the literature, and offer theoretical and practical implications for the study of human occupation. Two articles address gaps in the literature surrounding the study of human occupation with respect to occupation and end-of-life. Two articles provide in-depth analyses of phenomenological dimensions, and illuminate the power and possibility of phenomenological approaches for the study of human occupation, and beyond.

Finally, chapter eight offers emerging insights and reflections on the research. This chapter begins with a presentation of eight emerging insights related to occupation and end-of-life: living well while dying; identifying occupations at end-of-life; lived engagement in occupation as a fifth existential; rehabilitation and re-inhabitation; existential considerations in regard to spirituality and being; relational care; embodied understandings; and the ‘promise in things.’ This is followed by a consideration of two methodological insights regarding the study of human occupation, including a consideration of phenomenology as a fruitful methodological approach and the potential of embodied research. Five quality criteria are proposed as guidelines for assessing the ‘rigor’ of phenomenological work. I conclude with a discussion of ethical, methodological and personal reflections that emerged throughout my research experience.

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CHAPTER TWO: BACKGROUND TO THE STUDY

THE END-OF-LIFE CONTEXT: WHAT MAKES A 'GOOD DEATH?'

Introduction

In this chapter, the study background is presented with a brief overview of the end-of-life context in Canada, changing attitudes towards death over time, and a discussion of what the good death is proposed to entail. A number of significant tensions that indicate the importance of this research and its potential contributions to the study of human occupation and the hospice palliative care context in Canada are discussed. These include a need to: (a) examine the nature of occupation at end-of-life from the perspective of first-hand accounts, particularly in response to changing Canadian demographics and recent cutbacks to end-of-life services and resources; (b) consider the notion of good dying, and the potential for occupation to contribute to improved dying experiences; and (c) address the possibility that the role of occupation and occupational therapy services are being overlooked at end-of-life due to a limited understanding of what these roles entail. This chapter concludes with a presentation of the purpose and key questions of the study.

Situating End-of-Life in Canada

In this section, I review the literature on end-of-life (a second key construct in this study) in order to paint the scene for the study of end-of-life in the Canadian context. It is interesting to note that Canadian demographics continue to move toward a rapidly growing older population (Auger, 2007). Compared to 1981, the number of Canadian seniors (over the age of 65) in 2009 has doubled to approximately 4.7 million; this number is expected to double again by 2036 (Statistics Canada, 2010). The number of very old persons (years 80 and over) was projected to be approximately 6000 in 2009 and this number is expected to triple by 2036. By 2021, for the first time in Canadian history, the number of seniors is expected to surpass the number of children. Each year, it is estimated that approximately 247,000 deaths occur, a number that is projected to nearly double in 2058 (Statistics Canada, 2010). According to the Canadian Senate's (2000) report, 75 percent of people who die in Canada each year are over the age of 65.

While death and dying directly affects individuals with terminal illnesses, this experience has a rippling effect on the people involved. The process of dying is also a social experience in that it often involves a variety of other people, including family members, caregivers, health professionals and staff, community volunteers, legal consultants, religious institutions, and funeral directors (Auger, 2007). It has been proposed that the end-of-life process for one individual can affect the well being of five other people (Canadian Senate, 2000; Canadian Hospice Palliative Care Association [CHPCA], 2010). This means that every year, over 1.4 million Canadians are potentially affected.

The literature suggests that only 15-25% of Canadians in need of palliative care services have access to this specialized care (Canadian Senate, 2000; Quality End-of-Life Care Coalition [QELCC], 2007). There is a lack of funding for end-of-life services and it has been reported that hospice and palliative programs in Canada rely heavily and disproportionately on charitable donations (CHPCA, 2008). The Canadian Hospice Palliative Care Association (CHPCA) (2010) states that Canadian families bear 25% of the costs associated with home-based palliative care services. Between 2001 and 2006, the federal government provided annual funding of approximately 1.2 million dollars to the Secretariat on Palliative and End-of-life Care (Health Canada, 2002); however, in 2007, this End-of-Life Secretariat was disbanded and the funding was dramatically slashed to $470,000 (CHPCA, 2008, 2010). Funding cuts have been implemented for institutionally–based palliative care services, thereby increasing the need and use of home-based services. The wish to die at home is frequently cited in the literature (CHPCA, 2010; QELCC, 2008; Williams, 2002). However, the government has not matched the move to home-based services with an adequate increase in funding for home care, leaving, what the CHPCA (2008) describes as "a significant gap in the health care system" (p. 1).

According to the Honorable Sharon Carstairs (2005), changes must be made on both cross-departmental and cross-jurisdictional levels. More specifically, without sustainable funding, a well-coordinated and better implemented national strategy, greater accessibility to quality care, more education and training for health care professionals, increased research, and support for caregivers, the right to quality end-of-life care will not be met for the growing number of Canadians in need. While these limitations are currently and primarily impacting those who are directly receiving services and providing care, they will also indirectly influence the majority of Canadians at some point in life (CHPCA, 2008).

These statistics reveal a number of tensions that elicit concern for the Canadian healthcare system and for the aging population and their caregivers in the next several decades. They include indications that: (a) end-of-life care needs are rapidly increasing for the aging population who currently live within a context of limited resources and funding, (b) there is great potential for financial, emotional and physical strain on family caregivers, and (c) there appears to be a lack of national cohesion surrounding how to best implement end-of-life care. These issues point to a need for greater attention to the end-of-life experience, and raises the question ‘Why is death and dying, an inevitable life experience for every Canadian, not receiving due attention?’

Changing Attitudes Towards Death

To better understand death and dying in its current form, it is useful to consider a sociological perspective on its changing history. British sociologist Tony Walter (1994) mapped shifts and patterns in social and cultural attitudes towards death over time. His schema identified three types of death: traditional, modern, and post-modern. He suggests that these three types are “simplified ideas about social life that have a logical coherence but that do not exist in pure form in reality” (p. 47). They are characterized by particular historical periods, which shape and are shaped by social responses to death and dying. The purpose of presenting this schema is not to label or categorize dying according to rigid and specific periods of time, since the boundaries demarcating each period overlap and there are always exceptions to such a framework, but rather to illuminate changing trends (Walter, 1994) and their implications for death and dying in the Canadian milieu.

Traditional or Pre-modern Deaths

In Walter’s schema (1994), the traditional or pre-modern type of death refers to those spanning from ancient times and to the late 18th century. The ‘who’ in traditional deaths were most commonly young children and the life expectancy of the average adult was 40 years old (Walter, 1994). Deaths were caused by plagues and infectious diseases, and the trajectory of dying was short. Death and dying occurred in a community-based context, in that death occurred in the home environment. Here, the people who were dying were cared for primarily by their families, more specifically by the women. The number of hospitals was growing, but the home was the preferred place to die, due to its familiarity and comforts, coupled with the primitive medical knowledge and services available. The church and spiritual leaders played a significant role in overseeing the dying process; here, “the will of God” (Walter, 1994, p. 54) had control. Death was understood as inevitable, a familiar rite of passage as its presence was explicit and visible in everyday life. Therefore, people knew what to expect in the dying experience and had a very personal and hands-on involvement throughout.

This traditional attitude towards death is not a death-denying attitude, but rather what Aries (1981) refers to as the ‘tame death,’ the “oldest death there is” (p. 28). In the tame death, the dying individual is aware that he or she is dying and prepares him- or herself for death. The social context of the ‘tame death’ would be characterized by what Glaser and Strauss (2005, 2007) call an open awareness context. These sociologists conducted an ethnographic study in 1965 that examined whether social death could occur before biological death in hospitals. A significant finding was that there are different contexts in which the dying person is aware of his or her impending death. In an open awareness context, the individual is aware that he or she is dying, calmly resigning him- or herself for the inevitable end. According to Kübler-Ross (1969), an open awareness is considered to exemplify a necessary component of the ‘good death,’ in that the people who are dying have peacefully (though not to be mistaken as happily) accepted death and are able to open themselves up to the possibility of and preparation for a dignified end. The opposite, the closed awareness context, may be seen more frequently in the modern social context of death and dying, where death has become hidden from everyday life (Auger, 2007; Howarth, 2007).

Modern Deaths

Dying in the late 18th to the mid-20th century is characterized by Walter (1994) as the modern death, and is distinguished from the pre-modern era by several significant changes. Science, medical settings, and the physician replaced the role of religion, the church, and spiritual leaders in the dying process; authority was epitomized by the phrase “doctor’s orders” (Walter, 1994, p. 54). Other changes included: advances in medical technology, which offered more effective interventions and treatment; greater urbanization and an increase in specialized skills which made hospitals resource-rich settings for a variety of services; and the changing role of women, who began entering the work force and were no longer available to provide care at home (Howarth, 2007). Death began to more commonly occur in old age, and the life expectancy of the average adult increased to approximately 70 years (Walter, 1994). Since infectious diseases were controlled through medication and vaccinations, people were able to live longer and died of causes such as cancer and coronary diseases (Kellehear, 2007). The hospital began to be more appealing; it is currently the place of death for most Canadians (Auger, 2007; CHPCA, 2008).

Unlike the tame death at home, death is wild or unfamiliar for the dying individual in a modern context (Aries, 1981). Control is left in the hands of science and the physician. This type of death and dying setting began to spur anxiety and fear. A common response was to hide the terminal diagnosis from the person who was dying. According to Glaser and Strauss (2005, 2007), this is referred to as a closed awareness context in hospital settings, where the patient is unaware of his or her terminal diagnosis, and the physician, nurses, and even the family were all involved in keeping the patient's pending death a secret. In order to avoid arousing suspicion in the patient, the healthcare team and family 'managed' space and time; they managed space by holding private conversations that occur away from the patient's presence, and managed time by engaging in careful conversations with the patient that focus on the immediate versus future time. Further, Aries (1981) suggests that the community and family oriented death at home in the pre-modern period familiarized and connected people with the dying experience; by moving dying individuals to hospital settings and leaving care to specialized mortuary personnel and hospital staff, death became unfamiliar, invisible, individualized, and even potentially meaningless. Hospital settings can isolate and marginalize individuals from the community, contributing to social deaths, which can occur far before the biological (Glaser & Strauss, 2005, 2007; Kellehear, 2007).

Death Denial

In this modern setting, deaths are not seen to be an acceptable right of passage, but rather as avoidable and preventable (Walters, 2004). This attitude towards death is the basis of a prominent theory that arose in the mid-twentieth century, which suggests that social attitudes towards death and dying in North American and European countries are characterized by denial (Aries, 1981; Auger, 2007; Becker, 1973; Howarth, 2007; Seale, 1998).

The notion of death-denying is derived from Freud's (1940) theory that people deny or suppress what they fear (Becker, 1973; Howarth, 2007). This fear and anxiety about death may be due to a common feature of the end-of-life stage: it is more frequently than not, an unpleasant and sad experience. Death is associated with mourning and loss. According to Kübler-Ross (1969), depression is a key stage in the grieving process at the end-of-life. She suggests that loved ones often try to 'cheer up' the dying individual, and that words of encouragement can do the opposite of the message they intend to convey. Asking the patient to take an optimistic stance to his or her impending death can be interpreted as asking the patient to not think about death and dying and to resist feeling sad, both of which deny the dying experience. Kübler-Ross suggests that sadness is an essential part of the death and dying experience and should be acknowledged, rather than suppressed. Death and dying may also be feared because people may be apprehensive or frightened about what they do not know or are not prepared for (Special Senate Committee on Euthanasia and Assisted Suicide, 1995). Death and dying refers both to the end of living and the process in getting there, and for some, the latter can also be a source of anxiety. In de Beauvoir's (1964) narrative of her mother's dying experience, she writes of her mother:

> She believed in heaven but in spite of her age, her feebleness, and her poor health, she clung ferociously to this world, and she had an animal dread of death. She had told my sister of a nightmare that she often had. 'I am being chased: I run, I run, and I come up against a wall; I have to jump over this wall and I do not know what there is behind it; it terrifies me.' She also said to her, 'Death itself does not frighten me; it is the jump I am afraid of.' (p. 19)

Death invites the unpredictable, the arbitrary, and sometimes even the volatile; in most cases, we are unable to know when or how we will die or what the 'jump' will be like. Fear of the end-of-life process may contribute to the reasons why death is denied.

The theory that death was avoided during the modernization period in the twentieth century led British sociologist Gorer (1965) to suggest that death had taken the place of the topic of sex in the nineteenth century; where sex was a 'taboo' topic in the past, death had taken over its role. Howarth (2007) quoted Gorer's seminal work, stating "While natural death has become more and more smothered in prudery, violent death has played an ever-growing part in the fantasies offered to the mass audiences" (p. 31). Death has therefore become pornographic; natural deaths are hidden behind the closed doors of medicalized settings and violent deaths are sensationalized in the media (such as in video games, movies and 'them-not-me' portrayals of death in the news). Gorer's views were supported by Aries (1981), who states that, "we moderns…have banished death from daily life" (p. 11).

The contention that we live in a culture in which death is denied is not fully supported by all scholars. Critiques of this theory, by sociologists such as Talcott Parsons, Victor Lidz, and Allan Kellehear include: that changes in our everyday rituals surrounding death are not necessarily indicative of fear or denial but of acceptance and even scientific control of death; that the supposed universal fear of death, which the death denial theory is based on, is in actuality not universal; and that the nature of articulated fear can vary from individual to individual (Howarth, 2007). Kellehear (2007) points out that for centuries, people have lived anticipating death and the after-life journey, and that the challenges of death and dying have been social drivers for cultural development (i.e. for the development of laws, technologies, and rituals). He states:

> Death motivates and activates people like little else because historically biological death has been viewed as no death at all, but rather, the most complicated and challenging part of living…the great question confronting all who die, then, is how to maximize the conditions under which the dying might succeed in their challenging and often daunting otherworld tests. (p. 47)

For example, Kellehear suggests that like other animal species, the threat of death has spurred awareness of 'danger signs,' whether it is a predator, an illness, or a risky situation. Death can also incite impetus for how we should live to prepare for death, such as a commitment to religious doctrines. The way we die can therefore be a marker of human change, beacons of dominant social and cultural values.

While the denial of death has characterized the death and dying climate for the past several decades, Walter (1994) has suggested that another shift in attitudes has occurred. Today, in the post-modern social milieu, he proposed that there is a revival of interest in death and dying.

Post-Modern Deaths

Post-modern or neo-modern deaths are characterized by societies that are seeing a revival in the interest of death and dying, as seen beginning in the late 20th century and in the current end-of-life context. Death and dying is illuminated through many forms of communication, technology, and mass media, such as television, international conferences, training workshops, self-help books, and bereavement groups. Deaths in the post-modern setting are ‘sequestered’ in that they ideally occur in “the private world of the individual” (Howarth, 2007, p. 24). In this context, death occurs at even older ages, and the dying experience is prolonged due to improved living standards, greater emphasis on public health and health promotion, and even more superior medical technology. Diseases that were once near-immediate death sentences, such as cancer and AIDS, are now managed over longer periods of time; deaths are not just encountered, but prolonged. Therefore, people can live with illnesses much longer, requiring extensive periods of disease maintenance and pain-relief, and thereby necessitating longer and very costly stretches of time in the hospital and in long-term care facilities. As a result, governments encourage shorter institutionalized stays and there is a renewal of the promotion of death at home, motivated to a great extent by its cost effectiveness (Williams, 2002). Prolonged illness duration coupled with a more individualized experience of dying has led to a ‘doing it my way’ trend, where the dying experience is overseen not by religion or science, but by the individual (Walter, 1994). This period of time is characterized by personal expression, reflection and the reconstruction of personal identity and life meaning. Seale (1998) suggests that this is a time of risk awareness and avoidance. Death is considered in light of the degree of risk attached. According to Seale, what used to be risks defined by plagues and famines are now manufactured and abstract risks, such as global warming and terrorism. Individuals have greater responsibility than ever to control the possibility of death through managing risks and promoting health (i.e. decisions on whether to smoke, to eat red meat, to live in certain geographic areas, etc.). Individuals have less faith in single systems of expertise, like religion and medicine, instead relying on personal awareness, planning, and alertness. An example of this is taking out life insurance plans, which Seale (1998) suggests is not death denied but an active acknowledgement, attitude, and battle against death.

Summary

The purpose of this discussion was not to infer that the denial of death is a universal attitude. However, in consideration of the changing historical periods in which death and dying occur, this discussion may offer insight into how and why the current context of Canadian end-of-life care exists as it does today. The proposed revival of attention to death in the post-modern era (Walter, 1994) may have implications with respect to why public and governmental awareness and attention to quality palliative and end-of-life services has increased in the past few decades. Technological advances that can help prolong life and the proposed ‘do it my way trend’ have led to several ethically charged cases that have been raised in the media, such as assisted suicide, patient rights, and euthanasia (Special Senate Committee on Euthanasia and Assisted Suicide, 1995).

Despite a revival of interest in death, it seems that Canadians have both limited awareness and understanding of what end-of-life services offer. In 1997, an Angus Reid Canadian poll found that only 53% of the 1,500 Canadians that participated in the study had heard of hospice care and only 30% defined it as care for the terminally ill (Health Canada, 2002; National Research Advisory Committee of the Canadian Palliative Care Association, 1999). More recently, Claxton-Oldfield, Claxton-Oldfield, and Rishchynski (2004) distributed two surveys to 89 Atlantic Canadians to examine their awareness and understanding of palliative care. While 75.3% of the respondents claimed they had heard of palliative care, only 48.4 % defined it as care for the terminally ill, while others defined the term as care for the sick and care at home. Of those who had heard of palliative care, 40.8% were first exposed to it through personal experience of the death of a loved one. Surprisingly, when asked about the best ways to raise awareness about palliative care, one participant stated that he or she was “not sure that there is a necessity to inform the general public [about palliative care] unless a situation arises that palliative care may be needed” (p. 110). These studies speak to the limited awareness that many Canadians have of palliative and end-of-life care, despite the growing number of individuals that require these services.

The Good Death

While death is inevitable, the quality of the end-of-life experience varies considerably and requires further investigation. An editorial in the British Medical Journal posed the question ‘What is a good death?’ and concluded that this question could not be answered since there is a lack of research in the area, particularly from the perspectives of clients and their caregivers (Kendall et al., 2007).

Walter (1994) suggests that what constitutes a good death appears to have changed over time. For example, the traditional good death includes saying goodbye to one’s kin and being prepared to enter the afterlife journey. The modern good death may be characterized by occurring quickly, being well-controlled by medical experts, being painless, and being private. The post-modern or neo-modern good death adheres to the unique wishes of the dying individual, allowing a sense of autonomy and control. Walter (2003) proposes that the post-modern good death is highly influenced and varied by culture, and is determined by the degree of secularization (religion as a personal choice and dictating what good dying entails), individualism (individualism promotes autonomy), and length of the dying period (slow dying as a greater reality versus quick). While various perspectives about what a good death entails exist, the current umbrella notion of dying well in Canada can be drawn from the current hospice and palliative care literature, which promotes a hospice death.

The Good Death as a Hospice Death

The advances and initiatives by the Canadian government in the past two decades indicate a growing interest in the hospice and palliative care philosophy as a gold standard at end-of-life (Carstairs, 2005; CHPCA, 2006; QELCC, 2008). Hospice refers to a philosophy of care that was founded by Dame Cicely Saunders, who opened St. Christopher’s Hospice in Sydenham, London, in 1967. The philosophy of hospice is similar to the overall themes of the neo-modern dying experience, such as a focus on the self, relations, spirituality, and emotional expression (Walter, 1994). Hospice is defined by a number of key components including: holistic care; involvement of interdisciplinary teams; non-hierarchical care; care that is not rule bound; work that is viewed as vocational; and a commitment to research and education (Howarth, 2007). The hospice movement has proliferated worldwide and can exist as both a free-standing structure as well as services offered in the patient's home. The development of hospice has strong influences on what is considered the best or good dying experience today. In Canada, the CHPCA and the Canadian Home Care Association have developed 'gold standard' ideals with respect to four services: case management, nursing care, personal care, and palliative-specific pharmaceuticals; these recommendations are seen to be benchmarks for government funding and against which end-of-life facilities are to align and compare their services (CHPCA, 2006). Further, these recommendations are steps that contribute to the larger goal of the QELCC (2010), that is, that "all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice" (¶. 2). The Canadian Association of Occupational Therapists (CAOT) has also adopted this mandate in their position statement on occupational therapy and end-of-life care (CAOT, 2010). The four components of this mandate, dying with dignity, freedom from pain, surrounded by loved ones, and in a setting of their choice, will be examined in more detail. While these are inferred to be components of dying well in Canada, this list is clearly not exhaustive.

Dying with Dignity

The first component of the QELCC (2010) and the CAOT (2010) mandate is the notion of dying with dignity. Dying with dignity is often linked with the dying individual’s right to choose how he or she will leave the world. Patient requests for euthanasia and assisted suicide are often influenced by what patients articulate as a loss of dignity (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002). For example, in a study that reviewed the first year of the State of Oregon’s Dying with Dignity legislation, Chin, Hedberg, Jigginson, and Fleming (1999) compared two groups of terminally ill patients from the perspectives of their physicians. The case group was composed of individuals who chose to undergo physician-assisted suicide while the control group died without this fatal intervention. These authors found that at end-of-life, individuals in the case group expressed more concern with issues related to a loss of autonomy and loss of control of bodily functions than the control group.

Different forms of dignity have been documented in the literature. Chochinov (2006) distinguishes between two types of dignity: basic dignity which is innate, universal and moral in nature, and personal dignity, which is more individualistic and used in reference to indignities that can occur during the end-of-life experience, threatening one’s independence and autonomy. In his experiences as a hospice physician, Byock (1997) recounted three patient stories (all names are pseudonyms) that exemplified different forms of dignity at end-of-life. Wallace Burke found dignity through the honor of being cared for, that being a recipient of care can be a contribution to his family and community. Julia Rosauer achieved dignity at end-of-life through loved ones acknowledgement and expressions of appreciation to her for her many years of self-sacrifice and devotion. And although Hap Visscher initially thought that there was little of value to pass on to his children and grandchildren, through life review, he was able to find dignity in his accomplishments as a handyman and from childhood stories that were unearthed in his narrative. Street and Kissane (2001) identify four types of dignity in a discourse analysis of how dignity is portrayed at end-of-life, drawing on texts, internet sites, legislative statements and narratives. Of the four types, they suggest that the latter two are often overlooked. The first type is dignity as autonomy and self-determination. They suggest that while autonomy is claimed to be of central concern, it can often be conflated according to the interested party (i.e. bioethicists, legislators, activists), with quality of life domains (i.e. when clinicians conflate autonomy with holistic care). For Street and Kissane, dignity as autonomy pertains to generating contexts in which the patient can exercise control and capacity, however minimal this may be. The second is dignity as personhood or self-worth. This refers to honoring the individual as a human being, and the life world that he or she has developed, including his or her successes, strengths, talents, and relations. An example of an indignity in this instance is reducing the patient to his or her disease. Instead, dignified dying includes the “maintenance of self-worth, self-respect, and personhood in their fullest meanings” (Street & Kissane, 2001, p. 96). The third type is dignity as relational. This highlights the dynamic and evolving nature of dignity between persons. For Frank (2004), dignity is an interaction between people in which recognition of dignity is shared. He states, “There is no dignity outside of some people-like-us relationship, and people-like-us relationships require, among other foundational recognitions, shared recognitions of dignity’s maintenance or loss” (p. 209). This highlights the importance for health care workers to be aware of how they are affirming the dignity of their clients through words, gestures, and actions. Finally, the fourth type is dignity as embodied. This type of dignity highlights the body’s role in bridging our connection to the world and the body’s power in dictating the process and inevitability of life’s end. Street and Kissane (2001) found that in the discourse, patients often referred to the disarray, humiliation, uncleanliness, and shame associated with the loss of bodily boundaries and control (through bleeding, open wounds, and losing bowel control), what Street and Kissane refer to as the abject body. The body was seen to be a significant factor in suffering, but can also be a means in which the dying individual can continue to feel connected to the world, through touch, affection, presence, and respect.

The construct of dignity is, thus, quite complex and unique to the dying individual. While it may be publicly recognized in the media as tied to ethically charged end-of-life conflicts, it can also be localized in the experiences of everyday life, through and within our relationships as well as our bodies.

Freedom From Pain

Freedom from pain is the second proposed component of what dying well entails in Canada (CAOT, 2010; QELCC, 2010). Pain is commonly associated with bodily symptoms that often worsen as the dying process advances. Attending to the biological dimensions of the body is a key feature of the medicalization of death, which promotes the expectation that the primary goal of health care and the physician is curative and, subsequently, death is viewed as failure (Howarth, 2007). This expectation may contribute to the understanding that bodily pain is a component of bad dying. One of the participants in the study by Vig, Davenport, and Pearlman (2002) stated:

> A bad death - the one that I grew up with - was an older cousin whose wife had cancer, and it was the slow, eating kind. And she went two or three years of just constant pain….And that has stuck with me throughout the years as being a horrible way to die. (p. 1545)

Freedom from bodily pain and pain and symptom management are frequently articulated as very important factors for a good death (Steinhauser, et al., 2000; Vig et al., 2002; Vig & Pearlman, 2004).

There is, however, no single definition of pain. Pain can be physical suffering, but can also manifest itself in different ways. In fact, Cicely Saunders coined the term 'total pain' in the early 1960s, acknowledging that pain can arise from non-physical sources as well, including psychological, social, relational, emotional and spiritual pain (Clark, 2000; Egan, 2007). This concept highlights that pain can take on many forms and stresses the importance of listening to the patient since, as Saunders suggests, "Pain is what the patient says it is" (as cited in Egan, 2007, p. 294). It is a challenging task to attend to every type of pain, particularly since pain and the suffering it invokes often occur in silence. The unspeakable nature of pain and suffering is expressed in Frank's (2001) description. Drawing from his experience of cancer, he states:

> Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful. Suffering is loss, present or anticipated, and loss is another instance of no thing, an absence. We suffer the absence of what was missed and now is no longer recoverable and the absence of what we fear will never be. At the core of suffering is the sense that something is irreparably wrong with our lives, and wrong is the negation of what could have been right. Suffering resists definition because it is the reality of what is not. Anyone who suffers knows the reality of suffering, but this reality is what you cannot 'come to grips with.' To suffer is to lose your grip. Suffering is expressed in myth as the wound that does not kill but cannot be healed. (p. 355)

Egan (2007), an occupational therapist, proposes that responding to pain and suffering is a central responsibility of the profession, and that therapists should not overlook the dimensions of care that exist beyond simply conducting assessments and interventions. She suggests that responding to suffering requires that we act by remediating suffering when we can, by avoiding the infliction of further suffering, and by deepening and sharing approaches to suffering. However, responding to suffering begins by acknowledging first, that it exists. Egan draws on Frank (1991) to make this point: "What I wanted when I was most ill was the response, "Yes, we see your pain; we accept your fear" (as cited in Egan, 2007, p. 293). Pain exists in multiple forms, although it is commonly understood to pertain to symptom and discomfort relief. However, social, emotional, and spiritual forms of pain not only exist, but can be experienced through silence, and can subsequently be overlooked as important issues at end-of-life.

Surrounded by Loved Ones

Being surrounded by loved ones is the third component in the QELCC's (2010) and CAOT's (2010) mission statement, from which a good death in Canada can be inferred. The wish to be *with* when dying is characteristic of our way of being in our everyday lives. We do not live in vacuums. Our social relationships are an integral part of our lived experiences, and we are therefore involved in what German philosopher, Heidegger (1927/2008) refers to as our being-in-the-world. Levinas (1998) states that "being-in-the-world means being near things having a meaning, and whose coherent significance, in terms of the *concern for being*, precisely constitutes the *world.* And thus, being-in-the-world…is immediately to be *with* others" (p. 183-4). Of course, daily social relations exist on a wide range of levels, from strangers and acquaintances, to family, friends, and lovers. But it is mostly with the people we love that we "share our soul stuff" (words used by Brent, a dying person, to describe his friendship with Susan, as cited in Byock, 1997, p. 218). The ones we want to be with at end-of-life are likely those that mirror back to us who we are, where we have come from, and whom we matter to. When Mitch Albom

(1997) asked his dying mentor, Morrie, if he is worried about being forgotten, Morrie answered, “I’ve got so many people who have been involved with me in close, intimate ways. And love is how you stay alive, even after you are gone” (p. 133).

However, ‘being with’ at end-of-life is not always a brief experience. End-of-life can be drawn out and prolonged, and can involve the weight of caregiving responsibilities. While caregiving can be fulfilling and transformative, it can also harbor negative dimensions for dying individuals and their loved ones. People who are dying may feel that ‘being with’ at end-of-life is too much to ask of loved ones. Wilson (2000) found that participants were wary to lay burden on their loved ones because end-of-life care was seen as an obligation or duty; the “acts of caregiving can be ‘too much to deal with’ because ‘there is already so much to deal with’” (p. 1418). In fact, the thought of being a burden can lead to the desire to hasten death. For example, in 2000, Ganzini et al. explored physicians’ experiences with requests for assisted suicide in Oregon, a US state that legalized this act in 1997. The physicians reported that of their patients who requested this fatal intervention, 38% viewed themselves as a burden. People who are dying may feel it is a comfort to leave the labor of end-of-life care to health care professionals, to reduce the burden on their loved ones.

This fear of burdening loved ones may be tied to the relational component of dignity, particularly feelings of personal autonomy, and the desire to maintain any last feelings of independence. The threat of losing one’s autonomy may be lessened if a professional is able to take on tasks that may result in feelings of humiliation and shame (i.e. help with the loss of control with bodily functions). This may be related to the notion that dependency is not valued in Western cultures: “personal or individual autonomy-especially in Western society-is often conflated with the notion of being a whole person, so that dependency can be seen or experienced as threatening the integrity of personhood itself' (Chochinov, 2006, p. 91). Rejecting dependency may influence the reasons why people at end-of-life have difficulty accepting help from their caregivers.

Conversely, at times, it is the caregiver who refuses to take on roles that available professionals are able to do. Sometimes, it is an attempt to maintain a sense of normalcy in the relationship with the dying loved one. At other times, the weight of caregiving responsibilities may be too much to handle. Halifax (2008) proposes that there is a shadow side of caregiving:

> You probably are already familiar with the archetypes of caregiving, negative as well as positive. On the one hand there's the selfless saint, possessing seemingly endless resources of compassion and generosity. On the other there's the martyr-bitter, exhausted and unable to perform the smallest service without simmering resentment. While caregiving can be one of the most noble and useful practices life has for us, one that is healing for both dying people and their supporters, a glowing, beautified image of service can cast a very long, very dark shadow. (p. 113)

End-of-life relationships can often involve caregiving responsibilities, which may dictate new ways of being with others; individuals may not be fully prepared to take on new and/or different roles. For instance, one caregiver, in an ethnographic study investigating the meaning of the caregiving experience (Hasselkus, 1988), noted a strong sense of role loss in caring for her husband: "It's like I'm neither married, I'm neither divorced, I'm not widowed, I'm kind of in limbo" (p. 688). This study also identified examples of the shadow side of caregiving, such as tensions between caregivers and care receivers as well as caregivers and health care professionals. For example, with respect to the former, the care receiver's expectations of the caregiver were sometimes viewed as unreasonable. One caregiver reflected, "If I'm doing something in the kitchen and he calls me, he wants me to come right now, so you have to get yourself in the mood to not resent anything like that" (p. 688). Tensions also emerged between caregivers and health care professionals, when the invisible and sometimes conflicting meanings in which their care practices were situated were overlooked or misunderstood. While health care practitioners implemented care from theoretical and standardized approaches, caregivers often drew on reflective, experiential, and informal learning processes; when it came down to caregiving situations, these conflicting meanings could result in a tension of who 'knows best.' Therefore, while being surrounded by loved ones is often desirable at end-of-life, caregiving at home can also involve changing roles, changing expectations and tensions that people at end-of-life and their loved ones might not be prepared for.

In summary, relationships can be testaments to the lives we have built, the people we have become, and act as carriers or vehicles of our continuing legacy. 'Being with' at end-of-life can involve deep moments of transformation, sharing of one's deepest existential reflections and 'soul stuff,' and the privilege of caregiving. As such, being surrounded by loved ones during the dying process is often seen as an indicator of the good dying experience. Nonetheless, it is not always as ideal as one might hope. The emotional weight of the dying process, although having the potential to be enormously fulfilling and transformative, can also be taxing and traumatic. It may also involve: the shadow side of caregiving, the potential to foster feelings of relational dignity or indignity, and be a source of relational tensions between care receivers, care givers, and health care practitioners.

Preferred Location of Death

The fourth and final component of quality dying according to the CAOT (2010) and QELCC (2010) mandate is to experience end-of-life in a preferred location. Brazil, Howell, Bedard, Krueger, and Heidebrecht (2005) suggest that place of death is a strong factor that impacts the potential for good dying experiences. Preferences on place of death are usually discussed within a dichotomy between the home and institutionalized settings (including hospitals, medical settings, hospice settings, chronic care facilities, etc.) (Gomes & Higginson, 2006).

A common understanding is that the home is the preferred location for end-of-life care and death (World Health Organization [WHO], 2004). The home has been described as "an encloser of closest kinship relations" (Stanyer, 1994, p. 31), a safe haven, and a place of familiarity, intimacy, and comfort (Hasselkus, 2002; Stanyer, 1994). Death at home is cited as appealing due to reasons including: maintaining a sense of connection with the community, having the support and presence of loved ones and family, feeling the home is a more natural place to die, maintaining normalcy, and the home as providing a greater potential for autonomy (Brazil et al., 2005; Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004). A literature review investigating factors that influenced a home death by Gomes and Higginson (2006) found that people were more likely to die at home if they had: low functional status, expressed wanting to die at home, sufficient home care services, relatives living with them, and extended family for support.

The wish to experience end-of-life at home is not limited to dying individuals, but is often cited by their caregivers as well. For example, two Canadian studies investigating place of death preferences of seniors found that the home was generally the preferred location of care and death. Wilson (2000) conducted a grounded theory study and after interviewing 49 seniors with caregiving experience, she found that 46 of the participants considered the home to be the ideal location for end-of-life care and death. In a study by Brazil et al. (2005), investigating informal caregivers' perceptions on place of care and death, over 63% of the participants preferred the home.

However, disadvantages of the home as a place for end-of-life care have also been cited. It has been suggested that patients may not be prepared for the degree to which their home place is changed when it is the setting for end-of-life care (Williams, 2002). Patients may not be prepared for the invasion of illness equipment (i.e. commodes, respirators, and medication) and the on-going intrusion of home and health care personnel (such as physicians, nurses, therapists, and volunteers) (Gott et al., 2004). Therefore, while the home is hailed as the preferred location for death (WHO, 2004), clients and their caregivers may not be prepared for the challenges of the home as a setting for end-of-life care.

While the notion of dying at home is often characterized as a contributing factor to good dying, some studies have indicated that the preferred location of death can be mixed. A recent study by Stajduhar, Allan, Robin Cohen, and Heyland (2008) found that when asked where both the patient and caregiver preferred end-of-life care to be conducted, only 53.6% of the patients and 50% of the caregivers preferred the home to a hospital. This was also seen in a study by Vig et al. (2002), who interviewed geriatric outpatients about their attitudes on the end-of-life experience. These authors found that some participants preferred the home environment while others preferred to die in the hospital. The decision to have a hospital death is cited to be mitigated by a range of factors, including the wish to not burden the family, whether the home environment is able to be adapted to accommodate the patient’s needs, and whether there are adequate and sufficient home care services and family caregivers available (Brazil et al., 2005; Williams, 2002; Wilson, 2000). These studies suggest that institutional settings can also be places where good dying can be experienced. This is of interest, since, as stated earlier, the actual place of death for most Canadians is hospital settings (Auger, 2007; CHPCA, 2008).

These studies seem to indicate that the preference for place of death is mitigated by circumstantial factors and is highly individual. Client and caregiver preferences do not always align. However, both home and institutional settings have potential to be places that foster good dying experiences.

Summary

In summary, good dying in Canada is proposed to consist of four main components: dying with dignity, free from pain, surrounded by loved ones, and in a preferred location (CAOT, 2010; QELCC, 2010). As the preceding discussion has shown, these components are more complex than might be immediately evident. One component may potentially conflict or even negate another. For example, while a dying person may prefer the presence and assistance of a loved one in performing self-care occupations, this may invoke feelings of embarrassment, shame, and overt dependence, resulting in the loss of a person’s feelings of dignity. Moving toward a ‘good death’ is, therefore, a complex balancing act that strives to attend to each of these factors to the best degree possible, while at the same time working within institutional and financial constraints. What is key to all four of these components, in a post-modern era, is the goal of providing the utmost degree of personal autonomy. This can be seen in Walters' (2004) use of the phrase 'dying with panache,' which he describes as follows:

> It has the sense of dying in one's own way, in one's own style and may well include the elements of protest, complaint and awkwardness, perhaps with humour, perhaps with curses, without all the problems necessarily being resolved or all the relationships restored – but with integrity and honesty. (p. 408)

The complexity surrounding the notion of the 'good death' clearly highlights the need for more research that examines what people at end-of-life identify as contributing components to quality experiences.

Emergent Tensions and Key Issues

The background to the study reveals important tensions surrounding: the changing demographic population in Canada, and the ambiguous notion of what makes a good death.

First, the current Canadian context and its changing demographics will soon lead to a difficult period where the aging population will outnumber the young, the death and dying process will be prolonged, and the need for community and hospice services will be greater than ever due to the limited availability and costly expense of end-of-life and hospital services (CHPCA, 2008; QELCC, 2008; Statistics Canada, 2010). As we enter a 'post modern' attitude towards death (Walter, 1994), where the people dying are in charge of the death they hope for, one questions how to attend to the unique wishes of every patient, while aiming to understand and offer a national approach to quality end-of-life care. As such, there is a vital need for research drawn from the first-hand perspectives of people who are terminally ill. There is potential that these first-hand accounts can better inform effective service delivery. For example, in a study by Singer, Martin, & Kelner (1999), the perspectives of patient participants (dialysis patients, people with HIV, and residents in long term care facilities) on what constitutes a quality end-of-life experience were compared with the components identified by expert panels. These authors found that the patient-derived accounts were: more simple and straightforward, more specific, less bound by established concepts, did not use vague concepts like 'overall quality of life,' more focused on outcomes, and more 'authentic.' These authors suggest that focusing end-of-life initiatives on models by expert panels can potentially miss issues that are important to the people at end-of-life and their caregivers.

Second, the notion of 'good death' in Canada is not well understood. Potential components of a good death, as articulated in the QELCC (2010) and the CAOT (2010) mandates, are vague qualifiers and do not make explicit how they can be achieved. Further, the potential for occupation to inform quality moments in the end-of-life experience has not been extensively researched, and is not clearly elucidated by the disciplines of occupational science or occupational therapy. While this study does not aim to investigate the meaning of good dying directly, there is potential that findings about the embodied nature of occupation at end-of-life might illuminate ways in which occupation can contribute to improved dying experiences.

Third, from a rehabilitative standpoint, one might assume that these changing demographic service needs may offer many opportunities for occupational therapists. Indeed, the CAOT has indicated interest in and support for providing quality end-of-life care; in 2003-2004, the association became a member of the QELCC, following a professional issues forum on end-of-life at the CAOT annual conference where QELCC representatives were invited to participate as stakeholders. (CAOT director, personal communication, January 30, 2009). Despite national interest in collaborating to implement quality end-of-life care from an occupational therapy standpoint, less than one percent of Canadian occupational therapists are currently employed in hospice and palliative care settings (Canadian Institute for Health Information, 2008). This raises the concern that the role of occupation at end-of-life and occupational therapy services are potentially being overlooked.

Fourth, although the CAOT (2010) has proposed that occupation and occupational therapists are important in end-of-life contexts, little research on the end stages of life from an occupational perspective has been documented. The limited understanding of the role of occupation at end-of-life necessitated a need for an in-depth review of the occupation-based literature, to investigate what has been documented on this topic to date. This question was broadened to include the role of occupational therapy at end-of-life, due to the prevalence of the literature that was situated within and focused on occupational therapy care. I conducted a systematic literature review (see manuscript one, entitled *Occupation and end-of-life: A review of the literature*) to offer an analysis of the research undertaken on this topic to date. Considering the research on end-of-life in the occupation-based literature may shed light on the role of occupation in the current Canadian milieu.

Finally, findings from the systematic literature review detailed in manuscript one revealed further tensions specifically in regard to occupation at end-of-life. For example, the review indicated that limited research has been conducted on the nature of occupation in the end-of-life experience. The majority of the literature available considers occupation in relation to end-of-life from a therapeutic standpoint, and the role of occupational therapy and occupation in end-of-life settings appears unclear. This has important implications for how the role of occupation and occupational therapy is conveyed to members of the health care team, patients, families and policy advisors, and whether the importance of occupational engagement is communicated. The majority of the studies were situated within an American context, with the least number of studies from Canada. In terms of the methodologies adopted in the literature, there are limited empirical studies, with almost half of the unearthed papers in discussion, viewpoint, or commentary formats. None of the studies drew on the phenomenological tradition to better understand the living while dying experience. The emergent tensions from the background to this study and the systematic literature review point to the lack of literature that examines how occupation at end-of-life is directly lived and experienced by people who are terminally ill. These tensions suggest a need for further empirical research that examines the nature of occupation at end-of-life, and the potential implications that occupational engagement holds for facilitating end-of-life care. As such, the following purpose and questions of the study were developed.

Purpose and Questions of the Study

The broad purpose of this study was to:

> Examine the embodied nature of occupation at end-of-life, from the perspectives of Canadians 60 years of age or older who are diagnosed with a terminal illness.

This broad purpose was addressed in manuscript three of this dissertation. The conduct of this research also led to further relevant investigations that are presented in the remaining three manuscripts of the dissertation. First, the limited understanding of the role of occupation at end-of-life necessitated the need to conduct a systematic literature review on this topic (manuscript one). Second, as the purpose of this inquiry is to examine human occupation as lived and experienced at end-of-life, phenomenology was judged as the best means through which this question could be addressed. Given the debate concerning appropriate methodologies for the study of human occupation in the occupation-based disciplines, and the limited understanding of end-of-life occupation from a phenomenological perspective (as revealed in manuscript one), an in-depth investigation of what phenomenological methods offer the study of human occupation was undertaken (manuscript two).

Lastly, as chapter three will reveal, engagement with the phenomenological literature and inspiration from the work of Merleau-Ponty (1945/2006) on embodiment, led to questions about what an embodied approach, one that attends to the body in qualitative research would look like, and what it might have to offer qualitative research practices generally (manuscript four). These four manuscripts are detailed as follows:

a) Manuscript one is a systematic analysis using the matrix method of the published literature on occupation and end-of-life, framed around the question – What has been published about death and dying in the occupation-based literature surrounding the role of occupation and occupational therapy at end-of-life?

b) Manuscript two is an investigation of phenomenology as a methodology to study human occupation, framed around the question – What does phenomenology as a methodological approach offer the study of human occupation?

c) Manuscript three is a phenomenological examination of the embodied nature of occupation at end-of-life, framed around the question – What is the embodied nature of occupation at end-of-life, from the perspectives of Canadians 60 years or older who are diagnosed with a terminal illness?

d) Manuscript four is an investigation into embodied research as a methodological approach to phenomenological investigation, framed around the question – How does attention to the notion of embodiment enhance qualitative research practices?

