# The intentional pursuit of everyday life while dying: A longitudinal exploration of occupational engagement for working-aged adults living with advanced cancer

By

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# SUMMARY

People living with advanced cancer want to participate in everyday activities that give their life meaning for as long as possible. This desire remains a priority despite increasing dependence and cancer progression. Importantly, the loss of the ability to participate in valued activities can have detrimental consequences on a person's sense of self and well-being. In Canada, 84.9% of people choosing medical assistance in dying define their intolerable suffering as the inability to participate in valued activities. In the past five years since it was legalised, the number of people choosing to end their life this way has increased more than sevenfold. Despite this, a paucity of research describes how working-aged adults living with advanced cancer adjust to challenges in doing activities that are important to them