In the next chapter, an overview of the methodological and theoretical perspectives underpinning the doctoral research is detailed. This is followed by a presentation of the four integrated manuscripts described above, in chapters four, five, six and seven of the dissertation. The final chapter presents a discussion of emerging insights and reflections on the research.

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CHAPTER THREE: METHODOLOGY AND THEORETICAL PERSPECTIVES

Introduction

This chapter presents the methodological and theoretical perspectives informing this dissertation. It begins with an overview of the interpretive tradition as an epistemological underpinning. Phenomenological methodology and three important phenomenological philosophers are then introduced. This is followed by a presentation of the two theoretical perspectives informing this work: an occupational perspective and an embodied phenomenological perspective. The methods of the study are presented in Appendix A.

Epistemological Underpinnings: The Interpretive Tradition

Phenomenology is situated in an interpretive paradigm, which has particular epistemological assumptions that impact or guide the choices made in each part of the research process, that is, how the research is done (Guba & Lincoln, 1982). An interpretive stance attempts to make explicit the values and assumptions that are embedded within the researcher's methodological choices (Hesse-Biber & Leavy, 2004). These values and assumptions shape and are shaped by the researcher's epistemic community, whose members implicitly and explicitly contribute to the disciplinary standards by which theory choices are made and knowledge is generated (Kinsella & Whiteford, 2009). The following section introduces some of the epistemological assumptions underlying the phenomenological perspective adopted in this work.

An epistemological perspective is a philosophical orientation that provides a basis for deciding what kinds of knowledge are possible, how knowledge is obtained, and where the researcher is situated both in the human world and in the inquiry process (Crotty, 1998). For the purposes of this study, I adopted an interpretive stance to investigate the lived experience of occupation at end-of-life.

The interpretive tradition is fundamentally different from the positivist tradition. Key features of positivistic modes of inquiry include, "the supposed neutrality of observation, the 'giveness' of experience, the independence of empirical data from theoretical frameworks, the ideal of a univocal language, and belief in the rational progress of science" (Bohman, Hiley, & Shusterman, 1991, p. 3). In contrast, the interpretive tradition is marked by attention to alternative standards of research when investigating the human experience. A number of interpretivists argue that the natural scientific world (*Naturwissenschaften*) and the world of everyday human affairs (*Geisteswissenschaften*) are inherently and contextually different, and therefore warrant distinct approaches for their respective inquiries (Crotty, 1998; Schwandt, 1994, 2000). Scholars situated in the interpretive tradition agree that there are dimensions of the human experience that cannot be adequately studied from disengaged and disembodied perspectives. Taylor (1985) states that humans are self-interpreting beings and their actions and behaviors are pregnant with meaning. For Taylor, the purpose of interpretive research is to make sense of phenomena. The search for understanding, *Verstehen*, seeks to discern the meaning that emerges from the purposeful and goal-directed behaviors and actions of human beings in everyday life; to look for "culturally derived and historically situated interpretations of the social life-world" (Crotty, 1998, p. 67).

The distinction between the natural and human sciences and whether they require separate means of study is an issue of deep and controversial debate (Crotty, 1998; Kuhn, 1991; Rouse, 1991; Schwandt, 1994, 2000). For example, some thinkers, such as

Wilhelm Dilthey, contend that there is a strong demarcation between the natural and human sciences, which is influenced by their primary foci of study (Crotty, 1998). In this view, the purpose of the natural sciences is described as seeking causality and the nomothetic characteristics of human and worldly affairs, that is, the universal rules or laws governing hidden truths. In contrast, the purpose of human science is described as understanding and interpreting both idiosyncratic and inter-subjective human meanings that shape and are shaped by the world (Crotty, 1998; Taylor, 1985). Others suggest that the lines between the natural and human sciences are not distinct, that the two sciences can share similar purposes and methods (i.e. Max Weber), and that the work of natural scientists can also lead to significant changes in understandings, even if these new understandings were not the intentions of the researchers, and come to be recognized only in the work of later generations (Kuhn, 1991).

According to Giddens (1993), the interpretive tradition and its emergent branches are concerned "with problems of language and meaning in relation to the 'interpretive understanding' of human action" (p. 28). Key features of interpretive inquiry include concerns with language and meaning, both of which are dynamically tied to human action and behavior. First, as Crotty (1998) puts it, humans are "languaged beings" (p. 87). According to Gadamer (1975), language is the vehicle through which understanding occurs. For Taylor (1985), language is a means of communication that ultimately shapes our social practices:

> The situation we have here is one in which the vocabulary of a given social dimension is grounded in the shape of social practice in this dimension; that is, the vocabulary would not make sense, could not be applied sensibly, where this range of practices did not prevail. And yet this range of practices could not exist without the prevalence of this or some related vocabulary. There is no simple one-way dependence here. (p. 33-34)

Language is a means through which inter-subjective meanings, a second concept key to interpretivism, are shared.

The interpretive researcher aims to understand human action and behavior by examining the meanings that constitute these actions (Schwandt, 1994, 2000). Meanings are situated in that they are, according to Taylor (1985), for a subject (originating in the perspective of someone), of something (an action can be distinguished from its meanings), and in a field (has a relation to and can influence other meanings).

This section began with the premise that epistemological underpinnings say something about how we know what we know, that is, what kinds of knowledge are possible, how knowledge is obtained, and where the researcher is situated (Crotty, 1998). According to interpretivists, the kinds of knowledge that are possible emerge through the dynamic interplay between the human and the world. Emergent meanings are not conceivable without this relationship, that is, ‘something’ must be perceivable by ‘someone’ for any knowledge and for any meanings to surface (Taylor, 1985). Interpretivism does not place particular emphasis on either the knower or the known, indicating that their union is inseparable. Interpretivists suggest that knowledge is obtained through understanding and interpreting emergent meanings, and that language plays a central role in all interpretive endeavours. Gadamer (1975) would go as far as to say that understanding is interpretation. Common vehicles for meaning can be found in everyday life, including dialogue, symbolic tools, and rituals. Finally, the interpretive tradition proposes that like participants, the researcher, too, is intimately involved in the world and this involvement does not end when the research process begins. Unlike the methods of the natural sciences, the researcher is not expected to enter the research process from an objective, value-free, and neutral standpoint. Instead, the researcher's values and assumptions, history, and context are recognized as powerful influences on his or her interpretive lens.

The epistemological assumptions of interpretivism permeate the design and implementation of this research. A methodological approach rooted in the interpretive paradigm was deemed fitting, given that the construct at hand, human occupation at end-of-life, is dynamic, complex and ever-evolving.

Phenomenological Methodology

Phenomenology is both a philosophy and a methodological approach situated in the interpretive paradigm. Phenomenology seeks to examine phenomena from the perspective of first-hand accounts and through the lifeworld of people. Phenomenology is the art and science of drawing meaning and understanding from the way phenomena manifests in everyday experiences (Crotty, 1998; Heidegger, 1927/2008; van Manen, 1997). For phenomenologists, the starting point of knowledge generation is human experience. The second manuscript in this dissertation offers a detailed examination of what phenomenological approaches to research offer to the study of human occupation. Below is an introduction to three key phenomenological philosophers whose thinking informed the methodological approach to this research into human occupation.

Phenomenological Philosophers

Edmund Husserl

Phenomenology is said to have been founded by German philosopher Edmund Husserl in the early 20th century, although the term phenomenology can be traced back to the work of Kant and Hegel (Moustakas, 1994). Husserl was born in Prossnitz, a village in Moravia that was part of the Austrian Empire (the Czech Republic today) (Macann, 1993;

Sokolowski, 2000). His academic studies began in the natural sciences, including mathematics, physics and astronomy, all of which shaped his philosophical perspective. He was a student of philosopher and psychologist Franz Bretano at the University of Vienna and later, Carl Stumpf at the University of Halle. In 1900 he joined the philosophy department at the University of Göttingen and his last post was teaching in Freiburg, where he became a mentor to another prominent phenomenologist, Martin Heidegger.

Husserl originally developed phenomenology as a rigorous method of inquiry in response to the dominant scientific approaches of the time (Nakhnikian, 1990). Husserl critiqued the idea that traditional scientific methods of inquiry, interested in studying material things, were able to sufficiently address the nature and role of human consciousness in relation to the investigation of phenomena (Nakhnikian, 1990). Husserl's aim was to create a rigorous science that sought to understand human consciousness and to describe, versus explain, phenomena through the lived experience (Spiegelberg, 1960).

Martin Heidegger

Martin Heidegger's phenomenology picked up where his mentor, Husserl, left off, to the extent that some would say he "stole Husserl's thunder" (Sokolowski, 2000, p. 213). Heidegger was born in 1889 in Meßkirch. Unlike Husserl's academic background in the natural sciences, Heidegger's education was rooted in religion and philosophy and as a result, he was able to draw on a range of important philosophers, such as Aristotle, Kant, Plato, and Hegel and incorporate their work into his phenomenological vision (Sokolowski, 2000). While Husserl's phenomenology was epistemological in nature, Heidegger (1927/2008) describes his phenomenology as ontological, concerned with questions of what it means to be, stating, "*Only as phenomenology, is ontology possible*" (p. 60). Husserl's philosophical interests were varied, and he engaged in inquiry that considered issues such as language, perception, memory, and causality (Sokolowski, 2000). On the other hand, Heidegger was primarily focused on the notion or meaning of *Being*. According to Heidegger (1927/2008), Being is, "everything we talk about, everything we have in view, everything towards which we comport ourselves in any way…what we are is being, and so is how we are. Being lies in the fact that something is" (p. 26). In Heidegger's perspective, Being cannot be described as a thing or 'entity,' but rather refers to what it is to *be* an entity. For Heidegger, lived experience involves more than what appears or manifests through consciousness; instead, experience is defined or constituted by our being-in-the-world.

Maurice Merleau-Ponty

The notion of being-in-the-world was further extended in the work of French philosopher, Merleau-Ponty. Merleau-Ponty was born in 1908 in Rochefort-sur-Mer and raised in Paris (Carman, 2008). He attended the École Normale Supérieure, along with philosophers Jean-Paul Sartre, Simone de Beauvoir, and Claude Lévi-Strauss. Merleau-Ponty taught philosophy at a number of academic institutions, including the University of Lyon and the Collège de France. His work centered on the philosophy of perception and on the lived body. He proposed that human perception and experience is first and foremost an embodied affair; in other words, lived experience is characterized by bodily-being-in-the-world.

Implications for the Study

It is evident that the phenomenological perspectives of these three philosophers differ in their focus. However, all three philosophers, in varying degrees, inform the phenomenological perspective adopted in this study, and in manuscript two, I contend that there are lasting contributions of all three philosophers that are of significance to the study of human occupation. This work acknowledges a deep appreciation for Husserl's (1990/1907) original insights that phenomenology offers a rigorous method of inquiry, that it posits a reconceptualization of what knowledge entails, and the contention that phenomenon might be examined from fresh, naïve and wondrous perspectives. In addition, this work is informed by the work of Heidegger (1927/2008) and Merleau-Ponty (1945/2006). According to these two philosophers, everyday life is not constituted solely through consciousness but through our being-in-the-world; such being-in-the-world is deeply embodied, and at the heart of lived experience (see manuscripts two and four for an elaboration).

Two Theoretical Perspectives

Two theoretical perspectives inform the interpretive lens through which this study is conducted: an occupational perspective, and an embodied phenomenological perspective.

An Occupational Perspective

An occupational perspective informed by both occupational science and occupational therapy is adopted for this study. As such, this dissertation aims to contribute to basic understandings of occupation at end-of-life in realms that include but also go beyond health and well-being. This occupational perspective is grounded in the contention that engagement in occupations is a fundamental part of what it means to be human (Wilcock, 2006; Yerxa et al., 1989).

Consistent with the work of Hasselkus (2006), the occupational perspective adopted in this dissertation is shaped and inspired by the phenomenological tradition. Hasselkus proposes in her 2006 Eleanor Clark Slagle Lecture, entitled *'The world of everyday occupation: Real people, real lives,'* that everyday occupational experiences are phenomenological in nature. Hasselkus suggests that everyday occupations are so typical, routine, and mundane that their significance and beauty can be overlooked; in other words, the significance of occupation in our everyday lives is "seen but unnoticed" (p. 628). The phenomenology of our everyday occupational experiences illuminates the important meanings implicit in our daily routines, meanings that speak to what it means to be human. According to Hasselkus, occupation is an essential part of the rhythm of everyday life, and this "ordinary rhythm of daily living is the deep primordial nourishment of our existence. It is the 'truth'-the primary reality for each one of us" (p. 638).

In articulating an occupational perspective for this study, the four occupational dimensions of doing, being, becoming and belonging (Rebeiro, Day, Semeniuk, O'Brien & Wilson, 2001; Whalley Hammell, 2004; Wilcock, 1998, 2006) (See Table 1) are proposed as a useful framework. In addition, in recognizing a phenomenological orientation to occupation, the occupational perspective of this study is also informed by four existential dimensions that van Manen (1997) suggests pervade human existence: lived time, lived space, lived relations, and the lived body (See Table 1) (note: the fourth existential, the lived body, will be further elaborated in the second theoretical perspective, an embodied phenomenological perspective). In the following section, I introduce the four occupational dimensions, how they related to the four lived existentials, and their potential relevance to the study of human occupation at end-of-life.

Table 1: Two Theoretical Frameworks

Occupational Dimensions (Rebeiro et al., 2001; Whalley Hammell, 2004; Wilcock, 1998, 2006)	
Doing	The purposeful and active engagement in goal-oriented activities.
Being	Occupations in which one adopts a self-reflexive stance on what it means to be human and to exist.
Becoming	Occupations that reflect the situated nature of human existence in a continuing life process.
Belonging	Human occupation as involving social interactions and relationships; occupations that foster a sense of inclusion and social value.
Lived Existentials (van Manen, 1997)	
Lived time	(temporality) Time that is subjectively experienced, versus time that is characterized or governed by clock time.
Lived space	(spatiality) Space that is subjectively experienced, versus mathematical space.
Lived other/ relations	(relationality) The everyday, intersubjective relationships we maintain with others.
Lived body	(corporeality) The notion that human existence is constituted by our bodily-being-in-the-world.

Doing

In the occupation-based disciplines, doing is the purposeful engagement in goal-oriented activities (Whalley Hammell, 2004; Wilcock, 1998, 2006). Examples of doing are embedded in everyday life and for occupational scientists and therapists, doing is so much a part of the occupation-based lexicon, it is often used synonymously with the word occupation (Wilcock, 1998). Doing provides a means for social interaction, societal development and growth, and is the foundation of community, local, and national identity. Doing shapes and is shaped by the given-world. Social norms have rules of what kind of doing is rewarded and productive, and what is taboo and frowned upon. For example, brushing our teeth, being employed, shaking hands, and volunteering are all examples of things we do that are, in most Western contexts, socially accepted and encouraged, whereas rules have been established to prohibit certain doings, such as what have been socially agreed upon as criminal actions.

Doing is recognized in other disciplines as essential to human life, although occupational terminology is infrequently utilized. For example, Merleau-Ponty (1945/2006) rejected Descartes' famous dictum, *I think therefore I am*, and instead suggests that doing is what brings existence to light:

> Hence it is not because I think I am that I am certain of my existence: on the contrary the certainty I enjoy concerning my thoughts stems from their genuine existence. My love, hatred and will are not certain as mere thoughts about living, hating and willing: on the contrary the whole certainty of these thoughts is owed to that of the acts of love, hatred or will of which I am quite sure because I *perform* them. (p. 445)

Doing is recognized as an essential part of life, an essential part of what it means to exist and to be human, even though the term doing may not be framed from an occupational perspective in other disciplines.

Central to both occupational science and occupational therapy is the assumption that engagement in occupation can elicit personal meaning and purpose, and can ultimately influence one's well-being and health (Wilcock, 2006). When people are dying, engagement in occupations may be a vehicle in which to "rage, rage against the dying of the light" (Thomas, 1952/2009), a way to maintain meanings, and ultimately maintain a sense of living. The primary theme that emerged in a study by Vrkljan and Miller-Polgar (2001) is that doing = living. In more detail, their participants recognized that engagement in things that meant something to them - be it household chores, gardening, and daily walks - that these occupations 'saved their lives,' reminded them that they were still alive, still capable, still part of the world. At end-of-life, doing occupations might include activities such as writing a will, spending time with loved ones, writing poems, engaging in life review, praying, and meditating (Rahman, 2000; Steinhauser et al., 2000). Therefore, doing occupation is acknowledged as an essential part of human existence, and may take on enhanced significance in the face of advanced illness and at end-of-life.

Being

Being, although the most universal of concepts (Heidegger, 1927/2008), is a much more difficult construct to grasp than doing with respect to the study of human occupation. This may be due to its inherently abstract and philosophical quality. Being involves a self-reflexive stance to who one is and his or her orientation in the world. According to Wilcock (1998), being is defined as:

> being true to ourselves, to our nature, to our essence, and to what is distinctive about us to bring to others as part of our relationships and to what we do. To 'be' in this sense requires that people have time to discover themselves, to think, to reflect and to simply exist. (p. 250)

Whalley Hammell (2004) describes being as discovering the self in an occupation and as concerned with the nature of existence. Being is concerned with what it means to be, to be human, and to exist, and has therefore been of central concern to many philosophers and phenomenologists. As mentioned earlier, Heidegger (1927/2008) focused a great deal of his work on the notion of being, most particularly being-in-the-world. Being-in-the-world suggests that we are always situated in space. Van Manen (1997) describes this notion as lived space, one of four 'existentials' or essential themes of living. By this, he suggests that lived space is one of four fundamental and overlapping components of life that pervades human existence, and that is experienced by every human being. Lived space (spatiality) is described as “felt space” (p. 102). Felt space is not mathematically measured space, like distance or dimensions, but rather refers to the experience of space and the feelings that it can espouse (i.e. feeling small, vulnerable, or overwhelmed in an overpopulated, hectic city) (van Manen, 1997). One’s sense of being, from an existential standpoint, is always situated in-the-world, and subsequently experienced through lived or felt space.

With respect to death and dying, it is proposed that the question of being is probably clearer at this stage than at any other time in life (Chochinov et al., 2005; Thibeault, 1997). Facing death potentially compels people to engage in questions of ‘who we are,’ ‘what life means,’ ‘what is meaningful,’ and ‘what death takes from life.’ Being so close to life’s end illuminates how rarely these questions are raised in our everyday existence. As an example, Tolstoy’s (1886/2007) satirical novel traces the dying experience of Ivan Ilyich. Ilyich grows to realize how little in common he has with those close to him, how little they understand what he is going through, and how ignorant living can be:

> Death. Yes, death. And none of them knows or wishes to know it, and they have no pity for me….It’s all the same to them, but they’ll die too! Fools! First me, and later them, but it’ll be the same for them. And now they’re merry…the beasts! (p. 67)

The occupational dimension of being might be manifested through acts of self-reflection, through conversation, through presence, and even through sitting in silence in the end-of-life process. As Thibeault (1997) and Chochinov et al. (2005) suggest, in the dying stages, emotional issues and self-reflection are often viewed as higher priorities and potential sources of meaning. Toombs (2004), a woman with multiple sclerosis, notes that our culture emphasizes doing (being productive and useful) over being, and that the latter can be a source of self-worth and self-fulfillment. She quotes a woman with Parkinson's disease, who states: "I always imagined that when I became a grandmother, I would do a lot with my grandchildren. Then I got Parkinson's. However, now I realize that I can just be for my grandchildren" (p. 194). Thus, active doing may not be the sole source for meaning and purpose at end-of-life. Occupations that reflect Being should not be mistakenly regarded as acts of passive living, but rather as potentially significant mediums for fostering meaning and identity at end-of-life.

Becoming

With respect to the study of human occupation, becoming illuminates that human beings are situated in a continuing life process, always oriented towards future selves (Whalley Hammell, 2004; Wilcock, 1998, 2006). Wilcock's (2006) definition of becoming includes: "the idea of growing or coming into being; of living, moving, evolving energy; of aiming toward the highest level of personal development and self-esteem; of potentialities; of humanness; of self-actualization; and that it is an ever-incomplete process" (p. 149-150). Becoming highlights temporality and what can be achieved, the possibilities, in time. Van Manen (1997) distinguishes between lived time and objective time. Lived time, the second of van Manen's four existentials, is subjective and felt, such as time slowing down when we are bored or uninterested. There is a strong relationship between time and meaningful occupation. Meaningless occupations can make time feel as if it is standing still, while meaning-rich occupations can elicit a sensation called flow. Flow, a construct coined by psychologist Mihály Csíkszentmihályi (1990), is described as "the state in which people are so involved in an activity that nothing else seems to matter; the experience itself is so enjoyable that people will do it even at a great cost, for the sheer sake of doing it" (p. 4). Flow requires immersion into a meaningful occupation, and a harmony or balance between the challenge of the activity and the ability to master the skills required for engagement. Flow results in feelings of happiness and optimal experiences, and a lack of attention to or disregard for objective time. These happy or optimal experiences are not achieved by searching for them directly. Like John Lennon's famous quote "Life is what happens to you while you're busy making other plans," Csíkszentmihályi (1990) states, "it is by being fully involved with every detail of our lives, whether good or bad, that we find happiness, not by trying to look for it directly" (p. 2). Becoming is associated with goals of happiness, fulfillment, and self-actualization as we experience the temporality of life. Meaningful occupations become part of our unfolding autobiographies over time (Christiansen & Townsend, 2004).

In the dying experience, individuals commonly begin to reflect on their past and their course of becoming. In his book, *What dying people want*, David Kuhl (2002), a palliative care physician, recalls the following words by his dying grandfather: "Dying is hard work-not the physical part, but that part which is the inside of me, the work about who I am, who I have been, and who I will be" (p. xvii). A commonly cited event that many people face at end-of-life is the loss of independence. In one of Kübler-Ross' (1969) interviews with terminally ill patients, one woman noted, "I was always happy when I could take care of myself, do my own housework, and do things for the boys. That is what bothers me the most. That I feel that someone else has to take care of me now. That is very hard for me to accept" (p. 198). This is echoed in the novel *Tuesdays with*

Morrie. When asked what he dreaded most about the “slow, insidious decay” (Albom, 1997, p. 22), Morrie answers that someday soon, someone would have to assist him with toileting. This loss of independence is a frequently documented fear and a marker of the changing identities of dying individuals.

Becoming can stir feelings of loss and grief, but can also be a source of fulfillment and clarity. Following a diagnosis of inoperable pancreatic cancer, Richard Rorty (2007) mused that he wished he spent more time in his life with poetry:

> I now wish that I had spent somewhat more of my life with verse. This is not because I fear having missed out on truths that are incapable of statement in prose. There are no such truths; there is nothing about death that Swinburne and Landor knew but Epicurus and Heidegger failed to grasp. Rather, it is because I would have lived more fully if I had been able to rattle off more old chestnuts-just as I would have if I had made more close friends. (¶. 8)

It has been suggested that the process of becoming does not always cease when the final breath is taken or the heart releases its last beat. Seale (1998) states that social death can occur after physical or bodily death (such as through ancestor worship); from this it can be inferred that the process of becoming may continue even after physical death, through loved ones. Stories or life lessons about ‘my father’ may become stories about ‘your grandfather’ or ‘your great, grandfather,’ preserving one’s legacy of becoming over time and throughout generations. This brings us to the final element of this occupational framework, also poignantly raised in Rorty’s words and as a component of good dying, the importance and value of the Other in our lives and our need for belonging.

Belonging

In considering important realms and dimensions in the study of human occupation, Rebeiro et al. (2001) added an additional component, which they called belonging. Belonging refers to social interactions and relationships, the sense of being included, and the sense that one's life has social value. Social relationships are enforced and reinforced by daily occupations. These occupations can include engaging in conversation at the water cooler with colleagues, sharing common interests such as movies and music with friends, and eating at the dinner table with family. Belonging can be related to another of van Manen's (1997) four existentials, lived human relation. Lived human relation is experienced through corporeal bodies, the way that we touch, see, and interact with other humans in everyday life. This may be through waving one's hand in greeting, hugging another for comfort, communicating through language and gestures. Relationality allows the discovery of "a sense of purpose in life, meaningfulness, grounds for living, as in the religious experience of the absolute other, God" (van Manen, 1997, p. 105).

Frank (1995) draws on the work of Levinas (1998), who describes relationality as a moral endeavor, exemplified in the French philosopher's' famous dictum: "all men are responsible for one another" (p. 48). Frank (1995) describes this phrase as following:

> Persons live *for* others because their own lives as humans require living that way. The self is understood as coming to be human in relation to others, and the self can only continue to be human by living *for* the Other. (p. 15)

To be responsible for the other suggests that 'belonging' is essential to our being and that, for Levinas (1998), our relationships should be defined by generosity, compassion, and respect (Frank, 1995). This has implications for what we do and how we live. We are not passive recipients, but are actively involved in interactions of giving and receiving with the other. Bakhtin (1981) suggests that these interactions are fundamentally dialogic and, like a human being in the process of becoming, no word or dialogue can ever be finalized. Frank (2004) compares this to a host and guest: "Hosts never finalize guests; they remain open to whoever the guest may become" (p. 46). Egan (2007), an occupational therapist, draws on both Frank and Levinas to propose that in everyday practice, occupational therapists encounter people who are suffering and that it is their moral responsibility to first be aware of the underlying, and sometimes violent, presence of suffering, and secondly, to respond to the other in need.

The notion of belonging can be heightened at end-of-life, eliciting intense feelings of fear and loss when a loved one is facing death. Our lives are built around ourselves but also around the people in our lives, and these foundations are rattled by death (Lonergan, 1975). Lonergan (1975) describes philosopher Gabriel Marcel's perspective on death as espoused by the following statement: "To love a being is to say, 'Thou, thou shall not die'" (p. 28). An attribute that has been cited as an important task to do at end-of-life is saying 'goodbye' to loved ones (Steinhauser et al., 2000). For Hagar, the main character in Margaret Laurence's (1964) novel, *The stone angel*, saying goodbye to her oldest son occurs in the form of a release:

> 'If I've been crabby with you, sometimes, these past years,' he says in a low voice, 'I didn't mean it.' I stare at him. Then, quite unexpectedly, he reaches for my hand and holds it tightly. Now it seems to me he is truly Jacob, gripping with all his strength, and bargaining. *I will not let thee go, except thou bless me*. And I see I am thus strangely cast, and perhaps have been so from the beginning, and can only release myself by releasing him. (p. 304)

Therefore, while another cannot die for me (Heidegger, 1927/2008), the other plays a significant part of the experience. These felt, social relations are intimately tied to and elucidated through day-to-day occupations. As Levinas (1998) and Frank (1995) suggest, we live for others; the other has a significant impact on our everyday doings, our sense of being, and our process of becoming.

Summary

In summary, I have discussed one of the theoretical lenses of this study as an occupational perspective. This perspective is informed by the occupational framework of doing, being, becoming, and belonging (Rebeiro et al., 2001;Whalley Hammell, 2004; Wilcock, 1998, 2006). In addition, the relation of this framework to three of van Manen's (1997) four lived existentials - lived space, lived time, and lived relationality - has been explored. An occupational perspective views occupational engagement as a basic human need (Wilcock, 2006; Yerxa et al., 1989; Zemke & Clark, 1996). There is potential that occupational engagement may be essential to living well, even in the end stages of life.

In the current study, this occupational perspective led to theoretically informed questions and influenced the design of the interview guide (see Appendix B), and informed the interpretive lens of the study.

In the next section, I present the second theoretical perspective adopted in this work, an embodied phenomenological perspective.

An Embodied Phenomenological Perspective

The second theoretical perspective adopted for this dissertation is an embodied phenomenological perspective. Phenomenology as a methodological approach was introduced earlier in this chapter, and is elaborated in manuscript two. The notion of embodiment from a phenomenological perspective has been more deeply addressed in manuscript four. As such, a relatively brief description is presented in this section of the dissertation.

The embodied phenomenological perspective of this study is focused on the embodied dimensions of lived experience, as informed by the work of Merleau-Ponty (1945/2006).

In this regard, I am particularly interested in how everyday occupations are disclosed through a body that is lived and experienced. This lived body is not the same as the physical body depicted by Descartes' (1641/1996), although the Cartesian body has had a powerful influence on the way that medical professions administer and structure their care (Leder, 1990, 1992). For this reason the question of how the *lived body* (the one that informs the embodied phenomenological perspective of this dissertation) and the *physical body* (from a Cartesian perspective) compare requires clarification.

The Physical Body (Körper)

The Cartesian body is primarily a passive and physical body, what some philosophers might refer to using the German word *Körper* (physical body) (Leder, 1990). According to Descartes (1641/1996), human existence is constituted solely by the mind. He states:

> Simply by knowing that I exist and seeing at the same time that absolutely nothing else belongs to my nature or essence except that I am a thinking thing, I can infer correctly that my essence consists solely in the fact that I am a thinking thing…I have a clear and distinct idea of myself, in so far as I am simply a thinking, non-extended thing; and on the other hand I have a distinct idea of the body, in so far as this is simply an extended, non-thinking thing. And accordingly, it is certain that I am really distinct from my body, and can exist without it. (p. 54)

Descartes considers the human body as a "machine" (p. 58) that would function with or without the mind's will or control. Leder (1992) interprets Descartes' notion of the body as the Cartesian corpse, and proposes that this non-living entity has shaped the practice of modern medicine. Examples of the Cartesian stronghold, he suggests, include the growth and dominance of modern technology in health care, where medical practices rely on high-tech diagnostic techniques (i.e. X-rays, imaging and scans) and overlook the patient's illness experience. He provides the following example of a traditional physical examination:

> The patient is asked to assume a corpse-like pose, flat, passive, naked, mute. The entire ritual and context serves to reduce the living body to something almost dead. Personal identity is stripped away as the patient is removed from his or her habitual surroundings, activities, even clothes…ever when called to act or respond, it is largely in the machine-mode; the knee is tapped to provoke reflexes; the abdomen is poked to see if pain ensues; the patient is asked to take a deep breath to hear whether the lungs produce audible rales. (p. 22)

The conception of the Cartesian body as a physical machine-like appendage, has had a profound and lasting influence on the biomedical paradigm today (Carman, 2008; Leder, 1992). In fact, its penetration into the medical and scientific discourse has been implicitly adopted to the extent that it is often unquestioned and taken for granted (Carman, 2008). In contrast, the work of Merleau-Ponty (1945/2006) has introduced a renewed perspective of the body as lived and experienced.

The Lived Body (Leib)

In contrast to the Cartesian body, this work adopts a conception of the body as lived and experienced in everyday life. The German word *Leib* is used to refer to this lived body (Leder, 1990). The lived body is van Manen's (1997) fourth lived existential, and refers to "the phenomenological fact that we are always bodily in the world" (p. 103). Van Manen describes the lived body as a medium through which we engage with others in the lifeworld. Through the body, we can make evident but also hide our intentions, goals, expressions and emotions; our bodies act as a medium through which we reveal our individuality, our sense of who we are (Toombs, 1999; van Manen, 1997).

Merleau-Ponty (1945/2006) was highly influential in illuminating the body's central role in our everyday perceptual experience. He rejects the Cartesian body and Descartes' (1641/1996) proposal that human existence is governed solely by the mind. Instead, Merleau-Ponty proposes that our bodies are the absolute source: "the body expresses total existence, not because it is an external accompaniment to that existence, but because existence realizes itself in the body" (p. 192). From Merleau-Ponty's perspective, perception itself may be viewed as a bodily phenomenon; we are always in a state of bodily-being-in-the-world. In this view, it is through our bodily-being-in-the-world that our lived experiences are realized (Carman, 2008). The body as a path of access to the world, as a skillful and intelligent entity, and as encompassing intercorporeal dimensions, is briefly introduced below, and elaborated in manuscript four.

The body as a path of access.

Merleau-Ponty's philosophy illuminates the body's centrality in everyday experiences, as a path of access to the world. In everyday life, our bodies are most commonly experienced as a state of "near self-forgetfulness" (van Manen, 1998, p. 11), in that they are experienced as silent mediums through which we conduct our everyday lives (Leder, 1990). We typically do not notice our bodies when engaged in our day-to-day affairs. As Leder suggests, we do not notice our bodies, nor do we notice the clothes we wear, the chairs in which we sit, the mug from which we sip our coffee; our bodies and these worldly things recede or are absorbed in the background of our daily engagements, such as going to school, eating with friends, and caring for a child. As Leder (1990) states, "I live in bodies beyond bodies, clothes, furniture, room, house, city, recapitulating in ever expanding circles aspects of my corporeality" (p.35). It is in times when our bodies are unable to exist in a state of self-forgetfulness, such as in illness or injury, that we might come to realize and reflect on the body's essential role in our everyday lives (Leder, 1990). An awareness of the body can result in a changed perspective, in that the body is no longer experienced as a hidden vehicle for lived meanings, but as an object for reflection, scrutiny, and care (van Manen, 1998).

Skillful intelligence of the body.

It is important to note that the lived body as a medium for lived experiences does not imply passivity; on the contrary, the lived body is a dynamic, skillful and intelligent entity (Merleau-Ponty, 1945/2006). Just as we make efforts to ‘learn’ and develop from a cognitive standpoint (i.e. memorizing facts, studying for examinations), our bodies also actively and innately ‘learn’ (Carman, 2008; van Manen, 1997, 1998). Consider the skills required to drink coffee, to ride a bicycle, drive a car, or tie one’s shoelace; once these activities are initially learned, our bodies somehow ‘know’ how far to reach to grasp the hot mug, how to obtain a sense of balance and equilibrium, how much pressure to apply to a car break and how to navigate shoestrings with ease. In time, these actions do not require active thought - rather, our minds are often preoccupied with other intentions (i.e. reading the newspaper while drinking coffee or planning dinner while driving home) while our bodies are busily engaged. The body’s skillful intelligence allows us to engage in an intentional action (i.e. sitting down for dinner) without noticing the biological, physiological and anatomical wonder this action involves; the body’s skillful repertoire is so sophisticated that the bodily unity it provides is taken for granted (Toombs, 1999). By living through intelligent bodies, we are able to “gain access to experiences that give meaning to concepts of distance, direction, temporality, clarity, resistance, resilience and obscurity” (Kielhofner, Tham, Baz & Hutson, 2008, p. 72). Therefore, our bodies are not lifeless or passive vehicles for our mind’s doing; rather, human survival would not be able to flourish without our bodily intelligence.

Intercorporeality of the body.

Lastly, our experience of the body is not an internalized but rather an intercorporeal affair; our bodily-being-in-the-world suggests that we are situated in relation to the bodies of others (van Manen, 1998; Weiss, 1999). Intercorporeality presents a two-fold perspective on relational exchanges, in that we do not experience the other as an object in the world, nor do we share a single lived experience; as Csordas (2008) proposes, "we are neither isolated cogitos that must bridge a gulf of solipsism nor participants in the same shared subjective substance" (p. 113). In other words, intersubjectivity is not an abstract relationship between two people, but one that is dynamic and embodied. As van Manen (1998) suggests, our intercorporeal relations reveal a great deal about how we experience our bodies. For example, the simple gaze of another can elicit a range of emotions, from feelings of self-consciousness to empowerment, and a range of actions (such as the stern look a parent might give to a child). We might also discover our bodies through the observations of another, for instance when someone remarks that I am nervous or impatient because I am unconsciously tapping my fingers. Our interactions with others present a unique and complex bodily experience, one that does not cease to exist in a research context.

Therefore, the lived body (*Leib*) adds an embodied dimension to the physical, Cartesian body (*Körper*). The lived body adds complexity to Descartes' notion that human experience is constituted by people's existence as 'thinking things;' the lived body adds "a domain of practical possibility: the realm of the 'I can'" (Toombs, 1999, p. 76). It is this body, as a path of access to the world, a skillful and intelligent entity, and an incorporeal medium, that is at the heart of the embodied phenomenological perspective adopted in this work.

Summary

In summary, in this chapter I have presented the methodological and theoretical perspectives that inform this dissertation. These have included: an overview of the interpretive tradition as an epistemological underpinning; a brief description of phenomenological methodology; and an introduction to three important phenomenological philosophers. In addition, the two theoretical perspectives –an occupational perspective and an embodied phenomenological perspective - that inform this study have been presented.

It is important to note that the theoretical perspectives are two of many possible perspectives that could have informed this study. I have chosen these because of their salience with respect to the purpose of the research and the questions of the study. I have presented them here to make explicit my interpretive lens (Crotty, 1998; Kinsella, in press). The reader is directed to Appendix A for a detailed overview of the study design and methods.

In the next section of the dissertation, four integrated manuscripts are presented, followed by a concluding chapter that discusses emerging insights and reflections on the research.

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CHAPTER FOUR: INTEGRATED MANUSCRIPT ONE

OCCUPATION AND END-OF-LIFE: A REVIEW OF THE LITERATURE

Introduction

In Canada, approximately 285,000 deaths occur each year, a number projected to increase another 33 percent by 2020 (Statistics Canada, 2005). According to the Canadian Senate (2000), 75 percent of people who die in Canada are over the age of 65 and many require palliative support. However, “only 25% of Canadians who need palliative and end-of-life services currently have access to appropriate programs and services” (Quality End-of-Life Care Coalition [QELCC], 2007, p. 1). While the aging demographic is rapidly growing, funding for end-of-life services has conversely been slashed (Canadian Hospice Palliative Care Association [CHPCA], 2008).

As Canadians face the increased need for end-of-life resources to accommodate this changing demographic, questions about the role of occupational therapy and what it offers to palliative care teams become pressing. The topic of death and dying in the occupational therapy literature first emerged in the 1970s and early 1980s (Gammage, McMahon, & Shanahan 1976; Holland & Nelson Tigges, 1981; Nelson Tigges & Sherman, 1983; Picard & Magno, 1982; Pizzi, 1984). At that time, Holland and Nelson Tigges (1981) called for occupational therapists to be proactive in becoming involved in the hospice movement in order to prevent the profession from being excluded from contributing its valuable services in this area of care. If we examine the current state of occupational therapy in end-of-life settings in Canada, and the degree of its development since the early 1980s, the situation elicits concern. Less than one percent of occupational therapists work in palliative care settings (Canadian Institute for Health Information, 2008), which seems to suggest that, as Holland and Nelson Tigges predicted, occupational therapy services in this area are underutilized.

The purpose of this literature review, therefore, was to examine what has been published about death and dying in the occupation-based literature in order to contribute to understanding about the role of occupation and occupational therapy at end-of-life. Both occupational therapy and occupational science literature were examined to capture the widest breadth of information available.

Methods

For the purposes of this paper, occupation is defined as “all that people need, want, or are obliged to do” (Wilcock, 2006, p. 9) in their everyday lives. In line with the CHPCA (2010), the terms hospice and palliative care are drawn upon interchangeably to refer to “whole-person health care that aims to relieve suffering and improve the quality of living and dying” (¶. 2) The term end-of-life refers to the life stage that commonly begins with the diagnosis of a terminal illness.

The Matrix Model

This study drew on the Matrix Model of literature review (Garrard, 2007). The model consists of: a paper trail (keeping track of the search process), documents (organizing the emergent material), review matrix (creating a spreadsheet and abstracting pertinent information from each article), and synthesis (writing up a review of the literature). A systematic approach makes the process transparent, and presents the parameters used to inform the search and analytical process.

The literature search was conducted in two phases. In phase one, three electronic databases were utilized: the Cumulative Index to Nursing and Allied Health Literature, PsychINFO, and Web of Science. These databases index a broad range of literature pertaining to health science, social science, and allied health research, including occupational therapy and occupational science. Title searches were conducted using a combination of the terms Death, Dying, End-of-life, Hospice and Palliative with Occupation. Articles were excluded if they pertained to occupation as employment or occupational health and safety, or if they were published in a language other than English. In order to set boundaries on the search, the initial data base search was restricted to a 12 year timeframe, from 1998 to 2010. An assumption was made that this timeframe would offer an overview of the current literature, and that further ‘classic’ papers in the field could be identified through a review of the bibliographies of these papers.

The search of databases resulted in identification of 26 relevant papers. One article was excluded because it was not accessible to the University. In phase two of the literature search, the reference lists of each of these articles were reviewed using a snowball sampling technique. The criteria of the search were widened to include papers that were repeatedly referenced including those published before 1998. Through this process 15 additional articles were identified, such that a total of 40 articles were included in the review.

In terms of analysis, each article was read twice to gain a sense of the overall purpose of the paper. The following criteria were used to organize the data in the review matrix: full citation, purpose, participants and context, methodology/methods, analysis, findings, miscellaneous notes. Articles were thematically analyzed according to the following question: *What is the overall purpose of this article as it relates to the role of occupation* *and occupational therapy at end-of-life?* It is important to note that some articles can be included in more than one categorical theme, but were allocated according to what the first researcher interpreted as the main or most important finding.

Findings

The articles were published in the United States (18), Australia (8), the United Kingdom (7), Canada (6) and one with US/UK collaboration. Twenty-one of the articles were non-research based papers (56 percent) and the remaining 19 were empirical studies (See Table 2). Eighteen of the empirical studies drew on human perspectives and used adult participants (occupational therapists, students, clients, hospice staff and caregivers). The articles were analyzed into six major themes (See Table 3).

The Role of Occupational Therapy at End-of-Life

Twenty-one articles addressed the role of occupational therapy in palliative care. Two articles focused on advocating for occupational therapy's professional role in end-of-life care (Canadian Association of Occupational Therapists [CAOT], 2010; Holland & Nelson Tigges, 1981). Holland and Nelson Tigges (1981) proposed that the profession needed to take initiative and become an integral part of the hospice movement: "If we as individuals, and the profession at large, do not make an immediate commitment, we will once again be in the last row of the auditorium as a spectator...wishing we could be part of the action" (p. 373). Despite the priority placed on promoting the role of occupational therapy in end-of-life care, what this role entails is less defined.

Seven articles (Nelson Tigges & Sherman, 1983; Picard & Magno, 1982; Pizzi, 1984; Pizzi & Briggs, 2004; Trump, 2000, 2001; Trump, Zahoransky, & Siebert, 2005) specifically addressed the relationship between occupational therapy and hospice, in terms of the focus of care, and the fit between philosophies. Picard and Magno (1982) identified ways that hospice values differed from rehabilitative models of care: the focus of care at end-of-life is support versus treatment-focused care; palliation is the goal versus curative measures; care is provided by multidisciplinary teams versus individuals; and care is administered at the patient's home versus institutions. Occupational therapy with its traditionally rehabilitative framework elicits a paradox in an end-of-life context. Two articles specifically addressed this tension. Pizzi and Briggs (2004) encouraged therapists to reconceptualize their view of rehabilitation, and to adopt a 'rehabilitation in reverse' approach. This involves adapting to the patient's changing abilities over time to maintain as much functional independence and safety as possible. In contrast, Schleinich, Warren, Nekolaichuk, Kaasa, and Watanabe (2008) conducted a study investigating what palliative patients identify as rehabilitation goals and priorities. These authors proposed that not only is the notion of rehabilitation overlooked in palliative care settings, but these patients still valued maintaining independence. These two studies suggest a need to consider and potentially re-conceptualize what 'rehabilitation' entails to reflect its unique nature at this life stage. While the focus of rehabilitative occupational therapy and hospice care may differ, Trump (2000, 2001) has proposed that the philosophy of occupational therapy and hospice are closely aligned, due to their focus on living versus dying, quality-of-life, and client-centered care.

Trump further suggested that end-of-life care is within the profession's scope of practice, and that they are 'a natural fit.' A range of interventions have been documented as being within the scope of occupational therapy services in end-of-life care, including: the patient's activities of daily living (ADLs), psychological issues, exercise programs, splinting and positioning, energy conservation, relaxation techniques, seating and mobility, comfort, adaptive equipment, support and education for the family caregivers, connecting the patient with community services and supports, and conducting home assessments (Armitage & Crowther, 1999; Egan, 2003; Ewer-Smith & Patterson, 2002; Frost, 2001; Hasselkus & Davel Jacques, 1998; Littlechild, 2004; Marcil, 2006). Gammage, McMahon, and Shanahan (1976) proposed that occupational therapy has a unique role in supporting clients who are dying, as therapists: assist clients to adjust to the loss of old occupational roles and the facilitation of new ones, adapt activities and the environment to reflect the client's changing functional status, support clients through active listening, and foster the maintenance of client dignity and self-worth. Dawson and Barker (1995) further identified three main categories with respect to the therapist's role at end-of-life: problem-solver, educator/teacher, and networker/communicator. Several articles have suggested that fostering quality-of-life is a major focus for occupational therapy in this area of care (Egan, 2003; Picard & Magno, 1982; Pizzi, 1984; Pizzi & Briggs, 2004; Nelson Tigges & Sherman, 1983; Trump, 2000; vanderPloeg, 2001).

Many of the articles indicated that the role of occupational therapy in end-of-life settings is not clear-cut; roles can overlap with other members of the hospice team, making it difficult to discern occupational therapy's unique contribution (Dawson & Barker, 1995). Conversely, the contribution of occupational therapy at end-of-life can also be depicted as focusing on very particular areas of care. For example, Frost (2001) stated that ADLs are occupational therapy's area of expertise at end-of-life. Similarly, Littlechild (2004) found that therapists' main roles involved discharge planning, energy conservation, home visits and ADL management.

Some components of the occupational therapy role may prove more difficult to address in end-of-life settings. For example, while spirituality is proposed as an important part of therapy (Townsend & Polatajko, 2007), Rose (1999) found that addressing spirituality was a challenge for the therapists in his study. Eighty percent of the 44 occupational therapists stated that spirituality was an important part of their lives, 89 percent considered it an important part of health and therapy, and 75 percent agreed that spiritual issues were within the scope of their practice. Nonetheless, only 18 percent stated that they consistently address spiritual issues during assessments and 59 percent stated that when spiritual issues came up, clients should be referred elsewhere (i.e. a chaplain). Seventy-three percent reported that their education had not prepared them to address spiritual issues.

The predominance of articles addressing the role of occupational therapy in end-of-life care reveals its importance as a topic of discussion. These articles demonstrate that occupational therapy at end-of-life is unique from traditional models of practice. While it appears that the hospice movement and occupational therapy share similar philosophies of care, how this care is implemented in practice is more difficult to accomplish. A paradox exists in providing rehabilitative care at end-of-life. Although spirituality is an important area within the scope of occupational therapy practice, some therapists report feelings of discomfort and a lack of preparedness to address spirituality in palliative care.

Evaluating Occupational Therapy at End-of-Life

Six articles focused on examining occupational therapy in end-of-life settings, from both service (5) and educational perspectives (1). Two studies investigated this topic from the perspectives of the clients and carers. Kealey and McIntyre (2005) evaluated home-based occupational therapy services. One concerning finding was that clients and their carers reported low levels of understanding about the occupational therapists' roles. Clients also perceived that occupational therapists tended to focus more heavily on physical concerns versus psychological issues such as managing stress. A study by Jeyasingam, Agar, Soares, Plummer and Currow (2008) focused on examining the unmet needs of terminally ill clients and their caregivers. In both groups, the most frequently cited unmet needs were in the personal functional domain (i.e. stairs, transfers, walking).

Two articles focused on how occupational therapists spent their time in oncology and palliative care settings. One study focused broadly on how therapists allocated their time (Cooper & Littlechild, 2004), while the other focused on time spent on home assessments (Hoy, Twigg & Pearson, 2008). Both studies highlighted that non-direct or non-patient related activities (i.e. preparation, supervision and teaching, caseload management, travel) can take up a significant proportion of the therapists' time, and that these necessary parts of the therapeutic process can often be overlooked. A third study by Pearson, Todd and Futcher (2007) undertook a systematic literature review to investigate the use of a quality-of-life tool as an outcome measure for occupational therapists working in palliative care. They concluded that such a tool might help identify and prioritize problems, facilitate communication, and monitor changes in the patient's health status.

Lastly, one study sought to gain more information about palliative care education in occupational therapy schools in Australia and New Zealand and the preparedness of graduates to work in this field (Meredith, 2010). The researcher surveyed six occupational therapy programs and 24 clinicians working in palliative care settings. The findings indicated that 54 percent of clinicians reported no palliative care education in their occupational therapy training, and 75 percent indicated they felt unprepared to work in this field. Those who reported feeling more prepared indicated that they had received some degree of training. All six occupational therapy schools that took part in the study (of 15 invited to participate) reported that palliative care was addressed to some degree in their curricula, averaging 5.42 hours of educational time. The study concluded that more occupational therapy specific education in palliative care was required.

The findings of these studies might explain why the occupational therapy role at end-of-life may be misunderstood. For example, physical domains are often cited as a priority for clients and caregivers, which may create challenges in attending to other types of occupations. In addition therapists must juggle non-direct but essential aspects of care. Lastly, students may not be prepared to practice in this area of care.

The Experience of Occupational Therapists in End-of-Life Settings

A third theme that emerged in the literature review was the occupational therapist's experience of working in end-of-life settings. Two studies addressed the paradox between the aims of rehabilitative and end-of-life care. Bye (1998) investigated how ten occupational therapists managed this paradox if encountered. The core theme that emerged was '*Affirming life: Preparing for death*,' indicating that participants managed the paradox by reframing the focus, processes and outcomes of their care to attend to the client's state of living while dying. Rahman (2000) also investigated how occupational therapists experience this paradox. He found that *Patient care* was unique in this setting and included 'tuning in' and 'comfort care,' addressing the loss of patient roles, 'working towards death' through acts of closure, open conversation, active listening, and a ‘journey’ with the patient. *Professional issues* included being a ‘team player,’ advocating for the appropriate ‘use of OT,’ and the ‘dichotomous role’ of therapists who support and enable living while dying. The paradox was not seen to be a conflict for these therapists because of their prior experiences with end-of-life practice, and their ability to distinguish between rehabilitation versus goals oriented toward comfort.

Prochnau, Liu, and Boman (2003) examined the relationship between the personal and professional lives of occupational therapists working in palliative care. The study uncovered five themes that reveal how working with terminally ill clients can impact one’s personal life: a sense of satisfaction, hardships and difficulties, coping, spirituality, and growth. The findings suggest that occupational therapists working in end-of-life settings might experience intense emotional dimensions that contribute to their personal growth and ways of being in the world.

A study by Cipriani et al. (2000) explored occupational therapists’ experiences of coping with the death of clients. The results of 42 questionnaires and four interviews indicated that 95 percent of the respondents had experienced the death of a client. Over one-third of the respondents had not had formal training for coping with death and dying. Over one-third also stated that their current employers did not offer any type of support to aid them in coping. An important theme that emerged was the limited education on coping strategies in occupational therapy programs. Further, the therapists reported that both their personal and professional experiences with death and their level of maturity enhanced their ability to cope with client deaths.

Recently, an autoethnography was conducted by an occupational therapy student, who experienced a client’s death on a fieldwork placement (Warne & Hoppes, 2009). This student's experience echoes many of the themes that have been documented by other therapists - the emotional weight of working at end-of-life, a lack of education and coping resources, the power of occupation to affirm the end-of-life experience. For example, she described feelings of intense emotional lows:

> I sank to the floor, wrapped my arms around my knees, let my head drop and cried. I cried for Mr. R, I cried for his family and I cried for myself. There was nobody, not one person at that hospital whom I could talk to about what I had just experienced. My clinical instructor and I did not develop a relationship conducive for weighty, therapeutic discussions. (p. 313)

Warne also described four positive lessons learned from this experience: the power of occupation at a time of loss, learning to make a difference, learning to open gifts and incorporate insights gained from this experience into her everyday life, and the therapist she wanted to become.

These five studies highlight the tensions inherent in the experiences of occupational therapists in end-of-life care, such as: how therapists address the paradox of rehabilitative care at end-of-life, the intensity of emotional experiences, and the lack of supports available to help therapists cope with the loss of a client. In addition they also highlight many positive experiences such as: the power of occupation, personal growth, satisfaction, deep insights, making a difference, and thinking about who the therapist wants to become.

The Impact of the End-of-Life Experience on the 'Other'

Two articles specifically explored the experience of people involved in the end-of-life process, such as caregivers and loved ones. Reid and Reid (2000) discussed the occupational role of caregiving at end-of-life, noting that caregiving can be a source of distress due to role changes, role imbalance, and disability. Several recommendations were proposed to help caregivers strive toward balance, such as focusing on the positive, establishing built-in rewards, taking care to engage in personally fulfilling activities, accepting help, prioritizing roles and saying ‘no’ when necessary. A study by Hoppes and Segal (2010) identified three occupational responses in the bereavement process after the death of a family member: occupational accommodation, occupational assimilation and continuing occupational bonds. They explored how these occupational responses contributed to reconstruction of meaning, particularly in the areas of work, social participation and leisure. These two articles point to the implications of end-of-life care with respect to the occupations of family and loved ones.

Personal Reflections on End-of-Life Experiences

Two articles offered personal reflections on therapists’ experience with death and dying, involving a parent. Thibeault (1997) shared her experience of grieving the deterioration of her father’s mind, as he battled Parkinson’s disease. She highlighted five areas in her professional training that influenced her grieving process: theoretical understanding of grief and bereavement, knowledge of pathologies and prognoses, use of client-centered guidelines, access to professional networks, and the values inherent in occupational therapy practice. She reflected on how these dimensions impacted her family life, professional practice, and personal growth. Some insights included: a readiness to speak openly about spiritual issues with her father and recognition of how this fostered a sense of closeness; realizing that one’s professional understanding of practice still leaves room for creativity and personal intuition; and a focus on living in the present and allowing life to unfold in unpredictable ways. Hasselkus (1993) recounted her experience of caring for her dying mother. She shared insights into the power of presence, that is, just *being with* the care-receiver; the paradox of living while dying, including the difficulty of attaining typical occupational therapy goals of helping the person toward independence and participation; and the significance of occupation as a means to promote connection and communion versus loss and separation at end-of-life. Hasselkus urged occupational therapists to foster a sense of connection between the client and the caregiver(s) through occupation, suggesting that this offers a sense of communion that contributes to the experience of dying well. These two articles appear to suggest that one's knowledge as an occupational therapist and personal experiences with death are not distinct, but can inform each other.

The Nature of Occupation at End-of-Life

The final theme identified in the literature addresses the nature of occupation at end-of-life; an understanding of which may inform the role of occupational therapists in this context. Four articles addressed this theme. Pollard (2006) raised the question, 'Is dying an occupation?' which led him to consider some of the occupational implications of dying. He pointed out that spirituality can emerge through a number of occupations, including rituals and cultural celebrations, and creative activities. Death can also be a time for self-expression and affirmation, whether it is through passing on personal mementos or making a contribution. For Pollard, death is a period of "intense occupational significance" (p. 152). He noted that death does not have to terminate one's occupational potential and that through doing, being, and becoming one's legacy can continue.

Doing, being, and becoming (Wilcock, 2006) also framed a study by Lyons, Orozovic, Davis, and Newman (2002) that explored the occupational experiences of 23 day hospice participants. They found that: *Doing* involved losing and maintaining occupations, and engaging in activities that preserved physical and mental function; *Being* was evident through the participants' relationships, and their personal voyages into the self; *Becoming* occurred through unexpected new learning, through unfamiliar occupations, and through making a contribution. Their study emphasized how these three occupational dimensions may potentially guide practice goals in palliative care.

Doing had significant importance in a study by Vrkljan and Miller-Polgar (2001). These authors examined how three women engaged in occupation after their diagnosis of breast cancer, and associated meanings. The core theme that emerged was that 'Doing = Living,' illustrating "the connection between meaningful occupational engagement and one's self-perception as a capable and healthy individual" (p. 240). In this study, occupations were found to be an effective means of regaining personal control and a sense of normalcy in life.

Lastly, Davel Jacques and Hasselkus (2004) conducted a six-month ethnographic study to gain a deeper understanding of the meaning of occupation at end-of-life. Four domains were identified: '*Doing the things that matter: Continuing life,*' '*Getting everything in order: Preparation for death,'* '*It takes so long to die: Waiting'* and '*A gentle good-bye: Death and after-death.*' The authors proposed that "occupation is the good death" (p. 52-3), that is, occupation played a significant role in facilitating good dying experiences.

These four articles affirm the importance of occupation at end-of-life and may inform occupational therapy practice in the final stages of life.

Discussion

This literature review demonstrates that in the past few decades, the topic of death and dying in the occupational therapy and occupational science literature has begun to garner attention. The review revealed a strong focus on what the role of occupational therapy in end-of-life settings entail, with a number of articles discussing the scope of practice, the fit of the hospice and occupational therapy philosophies, and the paradox of providing rehabilitative care at end-of-life. Scholars have begun to evaluate the quality of occupational therapy care and the degree of palliative care training provided. Others have begun to examine the experience of the therapist, particularly in regard to how they cope with client death, and manage the paradox of offering rehab services when death is impending. Two therapists provided personal reflections on their experiences with death and dying, and how this informed their professional role (and vice versa). There is growing research on how the end-of-life experience impacts the 'Other,' which broadens the occupational therapy role beyond the patient. Lastly, some scholars have also begun to examine the nature of occupation at end-of-life, with findings that potentially inform the notion of dying well.

Some interesting insights drawn from this review regarding the role of occupation and occupational therapy at end-of-life include:

- While it has been proposed that occupational therapy and hospice philosophy are closely aligned, the paradox of rehabilitation at end-of-life may require re-conceptualization to better articulate the role of occupational therapy in this practice setting.

- Occupational therapists' unique contributions include their ability to adapt occupational performance to reflect the client's changing, and often deteriorating, functional status, and their ability to balance the challenge of affirming life while preparing for death.
- The occupational therapist's role may involve supportive interventions, such as active listening, open conversation, and simply being there and offering presence.
- An intimate relationship appears to exist between professional and personal end-of-life experiences, and how these inform each other.
- Everyday occupations, both ordinary and extraordinary, and the varied dimensions of occupation (i.e. doing, being, becoming) can take on different meaning and significance at end-of-life.
- Therapists have identified important factors contributing to their degree of comfort in working in end-of-life care (i.e. years of experience, palliative care education, personal experiences, and level of maturity).
- Working in end-of-life settings involves a level of emotional intensity that appears to benefit from preparatory education.
- A tension exists between the importance of spirituality at end-of-life and challenges to the provision of spiritually-oriented care in occupational therapy practice.
- There is potential for occupation to play a significant role in facilitating the 'good death.'

The findings of this study reveal important areas of consideration in regard to research, education and practice. In terms of research, further empirical studies into the significance of occupation and occupational therapy in end-of-life care are needed. Of the articles reviewed, the Canadian literature is the most limited. None of the articles examined the experience of children and young adults facing terminal illnesses, and only one study considered the impact of bereavement for people who have lost loved ones. There is also limited research on the caregiving experience. Given that care giving needs are expected to grow (CHPCA, 2008; QELCC, 2007), further research in this area is imperative.

A recurring thread in this review was the limited resources therapists had while coping with client death, and the lack of training in this area. Not only did therapists report little or no training, some also indicated that the facilities in which they were employed did not offer debriefing or support. Therapists reported that they often drew on personal experiences to help them cope.

Lastly, this study reveals that occupational therapy practice in end-of-life settings has not been firmly established, and difficulty understanding what occupational therapy service entails is a concern. The fluidity of the profession's scope of practice might make it difficult to discern when roles cross over with other disciplines (Frost, 2001; Littlechild, 2004). This raises questions about how occupational therapy services are conveyed and understood by patients, other disciplines, and policy administrators, and points to the need for coordinated educational and public relation efforts by members of the profession.

Conclusion

To our knowledge, this is the first systematic literature review on the role of occupation and occupational therapy at end-of-life to date. Another strength is that the authors followed systematic guidelines for conducting the review according to Garrard's

(2007) Matrix Method. In terms of limitations, important articles may have been missed if the search terms were not present in the titles of papers, the paper was not accessible to the university database, or if it was published in another language. Another limitation is the limited number of empirical studies conducted on this topic.

Although a body of literature has begun to emerge in the area of occupation at end-of-life, more empirical research studies are needed to better understand occupational therapy's unique role. Echoing Holland and Nelson Tigges (1981), it is time for professional action and commitment to a movement that is only on the rise; it is imperative that occupational therapists continue to make their presence known in end-of-life settings, from research, education and practice standpoints.

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Table 2: Methodological Breakdown

Methodology & Methods	Articles	Authors & Year
Empirical or Research-Based Articles [19 Total]		
Quantitative Articles [6 total]		
• Time based methodology	1	Cooper & Littlechild, 2004
• Survey Questionnaire	3	Meredith, 2010 Rose, 1999 Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008
• Audit	1	Hoy, Twigg, & Pearson, 2008
• Cross sectional prevalence study	1	Jeyasingam, Agar, Soares, Plummer & Currow, 2008
Qualitative [11 total]		
• Ethnography	1	Davel Jacques & Hasselkus, 2004
• Literature review	1	Pearson, Todd, & Futcher, 2007
• Autoethnography	1	Warne & Hoppes, 2009
• Survey Based Methods	1	Cipriani et al., 2000
• Generic qualitative methods (in-depth interviews, participant observation, focus groups)	7	Bye, 1998; Gammage, McMahon, & Shanahan, 1976 Hoppes & Segal, 2010 Lyons, Orozovic, Davis, & Newman, 2002 Prochnau, Liu, & Boman, 2003 Rahman, 2000 Vrkljan & Miller-Polgar, 2001
Mixed Methods [2 total]		
• Delphi survey & interviews	1	Dawson & Barker, 1995
• Interviews with pre-designed questionnaire	1	Kealey & McIntyre, 2005
Non-Empirical or Non-Research Based Articles [21 Total]		
• discussion papers, magazine articles, newsletters, comment papers, personal reflections, position statements	21	Armitage & Crowther, 1999 CAOT, 2008 Egan, 2003 Ewer-Smith & Patterson, 2002 Frost, 2001 Hasselkus, 1993 Hasselkus & Davel Jacques, 1998 [AOTA] Holland & Nelson-Tigges, 1981 Marcil, 2006 Littlechild, 2004 Picard & Magno, 1982 Pizzi, 1984 Pizzi & Briggs, 2004 Pollard, 2006 Reid & Reid, 2000 Thibeault, 1997 Tigges & Sherman, 1983 Trump, 2000 Trump, 2001 Trump, Zahoransky, & Siebert, 2005 [AOTA] vanderPloeg, 2001

Table 3: Occupation and End-of-Life: Six Themes

Thematic Purpose	Number of Articles	Article Authors
The role of occupational therapy at end-of-life	21	Armitage & Crowther, 1999 Canadian Association of Occupational Therapists [CAOT], 2010 Dawson & Barker, 1995 Egan, 2003 Ewer-Smith & Patterson, 2002 Frost, 2001 Gammage, McMahon, & Shanahan, 1976 Hasselkus & Davel Jacques, 1998 [AOTA] Holland & Nelson-Tigges, 1981 Marcil, 2006 Littlechild, 2004 Picard & Magno, 1982 Pizzi, 1984 Pizzi & Briggs, 2004 Rose, 1999 Schleinich, Warren, Nekolaichuk, Kaasa & Watanabe, 2008 Nelson Tigges & Sherman, 1983 Trump, 2000 Trump, 2001 Trump, Zahoransky, & Siebert, 2005 [AOTA] vanderPloeg, 2001
Evaluating occupational therapy at end-of-life	6	Cooper & Littlechild, 2004 Hoy, Twigg, & Pearson, 2008 Jeyasingam, Agar, Soares, Plummer & Currow, 2008 Kealey & McIntyre, 2005 Meredith, 2010 Pearson & Todd, & Futcher, 2007
The experience of occupational therapists in end-of-life settings	5	Bye, 1998 Cipriani et al., 2000 Prochnau, Liu, & Boman, 2003 Rahman, 2000 Warne & Hoppes, 2009
The impact of the end-of-life experience on the 'Other'	2	Hoppes & Segal, 2010 Reid & Reid, 2000
Personal reflections on the end-of-life experience	2	Hasselkus, 1993 Thibeault, 1997
The nature of occupation at end-of-life	4	Davel Jacques & Hasselkus, 2004 Lyons, Orozovic, Davis, & Newman, 2002 Pollard, 2006 Vrkljan & Miller-Polgar, 2001

CHAPTER FIVE: INTEGRATED MANUSCRIPT TWO

PHENOMENOLOGY AND THE STUDY OF HUMAN OCCUPATION

Introduction

Occupational scientists concern themselves with the study of human occupation. Yet, the question of how best to study human occupation is one that is only beginning to be debated in the literature. In 1991, Carlson and Clark suggested that many naturalistic approaches to occupational science research, such as ethnography, participant observation, case study and phenomenology, might face difficulties producing findings that offer in-depth understandings and practical applications for the discipline. We propose that one such methodology, phenomenology, offers a fruitful approach through which to engage in the study of human occupation and that further discussions about phenomenology in the field of occupational science are warranted.

The occupational science literature indicates that there is a growing interest in phenomenology as a methodological approach (Barber, 2004; Beagan & Saunders, 2005; Devine & Nolan, 2007; Downs, 2008; Gallew & Mu, 2004; Lin, Kirsh, Polatajko, & Seto, 2009; Mahoney & Roberts, 2009; Matuska & Erickson, 2008; McLaughlin Gray, 1997; Pearson, 1996; Reed, Hocking, & Smythe, 2010; Scheerer, Cahill, Kirby & Lane, 2004; Wright, Sadlo & Stew, 2007). In the Journal of Occupational Science, two theoretical articles by Barber (2004) and McLaughlin Gray (1997) have specifically focused on phenomenology as a methodology and its implications for occupational

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science. The former discussed human activity, narrative, and ethical responsibility as phenomenological dimensions that reveal deeper insights into the motives and meanings that underlie everyday occupations. The latter article examined the suitability of phenomenological research as an approach to study the essence of occupation (*what is and is not occupation?*), and drew heavily on the seven-step phenomenological method of philosopher Herbert Spiegelberg. In terms of how phenomenology is utilized as a methodological approach in occupational science research, there is a range of approaches represented, and the depth of the theoretical grounding in phenomenology varies significantly. Several studies offer broad and generic descriptions of what the methodology entails, drawing on generic qualitative resources to support their phenomenological standpoints (such as Creswell, 1998; DePoy & Gitlin, 1994; Lincoln & Guba, 1985; Patton, 2002). In addition, a number of studies do not appear to consider phenomenological philosophers (such as Husserl, Heidegger, Merleau-Ponty) in their work, and the epistemological assumptions about knowledge that these different philosophical perspectives entail.

The use of generic qualitative resources is not surprising given that: in-depth engagement with phenomenological texts requires extensive time and guidance, scholars often do not receive in-depth training in phenomenology during their preparatory studies, and even if more phenomenological sources are used, researchers face challenges in fully presenting their methodological approaches given limited word allocations for scholarly writing. Yet the result may be that readers conflate the tradition of phenomenology - which has a rich history, and is based on particular philosophical and theoretical assumptions about knowledge - with generic statements about qualitative research approaches such as their value in seeking ‘in-depth information,’ learning about ‘the participant’s experience,’ ‘understanding meaning,’ and ‘first person accounts.’ While these are important, we suggest that understanding the assumptions about knowledge, which a phenomenological approach brings to the study of human occupation, is important for advancing phenomenological work in the field.

This paper is therefore directed to occupational science researchers who seek to explore the assumptions about knowledge that the methodology entails, and those interested in phenomenology as a methodological approach for the study of human occupation. The purpose of this paper is not to provide a method for phenomenological inquiry, but rather to discuss five generative dimensions that we propose have remained central to the philosophy over time, and the implications for the study of human occupation. The dimensions considered include: knowledge generation, intentionality and the lifeworld, Being, the lived body, and first critique. These five dimensions reveal some of the philosophical and theoretical assumptions about knowledge that are embedded in the tradition, and reveal what phenomenology can offer beyond generic understandings. The paper draws primarily on the contributions of three major phenomenological philosophers: Edmund Husserl, Martin Heidegger, and Maurice Merleau-Ponty. While it is acknowledged that there are important points of disagreement amongst phenomenological thinkers, these have been well articulated by Dowling (2007) and are beyond the scope of this paper. Rather, the focus here is on an analysis of key assumptions about the nature of knowledge within the phenomenological tradition as a whole, and the consequent possibilities of phenomenology as a research methodology for the study of human occupation.

For the purposes of this paper, occupation is defined broadly as “all that people need, want, and are obliged to do” (Wilcock, 2006, p. 9). Phenomenological research is important for occupational scientists because it aims to elicit how taken for granted phenomena, such as everyday occupations, are lived and experienced (Hasselkus, 2006; Wilding & Whiteford, 2005). A phenomenological approach can be used to examine the way occupation presents itself through ‘small experiences,’ and such an approach may be seen to allow everyday, ‘in the world’ experiences to speak (Hasselkus, 2006). Phenomenology offers an approach for researchers to investigate the “delicate layerings” (Hasselkus 2006, p. 627) of occupation in the world.

What is Phenomenology?

Phenomenology is both a philosophy and a methodological approach with significant potential for the study of human occupation (Wilding & Whiteford, 2005). The battle cry of phenomenology extends back to the early work of German philosopher Edmund Husserl, who called for investigations that return ‘Back to the things themselves!’ Phenomenology seeks to examine phenomena from the perspective of first hand accounts and through the lifeworld of people. Phenomenology calls for researchers to acknowledge and attempt to put aside culturally ascribed assumptions, judgments and beliefs in order to consider phenomena from a stance of naiveté, critique and wonder (Carman, 2008; Crotty, 1998; Heidegger, 1927/2008; Merleau-Ponty, 1945/2006).

Phenomenology has a rich history, and theoretical depth. What phenomenology meant when it was founded by Husserl in the early 20th century differs from the understandings and use of it today (Sokolowski, 2000; Spiegelberg, 1960), and even among current interpretations, there is a great degree of variation. As the field of phenomenology continues to develop, it is difficult to demarcate the lines between its many branches and to articulate a single definition that encompasses its entirety (Spiegelberg, 1960). Indeed, Finlay (2009) has indicated that the question of what counts as phenomenology is still being debated today.

Nonetheless, there are some common themes in the philosophy that can be identified. In this paper we highlight five dimensions of phenomenology that offer generative possibilities for occupational scientists interested in engaging in phenomenological inquiry. These five dimensions include: (a) a re-conceptualization of knowledge generation (b) intentionality and the lifeworld, (c) the notion of Being, (d) the lived body, and (e) and the potential of phenomenology to reveal critical insights. These dimensions elucidate a complex methodology that has potential to contribute to scholarly conversations concerning approaches to the study of human occupation.

Five Phenomenological Dimensions

Knowledge Generation

Edmund Husserl (1859-1938) was a German philosopher who is frequently depicted as the 'father' of phenomenology. Husserl's unique philosophical contributions were instrumental as a foundation to the phenomenological movement; unlike later phenomenologists, he did not have any "overshadowing predecessors" and as such, he was "truly an original philosopher" (Sokolowski, 2000, p. 211).

For Husserl, the phenomenological movement began as a necessary step to address what has been referred to as a 'crisis of science' or a scientific 'turning point' in the early 20th century in Europe. Husserl asserted that modern science had been confronted by two challenges: first, that science had degenerated into "an unphilosophical study of mere facts" which meant the loss of "its significance for man's life as a whole," and second, that science was "incapable of coping with the problems of ultimate truth and validity" (Spiegelberg, 1960, p. 79). Husserl deemed that traditional modes of human inquiry were unable to sufficiently address the nature of human consciousness in everyday life (Nakhnikian, 1990). In response, he sought to reorient the scientific world 'back to the things themselves' by means of a rigorous philosophical method that examined phenomena as lived and directly experienced. His method sought to describe, versus explain, phenomena in the lived human experience (Sokolowski, 2000; Spiegelberg, 1960). Two important features of Husserl's phenomenological method that contributed to a new perspective on how knowledge could be generated were: the phenomenological or transcendental reduction, and eidetic intuition/abstraction. While later phenomenologists expressed alternative perspectives, and some identified what they considered flaws in Husserl's original philosophy, others defend the significance of Husserl's ideas for contemporary research (Giorgi & Giorgi, 2003; Moustakas, 1994). From either perspective, the aims of phenomenology are more deeply understood through comprehension of these beginnings.

First, the *phenomenological* or *transcendental reduction* involves a shift from the natural attitude to a transcendental state (Husserl, 1907/1990). The former is a "characteristic of our being in the life-world" (Schwandt, 2001, p. 147), and refers to the day-to-day, taken for granted and unreflective position in which individuals go about their daily lives. In contrast, a transcendental attitude consists of reflection upon the natural attitude, to examine intentional threads and worldly ties (Sokolowski, 2000; Spiegelberg, 1960). In this state, the researcher engages in *epoché*, that is, a suspension or ‘bracketing’ of prior understandings, assumptions, and beliefs that belong to the natural context of his or her life-world (Husserl, 1907/1990). Through epoché, researchers approach phenomena with a fresh perspective. It is in this state that researchers “look *at* what we normally look *through*” (Sokolowski, 2000, p. 50). The phenomenon, now stripped from its everyday, taken for granted understandings, is described in its naked form, in terms of its qualities and attributes as well as in terms of the individual’s descriptive and reflective accounts. Therefore, in a phenomenological reduction, the researcher seeks to elicit clarity and dispel the darkness of preconceived assumptions (Husserl, 1907/1990).

A number of phenomenologists following Husserl have suggested that Husserl’s epoché is impossible to ever fully achieve. They argue that human existence is intimately tied to what Martin Heidegger (1927/2008) described as a state of Being-in-the-world. Merleau-Ponty (1945/2006) elaborated on this notion:

> The most important lesson, which the reduction teaches us, is the impossibility of a complete reduction. This is why Husserl is constantly re-examining the possibility of the reduction. If we were absolute mind, the reduction would present no problem. But since, on the contrary, we are in the world, since indeed our reflections are carried out in the temporal flux on to which we are trying to seize….there is no thought which embraces all our thought. (p. xv)

What these later phenomenologists suggest is that if you consider how people actually are in their everyday lives, people are not preoccupied with single and consecutive thoughts within their consciousness; instead, people are already *in-the-world*, and much day-to-day activity is conducted without direct attention or consciousness about them (Magee & Dreyfus, 1987). Therefore, some researchers believe in the possibility of the transcendental reduction, that peoples’ everyday ways of responding can be bracketed out in the research processes (Moustakas, 1994), whereas others suggest that the nature of being-in-the-world means that everyday ways of seeing cannot be reduced by 'bracketing' these from the external world (Finlay, 2009). In the more descriptively oriented approaches of the transcendental reduction researchers attempt to bracket out and put aside what they bring to the research process. Other more hermeneutic and interpretively oriented perspectives question the extent to which a researcher can truly bracket the researcher's subjectivity out of the interpretive process. Finlay (2009) suggests that this dichotomy might more fruitfully be viewed as a continuum, in which specific research may be viewed as more or less descriptively or interpretively oriented.

A second feature of Husserl's phenomenological method is *eidetic intuition or abstraction.* According to Sokolowski (2000), this notion can be described as "identity synthesis" (p.177), in that the researcher attempts to identify empirical universals or essences - attributes of the phenomenon that are experienced and understood as true. The researcher begins by considering similarities among the same phenomenon (i.e. What makes a chair a chair? What are features that all chairs share?). Eidetic intuition seeks to grasp "the objectivity of essences" (Husserl, 1907/1990); the researcher is attempting to understand the phenomenon's structural eidos or form (Sokolowski, 2000), in other words, to "give shape to the shapeless" (van Manen, 1997, p. 88). Eidetic intuition also involves *imaginative variation*, described as questioning and confirming the phenomenon's necessities, the qualities which make it essentially so (i.e. Is a chair still a chair if it is painted red? Is a chair still a chair if it has no back? If it has five legs?). Sokolowski (2000) described imaginative variation as follows:

> We let our imagination run free, and see what elements we could remove from the thing before it 'shatters' or 'explodes' as the kind of thing that it is…if we run into features that we cannot remove without destroying the thing, we realize that these features are eidetically necessary to it. (p. 179)

Essentially, the dimensions of the phenomenon that do not cause it to 'collapse' under such eidetic intuition or abstraction are deemed essential to its essence (Giorgi & Giorgi, 2003).

What Husserl proposed was a new methodology for generating knowledge, based not on the preordained theories of the time, but rather on a way of investigating phenomena through how they appear directly in day-to-day life. For Husserl, it did not make sense to conduct research that did not reflect lived experience. This has relevance for the study of human occupation in that occupation-based researchers are attentive to the myriad of contextual factors that impact how people engage in everyday occupations (Dickie, Cutchin & Humphry, 2006; Townsend & Polatajko, 2007). The transcendental reduction and eidetic abstraction remind researchers to return 'back to the things themselves,' to begin inquiry with fresh eyes, and to reconsider the taken for granted and learned assumptions that they and others may have adopted with respect to the nature of occupation. Although many subsequent variations of phenomenology have emerged, Husserl's work shows that phenomenology begins with a return to the things themselves as a means of investigation. While researchers may adopt the phenomenological perspectives of later philosophers, one cannot deny the important contribution Husserl made to the phenomenological movement.

An example of how the study of human occupation might be enriched through a conception of knowledge that recognizes the phenomenological perspective of 'returning to the things themselves' is portrayed in a study by Finlay and Molano-Fisher (2008). Molano-Fisher is a post-lingually profoundly deaf person; together these researchers conducted a phenomenological study of her lived experience following a cochlear implant. Through phenomenological investigation, an interesting finding emerged: Molano-Fisher came to the realization that while most people "simply *hear* without thinking about it" (p. 260), she had always understood hearing to be a concerted effort. This finding allowed her to reconceptualize her experience with evening fatigue, and attribute this lack of energy not to laziness, but to the *work* of hearing. This phenomenological insight revealed that hearing, when experienced as *work* may sap one's energy, impact one's self-perception, and compromise one's capacity to do. While the impact of fatigue on occupational engagement is not a new concept, the phenomenological understanding of the *work* of hearing brings new insights into how this particular kind of fatigue might be managed for people with hearing loss. Such findings have important implications for people who live with, care for and research people with hearing loss, as well as people who live with hearing loss themselves, and are illustrative of the contributions to knowledge that phenomenological research invokes.

A second example is a consideration of what occupation reveals in everyday life, through both visible *and* invisible manifestations. Beagan and Saunders (2005) conducted a phenomenological study investigating how gender (masculinity) is constructed through what 11 young Canadian men do. The findings suggested that participants' experience of masculinity was constituted by occupations they actively engaged in (i.e. working out, eating right), but also by invisible doing. Examples of invisible doing included monitoring speech (avoiding words like 'dieting'), and avoiding activities that would appear effeminate (i.e. never openly admitting they compared or ranked their bodies against other men, never making it appear as if they were actively *trying* to obtain a masculine physique). This study illuminated that what people refrain from doing might hold symbolic significance, and raises questions about understandings of occupation bound by definitions such as ‘observable activity.’ This phenomenological research shows how such perspectives have the potential to elicit new knowledge about human occupation, by providing deeper insights into seemingly mundane and ‘normal’ day-to-day experiences.

Intentionality and the Lifeworld

Phenomenological perspectives ask two important questions: What is our human relationship to an external world, and what does our world consist of? These questions are addressed by two tenets: human consciousness as intentional and human existence as situated within a lifeworld already rich with meaning.

Intentionality, more specifically, intentionality of consciousness, is a key component of Husserl’s philosophy. Intentionality describes the mind as an entity that is always ‘conscious *of*’ something, and thereby directed towards that something. Intentionality means that, “every act of consciousness, every experience, is correlated with an object” (Sokolowski, 2000, p. 8); everyday experiences, thoughts, memories, and actions are all oriented towards objects in the world. Although this notion may seem obvious (of course we’re always thinking *of* something!), many renowned philosophers before Husserl’s time proposed the very opposite. Several philosophers, including Descartes, Kant, and Locke, contended that all human understanding is an internalized affair and that our minds are enclosed chambers separate from our bodies and the world (Carman, 2008). Intentionality suggests that how people know what they know is not limited to the confines of their minds, rather it highlights the inseparability of the knower and the known: “Consciousness is always consciousness *of* something. An object is always an object *for* someone. The object, in other words, cannot be adequately described apart from the subject, nor can the subject be adequately described apart from the object" (Crotty, 1998, p. 79).

This notion that human consciousness is always directed toward a world brings us to a related important construct, the *lifeworld,* which Husserl (1907/1990) described as follows:

> I find myself at all times, and without my ever being able to change this, set in relation to a world which, through its constant changes, remains one and ever the same. It is continually 'present' for me, and I myself am a member of it. Therefore this world is not there for me as a mere *world of facts and affairs*, but, with the same immediacy, as a *world of values*, a *world of goods*, a *practical world.* (p. 103)

The lifeworld is a world experienced, not merely observed (Finlay, 2008). Human lives are bound by time, space, social relations and bodily capacities in both objective (i.e. time measured by seconds, minutes, hours etc.) and subjective (i.e. the slowing down of time when one is bored versus the speeding up of time when one is engaged) senses (van Manen, 1997). From a phenomenological perspective, lived engagement does not occur in a vacuum, but in a lifeworld filled with world-stuff, objects whose meanings could not exist without human interaction and consciousness (Crotty, 1998).

Intentionality and the lifeworld have implications for research that examines human occupation. An example is revealed in Doyle's (2001a) study 'Bodies Inside/Out: A Phenomenology of the Terrorized Body in Prison,' which examined the experiences of political prisoners. Doyle described the lifeworld of a prisoner and revealed how intentionality is directed toward objects and their meanings. The prisoner was stripped of worldly possessions, and gained a habit of hoarding and stashing random objects that crossed her path:

> First, from bits of bone in her food, broom straw from her mattress, wire from her mattress frame, and teeth broken off her comb, she fashions a small sewing kit…with these handmade tools she makes a set of miniature dolls from soap and bits of her own clothing reshaped into tiny outfits, and she mends her years'-old clothing. (p. 83)

This woman's intentionality toward these objects is revealed in her words, there is "this 'promise' in things" (p. 86). Even within a restricted environment, her lifeworld was engaged through the occupation of making dolls. What might typically be considered meaning-less objects took on powerful occupational significance as her consciousness was directed toward and interacted with them.

Another example that illuminates the potential of research that attends to intentionality and the lifeworld is a study by Reed et al. (2010). This study found that the meaning of occupation can often be revealed through what they referred to as 'the call.' The call includes intentionality and lifeworld meanings (i.e. of care and concern) ascribed to others and things that 'call' people to engage in meaningful occupations. These authors described how one participant found meaning and passion in the occupation of gardening, "from what she notices needs to be done, which plant needs to be trimmed or which weed needs to be pulled out" (p. 144), and the enjoyment she experiences when her garden 'looks nice.' This example reveals that social meanings (i.e. what counts as a 'nice looking' garden) can emerge from how the intentionality of people, and their lifeworlds are engaged through occupation. Wright-St Clair (2008) also drew on the notion of 'the call' in a study that examined the meaning of being aged. She described one participant's experience of being aged as deeply ingrained with cultural meanings. For May, a Maori woman, being an elder involved the call to care for her mokos (grandchildren), including the pleasure and pride she described in preparing a meal for them during an unexpected visit. May stated, "on the marae (community meeting place), for the whanau (family) that comes in, the old people always make sure that the family has kai (food). This is how we were taught" (p. 154). In this example, preparing a meal is not simply an 'individual' occupation, but a call to exemplify one's cultural being, and a call to pass on this knowledge to other generations through example. As such, attention to intentionality and the lifeworld may contribute to knowledge about occupations and their (social, cultural, political) meanings beyond the individual, while drawing on first person perspectives as a medium to do so.

Intentionality and the lifeworld also have relevance for a current debate in occupational science concerning the utility of individualistic and transactional perspectives about human occupation (Barber, 2006; Cutchin, Dickie, & Humphry, 2006; Dickie et al., 2006). Dickie, Cutchin and Humphry have proposed that first person perspectives, commonly drawn upon in phenomenological inquiry, may not have the power or potential to elicit social and political knowledge in the study of human occupation. As such, phenomenology has been criticized as a contributing force in the over-reliance on individualistic perspectives in the discipline. Yet, we contend that phenomenology may be seen to command attention to overlooked human injustices, including the historical, contextual and worldly ties of phenomena, precisely because it attends to intentionality and lifeworld in its investigations. This is exemplified in Doyle's (2001a) writing on *Bodies of resistance: New phenomenologies of politics, agency and culture*, in which she studies the lifeworld and intentionality of prisoners. Her work sheds light on existential issues, but also on ethical, social, and political issues. For example, Doyle (2001a) found that "for a prisoner living in the 'death-world' of a fascist prison, the confiscation of things is actually a theft of the prisoner's spatial *and* temporal holding structures" (p. 85). Her work offers a deeper understanding of the violation inflicted when belongings of significance to one's lifeworld are stripped away, and raises systemic issues of significance in thinking about these 'subtle' forms of violence and how they are routinized in prison systems. Such study has the potential to contribute to knowledge in occupational science, for instance by informing understanding of constructs such as occupational deprivation (Whiteford, 2000), constructs which may be enriched by exploring the link between the lifeworld and intentionality of the individual and broader ethical, social and political issues.

Attention to intentionality and the lifeworld bring to light unique vantage points in the study of human occupation. These phenomenological constructs have potential to contribute to understanding about what people want to do, are able to do, and how they do it, within the everyday social, cultural, political world in which daily occupations are embedded.

Being

The third phenomenological dimension is a concept with significant philosophical depth: the notion of *Being*. While Being is not unfamiliar to the occupation-based literature, the notion of *Being* from a phenomenological perspective has not been deeply considered in the occupational science literature.

Being was of central interest to German philosopher Martin Heidegger. Heidegger (1927/2008) defined *Being* as that which is most close to us, in the sense that our existence is intertwined with a sense of being, but is also simultaneously "veiled in darkness" (p. 25), unnoticed and underlying our everyday affairs. In this sense, the construct of Being has commonalities with human occupation, which has also been depicted as taken for granted, all encompassing and mundane in nature (Hasselkus, 2006; Wilcock, 2006). Being is tied to the understanding that ‘something is’ and becomes manifest through “everything we talk about, everything we have in view, everything towards which we comport ourselves in any way” (Heidegger, 1927/2008, p. 26). To seek the meaning of *Being* is to search for its fundamental or essential structure, buried beneath its everyday manifestations. Heidegger suggested that scholars have lost sight of the ‘correct mode of access’ to understand *Being.* He proposed what he called *Dasein* as the best and only course to understanding *Being.* Dasein refers to individual human existence (Dreyfus, 1991). Dasein is a mode of being which is always self-interpreting, always in a state of trying to make sense of being: “Dasein always understands itself in terms of its existence - in terms of a possibility of itself: to be itself or not itself” (Heidegger, 1927/2008, p. 33). Dasein manifests itself in everyday life, through implicit and explicit practices, through observing, learning, mimicking, and doing in the world. Dasein highlights that being is Being-in-the-world. *Being* is not solely rooted in one’s consciousness, but is interwoven with other people, shared languages, cultures, and ways of doing things, that is, *in-the-world* (Heidegger, 1927/2008). For Heidegger, “human existence is involved in the working out of the possibilities that exist for us by virtue of our being ‘thrown’ into a particular cultural, historical, and familial world” (Leonard, 1994, p. 47). This notion of *Being-in-the-world* may be seen to have important implications for the study of human occupation.

In thinking about being, doing, becoming, and belonging (Rebeiro, Day, Semeniuk, O’Brien, & Wilson, 2001; Whalley Hammell, 2004; Wilcock, 1998, 2006) in the study of human occupation, being is a particularly difficult dimension to understand due to its elusive nature. Whereas elements of doing (occupational engagement, participation), belonging (social environment, social relations) and becoming (occupational development, occupational transition, temporality) are more readily grasped and attended to in research and practice, *Being* resists categorization. Yet, Heidegger (1927/2008) suggested that *Being* is the core of what it is to be human. In the study of occupation, emphasis on *Being* is frequently overshadowed by emphasis on one's ability to do. This may be the result of various influences such as the value Western societies place on independence, autonomy, and productivity (Iwama, 2005; Watson, 2006).

Being however encompasses more than simply doing; a point that is sometimes emphasized through the study of occupation in different cultures. Watson (2006), for example, argued that an Afrocentric worldview tends to value collectivism and interdependence – notions that have implications for ways of *being-in-the-world* - as significant components in occupational engagement. *Being* may also come to the fore in the face of crisis, illness, or disability, or in different life stages. Thibeault (1997) for instance, wrote about her experience of her relationship with her father as his Parkinson's disease progressed. She noted that the importance of 'presence' replaced what she had inferred as significant activities they shared in the past, such as intellectual debates and keeping up with the news. Thibeault observed that, "Simplicity, tranquility and presence now delimit significant 'activity.' Even when there is not the slightest movement" (p. 112).

The phenomenological notion of *Being* has much to offer the study of occupation. Such an approach directs attention to understanding how human occupations are experienced through *being-in-the-world*, and the implications for understanding doing.

The question of how *Being* shapes, motivates and informs occupational experiences is an important one for advancing knowledge in occupational science.

The Lived Body

A fourth area of attention in recent phenomenological thought is the lived body. According to French philosopher and phenomenologist Merleau-Ponty (1908-1961), lived experiences cannot be understood solely through intentionality - the notion that human beings are always 'conscious *of* something.' Our bodies also play an essential role in our day-to-day experiences. His work centered on the philosophy of perception and the lived body. Merleau-Ponty critiqued Descartes' (1641/1996) famous portrayal of the body as a 'machine-like appendage,' a passive conduit for the mind's work (Leder, 1984). According to Merleau-Ponty, the body is not to be viewed as a passive machine ruled by the mind, but rather as dynamic, intelligent and inseparable from human perception of the world - perception in this view is literally embodied. As such, he argued that the body is the 'absolute source' through which human beings 'simply are' or exist. He proposed that our experience of the world is made possible because humans are embodied agents. Merleau-Ponty's work brings the body's place in peoples' perceptual understandings of their everyday lived experience to the forefront. From this perspective, we do not *have* bodies, we *are* our bodies (Merleau-Ponty, 1945/2006). Therefore, "[bodily] perception is not some exotic object or process somewhere out there in the world, *it is us* [italics added]" (Carman, 2008, p. 95). Sociologist Arthur Frank (2002) summed it up well; reflecting on his experience of two serious illnesses, a heart attack and cancer, he wrote: "What happens to my body happens to my life" (p. 13). Thinking about the body as the nexus of lived meanings may contribute to a deeper appreciation of the way occupations are experienced *through* the body.

In the study of human occupation, phenomenological perspective attentive to the body can reveal rich insights. For example, Kielhofner (1995) wrote a paper in which he drew on phenomenological perspectives to examine the centrality of the body in occupational engagement. His phenomenological insights revealed five dimensions of the body in relation to occupation —as living, intelligent, intentional, adaptive, and experienced. In describing the intelligence of the body during the occupation of typing, he wrote:

> These same hands have learned where to reach for the word ‘occupation’ on the keyboard of my computer; they know it as a neat and compact set of movements organized in time and they spell out the word without directive…indeed, we are so reliant on our body’s ready knowledge of how to go about our daily routines that when we find the body disrupted by injury or disability we are at a loss for what to do. (p. 156)

Through examples focused primarily on hands, his phenomenological reflections revealed how the body is implicated in everyday occupations. The study raised important implications for considering the body in therapy - calling for care that attends not only to the client’s anatomical and functional body, but also to subjective bodily experiences. Kielhofner observed that, “our bodies link [us] to this physical world in a ceaseless communion that sustains life” (p. 164).

Merleau-Ponty (1945/2006) has suggested that the body is a knowing body, often adjusting and accommodating to the world without conscious thought or effort (i.e. shifting in our seats when uncomfortable) (Carman, 2008). In the occupation of mining, a study by Somerville (2006) offers a rich description of the ‘knowing body’ and reveals the ‘body’s skillful intelligence:’

> Miners initially learned safety from experienced workers in the mine, but over time they learnt from their own experience. They described the most important aspect of their embodied learning of safety as ‘pit sense,’ learned by the experiencing body in interaction with the physical and social environments of the mining work/place. In pit sense all the senses are employed in a complex interconnected way to provide information about whether the body-in-place is safe. This includes sound, smell, touch, and kinesthetic sense as well as other senses that have no name such as a sense of the heaviness of the air, the particular feeling of the air on the hairs of the legs or the backs of the ears, as well as an uncanny sense of just being uncomfortable. (p. 43)

Research that is attentive to the lived body can reveal understandings about the way people engage in everyday occupation in embodied ways. While the primacy of the body is often revealed in times of transition, illness and crisis (Kielhofner, Tham, Baz, & Hutson, 2008; Leder, 1990), this example points to the centrality of the body in the experience of everyday occupations. Phenomenological investigations that attend to the lived body may help occupational scientists gain deeper insights into the complexity and nature of human occupation.

First Critique

A number of scholars (Crotty, 1996, 1998; Doyle, 2001b) have recently argued that the critical features of the phenomenological tradition have been lost in newer streams of phenomenology. They have suggested that the critical origins of the tradition have not been adequately attended to in current conceptualizations, interpretations and applications. For instance, Doyle (2001b) has suggested that “phenomenology has always positioned itself as the philosophy on the edge, the philosophy which will name the ‘as yet unnameable’ or the ‘unthought’” (p. xvi). And Crotty (1998) has pointed out that phenomenology is concerned with a ‘first critique’ of preconceived interpretations of meanings and is suspicious of the meanings bequeathed by culture.

Phenomenology has the potential to offer a critique of normative perspectives, of master narratives, or of dominant discourses. For example, Greatrex-White (2007) conducted a phenomenological study asking the question ‘How is study abroad manifest in the experience of nursing students?’ She examined the unstructured diaries of 26 nursing students studying abroad. One finding was that the students’ experience of ‘Leaving Behind’ was not consistent with a prevalent theory (Oberg, 1960) that predicted cross-cultural adaptation in the form of a U-curve of elation-depression-elation. The experiences depicted in the students’ diaries were, instead, extremely diverse. Greatrex-White (2007) points out that this is an important finding because “it confronts those who would believe students who study abroad are a homogenous group and that study abroad follows a precise, predictable pattern that can then be planned for, managed, measured and researched” (p. 139). Through in depth study of the first hand accounts of students, dominant ideas and normative theories about cross-cultural adaptation in international fieldwork were questioned and challenged.

In her call for attention to the political possibilities of phenomenological investigation, Doyle (2001b) points out that phenomenologies often assume “critical orientations toward master narratives and use phenomenological approaches to destabilize those narratives” (p. xiv). A recent phenomenological study of ethical tensions experienced by occupational therapy students illuminates this point (Kinsella, Park, Appiagyei, Chang & Chow, 2008). The first hand accounts of students revealed systemic issues in the practice of occupational therapy that created ethical issues in students’ practice. While the dominant narratives of ethics frequently focus on individually oriented ethical tensions, the narratives of students revealed broader systemic issues that were implicated in their capacities to act in ways they deemed ‘ethical’. The study found that systemic issues such as systemic constraints, value conflicts, questionable behaviours by others, and power relations that invoked fear were revealed through the individual narratives of participants. This contributed to the critical insight that: while practitioners are "individually accountable for their practices, many ethical tensions appear to be of an *extra-individual* nature (Kemmis, 2005), generated by factors not readily within the control of the therapist; features such as social, cultural, material-economic, and political and policy dimensions can shape ethical tensions in practice" (Kinsella et al., 2008, p. 180). This reveals the critical potential of phenomenology, in the sense that critical insights of a systemic nature can be discerned through attention to the ways in which social phenomena live through each of us and are revealed in everyday experience (Brookfield, 2000; Kinsella et al., 2008).

In addition, phenomenological researchers engage in radical reflection to question taken for granted interpretations of phenomena. According to Doyle (2001b), phenomenologists attempt to bracket assumptions about a phenomenon as a means to critically reflect on culturally ascribed assumptions embedded in everyday ways of knowing. Merleau-Ponty (1945/2006) described phenomenological reduction as taking a step "back to watch the forms of transcendence fly up like sparks from a fire; it slackens the intentional threads which attach us to the world and thus brings them to our notice" (p. xv). In other words, phenomenologists do not simply examine the phenomenon at hand. They also examine the ‘intentional threads’ (the taken for granted understandings that are typically accepted as unproblematic) that people, including researchers, inscribe upon the phenomenon. Merleau-Ponty (1945/2006) wrote:

> I posit the stuff of knowledge when, breaking away from the primary faith inspired by perception, I adopt a critical attitude towards it and ask 'what I am really seeing'. The task of a radical reflection, the kind that aims at self-comprehension, consists, paradoxically enough, in recovering the unreflective experience of the world. (p. 280)

In returning to the question of 'what I am seeing,' Merleau-Ponty redirected attention away from culturally ascribed assumptions about the phenomenon to the phenomenon itself, and how it manifests in one's day-to-day experiences. Phenomenology does not take widely understood cultural interpretations at face value; rather it treats culture with a good measure of caution and suspicion (Crotty, 1998). It recognizes that culture has the potential to both enable and limit lived possibilities. In short, phenomenology involves "reflection with a vengeance; it is a wholesale reflection. Nothing is left out" (Sokolowski, 2000, p. 189).

In summary, the critical dimension of the phenomenological perspectives reveals that engaging with first hand accounts can reveal critical insights about cultural assumptions, master narratives, and dominant discourses, in a way that highlights important social issues and questions taken for granted interpretations. In addition, the phenomenological approach invites critical reflexive interrogation by researchers of their own situatedness in the research process, and the assumptions (individual and cultural) that inform their interpretations. It would be useful for occupational science scholars to reconsider the critical potentiality of phenomenological inquiry.

Conclusion

Kinsella and Whiteford (2009) have argued that those who study human occupation and uncritically adopt dominant approaches to knowledge generation may not recognize the validity and importance of other methodologies for generating knowledge. It is suggested that pluralistic approaches to understanding what counts as knowledge in occupational science is required (Kinsella, in press), and that there is a need to recognize lifeworld perspectives as contributing to legitimate forms of knowledge.

Phenomenology, offers a unique perspective for the study of human occupation in occupational science. A phenomenological perspective: (a) offers a unique vision of what knowledge generation entails; (b) reveals human intentionality and the lifeworld perspectives as significant; (c) views *Being* as of central concern; (d) attends to the lived body as a means of experiencing and knowing the world; and (e) brings the potential for critique of taken for granted interpretations of meaning to the study of human occupation. It is suggested that these five dimensions are not distinct but are interwoven and overlap. This paper offers insights into phenomenology and reveals that there are important theoretical assumptions about knowledge that phenomenological perspectives offer to the study of human occupation.

This paper reveals that phenomenology may be seen as much more than a broad aim to capture the meaning of phenomena through first hand accounts; it involves a refined and attentive perspective that can inform current understandings of occupation. Such a perspective attends to: occupational engagement as situated in the world of human perception, considerations of occupation beyond physical engagement to include the dimension of *being*, a reorientation towards the primacy of the body as a medium through which humans are occupationally engaged, and the ways in which first hand accounts of occupation may reveal significant insights of a critical nature about social, cultural and political issues. As Hasselkus (2006) has suggested, everyday human occupation is too often “seen but unnoticed” (p. 628). Phenomenology offers a rigorous methodology, capable of ‘noticing’ and of generating unique contributions and significant insights to the study of human occupation.

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CHAPTER SIX: INTEGRATED MANUSCRIPT THREE

A PHENOMENOLOGICAL INQUIRY INTO THE EMBODIED NATURE OF OCCUPATION AT END-OF-LIFE

Introduction

While occupational therapists propose that occupation is essential to human life across the lifespan, less than one percent of therapists work in palliative care and hospice settings in Canada (Canadian Institute for Health Information, 2008). This raises the question of whether occupation is receiving appropriate attention in the last stages of life, and whether occupational therapy services are being adequately utilized in such settings.

The findings of a literature review investigating occupation and occupational therapy at end-of-life (see manuscript one) revealed two important tensions including: various understandings of what the role of occupational therapy at end-of-life entails, and questions concerning whether occupation can potentially contribute to improved dying experiences. Occupational therapy services at end-of-life identified in the literature include: activities of daily living, energy conservation and relaxation techniques, positioning, seating and mobility needs, increasing comfort, evaluating and prescribing adaptive equipment, providing support and education for the family caregivers, connecting the patient with community services and supports, and conducting home assessments (Bye, 1998; Dawson & Barker, 1995; Egan, 2003; Prochnau, Liu, & Boman, 2003; Trump, 2000). Many of these services convey a rehabilitative versus a holistic

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focus. Occupational therapists working in a U.S. hospice have identified this as a potential reason that services are underutilized (Rahman, 2000). Some scholars question whether rehabilitative approaches are appropriate for terminally ill clients (Bye, 1998; Pizzi & Briggs, 2004). Further, what makes occupational therapy unique in this practice setting is yet to be firmly established, and as such services may overlap with other professions' domains. This ambiguity may make it difficult to convey the significance of occupation at end-of-life, to clients, colleagues and institutional administrators (Frost, 2001; Kealey & McIntyre, 2005).

Second, the Canadian Association of Occupational Therapists ([CAOT], 2010) recently endorsed the mandate of the Quality End-of-Life Care Coalition (2010) that every Canadian is entitled to a quality end-of-life experience. While the literature indicates that a primary goal is to improve quality of life in the end-of-life experience (Egan, 2003; Pizzi & Briggs, 2004; Trump, 2000), it is uncertain how occupation contributes to this goal. There is limited research that examines the role of occupation at end-of-life (Davel Jacques & Hasselkus, 2004; Lyons, Orozovic, Davis & Newman, 2002; Pollard, 2006; Vrkljan & Miller-Polgar, 2001). Nonetheless, a six-month ethnographic study by Davel Jacques and Hasselkus (2004) found that occupation played a significant role in facilitating good dying experiences; in their words "occupation is the good death" (p. 52-3). This is significant in light of findings that terminally ill individuals who are free to voluntarily choose lethal intervention report a decreased ability to participate in activities that make life enjoyable as a major factor influencing the decision to hasten their deaths (Oregon Department of Human Services, 2008).

Lastly, from a methodological standpoint, there is: (a) limited empirical research available on occupation and occupational therapy at end-of-life, (b) limited research from a Canadian perspective, and (c) no studies that investigate how occupation at end-of-life is experienced from the perspective of people who are dying (see manuscript one).

Purpose

The purpose of this study, therefore, is to examine the embodied nature of occupation at end-of-life, from the perspectives of Canadians 60 years of age or older who are diagnosed with a terminal illness. Occupation, in this study, is defined broadly as “all that people need, want, or are obliged to do” (Wilcock, 2006, p. 9) in their everyday lives.

Methods

Methodology

This study adopted a phenomenological approach, which examines everyday phenomena as lived and directly experienced (Heidegger, 1927/2008; Merleau-Ponty, 1945/2006; van Manen, 1997). In addition, specific attention was paid to an embodied phenomenological approach (Merleau-Ponty, 1945/2006), a perspective that recognizes the body as dynamic, complex and skillfully intelligent (Carman, 2008; Leder, 1990). Such a perspective begins with the understanding that human existence is not revealed solely through structures of ‘I think’ but rather through structures of ‘I can’ (Dreyfus & Dreyfus, 1999; Merleau-Ponty 1945/2006). In other words, the way we engage in the world through occupation is intimately implicated with embodied meanings. The phenomenological methodological work of van Manen (1997) guided several aspects of this study, informing both the semi-structured interview guide and the data analysis process.

Participants

Following approval from the university ethics review board, eight participants aged 63-80 with various diagnoses (primarily cancer related) were recruited to the study (see Table 4). The sample size is consistent with the 6-12 participants generally recommended for phenomenological inquiry (Thomas & Pollio, 2002). Participants were purposively recruited through key informants using the following inclusion criteria: age 60 or above, diagnosed with a terminal illness, life expectancy of 18 months or less, living at home, able to communicate in English, and without a medical condition that influences cognitive abilities or communicative skills. Health professionals from a local Hospice, a community homecare organization, and a community palliative care program acted as key informants to introduce the study to their patients, and to convey contact information to the researchers. Seven of the eight participants were living at home, and one was living in a long-term care facility at the time of the study.

Data Collection

Each participant engaged in two to four semi-structured interviews within the span of two weeks. The interview guide was used to guide the interview process, however the flow or direction of each interview was also guided by the emerging dialogue with the participant. The interviews concluded when all of the interview questions had been addressed. The purpose of the subsequent interviews was not to validate the participants' responses, as phenomenological researchers contend that no interpretive exchange can ever be replicated (van Manen, 1997). Instead, authenticity of researcher representations of participants' intended meanings was addressed by paraphrasing and checking in with participants about what was conveyed, and how this was being interpreted, as the interviews evolved. Interviews were held in the participants' place of residence, and audio-recorded and transcribed verbatim.

Two frameworks informed the design of the interview guide. The first draws attention to four occupational dimensions: *doing* (engagement in purposeful activities), *being* (self-reflexive orientation towards oneself and one's existence), *becoming* (situatedness within a continuing life-process), and *belonging* (social interactions and relationships) (Rebeiro, Day, Semeniuk, O'Brien, & Wilson, 2001; Whalley Hammell, 2004; Wilcock, 1998, 2006). The second draws on four existentials that reflect 'felt' or 'lived' experience in the world: *lived time* (e.g. time slowing down when bored), *lived space* (e.g. feeling overwhelmed in a crowd), *lived relations* (e.g. knowing how close to stand while in conversation), and *lived body* (e.g. attending to one's 'gut feeling') (van Manen, 1997).

Data collection also involved close participative observation: ongoing reflexive attention to entering the subject's lifeworld, while maintaining a phenomenological attitude and observational alertness to the situation at hand (Savage, 2000; van Manen, 1997). Insights from participative observation (i.e. artifacts, bodily gestures, emotional responses, and instances in the interview that 'stood out') were recorded through ongoing field notes and reflexive journaling.

Data Analysis

Data analysis involved a hermeneutic interpretation (Gadamer, 1975; Kinsella, 2006) of the interview texts guided by van Manen's (1997) framework for phenomenological analysis. This involved an iterative, reflective and dialectic process between: (a) detailed analysis to identify meaningful words and phrases (words and phrases participants emphasized, repeated, lingered on, etc.), (b) selective analysis to identify thematic patterns (mind-mapping of emergent themes that ‘stood out’ within and across interview transcripts, the researcher’s field notes and journal entries), and (c) holistic analysis to identify overall meanings (3-5 sentence summaries of each participant’s experience of occupation at end-of-life). Three hundred and ninety-five pages of interview text were analyzed for detailed and selective codes, using the research question as a guide. Reflexive dialogue sessions were held between the first and second author, and with an expert in human occupation and an expert in phenomenology. Through an iterative process of dialogue and global analysis, six major global themes were identified, and compiled into approximately 100 pages of thematized data, which serves as the basis for the findings portrayed in this paper.

Emergent Findings

Analysis of the interview data revealed six themes related to the embodied nature of occupation at end-of-life. Participants described orientations toward occupations that involved living with death, reworking everyday life, being guided by the will of the body, focusing on relationships, attending to the small things, and engaging existential orientations.

Living with Death

The theme of living with death was predominant in the findings. Living with the knowledge of impending death frequently informed the nature of occupational engagement at end-of-life. For instance some participants spoke of planning to do what they could before it was too late. For example, Cali took one last trip to see the ballet in

Russia, Julia took time to say her goodbyes, and special arrangements were made for Jim's two sons to be married within days of each other so their father would be present.

Another important occupation related to living with death was making end-of-life arrangements. All of the participants spoke about the ways in which they were occupied with preparations, such as planning the funeral: "We've talked already about my funeral with them. Sort of some of the things I'd like to see happen…[My son] is going to sing *my* favorite hymn...expressing how I feel" (PJ). Occupations surrounding planning for end-of-life frequently considered those who would be left behind. For example, PJ took time to teach his wife Gina to do the things he had always done, such as setting up a mousetrap and doing the taxes. Both Julia and David made sure their spouses' names were included on legal documents, and Maggie began clearing out belongings so her daughters would not be responsible for "getting rid of the junk."

All eight participants spoke of plans to pass on personal belongings, including those with deep sentimental value:

> We've got four gold coins that are special to me. They were given to me by my grandmother just before she died…I'm giving them to my grandson and I've written up ...the story behind it, so that he'll have it, and not just the four coins, but the meaning also, why they were special to me. (Jim)

In terms of living with death, a number of participants talked about the importance of certain occupations as a means to distract from thinking about end-of-life. In David's words, "Sometimes I just go out for a walk…it helps in two ways. Gets my lungs freer, [chuckles] and it lets you concentrate, or get your thoughts going in a different direction. So the other stuff fades into the background." A few participants indicated that dwelling on what one could no longer do led to feelings of depression, and even wishing for death:

> I wish I was dead [on some days]. Because I'm so tired, this is bad. You can't do this, you can't do that, you can't do nothing, you can't even go out and, and sit! No matter what you do, you're not comfortable, you cannot [even] set your pillow right. (Mary)

In summary, many end-of-life occupations confronted the reality of death and involved engaging in end-of-life preparations, such as planning funerals, passing on knowledge to loved ones, and deciding about the distribution of personal items. In addition, some occupations were seen as useful in keeping participants' minds from dwelling on their illness and impending death.

Reworking Everyday Life

For all eight participants, occupation at end-of-life frequently required a reworking of everyday life. Participants described the ways in which occupational engagement was often reworked in light of their illnesses. Julia described her changing orientation toward going to the doctor:

> I never used to think about going to my doctor before…I used to go once a year...I put it on the calendar and I would go. I never thought about it in between, and I never *cared* about it in between, and that was it. All of a sudden, your whole life...everything about your life is in the boundaries of doctors' appointments and medical procedures and medical stuff. And it just becomes a completely, completely different life.

Many participants described reworking everyday occupations. Sometimes even small and taken for granted occupations needed to be reworked in light of the challenges to accomplish them. For PJ, simply breathing and chewing were described as work at end-of-life. For Jim, the occupation of eating with others was suddenly experienced as frustrating and a hard thing to do:

> Everybody sitting around the table having a great time, you're sitting there watching everybody eat...It's hard to explain until you're in that situation because there's so much enjoyment in eating. I'm not just saying breakfast, I'm talking the Sunday dinner, everybody's home, everybody's sittin' around. How much time there's really spent eating, *quality* time. And then you can't participate, that is very, very frustrating, and that was really a hard thing for me.

Another way in which all of the participants spoke of reworking everyday life was through the adjustment to being at home more. The home was depicted by a number of participants as comforting. However, being at home was also experienced as restrictive:

> You become a prisoner of your own home. You can't go anywhere. For instance, my family went out west this year, my son is working there…And my daughter and her family and my wife and I, we wanted to go. But I couldn't go because I'm depending on all these needles. So they went, I didn't…And I cried when they left. (Jim)

In summary, for participants in this study, occupation at end-of-life frequently involved reworking everyday life in light of changes to the body. Participants spoke of how they worked to manage everyday occupations in light of their illnesses and in response to increased time in the home environment.

Guided by the Will of the Body

All eight participants spoke about the ways in which their everyday occupations were, to borrow Arthur Frank's (2002) phrase, guided by 'the will of the body.' Participants were attentive to how the changing body fostered new insights and experiences. Julia poignantly noted how we rarely pay attention to the body until it 'fails' us:

> It's funny, I don't think we pay attention to our bodies…They're just *there* and they do what you want to do, I never gave it a lot of thought…Most of the time, you tell your body to go and it goes and that kind of thing. There are times when...I think my body's failed me. Like …it's just not done its job or is not doing its job…My body is very different now than it used to be…It's certainly not the body that I was used to.

At one point, Cali became attentive toward her feet when she experienced them as not being her own:

> For a while, I didn't have any feet, they were somebody else's feet…I was in hospital and the occupational and the physiotherapy people were getting me up, I said, 'I don't know whose feet I've got, but they don't work worth a darn'…It's a funny, funny feeling…the first time the girl was giving me my shower and my feet were ticklish, I was so pleased 'cuz that meant the feeling was coming back. Now, normally, you don't even think about that, eh?

All eight participants indicated that they were more attentive to their bodies. They spoke of taking care not to push their bodies, and of listening to the body when it came to what they were able to do:

> My mind tells me that there's things I should be doing, but my body says, 'I don't feel like that today'...Your mind can tell you a lot of things and then your body says, 'Uh uh, don't think so.' (Cali)

In fact, participants spoke about the ways they modified their day-to-day occupations in response to their changing bodies. This could be seen through planning outings around where restrooms were located, microwaving refrigerated food to appease sensitive taste buds, and being careful not to lift grandchildren due to fear of injury. Jim stated that his changing body rendered feelings of "depression" and fear, to the point where he chose to turn off the lights when showering:

> Well, I was afraid to look at my own body. I would…cry when I saw my own body. We've all seen pictures of war, people all…skinny, bones sticking out. And that really…hit me, reminded me you know, like, those people didn't make it, *I* am not going to make it. So I just decided to overcome that fear, just turn off the lights [when I showered] so I wouldn't have to…see it.

In summary, for participants in this study, end-of-life occupations were frequently 'guided by the will of the body.' A number of participants indicated that more attention is paid to the body when it 'fails' to do what it has always done, and for one participant, when the body is experienced as somebody else's body. Many participants modified day-to-day activities to accommodate the changing body, and attended to emotions that the changing body elicited, such as fear and depression.

Focused on Relationships

Many participants spoke of the importance of relationships at end-of-life, and the occupation of being with family members and friends. Being with others was often depicted as the best part of the day.

> We [my wife and I] love sitting down for about an hour at night, and we just…either read the bible, watch TV or just…enjoy each other, just holding, have a few kisses here and there. That is special...She's been *amazing*. I'm surprised she's still with me. She is really *amazing*…I love her, I have a *lot* of respect for her and without her….life wouldn't be worth it. Honestly, it is something, it's *so* special. (Jim)

The occupation of spending time with family was frequently discussed. For instance, Jim talked about how spending time with his grandchildren helped him get through difficult times: "My grandchildren have pulled me out of the doldrums so many times…they were there when I needed them…they were there when I was really down." Julia spoke of how her husband's dedication during her illness deepened their relationship:

> Knowing he is there to support me and that everything you stood up for when you got married and they said, 'In sickness and in health' and all the rest wasn't just a pile of words…So I would say in that way, we're closer together...we're a team.

Being with others also involved people participants met along their illness journeys; for some participants, health professionals and fellow patients became significant people to spend time with:

> It's always nice to have company, you know, that kind of stands out…One thing that does kind of please me…a lot of the girls [who work in the facility] if they have a minute, they like to come in and chat with me. (Cali)

Another relational occupation that was frequently highlighted as important was spending time with God:

> At church, we stand up and we lift our hands [lifts both hands in an open position] and we praise God and then we worship him and it's a joyful thing…It's like when you're praying, you're communing. Your spirit is communing with God...it is a relationship. (Maggie)

A number of participants spoke of how the occupation of spending time with friends sometimes became challenging at end-of-life as some friends 'disappeared.' Participants observed that some friends were unable to handle the illness, and did not know what to say. Cali highlighted how friends predeceasing her was a challenge, making it a "lonely, lonely world."

Participants spoke of relationships at end-of-life as 'being with' others, but also as 'being there for others' by making positive contributions:

> You gotta find ways...so that you feel useful somehow. And I think it's up to each person with a life threatening illness, and I think most people do, find things, something that makes them feel useful, that they can still contribute…that's important. (Maggie)

In summary, occupation at end-of-life was frequently focused on participants' relationships with family, friends, health care practitioners, volunteers, other patients diagnosed with life-threatening illnesses, and God. Participants indicated that "being with others" and "being there for others" were important occupations at end-of-life.

Attentive to the Small Things

All of the participants appeared to engage in occupations at end-of-life that were attentive to or appreciative of 'the small things' in life. Many of the participants noticed, for example, the beauty in nature:

> I like to go on a walk through the bush….which is *wonderful*. I find that peaceful and especially now...I was looking at them the other day and they're so pretty. The thistles are *gorgeous*, they're purple, and they're beautiful…A couple of days ago, I went walking through there and I thought, 'Isn't it amazing, God even makes weeds look beautiful.' (Maggie)

Many participants described finding pleasure from the small things in their daily occupations:

> There are still a lot of things that give me pleasure…I do enjoy a good book. I enjoy going out…Even a phone call from a friend or someone I haven't spoken to in a while or whatever, like just having a conversation is enjoyable…My life isn't a series of negatives, uh, *yet*! [laughter] maybe, hopefully not ever. (Julia)

Sarah indicated her gratitude for the small things that others might take for granted:

> Every day is a treasure. Even though you say, 'Oh I'm so tired'. I'm glad I got up this morning, I'm glad I had a nice sleep, I'm *glad* I've got a beautiful bed to sleep in, and I'm *glad* that I've got these warm covers. I'm grateful for *everything*. (Sarah)

In summary, for all of the participants their appreciation and gratitude for seemingly mundane occupations appeared to be enhanced at end-of-life. Participants were appreciative of and attentive to what might be considered the 'small things' with respect to their everyday occupations.

Existential Orientation

Lastly, all of the participants described engaging in existential reflection at end-of-life; participants spoke about matters concerning the meaning of life and death. Some participants indicated that they were not ready to die:

> I don't want to die, just yet. I mean... I've got things I can *do*. I enjoy life. And I'd like to be here as long as I can. Because I'm in eternity for...forever [laughter]. So I've got long enough to spend there, I would like to have longer. (Maggie)

All eight participants engaged in the occupation of reminiscing about their lives. Sometimes this took the form of reminiscing about good times:

> That picture hanging on the wall, I bought it at our first girls' getaway…We drove, we went there, we had a *fantastic* time…we just laughed ourselves silly…I bought that picture at an auction...When we packed to go home, we set up the trunk, it was like doing a jig-saw puzzle to get everything in. So that picture reminds me of that trip, we had such a good time. (Julia)

Other times, reminiscence took the form of remembering things that might have been different in one's life:

> I wanted to be a pharmacist, that was what I *always* wanted to be and at that time, because there were so many fellas that had come back from the war, and they were getting more education, all those schools were full of men, so I would've had to wait. My doctor and my pharmacist at the time convinced me that that wasn't what I should do. You know, there again, the girls don't count. And so I took secretarial and went to work. (Cali)

Participants also engaged in existential reflection of a more spiritual nature. Some participants shared their confidence in an afterlife stating things like "heaven awaits" (PJ) or words of faith such as "If he wants me, he'll take me" (Sarah). Cali expressed some angst with respect to feeling deserted by God: "[I pray] usually before I go to bed...sometimes you think, 'Hmm, why has he deserted me?' [begins to cry] but…I don't think he has…So, that's about it, I think." Others questioned the religious turn at end-of-life. For instance Julia remarked:

> And I know that some people, as they get older and as they get sick, will start going to church, to synagogue, or whatever on a regular basis....sometimes I think it's a cop-out, because where were you the rest of the time, you know? Just because now the end is coming, all of a sudden, you believe?

In summary, for participants in this study, occupation at end-of-life was frequently oriented toward existential reflection. Existential orientations were revealed through the occupations of reflection on the meaning of life and death, reminiscence and life review, and reflection on spiritual matters and the afterlife.

Discussion

The findings of this study indicate that the embodied nature of occupation at end-of-life is a complex phenomenon, and raises questions concerning whether occupational therapists are adequately prepared to offer services that attend to the nuances of occupation at end-of-life.

The end-of-life context is unique; awareness of death as impending illuminates the absence of lived possibilities, the notion that death is “a present future, or an eternal present” (Merleau-Ponty, 1945/2006, p. 388). Time as limited informs a practice context that calls occupational therapists to address what clients identify as important and meaningful. The impact of time when perceived as limited (Carstensen, Isaacowitz, & Charles, 1999) suggests that a person’s social goals, preferences and behaviors can change as a result. Carstensen et al.’s work, consistent with the findings of this research, suggests that people tend to prioritize goals from which they derive emotional meanings when time is limited. Further research, some which might draw from the theoretical groundwork of other disciplines, is encouraged to better understand occupational engagement in end-of-life and time-limited contexts.

The literature reveals a paradox in providing rehabilitative interventions in end-of-life settings, which points to the potential need to expand traditional occupational therapy practices. This might involve attending to the importance of supportive aspects of care, through active listening, open conversation, presence, and by simply being-there with the client (Hasselkus, 1993; Rahman, 2000; Thibeault, 1997). It has been suggested that occupational therapists often engage in an ‘underground practice’ where practices that attend to the ‘real-life’ suffering patients experience are not documented as practice is often framed within a biomedical discourse (Fleming & Mattingly, 1994). In end-of-life care, the importance of supportive aspects of care may be amplified and might lend a useful channel through which therapists can offer more holistic attention to the dying experience. In regard to the emergent findings, practitioners might focus therapeutic intervention to a greater extent on how clients may: (a) ‘live with death’ in their final days; (b) rework their everyday lives in light of fatigue and bodily changes; (c) need to be guided by the will of the body; (d) prioritize relationships as a source of meaning as end-of-life approaches; (e) find significance in the ‘small things’ and (f) attend to existential dimensions of life, in whatever form that might take. Questions that therapists might utilize to better understand the occupational dimensions of a client’s end-of-life experience could include: a) Are there things you would like to do to help prepare for the upcoming days/weeks/months?; b) Thinking about your typical day before and after your illness, what parts of your everyday life have required the most change or accommodation?; c) You may be noticing a lot of changes in your body-how are you managing these changes?; d) Who have you been spending time with and what sorts of things do you do together?; e) Have you noticed any parts of the day that stand out to you as meaningful or enjoyable?; and f) How are you feeling within yourself? These kinds of questions may help identify everyday sources of meaning that might typically be overlooked. Such information can guide occupational therapy intervention, and help therapists identify ways that occupation can contribute to improved dying experiences.

There are several strengths of the study. First, the authors were able to engage deeply with the phenomenological literature and work with phenomenological scholars, which strengthened the methodological grounding. Second, all eight participants freely shared very rich descriptions of their experiences of occupation at end-of-life. In addition, each expressed appreciation for their involvement in the study; this suggests that research with people at end-of-life may not simply provide a voice for people who are dying, but can also be a meaningful occupation at end-of-life.

In terms of study limitations, a concern frequently raised as a limitation to phenomenological studies is the generalizability of the findings. However, phenomenological approaches do not claim or seek to reveal absolute truths that can be transferred into identical settings. Rather, the rigor of phenomenological research is measured by the degree to which the findings reveal lived experiences that readers can identify as familiar and possible as their own (van Manen, 1997). Such research is measured by the extent to which the question “What do I now know or see that I did not expect or understand before I began reading the text?” (Benner, 1994, p. 101) is appeased and fosters a deeper understanding of the phenomenon at hand.

Conclusion

The limited research examining the role of occupation at end-of-life, and the limited number of occupational therapists working in this practice setting suggests that there is more that the profession can offer people who are dying. Further research is required that examines how occupation contributes to improving end-of-life experiences, and avenues for delivering care that are attentive to dimensions of the lived experience that may be overlooked. Such research would support the CAOT’s (2010) mandate to support quality end-of-life experiences. While people with terminal illnesses may not be cured, there is potential to facilitate quality end-of-life experiences, and promise that occupational engagement can contribute to this goal.

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Table 4: Participant Demographics

Name *Pseudonym	Age	Diagnosis	Place of Residence
Maggie	73	Ovarian cancer	Home
Sarah	69	Non-Hodgkins Lymphoma	Home
Mary	79	Breast cancer	Home
Jim	63	Esophageal cancer	Home
Cali	78	Breast cancer, bone cancer	Long-term care facility
David	65	Bowel cancer	Home
Julia	65	Papillary Serous Carcinoma of the Endometrium	Home
PJ	80	Undiagnosed, doctors suspect extensive arthritis and lung disease restrict his breathing capacity	Home

CHAPTER SEVEN: INTEGRATED MANUSCRIPT FOUR

EMBODIMENT IN RESEARCH PRACTICES: THE BODY IN QUALITATIVE RESEARCH

Introduction

The purpose of this chapter is to inquire into how attention to embodiment can enhance qualitative research practices. The chapter begins with an overview of the notion of embodiment from a phenomenological perspective. This is followed by an examination of three dimensions of embodiment - the body as a path to access the world, the body's skilled intelligence, and the body's intercorporeality - and a consideration of the implications for research practices. The chapter draws on examples from the literature, and from Anna's doctoral research, 'the End-of-Life study' (Park Lala & Kinsella, in press), a phenomenological study that investigates the meaning of what people do (occupations) at end-of-life. The chapter concludes by proposing that attention to embodiment in research practices encourages new perspectives that illuminate the role of the body as a medium for lived meanings, and through which we may begin to better understand the phenomenon at hand.

Embodiment in Research Practices

The notion of embodiment has largely been neglected in scholarly investigations until recently (Johnson, 1999). Embodiment draws attention to the body as a means of "perceptual experience and mode of presence and engagement in the world" (Csordas, 1994, p. 12). Ellingson (2006) has argued that the absence of the body as a means of

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perceiving the world in qualitative social science research "obscures the complexities of knowledge production and yields deceptively tidy accounts of research" (p. 299). Similarly, Benner (2000) points out that neglecting our bodies as vehicles for lived and worldly meanings results in research that is "silent" about human experience. In the last decade, attention to embodiment has received increased attention in philosophy (Campbell, Meynell, & Sherwin, 2009), science (Gallagher, 2005) and social science (Johnson, 1999). Research that focuses on embodiment has also garnered growing attention in qualitative research practice; indeed, some scholars have suggested the need to re-embody qualitative inquiry (Sandelowski, 2002; Sharma, Reimer-Kirkham, & Cochrane, 2009).

An Embodied Phenomenological Perspective

Phenomenology is the art and science of examining phenomena from the perspective of people's firsthand accounts (van Manen, 1997). Taking a phenomenological perspective involves setting aside culturally ascribed assumptions and examining phenomena as lived and directly experienced (Heidegger, 1927/2008; Husserl, 1907/1990). In the phenomenological tradition, the lived body is considered a fundamental and grounding dimension of human existence, what some phenomenologists refer to as a 'lived existential' (other existentials include lived time, lived space and lived relations) (van Manen, 1997). French philosopher and phenomenologist Merleau-Ponty (1945/2006) has been particularly influential in illuminating the primacy of the body in human perception. Merleau-Ponty contends that day-to-day experiences cannot be fully encompassed through a conception of human beings as 'thinking things.' Rather he argues that the body is the absolute source; we do not have bodies, we are our bodies.

From this perspective, human beings are not spectators, but are rather involved, interwoven, and living in the world as embodied beings. In other words, the lived body is viewed as a means through which the world and our lived experiences come to be (Carman, 2008).

The Lived Body as a Path of Access to the World

An embodied perspective begins with the assumption that our bodies are mediums through which we experience the world. Leder (1990) describes the lived body as "first and foremost not a located thing but a path of access, a being-in-the-world" (p. 21). Rather than conceiving of the body as a static and lifeless entity, this perspective recognizes the body as always present in a state of bodily being-in-the-world, as a means of perception itself (Merleau-Ponty, 1945/2006).

Viewing the body as a path of access to the world, as a mode of being-in-the-world, brings new conceptual lenses to research practices. Such a perspective challenges the assumptions of a separate body ruled by the mind (inherent in Descartes' (1641/1996) famous dictum, 'I think therefore I am'). Some argue that Cartesian perspectives view the body as a passive, machine-like appendage, directed by consciousness and the mind (Ryle, 1949), rather than an entity richly implicated in perception itself (Merleau-Ponty, 1945/2006). Merleau-Ponty (1945/2006) points out that our active engagement in the world, our performance as opposed to only our thoughts, is what brings existence to light:

> Hence it is not because I think I am that I am certain of my existence: on the contrary the certainty I enjoy concerning my thoughts stems from their genuine existence. My love, hatred and will are not certain as mere thoughts about living, hating and willing: on the contrary the whole certainty of these thoughts is owed to that of the acts of love, hatred or will of which I am quite sure because I *perform* them. (p. 445)

Our bodies, in this view, are not structures of ‘I think’ but rather structures of ‘I can’ (Merleau-Ponty 1945/2006). The lived body as a path of access to inquiries about the world can readily be overlooked because the everyday body is typically recessive and invisible (Leder, 1990). Attention to embodiment reveals that while the primacy of the body is evident upon examination, its presence in day-to-day life is frequently concealed. Van Manen (1998) describes the body’s mode of being as “near self-forgetfulness” (p. 11); we tend not to notice our bodies in our everyday affairs, such as when we drive, wash the dishes, or go for a run. In fact, he says, a healthy body “thrives on the smoothness of forgetfulness” (p. 13).

In the End-of-Life study, an embodied perspective was brought to the design of research questions, and to the research lens. This contributed to data being collected that otherwise would probably not have come to light. For example, one participant in the research, PJ, describes an awareness of his body’s centrality to his existence through a coughing episode that could potentially end his life:

> You’re focused very, very much on that [life-threatening coughing] happening and your whole body is a part of it. And I know the end result will be that somehow I’ll collapse and I’ll be gone. And I trust I’ll be gone with the Lord. ‘Cuz Paul said, ‘To be absent from the body is to be present with the Lord’ … And yet there’s a real desperation, a quiet desperation to do what you have to do to get things going again … And then it comes back slowly, the breathing possibility. It’s something, when you’re plugged here in the earth.

PJ’s words speak of a world that appears to be unknowable and unliveable without the body; it is through the body that we are ‘plugged in to the earth,’ to be separate from the body is to be gone from the world. The body and its capacities render lived possibilities and attention to the body reveals the impossibility of conceiving of existence without a bodily channel. In addition, these findings highlight how the lived body as a path of access to perception of the world may become increasingly visible when the smoothness of our bodily access to the world is disrupted.

This example demonstrates how attending to embodiment in our research designs can illuminate embodied dimensions in the participants' responses, and offer a more in-depth perspective on their lived experiences. In the End-of-Life study, the significance of the body as a path of access to the world appeared to be amplified when taken for granted bodily access to the world was challenged, suggesting that the body's role in perception (as distinct from simply the mind) is often revealed in times when its path of access to the world is disrupted.

One important implication regarding the body as a path of access to perception in research is the situation where participants express feelings of separation from the body. According to Leder (1990), becoming conscious of the body and, at times, feeling disembodied is an important dimension of embodiment. He points out that even the mind as a 'thinking thing' that is associated with the brain is not how consciousness is actually experienced. Instead, we do not feel or see our consciousness originating or emanating from our brains, rather "human mentality can … seem immaterial, disembodied … this disappearance arises precisely from the embodied nature of mind. The body's own structure leads to its self-concealment" (p. 115). While there are experiences that may elicit feelings of separation from our bodies, or where we may seek to dissociate from our bodies, we are fundamentally embodied beings (Leder, 1990). Taking seriously the notion that the body is a path of access to the world, a mode of perception, may contribute to increasingly rich understandings of human perception, and can have important implications for research design and practice.

Bodily Intelligence

Attending to embodiment in the research process also draws attention to the body's skilled intelligence in the world. According to phenomenologist Merleau-Ponty (1945/2006) intelligence is not limited solely to the mind but also to the body; he proposed that "perception is a bodily phenomenon, which is to say that we experience our own sensory states not as mere states of mind, but as states of our bodies" (Carman, 2008, p. 80). Three interrelated concepts from Merleau-Ponty contribute to understanding the body's skilled intelligence in the world. Bodily schema refers to the body's skilled intelligence, its dynamic ability to know and engage the world, and to retain and develop skills over time: "my body is the fabric into which all objects are woven, and it is, at least in relation to the perceived world, the general instrument of my 'comprehension'" (Merleau-Ponty, 1945/2006, p. 273). Meilleure prise, translated as maximal or best grip on the world, refers to the body's preference to be in an optimal bodily state; for example, "for each object, as for each picture in an art gallery, there is an optimum distance from which it requires to be seen … we therefore tend towards the maximum of visibility, and seek a better focus as with a microscope" (p. 352). Motor intentionality involves the body tacitly adjusting to maintain a best grip on the world (Merleau-Ponty, 1945/2006); this involves attending to a felt sense of rightness and wrongness through tacit, directed and self-adjusting skill in efforts to find a state of bodily equilibrium (Carman, 2008). These three phenomenological concepts help us to better understand how we live through skilful and knowing bodies without actively thinking about how we do it.

The body's skilful intelligence may be overlooked in research due to the way the body reveals perceptual experience. Our bodily-being-in-the-world provides a unified experience; in other words, “we do not perceive the world in pieces or meaningless sensations but as a whole pregiven, prereflexive world” (Benner, 2000, p. 6). The body tacitly and selectively chooses what perceptual material is important to bring to attention, which allows us to go about our daily affairs without noticing or attending to our bodies. Bodily intelligence may also be overlooked as many bodily skills can be difficult to identify as they are hidden beneath our everyday activities and intentions.

An example of the body’s skilful intelligence is portrayed in the findings of an ethnographic study of miners (Somerville, 2006). The findings describe the body’s skilful intelligence in the context of safety while working in a mine:

> Miners initially learned safety from experienced workers in the mine, but over time they learnt from their own experience. They described the most important aspect of their embodied learning of safety as ‘pit sense,’ learned by the experiencing body in interaction with the physical and social environments of the mining work/place. In pit sense all the senses are employed in a complex interconnected way to provide information about whether the body-in-place is safe. This includes sound, smell, touch, and kinesthetic sense as well as other senses that have no name such as a sense of the heaviness of the air, the particular feeling of the air on the hairs of the legs or the backs of the ears, as well as an uncanny sense of just being uncomfortable. (p. 43)

Here, Somerville’s participants described their bodily intelligence, ways of knowing that were felt and experienced through the body. Using Merleau-Ponty’s concepts, bodily intelligence can be seen through the bodily skills in the workplace that the workers developed over time (bodily schema), how they learned to ‘know’ and attentively engage in ‘safe’ mining practices (meilleure prise), and how they skilfully attended and adjusted to their bodily cues of right and wrongness (motor intentionality). It is interesting to note that many bodily cues do not seem to have a name (i.e. the heaviness of the air).

According to Todres (2007), knowledge, felt in the body, is “the primary source of knowing” (p. 33) that exists before symbolization and language. Todres (2008) proposes attention in research practices to ‘embodied interpretation’ as a means to examine bodily ways of knowing. Embodied interpretation attempts to focus on what words cannot say, and on the junction and meanings that emerge between words and bodily felt sense. For example, the words of a participant can elicit cognitive understandings, but also an embodied, felt response that reveals a ‘lived sense’ of the informant’s account (Todres, 2007).

Researchers’ bodily intelligence - embodied responses that contribute to deeper interpretations of phenomena - may also contribute to research practices. These may not be considered or shared in textual research findings, although such responses may harbour important information about the findings themselves. As Sandelowski (2002) suggests, one concern about qualitative research is that interviews and textual accounts are hailed as the gold standard. What is said by participants is often taken at face value, yet she cautions that “people use interviews strategically to present, account for, and even justify themselves and their actions” (p. 106).

As an example of the significance of the researcher’s embodied intelligence, a situation arose in the End-of-Life study where the account of the participant was incongruent with what the researcher observed and ‘felt’ in an embodied way. One participant shared multiple anecdotes throughout the interview process about engaging in ‘hug therapy’ with many women in his community. He said:

> The nurses, they have a blood pressure clinic every Tuesday. They come up and the lady there she says, ‘You know … I thought you were spoiled before, but now I know it.’ She said, ‘This is the first time, at any clinic that I’ve been at, [where] as the patient comes in the nurses line up to hug him.’

This anecdote led to a ‘face value’ interpretation of his relationship with these health care workers in his community as friendly and mutually shared. Later, the first author was present at a blood pressure clinic when the participant reached out to hug a nurse; she nearly pushed him away, firmly stating ‘No, no.’ Although the nurse explained that due to the flu epidemic scare and the spread of germs, she was unable to hug or shake hands with her patients, this incident was unexpected and elicited surprise on the part of the researcher. Upon reflection, it was not simply the rejected hug, but the lack of warmth in the nurse’s demeanour and the distance she projected towards the participant (which did not reflect the friendly and loving relationships he had described) that elicited an embodied response:

> I perceived something beyond words by being present to my experiencing body within the physical and social research environment, and by attending to the tension between what my body was telling me and the verbal account rendered by the participant. It would be difficult to depict the tension in the room if one simply read an encounter transcript. (Anna’s reflective notes)

While there is little doubt as to the sincerity of the participant and this account, this example reveals how what is being said can never reflect the entirety of a phenomenon; our bodies also act as witness. Attention to the bodily intelligence of participants and of researchers potentially contributes to deeper embodied interpretations of what is occurring in the research context.

Intercorporeality

Another dimension that has relevance to embodiment in research is intercorporeality. Weiss (1998) stated that “to describe embodiment as intercorporeality is to emphasize that the experience of being embodied is never a private affair, but is always already mediated by our continual interactions with other human and nonhuman beings” (p. 5). Our interactions with others, our lived relations, are an important dimension of how we experience our everyday lives (van Manen, 1997). From a phenomenological perspective, intercorporeality highlights the space between individuals, but also the experience of being with the 'Other.' In other words, being with an 'Other' may be seen as an immediate, fully engaging, and unreflected experience (Pollio, Henley, & Thompson, 1997). Csordas (2008) draws on Ricoeur (1991) to show how intercorporeality influences embodied perception: "I understand myself on the basis of thoughts, feelings, and actions deciphered directly in the experience of others" (Csordas, p. 112). In terms of research, intercorporeality can be considered by examining the embodied response in the space between the researcher and the participant.

The way we are with the 'Other' is a bodily affair, which becomes manifest in our everyday, intentional ways of being, such as through the stern look a parent gives a child or an intimate kiss between lovers. Van Manen (1997) states that we form expectations about who people are based on our embodied responses (e.g. a voice on the phone) even before meeting (e.g. the disappointment you feel when the character in a novel-based film is not as you had imagined). The mutuality of our embodied subjectivity does not turn off in a research context (Burns, 2003).

Drawing on examples from the End-of-Life study, intercorporeality is examined from the perspectives of the researcher's body in relation to participants. The impact of inter-subjective, embodied interactions became evident in Anna's reflexive writings. First, the researcher's body in interaction with the bodies of participants can contribute to research processes and accounts:

> Participants often asked about my situation and placed assumptions about the kind of person I was based on, for example, my age (28) and ethnicity (Korean). My age impacted my relationship with my participants (all older than 60 years). Some participants alluded to my age in subtle and implicit ways. For instance, Cali shared an anecdote where she struggled to remember an actress she had seen perform in the 1950s. "You've probably never even heard of her," she pointedly said to me. Cali later

> became emotional about the loss she was experiencing as friends from her generation were predeceasing her…I noticed that her account stirred feelings of inadequacy and sadness in myself. The corporeality of my young age meant that I could never connect with Cali in the way that she longed for. (Anna's reflective notes)

From a research perspective, this same corporeality contributed to the quality and depth of what could be understood about Cali's experience at end-of-life. For instance, the loss of friendships that may occur as friends pre-decease a person and the emotions of sadness and loneliness that can ensue were enhanced by the intercorporeality (the age difference) fostered within this exchange.

Ethnic background can also be part of the intercorporeality of the research process. Anna noticed that her ethnicity could not be silenced in her interviews. In one instance (see below), the researcher's ethnic background led the participant to speak with caution, whereas for another participant, ethnicity was tied to his interpretation of the motivations of the researcher in undertaking research with people at end-of-life. These accounts suggest that the embodied presence of the researcher may influence what stories participants share, and their way of engaging with the researcher. They also reveal how some participants may have pre-conceived notions about who the researcher is in light of his or her corporeal (embodied) presence including characteristics such as ethnic background. Assumptions can be implicitly formed from the researcher's corporeal presence, before words are spoken.

> In one instance, the participant appeared to be concerned not to offend me when she drew on my ethnicity as a starting point for an anecdote. The participant asked me if I was Chinese. I said no, that I was Korean and she said, 'Oh okay, then this story won't offend you.' Then she conveyed a story about her son and his friend, Charles who was Chinese. It wasn't an offensive story so I was kind of surprised. I was expecting something that she might have interpreted as offensive. (Anna's reflective notes)

Intercorporeality can also be considered by examining the embodied response to the presence of the researcher in the participants' homes:

> Something that surprised me was the participants' openness about their involvement in the study. While I had indicated that their involvement in this study would be confidential on my part, several participants openly introduced me to neighbours and health care practitioners who unexpectedly stopped by. For one participant, it appeared that her friends even knew me by name. When I came in for the interview, she [Julia] was on the phone and before she got off, she said, 'I have to go because Anna's here.' So she's obviously told people about being involved in my study enough that she can refer to me in first person. … It became evident to me that I became somebody in her life … I also became an embodied being to people in her life, and I wondered how they pictured me, and how I had been described. (Anna's reflective notes)

Finally, through interactions with participants, researchers can gain a sense of bodily awareness as they become attentive to the changes in personal, embodied responses to different participants:

> I find it interesting thinking about how I am, how I react to her versus [another male participant]. When I'm with him, I find that I have to force myself to laugh a lot and to nod a lot and to joke around a bit because I feel that's what he wants … so I feel like I have to give him that. Whereas with her, you know I just sit and nod and I'm quite quiet … I'm noticing quite a difference between how I am, and that's a bit of a surprise to me … I find myself acting, kind of responding and orienting myself differently given the participant. They all just come from completely different worlds. (Anna's reflective notes)

These reflections highlight the intercorporeal nature of the research process, and offer insights into the difficulties researchers may face when actively trying to adopt the stance of a disembodied, neutral researcher. Further they suggest that perhaps researchers need to reflexively acknowledge the intercorporeality of the research process, and the implications of their embodied presence in the research sites and the relationships they inhabit. There are elements of who the researcher is that cannot be silenced (age, race, gender) and one may question whether it is ever possible to replicate a fixed version of who one is with each participant. Indeed, would the attempt to do so spoil the process of connecting with each participant and gaining rapport? As Burns (2003) contends, researchers are truly participants in the research, an ‘Other’ entering the participants lives and shaping what emerges as the research unfolds. The intercorporeal dimension of embodiment is revealed within the researcher and within the participant, within the space between them, and through the interactions between their lived bodies.

Conclusion

This chapter has proposed three dimensions of embodiment from a phenomenological perspective, and considered the implications for embodied research practices. First, we have argued that an embodied perspective may be seen as recognizing the body as a path of access, a medium through which the world comes to be (Merleau-Ponty, 1945/2006). From such a perspective, our experience of the world cannot be imagined without a body (Leder, 1990). Second, we have highlighted how the body may be seen as entailing a skilful, embodied intelligence that is often overlooked in research practices. Our bodily intelligence contributes to a ‘felt’ knowledge that exists even before symbolization and language (Todres, 2007; van Manen, 1997). Lastly, we have proposed that embodied research recognizes that embodiment does not occur in a vacuum but rather through intercorporeality, that is, our embodied, relational interactions (Csordas, 2008; Weiss, 1998). The intercorporeality of the researcher’s body may elicit pre-formed understandings, assumptions and responses from participants. The researcher’s body may adopt an embodied presence in the research context, and reveal its own embodied responses.

This chapter illustrates that there is more to our bodily way of being than we can often articulate, and that this has important implications for research practices. The body is not a passive, machine-like appendage, but rather the “nexus of lived meanings” (Merleau-Ponty, 1945/2006, p. 175). As Arthur Frank (2002) eloquently states, “what happens to my body happens to my life” (p. 13).

Attention to embodiment in research practices encourages new perspectives that honour findings beyond the text. We are not suggesting that textual accounts are not of merit, but that a large part of lived experience is overlooked when understandings and interpretations are drawn from textual accounts alone. By witnessing our participants’ and our own embodied engagement and responses in research, we may begin to better understand the phenomenon at hand and how our bodies serve as a means of perception itself. When entering a research setting, we and our participants cannot rid or shed what we bring: our bodily-being-in-the-world. In closing, we echo Todres (2008) who suggests that through embodied research practices, we may begin to elicit understandings that ring true in both the ‘head’ and the ‘heart.’

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CHAPTER EIGHT: CONCLUSION

EMERGING INSIGHTS: REFLECTIONS ON THE RESEARCH

Introduction

This work concludes with a consideration of insights and reflections arising from the doctoral research. I begin by discussing eight emerging insights about occupation at end-of-life that arose from the manuscripts in this collection. This is followed by a consideration of methodological insights regarding the use of phenomenology in the study of human occupation and embodied research approaches. Next, the criteria by which the quality of the phenomenological research might be judged are discussed. This is followed by a discussion of ethical, methodological and personal reflections that illuminate how this work has addressed unforeseen challenges and shaped my personal and scholarly growth. In a few instances, I draw on quotations from participants that may not have been included in the manuscripts due to word count restrictions.

Occupation and End-of-Life: Emerging Insights

In this section I discuss eight new insights that emerged from the research process. I draw on the literature, the data, reflections on what participants said, and discussions with health care practitioners and scholars who informed my interpretive understandings along the way. These eight areas represent ‘food for thought’ or starting points for discussion in thinking about occupation at end-of-life, and include: living well while dying, identifying occupations at end-of-life, lived engagement in occupation as a potential fifth existential, rehabilitation and re-inhabitation, existential considerations in regard to spirituality and being, relational care, embodied understandings, and ‘the promise in things.’ Although these eight emerging insights have been teased apart for the purposes of discussion, in actuality there is considerable overlap and intermingling between the topics addressed. At times comments or examples have been placed in one section when they might also have relevance to another.

Living Well While Dying

Manuscripts one and three suggest that broader notions of ‘living well while dying’ might involve a consideration of the role of occupation. As revealed in chapter two, what constitutes ‘quality’ at end-of-life is perceived in variable ways among terminally ill individuals. Further, Walter’s (1994) three types of death (pre-modern, modern and post-modern) indicate that what constitutes a good death can change over time. He suggests that the post-modern view of the good death is attentive to the wishes of the person who is dying, and involves facilitating a sense of autonomy and control.

While the Quality-End-of-Life Care Coalition (QELCC) (2010) and the Canadian Association of Occupational Therapists (CAOT) (2010) propose that “all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice” (Quality End-of-Life Care Coalition [QELCC], 2010, ¶ 2), these four components are ambiguous. The ambiguity surrounding what constitutes quality end-of-life experiences points to a need for further research on this topic, although Walters’ (2004) notion of dying with panache – “dying in one’s own way, in one’s own style” (p. 408) is a reminder that what quality entails at end-of-life is up to the individual and the caregivers involved.

The question of how to facilitate quality dying experiences is especially pressing given the current Canadian end-of-life milieu. With a rapidly aging older demographic, the shift from institution to home-based palliative care, and the growing end-of-life care needs within a context constrained by limited financial support from the government (Canadian Hospice Palliative Care Association [CHPCA], 2010; QELCC, 2007; Statistics Canada, 2010), the need to consider opportunities to facilitate quality end-of-life experiences is particularly pressing.

The findings of this study suggest that there is potential that occupational engagement is a medium that may contribute to living well while dying, in both direct and indirect ways. First, all eight participants explicitly described being engaged in occupations that facilitated quality moments in their end-of-life experiences. Some of these occupations included: reading a good book, a phone call from a friend, watching a television show, gardening, appreciating nature, reminiscing over good memories, playing with one's pet, volunteering, and for some, engaging in spiritual occupations (praying, reading scripture, attending church and bible study, and listening to worship music). Quality moments also frequently involved relational experiences, such as spending time with loved ones, friends, health care professionals, and with God. These examples illustrate that quality moments in the end-of-life experience through occupation are lived, although potentially sporadic, possibilities. Second, occupations were also seen to contribute to quality experiences in indirect ways. For example, freedom from pain is frequently cited as contributing to quality end-of-life experiences. While occupations might not directly influence the level of access and degree of effectiveness of pain medications, participants in this study often chose to engage in occupations that helped to distract them from their emotional suffering, deteriorating health, or thoughts about their death. For example, David described going out for a walk so that "the other stuff fades into the background." Mary spoke of keeping busy as much as she could, through occupations such as sleeping, reading and spending time with her dog Max, to avoid thinking about ‘the end’ and feelings of depression. Jim described the need to have “something to think about besides every ache and pain,” and the importance of his garden in this regard: “by having something to do, to have a seed, and grow a little plant out of it, or take a little cutting and grow a tree from that, now that is…an amazing thing to me.” Lastly, Julia spoke of the invaluable significance of reading: “If I’m feeling crummy or I’m just not feeling, or even if I’m feeling blue, like I’m feeling a little depressed…if I’m reading a book or something, it just takes me out of myself and it takes me away somewhere else, so I really love that.” What these examples demonstrate is that being engaged in occupation appears to have the power to contribute to quality moments, and thus to living well while dying, even in the midst of suffering.

The words ‘diversion’ and ‘distraction’ in the occupation-based disciplines have a tendency to elicit negative connotations. This stems from the use of occupations as diversions or distractions in the early years of the occupational therapy profession, particularly in the mental health field, and a sense that occupational therapy has moved beyond such approaches in current times (Polatajko, 2001; Reed & Nelson Sanderson, 1999). However, what is key to notions of diversion or distraction is the meaning behind the occupations themselves; early occupational therapy clients were ‘distracted’ through activities that might not harbor personal meanings for clients, such as arts and crafts. The proposal that engagement in occupation at end-of-life can be useful to distract individuals from perceptions of pain or to divert attention away from thoughts about death is centered on what each person identifies as personally meaningful; what constitutes a quality moment in one person’s life may not constitute a quality moment in the life of another.

In summary, the findings of this research have implications for persons at end-of-life, health care practitioners and caregivers in the sense that engagement in occupation has the potential to directly and indirectly contribute to fostering quality moments in this stage of life. According to the World Health Organization (2011), it is possible to implement effective palliative care within contexts that have limited resources. The significance of occupation for living well while dying is an important topic that this research has only begun to explore. I suggest that there is a need for further research that investigates the potential for occupational engagement, both ordinary and extraordinary (Davel Jacques & Hasselkus, 2004) to facilitate quality experiences at end-of-life and contribute to the good death.

Identifying Occupations at End-of-Life

The second insight addresses the question of how occupations might be identified at end-of-life, so that care practices might be designed to include occupational engagement as a potential means to elicit quality end-of-life experiences.

The participants in this study described orientations towards occupations that involved: living with death, reworking everyday life, being guided by the will of the body, focusing on relationships, attending to the small things, and engaging existential orientations. While the participants were engaged in a range of occupations, it appeared that the nature of occupation at end-of-life was qualitatively different compared to those engaged in other life stages. Participants frequently described being engaged in what some people might define as ‘grander’ occupations prior to their illness, such as productive work, traveling, fishing, teaching overseas, and dancing. They often reflected on being busy in the past: “I used to be a *really* busy person,” Julia noted. However, at end-of-life, people in this study described less participation in dimensions of occupations that involved ‘doing,’ and more engagement in nuanced dimensions of occupation such as being, becoming, and belonging. For example, this could be seen through participants’ attention to the small things in life (i.e. the beauty in nature, gratitude for what they had) and the pleasure participants identified in smaller, quieter and seemingly more mundane occupations (i.e. a phone call from a friend, reminiscence, and prayer).

The idea that the nature of occupation may change at end-of-life, and that quality experiences might be derived from small and everyday occupations that may typically be overlooked, suggests that identifying occupation at this life stage might be a challenge. Difficulty identifying what human occupation entails is not limited to the end-of-life context. As introduced in chapter two, human occupation itself is not characterized by a single definition, but is considered an evolving construct (Hinojosa, Kramer, Brasic Royeen, & Luebben, 2003). For example, some scholars have debated what distinguishes a task versus an activity versus an occupation (CAOT, 2002; Harvey & Pentland, 2004). According to Harvey and Pentland (2004), these three concepts are hierarchical, in that “tasks are undertaken as a means of accomplishing the activities that comprise an occupation” (p.64). In comparison, the CAOT (2002) reverses the definitions of task and activity, suggesting that an activity is the basic unit of a task. However, both sources propose that what makes an occupation an occupation is the context in which it is engaged, and the meaning(s) that engagement in occupation brings to life. This is one example of how occupation might be understood, although definitions of occupation are wide-ranging.

Human occupation may also be difficult to identify due to its “seen, but unnoticed” nature (Hasselkus, 2006, p. 628). Hasselkus (2006) offers two reasons for why this might be the case. First, she suggests that there is a tendency to reduce, simplify, and categorize complex constructs to make them understandable and accessible. While making occupation accessible to other disciplines and clients is important, she suggests that there is risk in “losing sight of the unique contexts and individual small behaviors of everyday life and everyday occupation that make up these sweeping categories” (p. 629). A second reason that occupation is “seen, but unnoticed” is that in our everyday discourse, occupation is often described using what Hasselkus suggests are ‘powerless’ words, such as routine, mundane, ordinary, everyday, basic, and taken for granted. Describing occupation using powerless language has important implications on what kinds of occupations are valued in everyday life; Hasselkus draws on the example of housework, which is often described as routine and ordinary, and the impact this had on devaluing women who work in the home. Therefore, varied understandings of what occupation entails and its “seen, but unnoticed” nature have the potential to contribute to difficulty in both identifying occupations and conveying their significance in everyday life to clients, team members, interdisciplinary colleagues, policy advisors, and others.

In light of these challenges, one might question the best ways to identify and research meaningful human occupation, and how it manifests in everyday life. Inspired by Hasselkus (2006), I propose that phenomenological approaches are particularly useful in eliciting descriptions of mundane and everyday phenomena, such as human occupation, because these methods are concerned with how these phenomena are lived and directly experienced (Benner, 1994a,b; van Manen, 1997). The findings and methodological contributions of the current phenomenological study offer insight into how occupations in the end-of-life experience might be identified and researched. For example, the current study was designed to elicit in-depth, descriptive accounts about occupation at end-of-life. The themes that arose through the findings of the study might prove useful in informing questions oriented toward discovering the occupations that individuals find meaningful at this stage of life. Some questions might include:

a) Are there things you would like to do to help prepare for the upcoming days/weeks/months? In what ways has your life been impacted by the diagnosis of your life-threatening illness? How are you and your family coping with your diagnosis?

b) Tell me about your typical day. Thinking about your typical day before and after your illness, what parts of your everyday life have required the most change or accommodation? Are there parts of the day that you manage well? Are there parts that you struggle with? How will you spend your time (what will you do) in the next days, weeks and months? What activities are important to you? Is there any unfinished business you wish to attend to in the days ahead?

c) You may be noticing a lot of changes in your body - how are you managing these changes? Are there changes in your body or bodily experiences that have surprised you? As your body's changed, have you noticed any implications for what you do in a day or how you do it?

d) Who have you been spending time with in these recent days? What sorts of things do you do together? What do you notice about yourself when you’re together?

e) Have you noticed any parts of the day that stand out to you as meaningful or enjoyable? Are there times in the day that go by quickly? Go by slowly? What are you doing during these times?

f) How are you feeling within yourself? Are there any thoughts or questions that you find yourself coming back to in recent days that you would like to discuss? How has your experience with this illness influenced your sense of who you are? Are there things you have learned or discovered about yourself throughout this experience?

These kinds of questions may help identify everyday occupations that might typically be overlooked, given that the nature of occupation may change at end-of-life and that human occupation is often “seen but unnoticed” (Hasselkus, 2006, p. 628). The questions presented above offer practitioners, caregivers, volunteers, friends and possibly researchers a starting point from which to identify and discuss the experiences of occupations in which individuals engage at end-of-life. Such questions have the potential to inform care that fosters more opportunities for people at end-of-life to engage in occupations.

Lived Engagement in Occupation: A Fifth Existential?

As stated earlier, occupational scientists and occupational therapists propose that human occupation is a basic human need (Wilcock, 2006) and that “individuals are most true to their humanity when engaged in occupation” (Yerxa et al., 1989, p. 7). For participants in this study the significance of lived engagement in occupation at end-of-life is no exception.

The significance of occupational engagement was reflected in participants’ statements that emphasized the importance of ‘finding ways to occupy one’s time.’ For instance the importance of being engaged was revealed in comments such as: “I could never just stay [home] without doing something” (Sarah) and “I don’t have a lot of hobbies, and that’s one thing that I regret. To keep me busy” (Maggie). Jim stated:

> Find something that you can occupy your time with because sitting in a chair, or laying in bed…gets to you. You have too much time to think and then you get a lot of negative thoughts, you gotta find something that you enjoy doing.

The importance of engagement in occupation was also identified in a study by Vrkljan and Miller-Polgar (2001). The participants in their study, women diagnosed with life-threatening illnesses, indicated that engagement in occupation was intimately associated with feelings of living.

The contention that engagement in occupation is associated with feelings of living raises questions concerning what is elicited when people are unable to engage in occupation at end-of-life. In this study, two participants indicated that being able to 'do nothing' and dwelling on what they could no longer do, led to feelings of depression and wishing for death to come. For instance, Mary stated, "I wish I was dead…because I'm so tired. You can't do this, you can't do that, you can't do nothing" and Jim recalled asking "Lord, take me home, get me out of here" during the period where he 'lived' in a reclining chair. Their words are consistent with the accounts of terminally ill individuals in Oregon, who report the decreased ability to engage in activities that make life enjoyable as a factor influencing their decision to receive lethal intervention (Oregon Department of Human Services, 2006, 2007, 2008).

When considering the findings in light of van Manen's (1997) four existentials of lived time, space, relations and the body, I began to wonder if engagement in occupation might be considered more than a basic human need (Wilcock, 2006) or a human right (Christiansen & Townsend, 2004; Whalley Hammell, 2008); rather, I wondered if lived engagement might be considered as a fifth lived existential, one that speaks to what it means to *be* human. According to van Manen (1997), lived existentials "pervade the lifeworlds of all human beings, regardless of their historical, cultural or social situatedness" (p. 101). If van Manen's definition is adopted, it appears that engagement in human occupation might be viewed as a contender in that, similar to the other four lived existentials, it is difficult to imagine human existence without occupational engagement.

Consideration of occupational engagement as a fifth existential has two potential implications. First, it could contribute to debates in the occupation-based disciplines concerning what does and does not constitute an occupation. For participants in this study, it seemed that small and seemingly mundane tasks or activities (i.e. chewing, taking clothes off a hanger, getting into bed) took on intense occupational significance when they were not able to be readily engaged, and since bigger occupations were often out of reach. For example, I interpreted PJ's difficulties chewing and getting into bed as occupations, rather than tasks or activities, due to the meanings they took on at end-of-life:

> Chewing is work. It's why I like jelly. I can break it up with my tongue. That's not as much work as using my teeth. You learn a lot about yourself, you know. Like I've had to re-think *everything* pretty well.
>
> It is a *wonderful* feeling to get into bed and pull up the covers. Breathe kind of normally and feel the warmth of the blankets. That is just an incredibly wonderful feeling. That's foreign to me!

Therefore, in different contexts or at different points in the life process, what might typically be defined as a task or activity can potentially change, and constitute an occupation. Practitioners and caregivers might heed caution in assuming that people at end-of-life engaged in seemingly insignificant tasks are not, instead, engaged in meaningful occupations. There is potential that people at end-of-life may draw meanings from engagement in what might be interpreted as seemingly small occupational pursuits.

Second, occupation as a fifth existential has implications for the question of whether we can ever be un-engaged in occupation. It is extremely difficult to think of a time of day when we are not engaged in *something*, even in circumstances where we would prefer to do something else, or when we are forced not to do by external parties. For example, in manuscript two, Doyle's (2001a) account of a prisoner who made little handmade dolls out of scraps of garbage demonstrates how human beings naturally engage in occupational pursuits, even in contexts of extreme restriction. This is not to suggest that people who are occupationally deprived, such as those in prison or refugee camps, are sufficiently occupationally engaged and therefore not deserving of different opportunities or aid. Rather, it suggests that people who might be defined as occupationally deprived or alienated do not suddenly take on a zombie-like state of occupational-nothingness. What is key is that people may be deprived of choice, self-fulfillment, and freedom, yet humans still appear to seek occupational engagement despite external conditions or restrictions in their lives.

Further scholarly work is needed to study lived engagement in human occupation as a possible lived existential, and as fundamental to human existence. This discussion has relevance for people at end-of-life, and for caregivers. For example, there is potential that 'tasks' and 'activities' may take on more occupational significance in this life stage. Engagement in smaller occupations might be interpreted as so mundane as to elicit feelings that one is engaged in very little; as PJ poignantly noted, "I've had to become more patient doing nothing." More work is needed to better understand the juxtaposition between 'doing nothing' at end-of-life and the proposal that we are always in a primordial state of 'doing something.' The latter underscores the importance of delivering care that attends to engagement in occupation as a significant part of the end-of-life experience. Lived engagement as a fifth existential calls for a deepened perspective on how occupation is conceptualized.

Rehabilitation and Re-Inhabitation

The fourth emergent insight refers to the paradox of offering rehabilitative care in end-of-life settings, a tension that is evident in the occupational therapy literature (Bye, 1998; Pizzi & Briggs, 2004; Rahman, 2000; Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008). There is potential that traditional understandings of 'rehabilitation' might be re-conceptualized to better fit the hospice palliative care paradigm. As stated in chapter two, the hospice paradigm involves holistic care, which attends to the physical, emotional, social and spiritual needs of the person who is dying and their loved ones (Howarth, 2007). While a solution to this paradox is not presented, I offer reflections as a starting point for further dialogue. This discussion was inspired by, and I am indebted to, personal communications with phenomenological philosopher Dr. Taylor Carman in 2008.

The term rehabilitation is rooted in the Latin *rehabilitare*, and refers to the notion of restoring or enabling back to a former state (Barnhart, 1995). On the other hand, inhabit refers to the notion of dwelling or occupying a habitat. The Latin root of rehabilitate is *habilitare,* which means to make fit, and inhabit is derived from the Latin root, *habitare* which means to dwell in. Both of these Latin roots allude to notions of spatiality; the participants' descriptive accounts point to what making something fit and dwelling in space might involve in terms of occupation at end-of-life.

Many participants described feelings of anxiety, a feeling of unsettledness at end-of-life. There are times where participants described moments of "terrible fear" (Maggie), feelings of "aggravation" (Cali), being "not comfortable," "uneasy" (Sarah) and "*very* depressed" (Jim). These feelings may be overlooked as simply responses to the illness experience. However, drawing on the phenomenological notion of Dasein these feelings of anxiety may allude to broader, existential concerns.

Dasein refers to individual human existence and a self-interpreting mode of being (Dreyfus, 1991; Heidegger, 1927/2008). Dasein's ontological mode of being is a state of being immersed, embedded and thrown into the world. What this suggests is that in daily life, human existence and one's mode of being (Dasein) goes largely unnoticed. According to Svenaeus (2010), Dasein can be realized through our everyday feelings and moods. He states that feelings and moods:

> are the basic strata of our facticity--of Dasein's being 'thrown' into the world where it makes itself at home. We find ourselves *there*, always already engaged in activities that *matter* to us and this 'mattering to' rests on an attunement, a mood quality, which the being-in-the-world always already has. (p. 4)

Therefore, changes in moods can act as signposts for changes in Dasein's ontological mode of being. One such mood is the feeling of anxiety. According to Heidegger (1927/2008), anxiety is more than just a feeling but a means through which Dasein's ontological mode, its thrownness in the world, can be revealed. As a result of anxiety, the ontological structure of Dasein – one's human existence and self-reflecting mode of Being - is illuminated:

> As Dasein falls, anxiety brings it back from its absorption in the 'world.' Everyday familiarity collapses. Dasein has been individualized, but individualized *as* Being-in-the-world. Being-in enters into the existential 'mode' of the 'not at home.' (Heidegger, 1927/2008, p. 233)

Heidegger describes anxiety as a feeling of 'uncanniness.' The German word for uncanny is *Unheimlich,* and *Heim*, in German, refers to the word home. What Heidegger proposes is that through anxiety, Dasein is revealed as no longer feeling at home in the world.

In our everyday lives, our being-in-the-world is constituted by its taken for granted nature. There is potential that the diagnosis of a life-threatening or terminal illness disrupts our very sense of being-in-the-world, to the extent that we no longer feel at home in the world, which can manifest in feelings of anxiety. These feelings might be elicited by a disruption in lived space, such as the familiarity of a home environment, rich with memories, artifacts, and meaning being replaced by sterile, meaning-less hospital wards or by lived time suddenly being dictated by the rigid schedule of a long-term care facility. It can also be revealed, as the stories of participants in this study illustrate, by the inability to engage in familiar occupations, such as chewing, getting into bed independently, eating a steak dinner, sleeping for an extended period of time, gardening, attending church service, and dancing.

The feeling of not being at home can be seen in peoples' descriptions of their experience with illness. For example, Arthur Frank (2002) reveals in his reflections on his experience with cancer pain at night, a feeling of living outside of everyday life:

> When I was awake at night in pain, I could have woken Cathie. I could have called her to witness the pain and to break the loneliness, but waking her would have violated the coherence of her natural cycle of daily life. She still worked during the day and slept at night. Her life retained the coherence mine had lost. I was outside that natural cycle…I lived my life out of place. (p. 32)

In the end-of-life study, Jim described his frustration at being unable to participate in Sunday dinner with his family, so much so that he would leave his house and go outside because "it got to [him]." The inability to engage in such a meaningful occupation rendered feelings of being not at home, even within his own home. These kinds of disruptions may seem to have surface meanings but, as the findings of this study reveal, they may be existentially poignant. Therefore, the loss of feeling at home in the world, through a loss of the cohesion of living within everyday life and the inability to engage in everyday occupations, can elicit feelings of anxiety. This anxiety reveals a disruption in one's sense of taken for granted existence in the world (Dasein's ontological mode of being); in other words, anxiety can elicit feelings of not being at home in the world.

I propose that in the context of thinking about occupation at end-of-life, it might be useful to rethink the notion of rehabilitation and how it might be extended to include the notion of re-inhabitation. The typical goal of rehabilitation is to foster and restore functional independence; the goal of re-inhabitation on the other hand would be to foster a sense of being-at-home in the world, to re-inhabit the world as home. Extending care beyond rehabilitation and focusing instead on existential changes that may emerge following a diagnosis of terminal illness may be more in line with the hospice paradigm, which aims to provide whole person, versus solely rehabilitative, care. Occupation-based scholars, practitioners, health care workers and rehabilitation policy makers would perhaps benefit from a perspective that is attentive to the kinds of existential changes that trigger disruptions to being-in-the-world at end-of-life. As Svenaeus (2010) suggests:

> It is the mission of health care professionals to try to understand such unhomelike being-in-the-world and bring it back to home-likeness again, or, at least, closer to home…Health care professionals must also address everyday life matters of patients with a phenomenological eye, addressing and trying to understand the being-in-the-world of the person's life, which has turned unhomelike in illness. (p. 4)

In health care practice, this might begin by becoming attentive to the possibility that persons at end-of-life may be experiencing feelings of anxiety, and that these may be related to feelings of not being-at-home in the world. Practitioners might attend to sources of change or loss in terms of everyday cohesion and the ability to engage in everyday occupations. An enhanced awareness of everyday being-at-home-in-the-world, and the consequences when this mode of being is disrupted, may help shift or extend the traditional focus of occupation-based intervention from rehabilitation (restoring back to a former state) to re-inhabitation (restoring to a state of being-at-home or dwelling in the world).

Existential Considerations: Spirituality and Being

Existential orientations were a major theme that arose for participants in the end-of-life study. The term ‘existential orientations’ was used to broadly encompass occupations concerned with reflecting on one’s state of existence and the meaning of life and death. While existential orientations could be associated with one’s sense of spirituality, the literature has indicated that spirituality is broadly defined and unique to each individual (Howarth, 2007). For some participants, spirituality was closely tied to religious faith, but for others, spirituality took the form of broader existential concerns and questions (i.e. When is it time to go? Am I ready to die? Is the way a person lives reflective of the way he or she dies?).

In this work, spiritual and existential reflections were engaged as occupations by all eight participants at end-of-life. Participants’ existential orientations included the time they spent engaging in occupations such as: reflecting on life and death (i.e. describing death as close, death as inevitable, their preparedness to die), reminiscing about good memories and past regrets, and engaging in spiritual reflection, most often associated with their religious faith (i.e. reflecting on the afterlife, spirituality throughout their life, questioning the role of religion). While these occupations may not typify ‘active’ or ‘physical’ forms of occupational engagement (i.e. doing), they were not simple occupational time fillers but more reflective of the occupational dimensions of being, belonging, and becoming.

While the term ‘existential orientations’ offered a broader consideration of occupations that are concerned with existence and the meaning of life and death, the presence of spirituality in the findings was a strong theme. The topic of spirituality and human occupation is prevalent in the occupational therapy literature, where spirituality has been proposed as a long-standing interest (Wilding, 2002). Currently, spirituality holds a central position in the Canadian Model of Occupational Performance (and Engagement) (CMOP-E). The CMOP-E depicts three components seen to facilitate occupational performance: personal components (affective, cognitive, physical and, at the center, spiritual), occupational components (self-care, productivity, and leisure) and environmental components (cultural, institutional, physical and social) (CAOT, 2002; Townsend & Polatajko, 2007). In occupational therapy, one definition of spirituality is that it is “the very essence of who we are as human beings” (p. 68) and as “the truest self, which we attempt to express in all of our activities” (Egan & DeLaat, 1994). Spirituality is not limited to religious connotations, but has been referred to broadly as “sensitivity to the presence of spirit” (McColl, 2000, p. 218).

Despite its proposed significance, and efforts by a number of scholars to better understand its nature (Egan & DeLaat, 1994, 1997; Kroeker, 1997; McColl, 2000, 2003; Unruh, 1997), definitions of spirituality and how to implement spiritual practices while enabling occupation continue to be elusive (Egan & Swedersky, 2003; Unruh, 1997). Given the various definitions of spirituality in the field, I wonder if one of the challenges of embracing spiritual practices might be impacted by the term itself. For example, the ambiguity of the term spirituality is not limited to occupational therapy, but rather it is a term that exhibits confusion in everyday discourse. Even if occupational therapists were to agree on concrete understandings of the term, would these understandings encompass the spiritual beliefs of the clients they serve? In terms of occupational therapy practice, there have been a number of studies indicating that therapists are unsure of their role in addressing spirituality in practice (Egan & Swedersky, 2003; McColl, 2000, 2003; Rose, 1999). In a study by Rose (1999), occupational therapists reported that spirituality was an important part of health and therapy, but described difficulty addressing spiritual issues with their clients. The majority of these therapists stated that it was more appropriate to refer clients to other professionals, such as spiritual chaplains, when spiritual issues emerged. The suggestion that spirituality, the central hub of the CMOP-E, might be better served by other disciplines raises the question of whether the relationship between spirituality and occupation has been adequately developed. There is potential that the term spirituality is not serving the study of human occupation well; perhaps attention to broader existential orientations might be a fruitful alternative approach.

Graham Bland, a spiritual care provider at a local hospital, suggests that spiritual care is focused on attending to the *human spirit*, which is not the property of any religious group (personal communication, December 8, 2009). Bland suggests that spirituality should be more broadly situated within the existential notion of *Being*. In the occupation-based disciplines, being has been described as “being true to ourselves, to our nature, to our essence” (Wilcock, 1998, p. 250) and as a concern with the nature of existence (Whalley Hammell, 2004). From a phenomenological perspective *Bein*g is: “everything we talk about, everything we have in view, everything towards which we comport ourselves in any way" (Heidegger, 1927/2008, p. 26). *Being* illuminates the ways in which human beings are not simply observing but are immediately present, living, experiencing, and engaging (Todres, 2008). When spirituality is defined as our essence as human beings (Egan & DeLaat, 1994), it elicits understandings similar to the existential notion of Being.

The idea that spirituality might be considered more broadly as *Being* has relevance for occupational therapy practice and for advancing the study of human occupation. With regard to practice, the findings of this study indicate that existential considerations (spiritual, religious, or not) were engaged as important occupations for the participants at end-of-life. This finding suggests that there might be value in facilitating processes of deep reflection at end-of-life. A useful way of facilitating existentially-oriented occupations might be to offer a list of questions to persons approaching end-of-life that address the intimate and personal aspects of one's existence. One important question suggested by Bland as useful in reaching the depths of one's sense of being was, 'How are you within yourself?' Other potential questions that he suggested as useful for fostering reflection on existential concerns include: What is my purpose? What has been my vocation? What have I been called to express with my own unique life? What do I believe? What values do I hold dear? And how have I shaped my abilities to reflect my values? These questions could potentially be introduced by practitioners, but also by volunteers, family members, and friends, or used as a stimulus for self-reflection at end-of-life.

In terms of the study of human occupation, I suggest that there is potential in a consideration of spirituality as existential being. For instance, if the existential notion of

Being replaced spirituality at the center of the CMOP-E, how might this change and shape practices of enabling occupation? Would practitioners and scholars be better able to attend to spiritual dimensions of the lived experience if it was framed broadly as one's existential experience of *Being*? And might the existential concept of *Being* provide a more useful language across cultures and geographies, a notion that more people might relate to? These questions invite a dialogue about possible conceptions of spirituality in the occupation-based disciplines that are more broadly based.

Relational Care

Engaging in occupations that were focused on relationships emerged as a significant theme for the participants in this study. This finding has potential implications for practitioners and caregivers in regard to considering the relational aspects of care in the end stages of life.

Relational priorities were evident within the occupational dimensions at end-of-life. For instance, relational aspects were often identified as a significant motivator to engage in certain occupations, such as: saying goodbye to loved ones, being present for life events (i.e. Jim's sons' weddings), including loved ones in end-of-life arrangements (PJ's wish for his son to sing at his funeral), attending to those being left behind (i.e. including spouses names on legal documents), and passing on personal belongings. Participants identified how bodily changes and fatigue often prevented them from engaging in relational activities, such as Jim's inability to participate in Sunday dinner and missing out on his family's trip to visit his son. Many also mentioned the changing nature of their relationships, when describing the need to rely on others more to engage in activities they could no longer do themselves. Some participants described taking pleasure in small relational occupations, such as a phone call from a friend (Julia). Relational occupations could also involve reminiscing about good memories with others, including trips with friends (Julia) and “my first love” (Maggie). Several participants also described their relationships with God as significant. While participants explicitly described engaging in relational occupations as a priority, their relationships were often highlighted as factors influencing their engagement in other kinds of occupations. Many participants described being with others as the best part of their day. For some, being with others was a time where “you don’t think about yourself as much” (Cali). PJ noticed that when he had visitors, “often I’ll get so engrossed…that I forget me.” Many participants credited their family as important supports for helping them cope through difficult times. Other relationships that were mentioned as important included faithful friends, pets, neighbours, health professionals, volunteers, people who could relate to their illness experience, church family, and God. The priority placed on relationships at this stage of life suggests that health care practitioners might focus therapeutic intervention to a greater extent on the relational dimensions of the end-of-life experience, including the relational dimensions of occupation.

These findings support other research (Hasselkus, 1993; Rahman, 2000; Thibeault, 1997) that points to the importance of relationally oriented care at end-of-life. Several studies in the occupation-based literature speak of the power of presence, simply being-there with the person who is dying. Hasselkus (1993) suggests that fostering a sense of connection or communion between the client and caregiver or practitioner can contribute to the experience of dying well. As an example, in the end-of-life study, being with a visitor or friend was important, even when it simply involved a friend’s presence; in PJ’s words “usually when Henry comes…I’ll have a sleep and he’ll read the newspaper or something.” Other examples of relational care in the literature highlight the significance of active listening and open conversation (Rahman, 2000; Thibeault, 1997). For example, an occupational therapist (Steve) in a study by Rahman (2000) indicated that family members were often reluctant to talk openly about death to his clients, although 85% of the clients Steve encountered expressed the wish to talk about their experience. This suggests that relational aspects of care, involving simple presence, active listening, and open conversation, may be important for health care practitioners, caregivers, volunteers, family member, and friends in end-of-life contexts. Occupations that focus on relationships may provide a means by which to foster relational connections, and are an area recommended for further research.

Relational aspects of care may already be part of the informal treatment plan of many practitioners, although such care may remain undocumented in their clinical charts due to assumptions that they are medically irrelevant. As an example, in their ethnographic studies of occupational therapists, Fleming and Mattingly (1994) found that therapists worked within two discourses: a medical discourse and a narrative discourse. The medical discourse represented the formal biomedical model in which therapists worked and documented their care; on the other hand a narrative discourse was seen to address the deeper, phenomenological and ‘real-life’ suffering that patients experience, and was often enacted through shared stories and through conversation with clients (Mattingly, 1998). Mattingly (1998) noted that therapists often felt caught between the formal medical treatment plans expected from them, and caring for the whole patient through relational and narrative dimensions of care. These ‘non legitimate’ and ‘non reimbursable' aspects of care were often undocumented in their clinical notes, resulting in what Fleming and Mattingly (1994) refer to as 'underground practice.' Mattingly (1998) reflects that it was often through small, human moments that meaning emerges in the therapeutic encounter:

> When therapists recognized the subterranean phenomenological waters beneath a humdrum task like relearning to dress oneself, their practice was directed more to the illness experience than to the disease. There was more generosity than I was prepared for. I saw small kindnesses rather than life-saving interventions. These went almost unnoticed by the therapists themselves. (p. 21-22)

Mattingly's work speaks to the importance of the relational aspects of care, and the power of addressing deeper phenomenological issues, which could emerge through the simple sharing of stories. As Mattingly (1998) points out: "treatment which is dramatic, conversational, and deeply meaningful to patient and therapist overwhelmingly predominates in 'best practice' stories I have heard" (p. 147).

Therefore, engaging in occupations focused on relationships may have implications for health care practice. In particular, relationships may motivate individuals at end-of-life to engage in a range of occupational pursuits, and conversely occupational pursuits may support and maintain the very relationships that some participants in this study described as the 'best part of their day.' Although further research is needed, this insight may also have implications for service administrators with respect to the significant contribution that relational care may have in health care delivery.

It may be easy to idealize relational care and suggest that relationships are of paramount importance at end-of-life. Yet, it is also important to recognize that there may be very real challenges in relationships of care at end-of-life. As pointed out by Hasselkus (1988) and Halifax (2008), potential challenges include: the weight of responsibility on the caregiver, the difficulty of maintaining a sense of normalcy in the relationship with a dying loved one, changing roles and potential role losses, and tensions among caregivers, care receivers and health care professionals with regard to expectations and care practices. The shadow side of caregiving suggests that community-based health care delivery may need to be organized in ways that support and attend to fostering healthy caregiving relationships. For instance, developing supportive care programs that assist caregivers by providing opportunities for respite, through access to support service workers, social workers and counselors, may be important factors to consider when creating contexts for positive relational care experiences at end-of-life. Further exploration of the ways in which relationships may contribute to occupational engagement, and how occupational engagement may contribute to relationships at end-of-life, are promising areas of future scholarship.

Embodied Understandings

Another emerging insight is related to the phenomenological notion of embodiment. Participants in this study identified a very different kind of body at end-of-life, one that called for attention. The notion that the lived body is often overlooked in the smoothness of everyday life (Leder, 1990; van Manen, 1998) suggests that when the body comes to fore in times of illness and change, people might not be prepared to manage its sudden presence or its impact on the everyday experience. For participants in this study, however, the body's presence at end-of-life could not be ignored. Two emerging insights regarding embodied understandings include human occupation as embodied, and embodied understandings in practice.

Human Occupation as Embodied

This study has illuminated ways in which human occupation may be embodied at end-of-life. The participants described experiences that pointed to ways in which they were guided by the will of the body.

Listening to the body at end-of-life has the potential to render a change in the experience of lived time. One key feature of occupation, according to the CAOT (2002), is that engagement organizes time. This is evident in the way we organize our day-to-day routines, such as grooming, preparing meals, attending classes, going to work, watching television, and dinner with family. The body is typically experienced as a medium through which occupations are engaged, yet it is usually unnoticed in the smoothness of everyday life (Leder, 1990; van Manen, 1998). However, for the participants in this study, the changed body and its coming to the fore impacted how they experienced and organized their everyday lives. Instead of living through structures of 'I am my body,' they lived through structures of 'I have a body.'

Occupational engagement organizes how time is experienced; often we are engaged in occupations that are directed towards future possibilities (i.e. cooking a meal for dinner, studying to graduate from university, working to pay the bills). However, as the stories of participants revealed, living according to the 'the will of the body' frequently required participants to live in the present, and often prevented the ability to commit to future plans, thus creating a sense of uncertainty. Committing to future plans became a challenge for several participants who identified the need to see how their body was feeling before they were able to plan what to do in a day. Many participants described the need to listen to their bodies versus their minds or will; this could be seen in statements such as “Barkis is willing, but the flesh is weak” (Cali) and “I’m game [to travel] up here [motions to head], it’s just if the rest of the physical plant goes with the mental plant” (Julia). As Sarah described, “I wake up in the morning and think, ‘Oh I’d like to do this,’ but once I get my feet on the floor, I think, ‘I can’t - I can’t do it.’”

Recognizing the need to organize occupations according to the body’s needs in present time has the potential to create a unique care context for practitioners and caregivers. For health care providers, treatment plans are typically organized towards a goal that will be obtained sometime in the future. Living at the will of the body calls for flexibility, and the tailoring of treatment to deal with present bodily capacities, which may frequently fluctuate. As Jim stated, “A day is never without a surprise.” For caregivers, family and friends, listening to the will of the body at end-of-life may call for enhanced patience and understanding; while future plans may be drawn upon to instill hope and excitement, these plans might also render disappointment for all if the body does not abide. Further research is recommended that examines the intimate relationship between the body and time, and the implications for occupation at end-of-life.

The lived body at end-of-life also illuminates the need to respond to its ‘call’ through adaptation. The findings in this study suggest that when participants’ bodies came to fore, they began to experience ‘having’ a body; the body became an object in the world through which people were intentionally oriented. At times, listening to the body involved adjusting everyday occupations to accommodate the body’s changing needs. For example, David became aware of where the restrooms were when out in public locations, Julia was instructed not to “lift anything heavier than a broom” and was consequently unable to pick up her grandchildren, and Jim described the changing body as rendering feelings of “depression” and “fear” which led him to turn off the lights to shower “so I wouldn’t have to see it.” Adapting how one engaged in occupations occurred through accommodating the environment (locating the restrooms) or accommodating the occupations themselves (never lifting a grandchild and turning off the lights to shower). It seems while personal and social meanings in the lifeworld can call us to engage in occupations (Reed, Hocking, & Smythe, 2010; Wright-St Clair, 2008), so too can meanings associated with the changing, unveiled body.

Interestingly, it appeared that the call to adapt engagement in occupation were often associated with the risks they suddenly posed (the risk of embarrassment if a bathroom was not found, the risk of injury from lifting a grandchild). However, in Jim’s case, the risk of seeing his deteriorating body trumped the risk of slipping in a dark shower, illuminating the body’s power to govern how occupations are engaged. In terms of end-of-life care, the lived body as a ‘call’ to adapt engagement in occupation has potential implications for practitioners and caregivers in regard to considering the extent to which people at end-of-life are oriented toward their bodily needs, the enhanced risks that are suddenly involved in everyday occupations, and the lengths to which people at end-of-life will go to accommodate occupations in response to their bodies’ demands.

The findings suggest that human occupation at end-of-life may be viewed as an embodied affair. In this study, the lived body came to the fore and had strong influences on how participants experienced time and organized their daily occupations, and how they adapted their engagement in occupation according to the body’s call. A view of human occupation as embodied reveals that what people do, through and according to their bodies, has important implications for how they engage in everyday occupations.

Embodied Understandings in Practice

A second emerging insight is that embodied understandings have relevant implications for practice. Van Manen (2007) proposes that, "all phenomenology is oriented to practice-*the practice of living*" (italics added, p.12). According to van Manen, a phenomenology of practice is grounded in pathic knowledge, that is, knowledge that is embodied, relational, situational, thoughtful and tactful. Pathic knowledge is difficult to conceptualize, represent and teach and yet it is deeply rooted in the way we compose ourselves in the world. Todres (2008) uses the term 'embodied relational understandings' to depict a similar notion. He proposes that qualitative research that is able to convey embodied, relational understandings in evocative and textured ways can sensitize practitioners to judgment-based care; while technical approaches to care focus on technique, skill, rules, control and standards, judgment-based care illuminates and embraces the complex, unique and messy process that is human life.

Embodied understandings are expressed or manifested in everyday actions, the way that people engage in relational and worldly affairs as embodied beings. Health care practitioners who are in tune with embodied ways of knowing might find themselves more prepared to handle ambiguous, messy and tough moments in practice. For example, Ray (2006) drew on embodied perspectives in her work with contemporary peacekeepers suffering from trauma. In her study, attention to embodiment involved acknowledging, versus avoiding or dissociating from, the body, as well as articulating inner experiences and sensations. Becoming sensitive to the body allowed peacekeepers to learn to release tensions, recognize bodily manifestations of significant experience (i.e. tears, groans), and remain attuned to the present. Ray described how embodied understandings allowed one soldier, diagnosed with post traumatic stress disorder to heal: "Mr. A. entered his body safely and became safely embodied…Mr. A found his voice and created a new narrative of meaning for his life" (p. 110). In another example of embodied understandings in practice, I recall one palliative care nurse who I spoke with who had worked in the community for many years and experienced hundreds of first-hand deaths. She stated that she had gained a wealth of experiential, intuitive knowledge, a 'when you know, you know' sense when it came to a person's time of death. She described being able to enter a room and read peoples' breaths, their facial expressions, which helped her identify what was going on with the family and helped guide her decision making regarding how to carry out the next steps in the care process. To me, she represented someone who displayed embodied understandings, yet these are not often discussed in health care.

The idea that embodied understandings can inform practice raises the question of how people learn to be more attentive to embodiment in the first place. In other words, there is a difference between teaching about the philosophy of embodiment and teaching embodiment as skillful practice. Learning how to engage in embodied research as a novice researcher was, for me, a methodological challenge. As I outlined in the methods section of the study design (Appendix A), embodied understandings were sought via four levels of attentive awareness: what participants said about their bodies at end-of-life, their bodily manifestations in the research process, my embodied experience in the research process, and the intercorporeality between the researcher and participant. As I discuss later, these four levels of attentive awareness of the body were difficult to juggle in a single interview session. The difficulties I faced trying to adopt multiple embodied perspectives suggests that embodied practices are *skills* that one acquires through experience, skills that have not likely been part of the conscious repertoire of most people in Western culture, and that might well be enhanced through education.

According to Todres (2008), insights gained from embodied practices can be extended into educative settings. He speaks of the potential of embodied lifeworld research to inform educative practices, and the possibilities of cultivating embodied understandings in scholars and practitioners; such understandings encourage scholars and practitioners to be attentive to context, to develop emotional and bodily intelligence, and to be empathic and ethically sensitive (Todres, 2008). Further research and dialogue is needed that considers how embodied understandings can be incorporated into practice, as well as in education contexts.

The 'Promise in Things'

A topic that was not discussed in the manuscripts, but which I view as an important insight arising from the research is the importance of objects in the lifeworld of people at end-of-life. As discussed in manuscript two, the lifeworld is an important phenomenological construct that acknowledges the intimate relationship human beings have with lived space and worldly objects. The lifeworld is first and foremost *experienced* (Crotty, 1998; van Manen, 1997); objects within the lifeworld therefore become important entities of consideration with respect to the study of human occupation. In the end-of-life study, the symbolic presence of artifacts came to the fore in many of the participant's descriptive accounts. While this was not deemed sufficient as an emergent theme regarding the nature of occupation at end-of-life, artifacts were prevalent in the background of the research, and this prevalence informs my reflections on how artifacts might illuminate the lifeworld experience.

The importance of artifacts at end-of-life has been alluded to in the occupation-based literature. In a paper by Hasselkus (1993), she reflected on the importance her mother placed on artifacts as she approached end-of-life. Hasselkus described how her mother had prepared for her daughter's visits, and insisted on organizing and reviewing personal belongings, from financial matters such as bank statements and checkbooks, to embroidered linens and the dress she had worn to her high school graduation. Hasselkus recalls her mother stating, "I want you to know where these are; I want someone to know *what* these are" (p. 718).

In the end-of-life study, artifacts that were present in the participants' homes were often points from which meaningful dialogue was sparked. Attention to artifacts was purposefully included in the design of the study (through close participative observation), as a means to attend to lifeworld and lived space and to consider their role in regard to occupational engagement. Some examples of meaningful artifacts included items participants had decided to pass on to loved ones, such as: jewelry (Cali, Mary, Julia), gold coins (Jim), a family clock (Jim), a train set (David), a bible (Maggie, PJ), and paintings (Cali, PJ). As Jim indicated, not only would he pass gold coins on to his grandson, but he had "written up the meaning of it ...the story behind it, so that he'll just have it, and just not the four coins, but the meaning also, why they were special to me." In my field notes, I reflected on the importance of artifacts and the participants' desire to show them to me. For example, Mary brought out jewelry and perfume she had saved for her grandchildren and Maggie directed my attention to a tattered bible she had found at a bookstore, stating “it looks terrible but…it’s just precious.”

I also noted that the meanings associated with everyday objects often appeared to change through the end-of-life experience. For example, Jim described his reluctance to use a pail when he vomited because “it just makes you feel like a little child again.” Although Julia described often feeling fatigued, she refused to stay in bed because she associated being in bed with being sick. It was interesting to see the nature of everyday objects take on new meanings in the end-of-life experience; how artifacts could harbor meanings associated with illness and child-like states.

The words of a female prisoner in Doyle’s (2001a) phenomenological study examining the terrorized body in prison summed up the significance of artifacts; in her words, there is “this ‘promise’ in things” (p. 86). This promise in things speaks to the occupational possibilities that artifacts hold. This discussion raises the issue of the extent to which artifacts associated with occupation can take on meanings of significance, as well as the extent to which artifacts may take on changed meanings at end-of-life. People at end-of-life may well benefit from family members and caregivers who ‘witness’ the meanings of important artifacts in their loved ones’ lives. Attention to meaningful artifacts could potentially inform therapeutic interventions directed at preparing oneself for death. People at end-of-life might intentionally share the meanings associated with significant objects with loved ones, offering a starting point for meaningful reflection and dialogue. In sum, there is potential that artifacts hold significant meanings and can be a source of rich insight into the lifeworld of people at end-of-life.

Summary

In the discussion above, eight emergent insights about occupation at end-of-life have been presented: living well while dying, identifying occupations at end-of-life, lived engagement in occupation as a fifth existential, rehabilitation and re-inhabitation, existential considerations regarding spiritual and being, relational care, embodied understandings, and the promise in things. These insights provide starting points for scholarly dialogue concerning the potential: that occupational engagement can contribute to quality end-of-life experiences; that questions informed by the findings of this work may prove helpful in identifying occupations at end-of-life; that human occupation might be considered as a constituent of what it means to *be* in the world; that end-of-life care might focus on restoring feelings of being-at-home-in-the-world; that spirituality might be considered more broadly as existential *Being*; that relationships are significant and that relational occupations may inform care practices at end-of-life; that embodied understandings have implications for occupational engagement as a bodily affair and for practice and education; and that lifeworld artifacts can harbor important meanings at end-of-life. These eight insights inform understandings about occupation, particularly in end-of-life contexts, that have relevance for people who are terminally ill, their caregivers, and health care providers. While further research and theoretical development is required, I propose that these emerging insights are useful points for discussion surrounding occupation and end-of-life.

Methodological Insights: The Study of Human Occupation

Phenomenology and the Study of Human Occupation

In the review of literature on occupation and end-of-life (manuscript one), a gap in knowledge about how people with terminal illnesses actually experience occupation at end-of-life was identified. This highlighted a need for research that attends to the first hand experience of people at end-of-life. Interestingly, none of the unearthed studies drew on the phenomenological tradition, a methodology particularly oriented toward eliciting accounts of first hand lived experience. Since I was interested in examining the nature of occupation at end-of-life as lived and experienced by older people who are terminally ill, phenomenology was deemed a fitting methodological choice to address the research question of the study.

In reviewing the literature in occupational science, it further became evident that little conceptual work on phenomenology as a means to study occupation had been undertaken. For this reason, it became important to examine phenomenology as an approach to the study of human occupation. Manuscript two represents the result of this investigation. This manuscript offered an introduction to phenomenological methodology, a consideration of its philosophical roots, and identified five dimensions that offer insight into phenomenology's theoretical underpinnings: a reconceptualization of knowledge generation, intentionality and the lifeworld, *Being*, the lived body and the notion of first critique. These dimensions informed the phenomenological perspective I adopted for this work. Husserl's (1907/1990) reconceptualization of knowledge generation helped rationalize that phenomenological inquiry is a rigorous approach to phenomena, and called me to more broadly consider what counts as scientific research. The constructs of intentionality and the lifeworld drew my attention to the ways in which people are situated and oriented within the lifeworld, and towards lifeworld objects (artifacts) and their potential meanings. The notion of *Being* resulted in deep reflections about its occupational significance for the eight participants at end-of-life, and led me to consider ways that it might be significant for understandings of spirituality in the occupation-based disciplines. The lived body had a significant influence on my phenomenological perspective, and led to an enhanced awareness of how the body manifests itself through everyday occupations and its role in shaping what emerges in the interview context. Lastly, the notion of first critique, reminded me that insights about a phenomenon are not separate from the intentional ties that culture instills. The consideration of phenomenology as first critique called for more attention to the taken for granted cultural assumptions that I brought into the study, which I attempted to illuminate in my reflexive journaling (these are further elaborated in my methodological reflections and presented later in this work), and raised some critical reflections concerning the cultural and taken for granted assumptions of biomedical and rehabilitative approaches in the context of end-of-life care.

In regard to situating phenomenology in the occupation-based disciplines, the methodological contributions of this work suggest that such research can: (a) offer insight into different categorical understandings about occupation (i.e. its form, function, meaning, essential elements, processes, etc.); (b) draw on individual perspectives to reveal important insights about occupation that have relevance on family, community, societal and population levels; (c) support researchers in discerning whether phenomenological methodology is an appropriate approach to examine their research questions; and (d) support researchers in undertaking rigorous and high quality phenomenological research. Furthering this last point, and due to the limited frameworks that assess ‘rigor’ in phenomenological research, I propose five quality criteria from which this phenomenological study, and others, might be assessed. I present these later in this chapter, and offer them as a potential methodological contribution to phenomenological research practices.

Lastly, despite arguments that phenomenological work might face challenges producing findings with practical relevance (Carlson & Clark, 1991), the current study suggests that important and practical insights about occupation can be revealed through phenomenological research. For example, the findings of this study point to qualitative and nuanced dimensions of occupation that may be overlooked in traditional approaches to care and may be significant at end-of-life. These findings have potential to inform, in a practical way, how care at end-of-life might be developed to attend to occupational priorities, and how improved dying experiences might be facilitated.

In summary, phenomenology is proposed as a useful, though underutilized, methodological approach for the study of human occupation. I propose that methodological contributions include a consideration of how: (a) five phenomenological dimensions may be useful for studying first hand accounts and lifeworld experience of occupation in everyday life; (b) five phenomenological dimensions may help inform a researcher’s phenomenological perspective and how one engages in phenomenological inquiry; (c) phenomenology offers a fruitful approach to address current discussions regarding the study of human occupation in the occupation-based disciplines; and (d) phenomenological research might be assessed for ‘rigor’ according to relevant quality criteria. In the case of this study, phenomenology elicited practical contributions regarding how occupation is engaged in the end stages of life, and fostered reflection on how care practices might be developed to improve dying experiences.

Embodied Research

As the study unfolded, I became increasingly interested in the notion of embodiment and the ways in which attending to the body might contribute to the research process. Manuscript four represents an investigation into what an embodied approach to qualitative research has to offer. This manuscript focused more broadly on the notion of embodied phenomenological perspectives in qualitative research. Inspired by the work of Merleau-Ponty (1945/2006), this manuscript: proposed the lived body as a path of access to the world, illuminated the body's skillful intelligence in the research process, and highlighted the relational dimension of intercorporeality. In this paper I suggested that deep insights can emerge when the body's role in everyday life, including the research process, is illuminated. The researcher's body was posited as a dynamic entity in the research process, a factor shaping how research evolves. I propose that embodied phenomenological approaches have fruitful implications for the study of human occupation and beyond, particularly with respect to how data about occupation might be revealed through the participant's body in the research process, as well as how an enhanced bodily awareness in the interview context might impact the researcher's observations.

The embodied phenomenological perspective has methodological implications, particularly in regard to how the body reveals itself in the interview process. First, an enhanced awareness of the body revealed that information about human occupation could be disclosed in non-textual ways. Below I offer two examples drawn from descriptive accounts of two participants and my field notes, which document the participants' use of their bodies in the interview. These descriptions were not included in the manuscripts due to word limitations, however they reveal insights about human occupation that I suggest are significant:

> To be out on the boat…whether I catch a fish or not, it doesn't matter, just to be there [fingers tap on table], it's just awesome, *that* to me is, is my pleasure…yeah, those are things where dreams are made of, I guess, so. I can, even just now, I can just picture it, me sitting there *[closes eyes, leans back and pretends to wheel in a fish]* with a fishing pole and just enjoying it, you know. Like, that is my pleasure. (Jim)

> Well, when I'm reading the bible, it's just a peace, it's a wanting to know …when I have music on, or praise and worship music on, sometimes I dance…I dance around. Sometimes it's just worship music and I just sing with it and I just feel peace and contentment. Because you're praising God and at church, we stand up and we lift our hands *[lifts both hands in an open position]* and we praise God and then we worship him and it's a joyful thing. The praise part is a joyful thing. (Maggie)

These descriptive accounts stood out for me because they demonstrated how these participants used their bodies while describing meaningful occupations. These accounts suggest that bodily manifestations might act as signposts for meaning in the interviews, and suggest that data about occupation might be missed if researchers rely on textual accounts alone. They also highlight the emergent understanding that human occupation is an embodied affair.

A second methodological insight is drawn from my enhanced awareness of my own body in the research context, and the intercorporeality between my body and the participants' bodies. There is potential that attention to these two levels of embodiment might have implications with respect to the development of rapport between researchers and participants. As Ellingson (2006) suggests, "acknowledging the body reaffirms researchers' common humanity with patients by keeping researchers on the same (messy, imperfectly controlled) level where patients must live" (p. 307). The body's ability to illuminate our 'common humanity' may lend insight into ways a researcher comports his or her body and manages intercorporeal dimensions (to the extent possible) when entering a research setting. As I discussed in manuscript four, there were aspects of my body that I could not change (my age, my gender, my race), which shaped the way in which participants responded to me, the stories they shared, and the interpretive findings that emerged. However, upon reflection, there are several aspects of my bodily presence and intercorporeality that I could control in the research context, such as: my attire, the spatial orientation between myself and the participant (are we at eye level, directly facing each other), the degree of eye-contact, the tone of my voice, my posture, and my facial expressions (smiling, nodding, etc.). The extent to which these bodily aspects impacted the findings and my relationship with the participants is difficult to discern; however, I suspect that they may have influenced the degree of rapport that arose with my participants. As introduced in Appendix A (interview logistics), rapport is described as an interactive experience associated with feelings of empathy, understanding, and collaboration (Gaglio, Nelson, & King, 2006; Springwood & King, 2001; Wood, 2001). Researchers aim to develop rapport as a means to manage power dynamics often inherent in participant/researcher relationships (Gaglio et al., 2006; Magolda, 2000; Sherif, 2001; Thomas & Pollio, 2002). The body can impact the relationship between the researcher and participant, and can influence what emerges in the interview process (Burns, 2003). For instance, if a participant noticed that I was looking down or away or presenting a blank stare, this might have been interpreted as a lack of attention or interest. This could lead a participant to deem that what he or she was saying was boring, irrelevant, or not what I wanted to hear, and potentially result in a premature closure to the discussion or to a ‘thin’ account (as opposed to a thick description) of the experience. Attention to the body and a consideration of what researchers can and cannot control in regard to their bodies has the potential to assist researchers in developing positive rapport, and subsequently enhancing the potential to gather rich data.

These two methodological insights related to embodied research – the potential for important meanings to manifest through a participant’s body and the potential benefit of enhanced awareness of the researcher’s body – have implications for research design. I suggest that qualitative researchers might consider ways to collect data that attend to the body (i.e. research designs and field notes that focus on the body, video recordings, body mapping or third party observations) to optimize the collection of data concerning the lived body. As I suggest later it is difficult to juggle attention to multiple bodily perspectives in a single interview, which might potentially render missed opportunities for valuable data. Finding a second set of ‘eyes’ might be one solution.

In summary, this section discussed methodological insights in regard to embodied research. The potential value of an embodied approach to research has been explored and presented in manuscript four. I further propose that attention to embodiment in the research process may illuminate how data about occupation can be conveyed through the bodies of participants during interview sessions. I also propose that attention to the researcher’s body and intercorporal dimensions may potentially help researchers develop rapport and optimize possibilities for gathering rich data. Further scholarly dialogue and research concerning ways to investigate the lived body and attend to the body in research designs and settings are recommended.

Five Quality Criteria

At the end of a research study, the researcher, the reviewers and the readers are faced with the question: Was this study any good? I propose five quality criteria to help respond to this question in the context of the current study.

Researchers have typically articulated notions of rigor that propose if certain standards are met, the research can confidently be deemed to have been well executed. Qualitative researchers have begun to articulate particular standards of rigor and their applications to a growing range of qualitative methodologies. Unlike quantitative methodologies, the scholarly conversation concerning how to assess the quality of qualitative research is less well developed, which may contribute to the perceptions that qualitative work is ‘soft’ and ‘unscientific’ (Hesse-Biber & Leavy, 2004). The methodological conversation concerning what constitutes quality is particularly relevant for the study of human occupation, where qualitative research is on the rise (Clark, 2006; Molke, Laliberte Rudman & Polatajko, 2004; Wilcock, 2003).

There are few resources that guide phenomenological researchers about how to assess the quality of a study. In my search for guidance regarding rigor and phenomenological research, the few quality criteria guidelines available (Annells, 1999; Giorgi & Giorgi, 2003; Thomas & Pollio, 2002) were not deemed a suitable fit due to implicit tensions between these guidelines and the aims of the phenomenological tradition. These tensions included: the appropriateness of drawing on language that parallels those used to assess rigor in quantitative research (i.e. terms such as generalizability); post-positivistic remnants and underpinnings; and the degree of comprehensiveness. The last tension refers to the idea that qualitative criteria are often solely concerned with the question of whether a study is a rigorous study. In this work, however, I aimed to attend to both the rigor of the study, and the question of whether the study was reflective of good *phenomenological* work.

With respect to rigor in qualitative research, Sandelowski (1993) suggests that, "rigor is less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work" (p. 2). In light of this spirit, I drew on the insights and lessons of several phenomenological researchers regarding research quality (Benner, 1994b; Giorgi & Giorgi, 2003; Smythe, Ironside, Sims, Swenson, & Spence, 2008; Thomas & Pollio, 2002; van Manen, 1997) and the contributions of other qualitative research scholars (Sandelowski, 1993, 2002; Schwandt, 1994) to consider the degree of methodological adherence to the phenomenological tradition when considering how to attend to the quality of my work. I propose five criteria by which to judge the quality of the research: comprehensiveness of the data; transparency of the research process; the phenomenological nod; a critically reflexive lens; and the fruitfulness of the findings. I offer these quality criteria as one developing framework, and provide examples of how they were attended to in the research process.

Comprehensiveness of the Data: Were In-depth Understandings Achieved?

Phenomenological researchers aim to gather rich and in-depth data, what anthropologist Clifford Geertz (1973) classically described as 'thick description.' Thick descriptions do not merely detail the actions and behaviors of participants, but also the contexts in which these occur. Geertz draws on an example by Ryle, to make obvious that while the single action of a wink can be described as a contraction of the eyelid (thin description), the context in which the wink occurs can make a vast difference to any interpretations of the meaning of the wink; whether the wink is simply a twitch, a communicative act, or a parody of another, more is learned about the action through thick descriptions that shed light on the context in which the action occurs. What is of interest is the meaning behind the phenomenon, whether it is a wink, the experience of grief, or the lived experience of occupation at end-of-life. Thick descriptions are important in helping to elicit or gain enhanced understanding – or *verstehen* - of the lived experience (van Manen, 1997). In terms of phenomenological inquiry, van Manen (1997) suggests that:

> Interview material that is skimpy and that lacks sufficient concreteness in the form of stories, anecdotes, examples of experiences, etc., may be quite useless, tempting the researcher to indulge in over-interpretations, speculations, or an over-reliance on personal opinions and personal experiences. (p. 67)

Creating conditions that facilitated rich, in-depth data collection, and that fostered participants' capacity to render thick descriptions, was considered important for attending to the comprehensiveness of the data. This was attended to in the study design in two ways. First, I aimed to recruit a sufficient number of participants according to the guidance of phenomenological scholars. More specifically, Thomas and Pollio's (2002) suggestion that an adequate sample size can range from 6-12 descriptive accounts was followed, with the understanding that the number could have been adjusted as the study unfolded. It was hoped that the variations in the participants' lived accounts would help me identify key structures in their experiences. Second, the interview process spanned two or more separate sessions, with time in between for both myself and the participants to reflect on new horizons of understanding in order to revisit these in future sessions. Past interviews often served as starting points for further data collection (i.e. "The last time we spoke, you mentioned your cat Jade. Tell me more about her"). It is important to note that the purpose of multiple interviews was not to member check or validate a participant's response but rather to seek elaborations and more comprehensive understandings. Member checking is not recommended in phenomenological research; one reason why, as Sandelowski (2002) points out, is that participants may "forget what they have said, regret what they have said, feel compelled to agree with researchers, or, as we all do, have the need to present themselves in different ways at different times" (p. 108). Similarly, Smythe et al. (2008) draw on Heidegger's notion of 'thisness' to emphasize our 'in-the-midst' state of being during the research process. An effort was made to recognize that what was said in each interview was said in that moment, in that particular time and place, and to seek more comprehensive understandings in each session. Conducting multiple interview sessions over a span of time offered opportunities to gather rich and thick phenomenological accounts, and to attend to what I propose as the first quality criteria of the research - comprehensiveness of the data.

Transparency of the Research Process: Can the Reader Understand How the Interpretations Were Reached?

Qualitative researchers often aim to be as transparent as possible throughout the research process by providing notes about the conduct of the study, comparable to what other researchers refer to as an 'audit trail' (Patton, 2001). I propose transparency as a second important criterion in phenomenological research. Transparency (to the extent possible) allows readers to judge whether the interpretive findings were appropriate given the context in which the research occurred. In the context of data analysis in qualitative research, Schwandt (1994) suggests that:

> The interpretation or decision one makes cannot properly be said to be verifiable or testable. Rather, at best, we can appraise the interpretation by applying norms or

> criteria that are compatible with the very condition that demands we interpret in the first place. (p. 122)

Given the interpretive nature of qualitative inquiry, it is important not to overlook the context bounding the study. Being as transparent as possible about the context of the study may help the researcher to better contextualize his or her interpretations, and the reader to better understand how the interpretive findings were reached.

In phenomenological research, a transparent process allows the reader to determine whether "'convincing evidence' has been brought forth in favor of the description offered" (Thomas & Pollio, 2002, p. 41). In this study, I documented the conditions and contexts in which the research took place through field notes and journaling, striving to make note of as many details as I could. In writing up this research, I made efforts to situate myself as a researcher in relation to the study, to articulate my personal and theoretical perspectives, to be explicit about the context in which the study occurred, and to offer sufficient detail in outlining how the study was carried out. Although publication word limitations restrict the degree of detail that can be conveyed within a manuscript, the feedback of scholars with extensive publishing experience, such as my supervisor, thesis committee members and the reviewers and editors of my manuscripts, was helpful to identify and respond to gaps in the transparency of my work. Efforts to be transparent in the research process do not imply that every reader will necessarily agree with the choices and interpretations I made, but rather that he or she is able to, at minimum, understand and hopefully appreciate how I came to my findings (Thomas & Pollio, 2002).

The Phenomenological Nod: Do the Findings Resonate for the Reader?

The ‘phenomenological nod’ is proposed as a third quality criterion. The phenomenological nod occurs to the extent that the research findings are ‘validated’ by the reader (Thomas & Pollio, 2002). Validation is not used in the same sense as it is typically adopted in experimentalist research (that the findings are cogent, justifiable and ‘true’); rather validation is considered according to the possibility that a participant’s experience could be the reader’s experience (van Manen, 1997), that the researcher is able to effectively convey interpretive findings that hold the thinking of the reader in a way that calls them both to wonder (Smythe et al., 2008). This is seen in the phenomenological nod: “a way of indicating that a good phenomenological description is something that we can nod to, recognizing it as an experience that we have had or could have had” (van Manen, 1997, p. 27). Smythe et al. (2008) refer to such understandings as “graced moments, when there is a shared sense of belonging to the insight that seems to go beyond what was said, yet is felt and understood as ‘being true’” (p. 1396).

What is of main concern is not whether the ‘true’ or ‘correct’ interpretation is achieved. Rather, the focus is on whether a legitimate interpretation amongst a plurality of possibilities is reached (van Manen, 1997). In other words an interpretation that rings true for the reader. According to Giorgi and Giorgi (2003), there are no ‘perfect’ descriptions, only accounts that are adequate or inadequate. These descriptions are meant to give rise to findings or meanings that resonate beyond the individual in the sense that they are typical, inter-subjective, and shared in character (Giorgi & Giorgi, 2003; van Manen, 1997).

The phenomenological nod was attended to in this research in two ways. First, I strove to engage in a thoughtful approach to interviewing. Efforts were made to be attentive and not fall prey to weak interview techniques or poorly crafted questions. For example, the interview guide was designed to begin questions with ‘what’ versus ‘why’ to elicit descriptive responses, versus facts and opinions (Thomas & Pollio, 2002). In striving to portray my understanding, I frequently tried to reflect back what the participants communicated through paraphrasing. Phrases such as ‘I hear you are saying that…’ and ‘As I understand it…’ were used to confirm the participants’ descriptive accounts. This also helped to ensure that the findings were deemed to be an authentic interpretation of the participants’ accounts. According to Benner (1994a), a successful interpretation is realized when the participant is able to say, “You have put into words what I have always known, but did not have the words to express” (p. xviii).

Second, in efforts to elicit the phenomenological nod, I strove to remain faithful to the participants’ lived accounts by focusing on their words in the analysis process and using these as the heart of the representation of the findings. Efforts to stay true to the participants’ accounts were attended to in two ways. First, I tried to fairly represent the participants’ intentions, as I understood them, within the contexts in which they were shared. Frank (2001) recalls a friend who participated in a qualitative study, and the feelings of disrespect she encountered when she saw the fragmented portrayal of her narrative. I remembered this story during my analysis process, and aimed to the best of my ability to maintain the integrity of the participants’ accounts; special care was taken to this end, particularly in situations where the degree of detail needed to be sacrificed (i.e. publication word limitations). Second, as I alluded to earlier, I recognized that particular wording had specific purposes and specific meanings at the moment of the utterance, and that such meaning might well be different in a different context. As Bakhtin (1981) states:

> If we imagine the intention of such a word, that is, its *directionality toward the object*, in the form of a ray of light, then the living and unrepeatable play of colors and light on the facets of the image that it constructs can be explained…as its spectral dispersion in an atmosphere filled with the alien words, value judgments and accents through which the ray passes on its way toward the object, the social atmosphere of the word, the atmosphere that surrounds the object, making the facets of the image sparkle. (p. 277)

Bakhtin emphasizes the uniqueness of what occurs in dialogue, the impossibility of replicating what results in dialogue, and the significance that utterances have, in harmony or dissonance, with the broader climate of the time. In recognition of the significance of utterances in the moment, I did my best to honor the participants' words in the final text, by staying close to the language they used, and resisting the urge to transpose or stratify their descriptive accounts with flowery embellishments or academic jargon.

Therefore, the phenomenological nod was attended to by being mindful to use careful questioning to elicit good phenomenological descriptions, as well as faithfulness to an authentic portrayal of the participants' lived accounts as I came to understand them.

A Critically Reflexive Lens: Do the Interpretations Bring New Insights into the Everyday Experience?

As stated in manuscript two, Crotty (1998) suggests that phenomenology in its original version was inherently critical in nature, even if modern variations of the tradition have become less so. The early phenomenologists, such as Husserl (1990/1907) and Heidegger (1927/2008), stressed the importance of critically examining the intentional threads that tie us to a meaning-rich world. Phenomenology is critical to the extent that it is concerned with a 'first critique' of preconceived interpretations of meanings and is suspicious of the meanings bequeathed by culture (Crotty, 1998). Doyle (2001b) notes that "phenomenology has always positioned itself as the philosophy on the edge, the philosophy which will name the 'as yet unnameable' or the 'unthought'" (p. xvi).

A challenge in conducting phenomenological research is not that we know too little about the phenomenon, but that we know too much (van Manen, 1997), and that this knowing becomes taken for granted and informs our interpretations of the world. Adopting a critical perspective within phenomenology involves illuminating and critically reflecting on these culturally ascribed assumptions. As Smythe et al. (2008) suggest:

> If we can free ourselves from the noise that tells us all that is already known as information then we may find ourselves amidst the clearing, the open space where thoughts are free to play and roam, where fresh insights emerge, shyly. (p. 1391)

One of the aims of phenomenological research is to challenge taken for granted views, by eliciting insights that will help identify "sources of innovation and liberation within everyday practices" (Benner, 1994b, p. 123).

In terms of my research, I aimed to make my prejudgments and taken for granted views on end-of-life, death and dying, and human occupation explicit. I aimed not to be unthinkingly swayed by normative cultural assumptions, being cautious, as Finlay (2003) suggests, not to allow these to predominate in the analysis of the research findings. Rather, I attempted to be mindful and to adopt a critically reflexive lens as the research unfolded (Finlay, 2003; Giorgi & Giorgi, 2003). I strove to maintain a suspicious and skeptical awareness of my position in the research process, and to be aware of my situatedness as an interpreter of the stories I heard. I also engaged in reflexive journaling throughout the research process, to reflect on how previous learning and experiences have influenced the way that I have come to understand the world, and death and dying. Maintaining a critically reflexive lens helped shed light on my assumptions, illuminating how these assumptions informed and directed taken for granted interpretive positions, and hopefully helped elicit new insights and interpretive possibilities.

It is important to note that the reader has a critical role to play as well. According to Benner (1994a), “the reader plays an active role in critically reading the interpretive work, judging the textual evidence presented by the author, and judging the interpretation against the reader’s own knowledge of the subject and text including aesthetic appreciation” (p. xvii). Therefore, critical insights do not end when the findings are written, bound and circulated, but may continue with every new reading.

While phenomenology as ‘first critique’ holds promise for human inquiry, this research did not begin with a critical perspective in mind. Rather, the purpose of this study was to investigate the phenomenon at hand. However, the findings of this work open avenues for critique of current practices and for further research located in a more overtly critical perspective. For example, stories of the lived experience of occupation at end-of-life challenge a rehabilitative orientation to services in end-of-life care. The significance of relationships and the importance of existential concerns to the participants suggest that care at end-of-life might be reoriented to encompass these more nuanced occupational dimensions. However, being responsive to clients’ relational and existential needs at end-of-life may lead practitioners to engage in what Fleming and Mattingly (1994) refer to as underground practices, relational practices that may not be documented in clinical charts because these approaches are not deemed as ‘legitimate’ care within biomedical discourses of care. Further research that examines ‘underground practice’ in the context of end-of-life care, and the ways in which such practices may indeed be meeting important needs of clients is required. In this study, the first hand phenomenological accounts of people at end-of-life have potential to contest taken for granted assumptions about the rehabilitative culture in which end-of-life services are often organized. Therefore, phenomenological work does not end at the individual, but can reveal deep insights about individual and possibly collective experiences that may challenge taken for granted cultural norms.

Fruitfulness of the Findings: Are the Interpretive Insights Useful?

Finally, the findings of the research must have some relevance or fruitfulness. As van Manen (2007) states:

> In doing phenomenological research, the aim is not to create technical intellectual tools or prescriptive models for telling us what to do or how to do something. Rather, a phenomenology of practice aims to open up possibilities for creating formative relations between being and acting, between who we are and how we act, between thoughtfulness and tact. (p. 12)

Here it is important to note that interpretive work has often been charged with being solely case-oriented and ungeneralizable. Yet in phenomenology, the idea of generalizability is viewed as inherently impossible given that no two lived experiences, no two horizons of meaning have been shaped and generated in exactly the same way. The fact that phenomenological findings may not be generalizable however does not mean that they may not have fruitful, transferable or practical implications.

Benner (1994a,b) suggests that the aim of phenomenological research to advance understanding is powerful because it is fully engaged in the human world. She notes that interpretive insights can impact human action and behavior in practical ways: “interpretive phenomenology does have a major role to play in public policy by its power to make the concerns, voice, habits, and practices of people visible and in recommending public policy that is attentive to differences and concerns" (Benner, 1994b, p. 123). Therefore, it is a mistake to assume that phenomenological work has no real applications in the world, as it is deeply situated within it. To deem phenomenological findings as irrelevant is to undermine the capacity of authentic lived experience to shed light on the lived world.

For instance, fruitful findings from this study are being disseminated through conference presentations, publications, and through participation in a draft of the Canadian Association of Occupational Therapists' position statement on end-of-life. By disseminating the research findings to occupational therapists and occupational scientists and practitioners working in end-of-life care, it is hoped that changes in practices related to occupation at end-of-life may occur by those who think deeply about the findings. In addition, it is hoped that deeper understandings about phenomenological inquiry and embodied research will be advanced through publications and presentations directed to occupational scientists and other qualitative researchers.

In terms of fruitfulness and dissemination of the research, two manuscripts have been accepted to academic journals (*The Canadian Journal of Occupational Therapy* and *The Journal of Occupational Science*). Another manuscript is in press as a book chapter in *Creative spaces for qualitative researching…Living research*. The findings of this study have also been presented at: the World Federation of Occupational Therapists 2010 Conference in Santiago, Chile (*Sharing the World of Occupation from Latin America*); the Canadian Society of Occupational Scientists and Society for the Study of Occupation (SSO) Joint Occupational Science Conference 2010 (*Redefining Boundaries and Bridges* *in Occupation*); and the Ontario Long Term Care Association Applied Research Education Day 2010 (*Quality End-of-life Care in Long Term Care*). I am also currently revising the Canadian Association of Occupational Therapists Position Statement on End-of-Life, which will have practical relevance for guiding the practice of occupational therapists in this area.

Summary

In summary, five criteria for assessing quality in phenomenological research have been proposed and attended to in this study. These include the comprehensiveness of the data, transparency of the research process, the phenomenological nod, a critically reflexive lens, and the fruitfulness of the findings. In the next section, ethical considerations for the research are considered.

Ethical Considerations in Research at End-of-Life

In this section, I discuss two ethical issues for consideration when conducting research with people at end-of-life: the recognition that terminally ill individuals are vulnerable and the issue of letting go in the researcher/participant relationship.

Terminally Ill Individuals as Vulnerable

An important and frequently cited ethical tension in regard to end-of-life research must be addressed; the question of whether it is appropriate to engage in research that includes people who are terminally ill. This stems from the recognition that people at end-of-life are deemed a ‘vulnerable’ population. What constitutes a vulnerable population, from a research standpoint, is whether potential participants are “unable or less able to protect their own interests” (Hawryluck, 2004, p. 225). Concerns have been raised in the literature regarding a terminally ill person’s ability to fully appreciate what research participation involves, often due to uncontrolled pain or distressing symptoms that may affect their quality of life and subsequently their decision making capacity (Hawryluck, 2004). Other concerns are related to the risk of causing unnecessary exhaustion or involving participants during a time when they are preoccupied with many emotional and stressful end-of-life issues (Lawton, 2001). There are those who strongly oppose the inclusion of terminally ill research participants. For example, George Annas (1996), a professor of health law, bioethics and human rights, states that, "terminally ill subjects with less than 6 months to live should be disqualified from human subjects research. Desperate, and therefore, too vulnerable, they are unable to distinguish research from treatment" (as cited in Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006, p. 406). However, on the other side of the debate, there is growing literature that argues that a marked exclusion of people at end-of-life from research may also be unethical (Fine, 2003). In addition, there is evidence that people at end-of-life want to be involved as participants in research, or at least given the choice as to whether to be involved or not (Addington-Hall, 2002; Tuffrey-Wijne, Bernal, & Hollins, 2008). Hospice participants in a study by Terry et al. (2006) stated that they felt it was very important to include the perspectives of patients and their caregivers, particularly with respect to informing effective end-of-life services. Some of the participants stated that participation in end-of-life research allowed them to give back: "Not everyone gets the chance to know when they are dying, so I say yes let me help" (p. 408), and that they wanted to continue to participate in meaningful activities: "I think people forget that we are still people, with lives outside of being the dying person" (p. 408). Some participants indicated that they were aware that research at end-of-life could benefit others: "when you get this far you need things to be proper, and if there is no research here it could be terrible" (p. 409). Other potential benefits of participation identified in the literature include the potential therapeutic effects that research can have on dying persons and their families by eliciting feelings of purpose and meaning, and other perceived benefits such as companionship and the validation of being able to engage in a meaningful activity (Fine, 2003; Terry et al., 2006; Tuffrey-Wijne et al., 2008). The terminally ill participants in the study by Kendall et al. (2007) further reported that they preferred qualitative research methods, stating that they felt "these methods allow people to raise and contextualise issues important to them" (p. 3).

In this doctoral study, all of the participants conveyed their pleasure with being involved, and spoke about the opportunity to contribute, using such phrases as "I did enjoy this, talking to you…I hope you get some use out of it and...that some people will get some use out of it too" (Jim) and "It's been a pleasure discussing things with you" (PJ) and "I hope it helped you out" (Sarah). The pleasure and validation that this study appeared to elicit in participants was reciprocated; engaging with these eight individuals, being welcomed into their homes and bearing witness to their stories was truly my honor.

In summary, those with an interest in undertaking research with people at end-of-life are encouraged to be aware of the potential ethical issues in working with this population. I suggest that it is important not to discount this population, but rather to be vigilant about potential ethical issues with persons at this stage of life, and to be sensitive with respect to such issues in the research design. Questions that researchers might consider include: What is the approximate life expectancy of the participants I would like to recruit? How will I accommodate their unique needs (i.e. fatigue, emotional issues and distress)? How will I respond if/when a participant becomes distressed? Am I fully aware of the potential risks and benefits that the participant might incur? How will I honour, in an ethical manner, the stories that participants share with me? And how will I be respectful of the limited time they may have left?

Researcher/Participant Relationships: Letting Go

One ethical tension I faced in this study was the experience of letting go of my relationship with participants. From an ethical standpoint, research participants are not to be contacted once the contractual agreements regarding participation in the study have ended. While I understand the logistical purposes of this ethical guideline, I question whether it infringes on the human side of the experience. There was something about connecting with these participants, being privy to deep and personal details, becoming ‘someone’ of significance in their lives and then abruptly cutting off the relationships that felt unnatural. I felt that this was not a one-sided discomfort, but that it was a disappointment for some the participants as well. For example, when I mentioned that I would like to come back one last time to wrap up the interview with Cali, her disappointment was evident in her tone when she responded “Oh, just one last time?” I also received open invitations to visit David any time I was in the neighbourhood, even after I expressed that I was ethically unable to do so. While I did my best to find a sense of closure, making sure to express my immense gratitude for their participation and, with some participants, a hug or handshake goodbye, I felt sadness and regret as I walked away. Perhaps it was knowing that not only would I likely never see them again, but also that they would die in the upcoming months. I often wonder whether my participants are still alive and living well. While the purpose of ending the research relationship is founded on the precaution to do no harm and the desire to not inflict any sense of obligation, coercion or violation of privacy, I wonder whether this could backfire. I wonder about the possible negative consequences of abruptly letting go of relationships that inevitably unfold during the research process, and the feelings of abandonment such actions might instill.

These two ethical issues raise important considerations for any researcher with an interest in engaging in end-of-life research. If one is comfortable with recruiting people who are terminally ill, one must be prepared to encounter those who are not, which might potentially result in the methodological challenge of gate-keeping (discussed shortly). One might also consider ways to gain a sense of closure when letting go of relationships with the participants, and ways to ensure that letting go does not have its own, inherent negative effects on all involved in the study.

Methodological Considerations

At this point in the doctoral process I have presented findings that I hope will foster further research surrounding occupation at end-of-life. This has also led me to revisit some of the methodologically difficult moments in the research process and to articulate some reflections and caveats that I encountered in case this is helpful to other scholars interested in embarking on end-of-life inquiry. In the next section I discuss some of the insights that I have gained that I wish I could have known as the more eager and naïve Anna who embarked on this journey. These include reflections about gate-keeping, participant attrition, the emotional intensity involved in end-of-life research, the use of language, and the challenges of wearing many hats. In addition, I reflect on limitations and strengths of the study and areas for future research.

Gate-keeping

One of the barriers that researchers might face in participant recruitment at end-of-life is gate-keeping. Scholars have identified rigorous gate-keeping from both ethics boards and healthcare personnel in terms of participant recruitment with this population (Ewing, Roger Barclay, McCabe, Martin & Todd, 2004; Jordhoy, Kaasa, Fayers, Ovreness, Underland, & Ahlner-Elmqvist, 1999; Kendall et al., 2007; Raudonis, 1992). The gate-keeping by health care personnel raises a bit of a conundrum. On the one hand it seems more sensitive to introduce a patient to a potential research project through someone in his or her circle of care; on the other hand, professional intermediaries may serve as barriers to recruitment, even before the participant is approached. My search for participants was, at times, disheartening. I met with an extensive number of health professionals (approximately 25+) from a number of health care settings (hospitals, community care organizations, hospices) to discuss my study and seek interested professional intermediaries. While the vast majority acknowledged the value of my work, only six actively recruited participants on my behalf. I encountered one particularly challenging networking experience, where setting up a single meeting with an important person in the ethics process involved several emails and phone calls over the span of three months. Overall, while I managed to recruit a sufficient number of participants to my study, I did not anticipate the length of time or the degree of investment it would take to reach this goal. Potential challenges with gate-keeping and an extended participant recruitment process might be an issue for other researchers to consider in their study design.

Participant Attrition

The potential for participant attrition is greater when engaging in research with terminally ill participants due to the nature of their illnesses. Thankfully, none of the eight individuals recruited to my study requested to withdraw from the study, nor did any of the participants pass away during my time with them. Nonetheless one potential participant who agreed to be contacted died before I was able to meet her. I recall sitting in Starbucks, drinking a ginger tea and eating a pumpkin loaf when I received a call from this woman's daughter-in-law, bearing the news. I remember feeling guilty, to burden the family with the need to return my phone call at this time. I reflected:

> I am left with an open, unfinished feeling. Who was participant seven? What was she like? Was someone with her when she died? Did she die well? Was she able to find meaning in her final days?...It's funny that I feel imprinted by her death, and yet I didn't know her at all. I knew this situation was a possibility and yet I'm still caught off guard.

Several health professionals warned me of the unpredictable and idiosyncratic nature of terminal illnesses. Physicians and health care practitioners often do not provide an exact time-line of life expectancy because of this variability. I suggest that researchers working with people at end-of-life bear in mind the risk of attrition, and consider the ways in which they prepare for the potential loss of participants during the research process.

Emotional Intensity

As manuscript one revealed, the emotional intensity involved in working with people who are terminally ill is an issue of concern, particularly for students and inexperienced practitioners (Cipriani, et al., 2000; Prochnau, Liu, & Boman, 2003; Warne & Hoppes, 2009). In light of this literature and my past, personal experiences with death and dying, I made several efforts to prepare for emotional situations in the interview process, and to be attentive to my own emotional needs.

I prepared myself for potential emotional situations in interviews by (a) bringing boxed tissues to the interviews, (b) embodying a caring, respectful, genuine and sensitive demeanor, (c) offering to terminate interviews or participation in the study if it appeared that involvement was causing severe emotional distress, and (d) bringing a list of local end-of-life support services in case they were required. It is important and validating for me as a researcher to note that none of the participants requested to be withdrawn from the study, nor did they communicate the desire to terminate an interview during emotional moments. During emotional moments, out of respect for privacy, the recorder was turned off, and the participants were given time to cry and compose themselves. In these moments, participants were asked whether they wished to complete the interview another day, however they all verbally indicated that they desired to carry on.

One question that frequently arises when I share my work is how I took care of myself emotionally. Throughout the research process, I engaged in reflexive journaling, debriefing with my supervisor, and taking care to rest between sessions. I also found relaxation and balance through the support of my husband, family and friends. However, I found myself surprised by the nature of the emotions that I witnessed and experienced throughout the interview process. I can attest that some participants experienced extremely sad end-of-life experiences, which elicited feelings of empathy, sorrow and fear. However, I also felt deeply privileged to bear witness to some equally beautiful accounts and memories from each participant, stories so filled with joy and love that they seemed almost tangible. In the time I spent with my participants, I cried only once during an interview with Jim; I was unable to hold back my tears when Jim began to talk about his wife and how, “without her, life wouldn’t be worth it.” This interview segment brings tears to my eyes every time I review it, and I have struggled to hold back my emotions when I share it at conferences. Yes, end-of-life research might harbor heartbreak and distress, but researchers are also encouraged to be prepared to be struck to the core by words so poignant and stories so stirring that you catch yourself holding your breath. There is much joy and beauty at end-of-life, even though you know how the story ends.

Language Use at End-of-Life

Another methodological reflection surrounds language use at end-of-life, and the static nature of textual data. In terms of end-of-life language and communication, certain terms and phrases can foster ambiguity. When meeting with different professional intermediaries, it became apparent that the phrase ‘life expectancy of one and half years or less’ in my inclusion criteria was somewhat awkward and posed some difficulty in regard to identifying eligible patients. It became more convenient to adopt health-care terminology, drawing on a clinical assessment tool used to assess and monitor a patient’s functional status at end-of-life, the Palliative Performance Scale (PPS) (See Appendix H). The PPS assesses a patient according to five criteria: ambulation, activity and evidence of disease, self-care, intake (oral consumption), and conscious level. A patient who is independently functional without any evidence of disease would receive a score of 100 percent, whereas 0 percent represents death. The professional intermediaries suggested a range of 40-60 percent (referred to as the transitional stage) would help them identify patients appropriate for this study. From this point on, I used the phrase ‘life expectancy of one and a half years or less’ when I broached the study with new intermediaries in the community, and drew on the PPS if this terminology appeared unclear. Second, one of the challenges I faced was how to incorporate the language of death and dying into the letter of information. Engaging with the literature surrounding death and dying, particularly from occupational and sociological perspectives, led me to use death and dying terminology with ease and in a purposeful way. I thought that doing so would help avoid participating in a death denial attitude. However, my meetings with a few palliative care practitioners in the community raised my awareness of the loaded nature of these terms, and their suggestions helped me to rework my letter of information in a more sensitive manner. For example, one physician recommended the term ‘advanced illness’ in place of terms such as ‘terminal’ or ‘dying.’ Given that I was recruiting people with terminal illnesses, using the term ‘end-of-life’ was unavoidable. I reflected in my field notes that even the phrase ‘end-of-life’ caught the participants’ attention while reading the letter of information. One participant, who asked that I read the letter to her, stopped me when I got to those words. She asked me to repeat the sentence and after a moment of silence, said “Oh, yes, I suppose, I suppose that I am, um, there” and noted that she was no longer young. In some ways, it seemed that term ‘end-of-life’ marked or labeled these participants as ‘people who were dying’ versus ‘people who were living.’ From a research standpoint, I wonder how this assertion could have been avoided, knowing that if an opposite approach was broached (not using death and dying terminology at all), it may violate the notion of informed consent.

The static nature of textual data was a second conundrum related to the complexity of everyday language and communication. For example, transcribed interview texts do not reveal changes or emphasis in intonation or bodily gestures, which can greatly impact the interpretation of the interview. I reflected that the term ‘mmhmm’ is complex and has multiple purposes, such as to convey a sense of affirmation or to express agreement, to indicate that you are listening, to encourage the participant to go on, and even to convey a question (mmhmm?). I realized too late the multiple meanings inherent in a single verbal expression. If I could transcribe the data again, I would try to textually indicate the different kinds of ‘mmhmm,’ particularly when they shaped the direction of the interview. Over time, I also noticed that ‘mmhmm’s’ often broke up the flow of a participant’s descriptive account and I learned to nod in place of mmhmm’s to demonstrate that I was listening. Further, if I could do the study over again, I would include in the ethics process a proposal to publicly share audio-recordings of the participants’ accounts to enhance the power and depth of the messages they shared. My verbal re-counts of the participants’ original words do not seem to do them justice.

Wearing Many Hats

Another methodological reflection is in regard to the difficulty I experienced in wearing different theoretical hats in the research process, and the difficulty representing these different perspectives as one coherent whole. I designed this study to investigate one particular phenomenon: the embodied nature of occupation at end-of-life. This required wearing theoretically informed hats that were refined to be attentive to:

a) the participant’s lived experience of occupation
b) four occupationally oriented dimensions (doing, being, becoming, belonging)
c) four lived existentials (lived time, lived space, lived relations, lived body)
d) and embodied practices in everyday life.

The embodied phenomenological hat was further complicated in that it required an attentiveness to the participant's experience of embodiment at end-of-life, the participant as well as the researcher's embodiment in the research process, and the dynamic, intercorporeal relations between them. Each of these hats was drawn upon with the thought that together, they would offer a rich perspective with which to examine the central phenomenon of interest.

Wearing different hats was a juggling act in the data collection process. I learned quickly that interviewing is an exhausting process! At no time was my mind able to rest or wander while engaged in a dialogic exchange. Being present in the interview seemed to require more than a double attention (Wengraf, 2001); rather, the attentive skill required in the interview process was all encompassing, requiring all my senses to be vigilantly on guard. I was forced to learn quickly how to intuitively draw on different hats to elicit descriptive accounts, aware that this is a skill that is developed over time and with experience. I often wonder if my interview experience with my first participant would have been different if it was informed by what I had learned and gained by my last.

The data were analyzed from different theoretically informed perspectives, each of which offered a useful medium through which to organize the chaos of raw interview transcripts. However, it became evident that trying to write a single paper that was able to attend to the quantity of data that emerged from each perspective was extremely difficult, particularly given the word limitations outlined by publication guidelines. As a result, manuscript four emerged as an extra paper, one that was able to engage in a deeper way with the embodied dimensions of both the participants' and the researcher's experiences.

A second findings paper offered freedom to explore and present important insights about the body that could not practically be offered in manuscript three.

There is potential that without careful and rigorous planning in the study design, a researcher might face difficulty reconciling different theoretically informed perspectives. In my experience, being able to deeply delve into the occupational and phenomenological literature allowed me to consider ways in which these two theoretical perspectives can inform and enrich the other. While a specific research question was examined in this study, the quantity of data collected is teeming with further possibilities for scholarly work. I intend to revisit the data, drawing on different theoretical perspectives and sub-questions, to further contribute to knowledge about occupation at end-of-life.

Limitations of the Research

One potential limitation of the study is the degree of experience and expertise that I have as a novice researcher. I entered the doctoral program directly from a clinical masters degree, and with limited research experience. As such, I would characterize this dissertation process as one of learning; all that I have achieved and gained cannot be fully realized without acknowledging the ‘one step forward, two steps back’ process it took to finally arrive at this stage of the research. However, I cannot help but wonder if being a developing researcher might have its advantages. I wonder if being a student allowed opportunities to be more open, brave, experimental and maybe even creative than a seasoned researcher…or whether I am being optimistic in wondering this in the first place. Despite any advantages, there is potential that a more developed phenomenological scholar could have elicited more in-depth, descriptive accounts from the participants, and offered more insightful interpretive findings. Or could have, at minimum, completed this research with more efficiency and grace.

A second and significant contributing factor in my uphill phenomenological journey was the lack of methodological guidance available on how to conduct phenomenological research. As I stated in chapter three, there is no single understanding of what phenomenology as a philosophy or a methodology entails. This lack of methodological guidance and the breadth of philosophical possibilities leave a novice researcher with quite a swamp to wade through. I still question if I ‘stopped’ reading, ‘stopped’ analyzing and ‘stopped’ thinking at the right time (and whether I actually ‘stopped’ any of these, and if this right time even exists). It was a struggle to learn to balance the attention and immersion that phenomenological inquiry requires, with the practicalities of completing a dissertation in a timely manner.

In terms of phenomenological research, as I mentioned earlier, a commonly cited limitation is the generalizability of the findings. I have been explicit that the purpose of phenomenological research is not to present causal findings that can be replicated exactly in similar contexts, but rather to represent the lived experiences shared by participants in such a way that one could imagine it as one’s own. As such, the findings of this study are reflective of the stories I heard about the experiences of the eight participants. There is much to be learned from such stories that may be of practical value and may be transferable to other contexts.

Another potential limitation of the study is the limited demographic variability of participants, particularly in terms of cultural and ethnic backgrounds. I wonder how a broader range of cultural and ethnic backgrounds would impact the findings. This interest is rooted in my own experience as a Korean-Canadian woman, and first hand knowledge about how culture can impact end-of-life perspectives. This points to just one area of research regarding occupation at end-of-life that requires attention, given the diverse range of ethnicities in Canada.

Another potential limitation is the surplus of data that could not be represented in the manuscripts presented here. There were approximately 395 pages of transcribed data as a result of the end-of-life study. I intend to continue to work with further secondary analyses of the data.

Lastly, there were some limitations with respect to the compilation of an integrated manuscript style thesis. One challenge was the limitation on word count dictated by publication regulations; typical manuscript guidelines permitted submission ranging from 4000-5000 words. This was particularly challenging given the quantity of data that I gathered in this study. Further, each manuscript was shaped according to the audience it was intended for, and in collaboration with the feedback obtained from doctoral committee members, journal peer reviewers and editors. Integrating these different voices was at times a challenge, and may have influenced the representation of the thesis as a whole. Nonetheless, these limitations are acknowledged as part of the academic process, and are recognized as an important learning experience. I expect that if I had adopted a traditional monograph style thesis, numerous challenges of a different nature would be inevitable.

Strengths of the Research

One strength of the research is the depth of stories that participants shared with me, and the richness of the data. As I suggested earlier, rich and in-depth data are important for achieving rigor in phenomenological research. Positive reviews of the manuscript by dissertation committee members and blind peer reviewers suggest that the findings elicited the ‘phenomenological nod.’ It is hoped that other readers will see the plausibility of the stories represented in the findings.

Another strength is that the research is timely. Given gaps in the literature concerning occupation and end-of-life, particularly in light of changing Canadian demographics, this study contributes to knowledge in an area that has been under-researched in the occupation-based fields. In a time when occupational scientists are actively debating how to best study human occupation (Barber, 2006; Cutchin, Dickie & Humphry, 2006; Dickie, Cutchin & Humphry, 2006; Kinsella, in press; Kinsella & Whiteford, 2009; Larson, Wood & Clark, 2003; Molineux & Whiteford, 2006; Rudman et al., 2008), this study offers important theoretical contributions regarding phenomenology as a fruitful methodology and calls for dialogue concerning the merits of attending to embodiment in qualitative research practices.

A further strength is methodological. I was very fortunate to have the time to engage deeply with the phenomenological literature, knowing well that many other researchers do not have this luxury. I also received a great deal of support for my learning about phenomenological methodology throughout my doctoral experience in that I was guided by scholars with extensive expertise in this kind of research. Throughout my early studies, I was also a part of a phenomenology group with fellow doctoral classmates, where we were able to freely ask and discuss questions and issues about the conduct of phenomenological research (no matter how random or silly). I am indebted to these many supports for my development as a phenomenological researcher.

Another strength is the impact this study had on the people involved, particularly the researcher. While I cannot attest to this with certainty (it was never explicitly asked), I do feel confident that participation in this study offered participants a meaningful occupation at end-of-life. As I stated earlier, several participants expressed that they enjoyed my visits and the opportunity to contribute to research. I suspect that there are other Canadians who may feel they are unable to ‘do’ as much at end-of-life as at other times, like PJ who stated, “Well, I can’t do much, just sit and yak.” And yet the power and potential of ‘yakking’ together had many transformative impacts, both on a personal level and on a scholarly level (these will be elaborated in my personal reflections which are presented shortly), and hopefully the impact will move beyond the personal as others engage with the texts of the research. Becoming a part of my participants’ lives, and for them to be a part of mine even for a short period of time, resulted in changes I did not anticipate or expect. In this sense, I can say that this study made an impact on one fortunate person. I sleep well at night and look back on this experience with nothing but gratitude.

Possibilities for Future Research

The findings of this study point to a number of areas that call for further attention and research. With respect to occupation and end-of-life, the following topics are proposed as priorities for occupational scientists and occupational therapists. This list is clearly not exhaustive or reflective of the numerous tensions raised within the four manuscripts, but I offer them as important starting points for further research:

- I suggest that further research is required that directly addresses the question: In what ways do everyday occupations contribute to the good death? The current study examined the embodied nature of occupation at end-of-life, and points to ways that end-of-life care practices might be designed to foster meaningful experiences through occupation; however, research that specifically seeks to investigate the relationship of occupation to the ‘good death’ is suggested.

- The interview guide was informed by two theoretical frameworks: the four occupational dimensions of doing, being, becoming and belonging (Rebeiro et al., 2001; Whalley Hammell, 2004; Wilcock, 1998, 2006) and the four lived existentials of lived time, lived space, lived relations, and the lived body (van Manen, 1997). Further research is suggested that investigates how occupations in general, and occupations at end-of-life, are experienced in relation to each of these dimensions.
- Rapid changes in Canada’s demographic population, and the shift from institutional to community care, point to a need for further research that investigates occupational experiences in home and community contexts.
- I suggest that research is required that investigates the occupational experiences of other demographic groups diagnosed with terminal illness, such as children, teens and younger adults, whose voices appear to be missing in the end-of-life dialogue.
- Given that the end-of-life experience impacts not only the person dying, but also their families and caregivers as well, I propose that further research is required that attends to the occupational needs of caregivers and the bereaved.
- Given that relationships have been shown to elicit experiences of dignity at end-of-life, and relationships have been identified as overlooked in the end-of-life

discourse, I propose that further research is required that investigates relationships and relational care at end-of-life.

- I suggest that further research is required that investigates the ways that everyday occupations shape and contribute to existential meanings at end-of-life from the perspective of people who are terminally ill. Further investigation regarding existential considerations at end-of-life, particularly with respect to spirituality and *Being,* have the potential to inform what the ‘good death’ might look like.
- Lastly, I suggest that research is required that investigates more deeply the ways in which human occupations are embodied at end-of-life. It has been suggested that the typically unnoticed body comes to the fore in the illness experience, but how its presence is managed has not received due attention. The findings of this study suggest that the way people negotiate the ‘will of the body’ can impact how they structure their occupations at end-of-life.

Summary

Eight methodological reflections have been presented that illuminate some of the unexpected challenges that end-of-life researchers may encounter. Even though many efforts were made to be as prepared, sensitive, and attentive as possible, a number of methodological surprises materialized. It is my hope that my reflections on these issues further contribute to the transparency of the research process, and might be of interest and assistance to other researchers engaged in research with people at end-of-life.

Research as a Journey

I close this work with a few personal reflections on my engagement with this research. This research has been an enriching experience and has influenced my life in more ways than I ever expected.

Where I Have Been

When I began my work on the topic of end-of-life, I identified that one of the assumptions I brought into the research was that death at old age was justifiable and that knowing one has lived a long life contributes to a sense of peace with the whole notion of death. The most striking realization I have encountered is that death can be tragic at every age, and that older people still lead, and try to lead very meaningful lives. As Maggie stated:

> And you know...I used to think...that when an older person gets a fatal disease or a life threatening disease, 'Oh well' you know, 'they're old.'…but when you're that person, it hits you just the same because there's other things that you care about. You...still care about your children, and you still want to do things, you still want to be active, you still want to be contributing and stuff like this. And no it's not nearly as bad as younger people or people who have small children, that would be horrible. I don't know how I'd cope with that. I really don't. But just because a person is older doesn't mean that you know, they don't have issues too with a terminal disease. When they have loved ones that they don't want to leave and they've lived their life and…dreamt of doing some traveling and golfing and…you can't. That's a bit of a disappointment. So you have to find other things…But we seniors, we have issues too, when you're faced with a life threatening illness, it's just different issues.

The realization that death can be quite tragic, even at an older age has changed my outlook on my aging self. Although at times this insight evades me, I feel a more profound appreciation for my place in life, the purpose of my life, and the fragility of life. As this research progressed, I found myself seeking calm in stressful moments, reminding myself that 'this too shall pass' and not to take it all so seriously. Others might attribute this change to 'growing older' or to 'becoming more mature,' but I truly believe that the stories I heard through my experience of being with people who are dying offered deep insight into the importance of appreciating each moment. Being able to engage in lifeworld-oriented research, I learned first-hand what phenomenological research aims to elicit: that the lived experience of another person renders *possible* lived experiences for another.

A second assumption that I brought into the research was that death was always a dark and sad experience. As I shared in chapter one, my experience with death prior to this study was mainly from a pew-perspective, where I was donned in black, and expected to express nothing but sorrow. What these eight participants exposed me to is the beauty and tenderness that can be shared at end-of-life. When the opportunity is available, there is room for laughter, tears, release, appreciation, joy, affection and fulfillment; improving quality end-of-life experiences seems to involve finding ways to make these opportunities a reality versus a dream.

Where I Am Now

This study has impacted my way of being in everyday life. I share some reflections regarding a newfound need to prepare for death, an enhanced awareness of my own embodiment, and the need to write, write, write! I close with a few words detailing ‘what is next’ for me upon the completion of this work.

Preparing for the End

During this study, I became more aware of my lack of preparedness for my own death, and the eventual deaths of my loved ones. My journey in this research enacted a need for active change in my life. I became a driving force in helping to set up my parents’ will, persuaded my husband that we needed to invest in life insurance, and started to speak more openly about my parents wishes when they pass away. My mother, sisters and I had a frank talk about belongings that my mother wanted to pass on, and she showed us the few items my grandmother had already passed along to her. I was pleasantly surprised at how easy it was to talk about death; however, I wondered whether this was rooted in my experience with death and dying research or in the persistent feeling that it will happen sometime, in what seems forever away, in the future. I wonder if these changes would have occurred organically had I not been immersed in work that forced me to think about death everyday.

I am an Embodied Being

This research has led me to become more aware of my embodiment in everyday life. Consistent with the literature, the centrality of my body often became especially apparent during atypical life experiences. During my doctoral experience, I encountered an unfortunate accident with a pressure cooker that left me with small, second degree burns. I wrote in my journal about how this experience brought my body to the fore, how it changed my sense of lived time (the routine of caring for my burns, the time spent researching treatments and emailing medical friends for advice), of lived space (choosing to stay at home to avoid being outside in the sun), and my use of artifacts (using an umbrella when I ventured outdoors to shield my burns, and the confused gazes of strangers who wondered whether I had a clairvoyant sense of impending rain, if this act was out of vanity, or whether I was simply a strange or eccentric person). My perspective on this embodied experience was enhanced through my research; instead of merely going through the actions, I was able to reflect on some of the existential meanings this experience disturbed. The first time I inadvertently scratched a healing area, I realized that my body was receding back to its everyday way of being, almost as if I was re-entering the world through my body.

My body has also come to fore in recent months, as I am pregnant with my first child. I have never been so attentive to how I feel within my body. I relish in every new experience - deciphering first kicks, caressing my blossoming belly, and embracing the feeling of new life within me. For the first time in my life, I am experiencing the body not just as a vehicle for lived meanings, but as a vessel, a haven, and a home. I am in love with my body, for all its biological wonder and its intuitive ability to somehow know what to do next. And yet, I am also terrified of my body, aware of the lack of control I have in fending off the small possibility of its betrayal. How ironic, to be bringing life into the world and on the flip side, to be witnessing the end-of-life reflections of others, and facing illness and death as a growing reality amongst my loved ones. The circle of life has never been so blatantly clear.

Writing

As a scholar, I have become more attentive to the important need to write, write, write before the small and subtle details of my lived experience begins to fade. In retrospect, I wish that I had taken more care to balance my data collection process. If I could do it again, knowing now how much time and energy attentive writing can take, I would have spread out my data collection process more evenly so that I could include even more time to write in my journal. Many of the new insights drawn from this work emerged from my time journaling and writing my field notes.

My experience has also allowed me to become more attentive to the nuanced nature of lived experience. Last year, I wrote a journal entry when my best friend’s father passed away. I had encouraged her to write about her experience, suggesting that it might be cathartic. At the time, she felt too close to the moment and too emotionally raw. Instead I wrote about my perceptions of this death that struck so close to home. I became aware of my developing ability to perceive more of the nuanced details of such experience:

> *The death of my friend's father, a man who I have known for almost 20 years, occurred in the middle of my dissertation proposal process. Having some background on death-related theory, important constructs, important thinkers in the field, I found myself more perceptive of the smaller details, the loaded nature of what was said and done throughout the experience. The first time my friend called me after her father had passed, her voice was thick with sorrow and regret. She asked, "There must be a heaven, right? Where else would he be?" before dissolving into tears. Despite what I had learned these past several months, I found that I was at a loss for words; no word seemed to give this moment justice and no word had the power to elicit even the smallest comfort. At the visitation, she wailed, "He's so pale. He's more dead now than when I saw him before." She told me later that she now understood why people crawled into coffins, unable to physically let go. She told me that she had stroked his hands, his face and shook his clothes, begging him to get up. She said "He felt like my dad, but he was so cold, his body was so hard." They had to physically pull her away from his coffin. After hours of sobbing and when the line of visitors had ceased, her body was slumped with exhaustion, until the funeral director began to close her father's coffin. Her cries deafened the room: "He's not in there, my father can't be in there." Back at her home, she and her siblings mused that it was the most quiet they had ever seen their father. They described him as a noisy man, always puttering around, closing doors, breathing heavily, and rustling papers. "Even when he slept, he snored!" his daughter reminisced. After his body was cremated, my friend confided with me her regrets with the decision. She described the situation as unsettling in her heart, the transition from her father's body to take up such a big space, lying in a big coffin, to being reduced to ashes in a small ceramic box. She felt that she could not pray or speak to him in his new resting place, a peach-colored cubby, one of many that filled the wall of these new-aged tombs. We reflected on how these cubbies seemed like miniature apartments, some higher models with contemporary glass walls, decorated with keepsakes-flowers, cards, and pictures. She wondered if she should decorate her father's, as if he had moved into a new home.*

These observations differ vastly from my original journal entries that detail my first experiences with death in that my original writings focused heavily on feelings and surface observations. Over time my writing has become more attentive to the nuanced aspects of lived experience. Writing, which allows these experiences to become more tangible, is a skill I hope to continue to develop in my career, but also one that I hope continues to permeate into my everyday life as a means to witness important lived experiences.

What is Next?

I conclude this work with the question, ‘what is next?’ In terms of the research itself, I hope to continue to write and publish manuscripts from this study, and to disseminate the findings through presentations and public talks. Some ideas brewing for future papers include: quality criteria and phenomenological research, a case study on embodiment at end-of-life drawing on Jim’s experience, the role of spirituality and existential issues at end-of-life, and the significance of everyday artifacts in human occupation at end-of-life. I hope to continue to develop a research program surrounding occupation at end-of-life and phenomenology as a methodology. In preparing revisions for the Canadian Association of Occupational Therapists Position Statement on End-of-Life, the director of professional practice noted that she considered me an ‘expert’ in this topic given my experience with the literature. At a recent Joint Occupational Science Conference 2010, a student referred to me as a ‘phenomenological guru.’ In both instances, I wondered who the expert was standing behind me. The words ‘expert’ and ‘guru’ are reserved for much more experienced scholars, and did not seem appropriate given the ‘scholar in development’ hat I cannot seem to take off (and wonder if I ever will). I hope to share the little or the lot that I have come to know so that others can also reap the many benefits that I have gained from engaging in this research. Ideally, I would like to begin a movement to include some degree of palliative care education in the Canadian occupational therapy curricula, as it appears that students are the most disadvantaged in this practice area due to the lack of education and supports available, and due to their limited practice experience.

The immediate future holds great joy. Soon, my husband and I will welcome our new baby, a son, and I will wear a new and long-awaited ‘mother’ hat. I expect in the coming years, there will be many deaths and adversities that will touch my life. But I look to them with a renewed sense of strength and hope, armed with newfound skills that I expect will help me face these experiences with more confidence and from a perspective that looks for possibilities in small and overlooked moments.

In conclusion, I end with the following quotation from phenomenological researchers (Smythe et al., 2008) that poignantly articulate the purpose and promise of lifeworld inquiry:

> We offer our thinking in humility knowing it as good as could be, yet lacking. We will hope others will ‘think on,’ as we do ourselves. There is unlikely to be a ‘yes’ or ‘no’ answer amidst our findings but rather tentative suggestions, hints of possibilities, discussion to pen more questions to ‘wonder.’ This approach to researching is complex; every experience has layer upon layer of meaning embedded within it. No one will ever get to the bottom or some kind of Archimedean point-the truth that is ‘all-that-there-is’ once and for all. The complexity and mystery of what it means to be human will always have the last word. (p. 1391-2)

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APPENDIX A: STUDY DESIGN AND METHODS

Phenomenological Inquiry

The purpose of phenomenological inquiry is to illuminate taken for granted, mundane, and ordinary phenomenon through an investigation of first hand, lived experiences of that phenomenon. In phenomenological research, the inquirer is interested in the possibility that a participant's descriptive experience could be *our* experience (Benner, 1994; van Manen, 1997).

The methods involved in phenomenological inquiry are not a strictly laid out, agreed upon blueprint. Phenomenological research is an evolving process, requiring a degree of freedom and flexibility. As van Manen (1997) states, "a certain openness is required in human science research that allows for choosing directions and exploring techniques, procedures and sources that are not always foreseeable at the outset of a research project" (p. 162). The researcher might be compared to a sailor, who allows the flow of data to guide the direction of research, while at the same time navigating the course to eventually reach the destination, which is increased clarity about the phenomenon being investigated. As phenomenological philosophers do not put forth methodological guidelines on how to engage in phenomenological inquiry, the work of van Manen (1997) and other phenomenological methodologists were drawn upon for procedural guidance.

In this section, I outline the procedural methods that I adopted in this study including: sampling methods, participant recruitment, data collection, ethics and data management, and data analysis.

Participant Sampling Methods

Criterion sampling, defined as purposive recruitment according to a set of criteria, was used in the hope of recruiting participants who would be able to contribute to data that is in-depth and information rich (Patton, 2001). In light of projected Canadian demographics, including a rapidly aging population and longer dying periods (Statistics Canada, 2010), the inclusion criteria included: terminally ill adults; age 60 or above; a life expectancy of one and a half years or less; living at home (or in institutionalized settings if necessary); able to fluently read, speak and comprehend the English language; and cognitive awareness, without any medical condition that would influence his or her ability to communicate (i.e. dementia, delirium, etc.).

In qualitative inquiry, determining sample size is not guided by numerical calculations, such as statistical significance or statistical power, but is rather guided by researcher judgments (Sandelowski, 1995) about sufficient "information-richness" (Patton, 2001, p. 245). Sandelowski (1995) suggests that a sufficient phenomenological sample size can range, depending on the study purpose, from one specific case to 50 thick descriptions. Thomas and Pollio (2002) propose that a range of 6-12 participants is an appropriate number for phenomenological inquiry. As such, I aimed to recruit eight to ten participants, a number that was open to change and sensitive to the vulnerable nature of this population. The term 'vulnerable' refers to the recognition that this is an emotionally and physically sensitive stage in life, and that there could be a potential need for persons to withdraw from the study, given that the participants were terminally ill.

Participant Recruitment

Participants were recruited through professional intermediaries already in the participants' circles of care. The term 'professional intermediaries' was used to refer to health care professionals employed in end-of-life settings, including occupational therapists, community and hospice nurses, case managers, social workers and spiritual care workers. These professional intermediaries identified patients who they deemed fit the criteria for the study. They approached potential participants and distributed information flyers (See Appendix C for flyer details), and communicated participants' confidential contact information after obtaining the participants' consents.

I purposefully sought out potential participants living at home in the community for the following reasons. First, as the aging population increases (Statistics Canada, 2010), the need for homecare services to offset the financial costs of long-term care facilities and hospitals becomes greater. Second, the home is often a place of comfort, privacy, familiarity, and security (Hasselkus, 2002; Stanyer, 1994). As mentioned earlier, van Manen (1997) describes the home as a place where "we can *be* what *we are*" (p. 102), and it is this bodily 'being' that is of interest in this study.

Eight participants were recruited for this study: three men and five women; ranging in age from 63-80; primarily diagnosed with cancer (7); and primarily living at home (7) (one participant moved to a long-term care facility prior to the commencement of the study). See Appendix D for an overview of the participant demographics.

Participant Involvement: Risks & Benefits

Each participant was provided with a twenty-dollar gift card to Shoppers Drug Mart as a small stipend for his or her involvement in the study. The funding for these gift cards was received through the Health and Rehabilitation Sciences Graduate Thesis Research Fund at The University of Western Ontario.

Potential benefits that have been documented in the literature as arising from participation in interview-based phenomenological studies include enhanced self-awareness, a sense of empowerment, catharsis, and a voice for disenfranchised persons (Thomas & Pollio, 2002). The reflective and dialogic nature of in-depth interviews can illuminate participants' life histories, and potentially render fulfilling and enriching experiences (Thomas & Pollio, 2002).

There were no expected risks associated with participation in this study. Although the participants had been diagnosed with terminal illnesses, the structure of the study design was not expected to incur physical or any other type of harm. It was indicated in the letter of information (Appendix E) that each participant would be able to withdraw from the study at any time in the research process. If a participant expressed feelings of unease or distress, I planned to terminate the interview if requested and, if it was deemed desirable or necessary, I would have offered the participant the option to be withdrawn from the study. In the few instances when a participant became emotional and cried, I turned off the recording devices and provided time for the participant to compose him or herself. None of the participants requested to be withdrawn from the study, and all expressed the desire to continue with the interview. Appropriate follow-up supports were prepared in the eventuality that the interview process elicited undue distress. For instance, debriefing sessions were investigated and could have been arranged with the agency providing services to the client, if he or she was receiving home care. Nonetheless, none of the follow-up supports were deemed necessary or requested.

Data Collection

I conducted two to four interview sessions, lasting between an hour and two and a half hours, with each participant. The first meeting involved general introductions, a review of the letter of information (Appendix E), signing of the consent form (Appendix F), participative observation, and the beginning of the interview process. The subsequent meetings occurred within two weeks of the first, and concluded when the interview guide had been fully reviewed. An extended interview process was not seen to be a limitation; in fact, a prolonged engagement with the participants has the potential to engage deeper reflection and may assist researchers to develop further interpretive insights (Guba & Lincoln, 1994; van Manen, 1997). All sessions were audiotaped, and each interview was transcribed verbatim.

The Phenomenological Interviews

Interview Design

The interview guide was designed and informed by the two theoretical perspectives, and drew on the four occupational dimensions of doing, being, becoming, and belonging (Rebeiro, Day, Semeniuk, O'Brien, & Wilson, 2001; Whalley Hammell, 2004; Wilcock, 1998, 2006), and the four lived existentials of lived time, lived space, lived relations, and the lived body (van Manen, 1997). The full interview guide can be found in Appendix B.

With respect to constructing the interview guide, Thomas and Pollio (2002) suggest that readers must unlearn how they typically ask questions, to help draw out rich, descriptive phenomenological responses from the participants. They state that "the phenomenological question is not designed to elicit a theoretical explanation or statement; hence, 'why questions' which lead individuals from description to theory are avoided" (p. 24). They propose that using 'what' questions helps the research elicit more detail-oriented accounts of the participant's experience. These recommendations were used to inform the design of the interview guide.

Before the data collection began, I provided the interview guide to occupational therapists who were working in palliative care settings and to experienced phenomenological scholars, to help assess the quality of the interview guide, the appropriateness of the language (i.e. avoiding overly theoretical and philosophical terminology) (Benner, 1994), and to optimize the likelihood of obtaining rich and thick data.

Interview Logistics

There are three reasons that the interviews were conducted over multiple sessions, and over the span of several days. The first is consideration of the conditions and parameters of the research situation. It was expected that the participants might be sensitive to the symptoms of their illnesses. In an effort to respect their potentially vulnerable physical and emotional states, I strove to avoid creating conditions that might cause unnecessary fatigue. Rushing the interview process could have also compromised the possibility of obtaining the richest and most descriptive data feasible.

The second reason was to develop a sense of rapport. Rapport has been a frequently overlooked dimension in research planning (Sherif, 2001). Rapport is associated with emotions and descriptors such as empathy, understanding, collaboration, and loyalty (Gaglio, Nelson, & King, 2006; Springwood & King, 2001; Wood, 2001) and is required to negotiate or balance power dynamics or resistance (Gaglio et al., 2006; Magolda, 2000; Sherif, 2001; Thomas & Pollio, 2002). Power imbalance can exist on both ends of the researcher-participant relationship. Researchers have power in terms of setting the research agenda, making judgments on what to include and exclude in interpretation and analysis. Participants, however, have a significant degree of power in terms of controlling what they say, how they say it, what they leave out, and when to end the interview (Corbin & Morse, 2003; Gaglio et al., 2006). Rapport can contribute to the likelihood of collecting rich and thick data (Gaglio et al., 2006). It was therefore important to set the stage accordingly. When considering rapport, both context and time were considered to be important. With respect to the context, the study was designed so that data collection would optimally occur in the home environment, which was assumed to be the setting with maximal comfort and security. With respect to time, the potential for the level of rapport to grow over the course of the research process was recognized (Corbin & Morse, 2003), and the decision to carry out the data collection process over several days was made.

Finally, the third reason to prolong the data collection process was to build a conversation triad, a three-way conversation (van Manen, 1997). A conversation often begins as a chat, an interaction between two individuals. The chat begins with the researcher, who is asking the questions and continuously returning the focus of inquiry back to the phenomenon at hand, and to the participant who is the expert in the first hand-experience of the phenomenon. As the conversation begins to build, a third element in the triad is added, the “notion to which they are both now oriented” (van Manen, 1997, p. 98), that is, the phenomenon itself. Orientation towards the phenomenon occurs when the individuals become invested and committed to the task at hand, and they find a mutual sense of connection and caring about the research question. This orientation involves "sense-making and interpreting of the notion that drives or stimulates the conversation" (van Manen, 1997, p. 98). Allowing the data collection to occur over time was purposeful in that it had the potential to provide opportunities for participants to become more aware, reflective, and engrossed with the research question.

The Interview Process

The interviews began with a general introduction, which included simple chatting and conversation, an explanation of the study design, collection of demographic information (i.e. age, gender, cause of terminal illness, and a brief illness narrative) and the signing of informed consent forms (Appendix F). It was necessary to collect participant identifiers to allow a subject's information to be withdrawn from the data set if he or she chose to terminate involvement in the study.

The first interview was conducted with the hope of building a sense of mutual trust, as well as gaining a broad and general understanding of the participants' typical day. Gaining a sense of the participant's day-to-day living-while-dying was an important step in data collection. In phenomenological inquiry, it is not of merit to focus immediately on singular parts or moments without a broader understanding of the whole or, what Sokolowski (2000) calls, the 'concretum of experience.' Sokolowski suggests that moments exist in a continuum of daily living and "whenever [moments] exist and are experienced, they drag along their other moments with them; they exist only as blended with their complementary parts" (p. 24). Therefore, occupations were considered in relationship to the broader experience of 'living,' rather than in and of themselves.

The continuation of the in-depth interview occurred in the subsequent sessions. Between the first and second interviews, the field notes and the interview transcripts were read in search of material that would further inform the interview experience. The information obtained in these interviews in conjunction with the field notes and my observations of the lived space (i.e. any symbolic artifacts) informed subsequent interviews.

Throughout the interviews, attempts were made to engage in attentive listening and to limit interruptions by the researcher to the bare minimum, in order to allow participants to personally and authentically structure their stories (Benner, 1994). When there appeared to be gaps, inconsistencies, or a lack of detail, probes and paraphrasing were used to elicit clarification. I strove to use participants' experiential descriptions and to remain faithful to the wording of participants' accounts, in place of using abstract scholarly language as I checked in with participants about my interpretations of what was being said. I made efforts to gently re-direct participants if and when they began to impose interpretation and/or causative opinions about the phenomenon, or if the interview took an overly tangential turn.

The conclusion of the interview process occurred when it appeared that we, the participant and myself, had mutually reached a "fulfilled silence" (Bollnow, 1982, as cited in van Manen, 1997, p. 99). This silence is similar to the notion of saturation of data, when no new themes of significance appear to be emerging. It is important to note that a fulfilled silence is a sense of saturation *at this point in time* (van Manen, 1997). Fulfilled silence is a mutual and shared experience that occurs between the researcher and the participant.

Close Participative Observation

I engaged in close participative observation, which involves the researcher entering and participating in the subject's lifeworld, whilst maintaining a phenomenological attitude and observational alertness to the situation at hand (van Manen, 1997). The term *participative* is compared to the more commonly used *participant* observation, where the researcher objectively observes the subject and maintains a degree of detachment or distance between them. The term participative was used to signify and emphasize the bodily experience of the researcher as a potential source of data in the research process (Savage, 2000). Being attentive to the body as the source of being-in-the-world (Heidegger, 1927/2008; Merleau-Ponty, 1945/2006) is related to the researcher's epistemological assumptions about what it means to know. In this case, knowing was seen to be informed by bodily experiences. Therefore, while language is a significant vehicle for meaning, an assumption was made that there is much to be communicated from bodily senses and gestures. Merleau-Ponty (1945/2006) states that, "what is important is how they use their bodies, the simultaneous patterning of body and world in emotion" (p. 219). From this perspective, verbal communication alone is insufficient for understanding the lifeworld of another. Participative observation acknowledges the researcher's involvement in the participant's lifeworld, simply by *being* there, being in his or her lived space and time as a lived other (van Manen, 1997).

Being present in the participants' homes offered insight into their lived space. Drawing on Hasselkus' (1993) contention that artifacts can have intense symbolic meaning for dying individuals, the participants were asked about symbolic artifacts, objects that they use in occupational engagement, and consideration was given to how these objects influence the construction of meaning. For example, if there were notable objects in reach of the participant, such as a rosary or a craft, I asked the participant to share more about it. I detailed my observations from the close, participative observation in my field notes immediately after each session.

Embodied Methods

Drawing on Merleau-Ponty's (1945/2006) notion that being-in-the-world is a bodily affair, an embodied methodological approach was adopted. As stated earlier, Sandelowski (2002) reminds researchers that they are always situated in the world as embodied agents, even whilst involved in the inquiry process. She suggests that Western culture tends to prioritize the mind over the corporeal experience. For example, the in-depth interview is often hailed as the gold standard in data collection in that it offers a verbal and supposedly authentic avenue into the worlds of the participants (Seale, 1998). However, researchers may be able to obtain a more holistic immersion in the research by incorporating multiple vehicles for data collection that are attentive to our bodily perceptions of the world (Merleau-Ponty, 1945/2006). In phenomenological inquiry, multiple sources of data are preferred to avoid the use of an overly narrow and disembodied perspective of the participant's life world (Benner, 1994; Sandelowski, 2002). Csordas (1999) contends that there is no single best way for eliciting bodily-attentive data and that what is most important is to be vigilantly attentive to the presence of bodily material in the data, whether the data is primarily verbal or not.

Adopting an embodied perspective involved attention to the body's presence in the data, both verbal and non-verbal. In this study, I drew on four levels of attentive awareness. First, I was attentive to what the participants said about their bodies in their descriptive accounts. I included direct questions about the body in my interview guide (Appendix B), such as ‘What has your body’s experience of living with an illness been like?’ and ‘What do you notice has changed in your body?’ However, I recognized that participants might also speak in embodied ways without these direct triggers; the body may emerge organically through descriptive accounts of their lived experience of occupation (i.e. mentioning their bodies as they shared anecdotes or described a typical day). Second, I attended to how participants comported their bodies within the interview experience. This involved being attentive to bodily details such as the participants’ gestures or emotional responses (i.e. finger tapping, mimicking, gesturing for emphasis, crying), and making note of these in my field notes immediately after each interview session. Third, I recognized that embodiment does not end with the participant. In an effort to attend to Sandelowski’s (2002) contention that the researcher’s body is taken for granted in the research process, I tried to bring an enhanced awareness to my body during the interview process by journaling about my own emotional reactions, gut feelings, and bodily presence after each interview. Lastly, I was attentive to the intercorporeality between the researcher and the participant, recognizing that embodiment is not an individual affair, but also comes alive in the space between people (van Manen, 1998). Reflections on these observations were recorded in my field notes and journal. Therefore, in this study, an embodied phenomenological perspective involved attending to four levels of embodied awareness.

Interpreter Reflexivity

Reflexivity can be defined as “the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes" (Finlay, 2003, p. 108). Prior to beginning the data collection process, I engaged in journaling about my direct experiences with death and dying, in an attempt to elicit some of the taken for granted assumptions. I detailed memories about different funeral services I had attended as well as my responses to these deaths and the impact they had on my life. These entries assisted me to become more cognizant of my historical and cultural experiences with the end-of-life experience and to reflect on the research context, and my values and preunderstandings. Finlay (2003) suggests that without self-examination, there is a risk of allowing our values and assumptions to lead the research findings. Reflexive journaling is a method that takes into account what many phenomenologists (Heidegger, 1927/2008; Merleau-Ponty, 1945/2006) as well as other human science researchers suggest (Benner, 1994; Frank, 1995, 2004; van Manen, 1997): that it is impossible to detach ourselves from our backgrounds and perspectives, and it is within our unique stances that interpretation is possible. As Merleau-Ponty (1945/2006) notes, "all my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless…I am the absolute source" (p. ix).

I engaged in documenting detailed field notes, which were taken after each interview session, in an attempt to remain as close to the data as possible. In these, I tried to record every thought, observation and 'moments that stood out' before they eluded me. Special attention was paid to bodily responses, symptoms and manifestations, such as postures, gestures, facial expressions, recoiling, reaching out, and sighs, which may be significant points for reflexive inquiry. I included a journaling element to these field notes, adding emerging interpretive insights when relevant.

Ethics and Data Management

This study was approved by the University of Western Ontario Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) (see Appendix G) on July 24th, 2009.

Participant confidentiality was strictly managed throughout the research process. All hard copies of the data were stored in a locked filing cabinet in a University laboratory and all electronic data were kept on a password protected macbook laptop with coded file names. Pseudonyms were used for all participants, and I was the only person with access to any identifying material. The data were backed up on a USB memory key, which was also stored in the locked cabinet. All material will be stored for a period of ten years, at which time the material will be destroyed.

Data Analysis and Interpretation

The data were analyzed with a focus on deepening understanding of the phenomenon of interest: the embodied nature of occupation at end-of-life. From a phenomenological perspective, analysis involves looking at what is normally looked through (Sokolowski, 2000) and examining the phenomenon against the culturally informed understandings I have brought to the research and attempted to make explicit (Finlay, 2009). Data analysis involved a deep and engaged immersion with the data, which informed my interpretation of the interview texts, the data collected in my field notes, and my journal entries. The use of multiple data sources is supported in phenomenological inquiry because it offers a variety of perspectives on everyday, shared understandings on the phenomenon of interest, and avoids a narrow and isolated stance (Benner, 1994).

Benner (1994) contends that, “The guiding ethos is to be true to the text. Throughout the interpretive project the researcher asks, ‘What do I now know or see that I did not expect or understand before I began reading the text’” (p. 101). Drawing on a hermeneutic approach (Gadamer, 1975; Heidegger, 1927/2008; Kinsella, 2006), textual analysis occurred in three main stages: (a) holistic analysis (gaining a global sense of the participant’s lived experience of the phenomenon), (b) selective analysis (drawing on an occupational framework and lived existentials to elicit meaning units), and (c) detailed analysis (a search for words or phrases that carry deeper meanings) (van Manen, 1997). Although this analysis process is presented in a linear format, the process involved a dialectical movement between the three stages that informed how they came together to produce interpretive clarity and deeper insight.

Holistic Analysis: Reading for Global Meanings

Once the data were transcribed, each transcript was read as a whole as I sought to elicit an overall sense of meaning from each participant’s descriptive account (Benner, 1994). For Gadamer (1975), understanding occurs through expanding circles as the reader moves between the whole and the parts:

> Understanding is always a movement in this kind of circle, which is why the repeated return from the whole to the parts, and vice versa, is essential. Moreover, this circle is constantly expanding, since the concept of the whole is relative, and being integrated in ever larger contexts always affects the understanding of the individual part. (p. 189)

This holistic interpretive process was undertaken for each of the participant’s transcripts. Following a reading of a participant’s transcript as a whole, I documented immediate responses and notes concerning what stands out right now. Although three to five sentence summaries of the global meanings that stood out for each of the participant's transcripts were originally planned, it was extremely difficult to depict the entirety of what participants' told me about their experience within such limitations. Dialogic sessions with my supervisor helped reveal common mistakes novice phenomenological researchers make in over-interpreting the participant's words and making assumptions about how the participants' 'felt.' As a result, these summaries offered a learning opportunity to practice drawing directly on the participant's accounts and becoming attentive to bias and my own interpretations. These summaries were deemed to be initial reactions, a starting point for analysis; indeed, upon deeper thematic and detailed analysis, these initial interpretations revealed their thin and surface character, as rich themes began to emerge, develop and evolve.

Selective Analysis: Identification of the Parts

It has been argued that too often, thematic analysis consists of an overly systematic tallying of selected terms, elements or codes within the text (Thomas & Pollio, 2002; van Manen, 1997). However, thematic analysis in phenomenological inquiry is a much more immersed, creative and complex process. Van Manen (1997) states that,

> Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure-grasping and formulating a thematic understanding is not a rule-bound process but a free act of 'seeing' meaning.' (p. 79)

Themes are described as components in the data that give "shape to the shapeless" (p. 88).

The thematic analysis in this study began by re-reading each of the transcripts with particular interest in pieces that seem essential to the lived experience of occupation at end-of-life. Benner (1994) proposes that the aim of interpretive phenomenology is to draw out patterns of commonalities and differences among the different lived experiences of the phenomenon. Each of the participant's transcripts was initially analyzed on its own, examining potential themes within each of his or her lived experiences. Each transcript was combed through a number of times, each time with a different purpose:

Selective Analysis for Each Participant

a) The selective analysis began by flushing out potential themes and quotations that stood out and resonated within the participants' transcripts.

b) To improve the flow of the transcripts, interjectory sounds of affirmation (i.e. mmhmm) were removed when it was deemed that they did not change the flow, direction or interpretation of the interview, in an effort to make the reading more succinct. Phrases and metaphors that 'stood out' were highlighted, and meaningful words were bolded as signposts for deeper analysis.

c) Selective summaries were created for each participant. Here, the transcripts were read and potential excerpts from the transcripts were organized according to the original question of the study: What is the embodied nature of occupation at end-of-life? This process included drawing from the two theoretical frameworks that informed the interview guide (the occupational framework of doing, being, becoming, and belonging (Rebeiro et al., 2001; Whalley Hammell, 2004; Wilcock, 1998, 2006) and van Manen's (1997) four existentials, lived space, lived time, lived relations, and the lived body) to focus attention on descriptive accounts that spoke to these eight dimensions both directly and indirectly. The potential themes that began to emerge were allotted according to the research question for organizational purposes. It is important to note that the same quotations could have multiple interpretations. In efforts not to fall prey to an insular and one-track interpretation, these quotations were replicated within every theme of relevance. Any themes or quotations that did not appear to address any of the research themes directly were grouped under the heading of 'Emergent' at the end of each participant's selective summary.

d) Due to the immense amount of data, occupational profiles were created for each participant. These included a brief summary of their illness experience, information about their family situation, place of residence, and a 'typical day.' A list of past occupations and current occupations, and potential meanings associated with each of these occupations were also identified.

Selective Analysis Across Participant Transcripts

a) The next phase of selective analysis compared themes across the participants' selective analysis summaries. This began with a mind-mapping process, first for each participant and then across participants. This mind-mapping process evolved through dialogic meetings with my supervisor.

b) Smaller subthemes began to collapse within large meaning units. Broader themes emerged and were identified by the frequency in which they occurred, the depth and breadth within each theme, and the extent of resonance that the themes elicited.

Detailed Analysis: Symbolic Words and Phrases

In this part of the analysis, the transcripts were reread using a line-by-line approach, in search of exemplars, repetitive and emphasized words and phrases. Singular phrases and words can be extremely symbolic and meaning rich. As such, idioms and catch phrases were of particular interest. Van Manen (1997) suggests that idiomatic phrases are “born out of lived experience” (p. 60) and are therefore powerful signposts for meaning. Other examples include the participants’ use of metaphors, and analogies, all of which can be powerful purveyors of meaning. Sensitivity to these types of phrases is considered an excellent example of what attentive phenomenological inquiry entails; that is, filtering the ordinary, mundane and everyday experience to uncover their richer, essential meanings. Thomas and Pollio (2002) contend that metaphors are drawn upon when ordinary language is unable to fully convey the entirety of what people are trying to express.

Summary

The data analysis process consisted of three stages that led to the identification of themes characterized by the essential structures of the experience of the phenomenon (van Manen, 1997). The overall aim of this analysis process was *verstehen*, a deeper understanding of the phenomenon of interest – the embodied nature of occupation at end-of-life. According to van Manen (1997), “the essence or nature of an experience has been adequately described in language if the description reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner” (p. 10).

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APPENDIX B: THE SEMI-STRUCTURED INTERVIEW GUIDE

Demographic Information

1. What is your name?
2. What is your age?
3. What is your gender?
4. What is your current living situation? (i.e. home, hospice, palliative care unit etc.)
5. What do you understand about your illness? Can you briefly describe the course of your medical history related to your diagnosis (including: What is the cause of your diagnosis? What led you to seek medical attention? When were you diagnosed?)?

Interview Guide

1. When you were diagnosed with your illness, what was that like for you?
    a. How did you experience the reaction of other people (your family, friends) to your diagnosis?
    b. How do you experience your illness in your everyday life? Can you give me some examples of things that may have changed?

2. Can you paint a picture for me of what a typical day is like for you?
    a. What do you do?
    b. In what ways do you experience a typical day now as similar or different compared to prior to your illness?
    c. What priorities do you set regarding what you do in a day?

3. What kind of activities do you engage in on a regular basis?
    a. In what ways do you decide what you will do and when?
    b. What kinds of priorities do you set with respect to your activities?

4. In what ways do you spend your time?
    a. What sorts of activities do you spend your time doing?
    b. What factors influence how you spend your time?
    c. What do you notice about time when you are doing these daily activities? (Are there times during the day that go by quickly? Go by slowly? Tell me more about what you are doing during these times.)
    d. What have you noticed about time since you have become ill? Have there been any changes that you have noticed in how you experience time?

5. Where do you spend most of your day?
    a. Why is this the location [place/room] in which you spend most of your day?
    b. What stands out for you in this [place/room]?
    c. How does it make you feel to be in this [place/room]?
    d. Are there things around you or things that you own that have important meanings to you? What are they? Can you give me an example of the significance this item has in your life?

   e. I notice that you have ‘artifact X.’ Tell me more about it.
   f. Are there things that you own that you will pass on to loved ones? Tell me more about them. Why are they important to you?

6. Who do you spend time with in a typical day?
   a. What sorts of things do you do with [him or her]?
   b. How do you experience your time with [him or her]?
   c. What meanings do these shared times have for you?
   d. What has changed, if anything, in your experience of everyday relationships since you were diagnosed with this illness?

7. Given your typical day, what part(s) do you experience as standing out for you?
   a. What are the things that you do on a day-to-day basis that bring you pleasure or joy?
   b. What is it about your day that you find meaningful?
   c. What do you notice or feel within yourself during these meaningful parts of the day? (What do you see, taste, smell, touch, and hear?)
   d. Are there dimensions of the day that you experience as challenging or difficult?
      i. Can you describe, elaborate on these?
      ii. What is involved?

8. Thinking back, how has your experience of living with this illness influenced your sense of who you are?
   a. In what ways, if at all, has becoming ill contributed to who you have become as a person?
   b. Are there things you have learned or discovered about yourself throughout this experience?
   c. What has your body’s experience of living with an illness been like? (i.e. through your senses--taste, smell, vision, hearing, touch?)
   d. What do you notice has changed in your body?
   e. What changes, if at all, do you notice about the way you feel towards your body?

9. Do you reflect on your past?
   a. What types of things or memories do you reflect back on?
   b. What past experiences stand out for you?

10. How will you spend your time (what will you do) in the next days, weeks and months?
    a. What is it about these activities that are important to you?

11. Drawing on your experience, what advice would you give to others who are living with advanced, life-threatening illnesses?
    a. How to spend time?
    b. Who to spend time with?

    c. What to do?
    d. How to live?

12. Is there anything else about your experience living with an advanced, life threatening illness that you would like to tell me that we have not discussed already?
    a. Do you have any further reflections?

Probes: In what way? Can you give an example? How did you become aware of it? Who said what? Describe that in more detail. Describe what you were feeling at that moment (i.e. smell, sight, touch, taste, see). Tell me more about that. What was your experience of that?

APPENDIX C: THE RECRUITMENT FLYER

University of Western Ontario

Invitation to Participate in a Research Study

The purpose of this study is to examine the lived experience of occupation at end of life from the perspectives of Canadians over the age of 60, living with advanced, life-threatening illnesses.

What is involved?

Participation in this study involves two or more interviews that will be audio-recorded, and held within the span of two weeks. The primary and secondary investigators in this study are the only people that will have access to the data. Your information and contributions will be kept ***completely confidential.***

What are the eligibility requirements?

To participate in this study, you must be 60 years of age or older, living with an advanced, life-threatening illness, able to read, speak and comprehend English, and without any medical condition that may influence your ability to communicate (i.e. Alzheimer’s disease).

When and where will the interviews be held?

The interviews will be arranged at a time of your convenience and conducted in your current location of residence (home or medical setting).

What are the risks and benefits of participating in this study?

There are no expected risks associated with participation in this study. The structure of the study is not designed or expected to incur any type of harm. You may withdraw from the study at any time in the research process. There are no direct benefits associated with your participation in this study.

For further details about this study or to sign-up, please contact
Anna Park Lala
Dr. Anne Kinsella

APPENDIX D: PARTICIPANT DEMOGRAPHICS

Name *Pseudonym	Age	Diagnosis	Place of Residence
Maggie	73	Ovarian cancer	Home
Sarah	69	Non-Hodgkins Lymphoma	Home
Mary (Slovenian background)	79	Breast cancer	Home
Jim	63	Esophageal cancer	Home
Cali	78	Breast cancer, bone cancer	Long-term care facility
David	65	Bowel cancer	Home
Julia	65	Papillary Serous Carcinoma of the Endometrium	Home
PJ	80	Undiagnosed, his doctors suspect extensive arthritis and lung disease restrict his breathing	Home

APPENDIX E: LETTER OF INFORMATION

Letter of Information

A Phenomenological Inquiry into the Embodied Nature of Occupation at End of Life

Researchers

Anna Park Lala, PhD (Candidate), MSc(OT), BSc, Doctoral Student Investigator

Anne Kinsella, PhD, OT Reg.(Ont.), Principal Investigator

Description of the Study

Occupational scientists and occupational therapists propose that everyday occupations (the things that people need, want and have to do) are both essential to human life and can facilitate meaningful experiences (Canadian Association of Occupational Therapists, 2002, 2008; Hasselkus, 2006; Wilcock, 2006; Yerxa et al., 1989; Zemke & Clark, 1996). However, it is uncertain what people at end of life identify as occupations that facilitate meaningful experiences. People at end of life have acknowledged that a limited ability to participate in activities that make life enjoyable negatively impact their end of life experiences (Oregon Department of Human Services, 2006, 2007, 2008). This study seeks to examine everyday occupations, both ordinary and extraordinary, at end of life, and their potential to contribute to good end of life experiences (Davel Jacques & Hasselkus, 2004).

Study Purpose

The purpose of this study is to examine the lived experience of occupation at end of life from the perspectives of eight to ten Canadians over the age of 60, living with advanced, life-threatening illnesses. Each end of life experience will be unique. What the researchers hope to obtain from the data is a more in-depth understanding of the potential for everyday occupations to contribute to meaningful end of life experiences.

Study Invitation

You are being invited to participate in a research study that aims to investigate the end of life experience from the perspectives of persons over the age of 60, living with advanced, life-threatening illnesses. Your reflections will make an original contribution to understanding what the end of life experience is like, and the types of activities that can impact meaningful experiences at this stage. This study is being conducted as part of a requirement in the Doctor of Philosophy (Occupational Science) program at the University of Western Ontario.

What Does Participation in this Study Involve?

This study involves two or more interviews that will be audio-recorded, and arranged at your convenience within the span of two weeks. Two or more interviews are included to ensure that a sufficient amount of time is available to complete the interview guide, and to best accommodate your needs (i.e. in case of fatigue, or preference for shorter meetings). The interviews will be conducted in your current place of residence (i.e. home, hospital, long-term care setting, etc.). You will be asked to provide information about your everyday activities and your experience of living with an advanced, life-threatening illness. In addition, basic information about your age, medical diagnosis, and a brief history of your illness experience will be requested. This information will allow you to be withdrawn from the data set should you choose to be removed from the study.

There are no expected risks associated with participation in this study. The structure of the study is not designed or expected to incur any type of harm. You may withdraw from the study at any time in the research process. There are no direct benefits associated with your participation in this study. Compensation will be provided for involvement in this study through a 25-dollar gift card to Shoppers Drug Mart.

Eligibility

To participate in this study, you must be 60 years of age or older, living with an advanced, life-threatening illness, able to read, speak and comprehend English, and without any medical condition that may influence your ability to communicate (i.e. Alzheimer's disease). Please let the researcher know if you are involved in any other study at this time.

Privacy and Confidentiality

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you agree to participate, all identifying information will be removed from your interview transcript. Your name will be replaced with a pseudonym. The results of this study may be used in academic publications or presentations. No information that discloses your identity will be released or published without your specific consent. The primary and secondary researchers will be the only people with access to the research material. Research materials will be stored in a locked filing cabinet at the University of Western Ontario, and destroyed after a period of ten years. The transcripts may be taken off of University premises to the student researcher's home during the analysis process. All identifiers will be removed from any material taken off site, and will be stored on a password protected computer. All information will be strictly confidential. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. Your attending physician will be notified of your involvement in this study.

Contact Information

If you have any questions about your rights as a research participant or the conduct of the study, you may contact the Office of Research Ethics.

If you have been recruited through St Joseph's Healthcare Centre or the London Health Sciences Centre, and have any questions about your rights as a research participant or the conduct of the study you may contact the Lawson Health Research Institute.

For further information about this study, please contact Anna Park Lala or Dr. Anne Kinsella. You will be given a copy of both this letter of information and the consent form once it has been signed.

Anna Park Lala, PhD Candidate

Department of Health and Rehabilitation Sciences

University of Western Ontario

APPENDIX F: PARTICIPANT CONSENT FORM

A Phenomenological Inquiry into the Embodied Nature of Occupation at End of Life

"I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction."

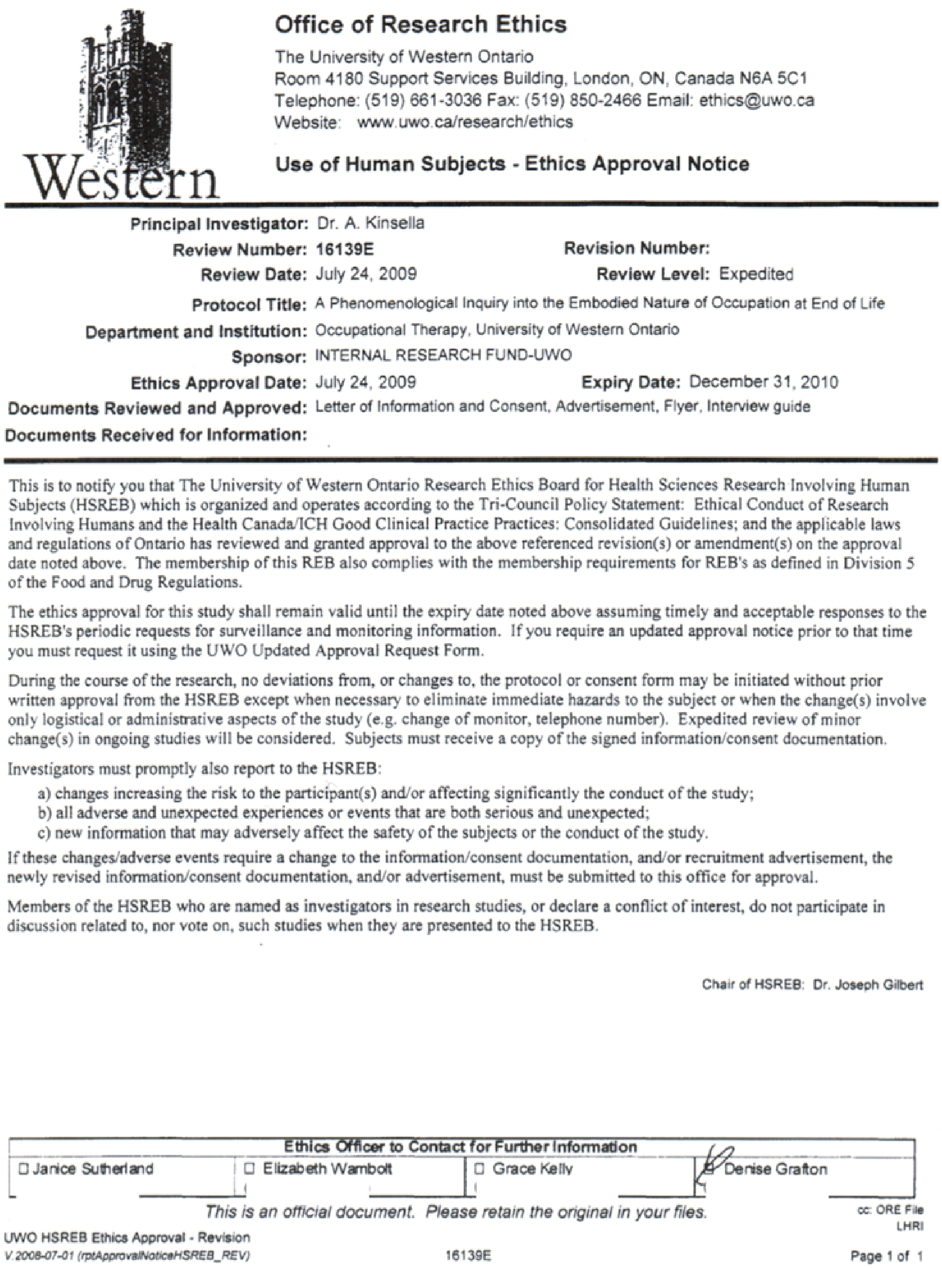
Signature of Research Participant:____

Print Name: ________________________________ Date: ____________________

Signature of Person Obtaining Consent:___________________________________

Print Name: _______________________________ Date: ____________________

APPENDIX G: WESTERN ETHICS BOARD FOR HEALTH SCIENCES RESEARCH INVOLVING HUMAN SUBECTS APPROVAL LETTER



Office of Research Ethics
The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Western

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. A. Kinsella
Review Number: 16139E **Revision Number:**
Review Date: July 24, 2009 **Review Level:** Expedited
Protocol Title: A Phenomenological Inquiry into the Embodied Nature of Occupation at End of Life
Department and Institution: Occupational Therapy, University of Western Ontario
Sponsor: INTERNAL RESEARCH FUND-UWO
Ethics Approval Date: July 24, 2009 **Expiry Date:** December 31, 2010
Documents Reviewed and Approved: Letter of Information and Consent, Advertisement, Flyer, Interview guide
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert

Ethics Officer to Contact for Further Information			
☐ Janice Sutherland	☐ Elizabeth Wambolt	☐ Grace Kelly	☑ Denise Grafton

This is an official document. Please retain the original in your files.

cc: ORE File
LHRI

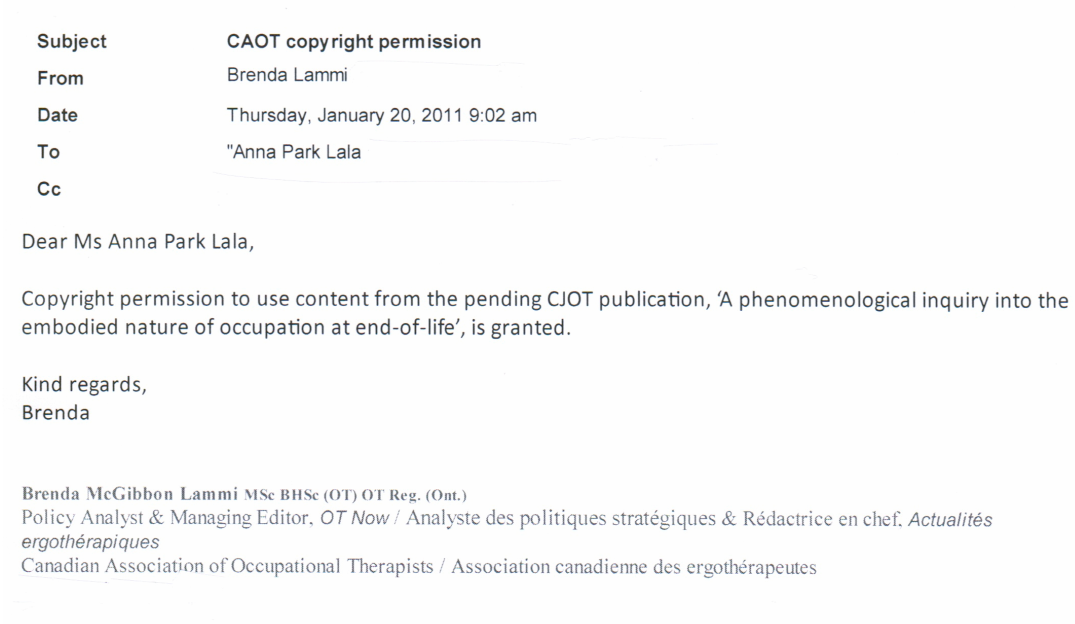
UWO HSREB Ethics Approval - Revision
V.2008-07-01 (rptApprovalNoticeHSREB_REV) 16139E Page 1 of 1

APPENDIX H: PALLIATIVE PERFORMANCE SCALE (PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance Necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive Disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly Assistance	Normal or reduced	Full or Drowsy +/ Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/ Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/ Confusion
10%	Total Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death				

This copy of the PPS was provided by two professional intermediaries involved in the current study. The original source can be located from the following reference: Anderson, F., Downing, G.M., Hill, J., Carorso, L., & Lerch, N. (1996). Palliative Performance Scale (PPS): A new tool. *Journal of Palliative Care, 12*(1), 5-11.

APPENDIX I: COPYRIGHT RELEASE



Subject	**CAOT copyright permission**
From	Brenda Lammi
Date	Thursday, January 20, 2011 9:02 am
To	"Anna Park Lala
Cc	

Dear Ms Anna Park Lala,

Copyright permission to use content from the pending CJOT publication, 'A phenomenological inquiry into the embodied nature of occupation at end-of-life', is granted.

Kind regards,
Brenda

Brenda McGibbon Lammi MSc BHSc (OT) OT Reg. (Ont.)
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Post-secondary Education and Degrees:	The University of Toronto Toronto, Ontario, Canada 2000-2004 BSc
	The University of Western Ontario London, Ontario, Canada 2004-2006 MSc(OT)
	The University of Western Ontario London, Ontario, Canada 2006-2011 PhD
Honours and Awards:	*Nominee,* Teaching Assistant Award The University of Western Ontario 2008
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Related Work Experience	Teaching Assistant The University of Western Ontario 2006-2009
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Publications:

Book Chapter

Park Lala, A., & Kinsella, E.A. (in press, 2011). Embodiment in research practices: The body in qualitative research. In J. Higgs, A., Titchen, D. Horsfall, & D. Bridges (Eds.) *Creative spaces for qualitative researching…Living research*. Rotterdam, The Netherlands: Sense Publishing.

Peer-Reviewed Journal Articles

Park Lala, A., & Kinsella, E.A. (in press, 2011). A phenomenological inquiry into the embodied nature of occupation at end-of-life. *Canadian Journal of Occupational Therapy, 78*(3).

Park Lala, A., & Kinsella, E.A. (in press, 2011). Phenomenology and the study of human occupation. *Journal of Occupational Science, 18.*

Kinsella, E. A., **Park, A.,** Appiagyei, J., Chang, E., & Chow, D. (2008). Through the eyes of students: Ethical tensions in Occupational Therapy practice. *Canadian Journal of Occupational Therapy, 75*(3), 176-183.

Rudman, D., Dennhardt, S., Fok, D., Huot, S., Molke, D., **Park, A.,** & Zur, B. (2008). A vision for occupational science: Reflecting on our disciplinary culture. *Journal of Occupational Science, 15*(3), 136-146. (Note: authors listed alphabetically after first author.)

Park, A., Guptill, C., & Sumsion, T. (2007). Why music majors pursue music despite the risk of playing-related injuries. *Medical Problems of Performing Artists, 22*(3), 89-96.

> **Park, A.,** Guptill, C., & Sumsion, T. (2008). Warum musikstudenten trotz des risikos spielbedingter verletzungen weitermusizieren. *Musikphysiologie und Musikermedizin, 15*(1), 6-18. [German Translation]

Conference Presentations:

Park Lala, A., & Kinsella, E.A. (2010, October). Assessing the quality of phenomenological research: Five quality criteria. *Joint Occupational Science Conference* [The Society for the Study of Occupation: USA and the Canadian Society of Occupational Scientists]. University of Western Ontario, London, ON.

Park Lala, A., & Kinsella, E.A. (2010, October). A phenomenological inquiry into the embodied nature of occupation at end-of-life. *Joint Occupational Science Conference* [The Society for the Study of Occupation: USA and the Canadian Society of Occupational Scientists]. University of Western Ontario, London, ON.

Park Lala, A., & Kinsella, E. A. (2010, May). A phenomenological inquiry into the embodied nature of occupation at end-of-life. *World Federation of Occupational Therapists Congress XV,* Santiago, Chile.

Park Lala, A. (2009, June). A perspective on occupational perspective. *Canadian Association of Occupational Therapists Annual Conference*, Ottawa, ON.

Park, A., & Huot, S. (2008, June). Home sweet home: Impacts of illness and migration. *Canadian Association of Occupational Therapists Annual Conference*, Whitehorse, YT.

Huot, S., & **Park, A.** (2008, May). From place to space? Changing notions of 'home sweet home' due to illness and migration. *4th Canadian Occupational Science Conference,* Thunder Bay, ON.

Molke, D.K., Dennhardt, S., Fok, D., Huot, S., Laliberte Rudman, D., **Park, A**. & Zur, B. (2008, May). Reflecting on relevance: Making occupational science matter. *4th Canadian Occupational Science Conference*, Thunder Bay, ON.

Zur, B., Laliberte Rudman, D., Dennhardt, S., Fok, D., Huot, S, Molke, D., **& Park, A.** (2008, May*)*. Placing Occupational Science: Reflecting on our disciplinary culture*. 4th Canadian Occupational Science Conference,* Thunder Bay, ON.

Park, A., Guptill, C., & Sumsion, T. (2007, June). Why music majors pursue music despite the risk of a playing related injury. *Performing Arts Medicine Association Symposium*, Aspen, CO.

Poster Presentations:

Park Lala, A., & Kinsella, E.A. (2010, November). The nature of occupation at end-of-life. *Ontario Long-Term Care Association 2nd Annual Applied Research Education Day.* Toronto Congress Centre, Mississauga, ON.

Park Lala, A., & Kinsella, E.A. (2010, May). Phenomenology and human occupation: Situating occupation and advancing understanding. *World Federation of Occupational Therapists Congress XV,* Santiago, Chile.

Park, A., Guptill, C., & Sumsion, T. (2007, July). Why music majors pursue music despite the risk of a playing related injury. *Canadian Association of Occupational Therapists Annual Conference,* St. John's, NL.

Guest Lecture:

Park Lala, A. (2009, April). *Occupational science: An introduction*. School of Occupational Therapy, New York University, New York, NY.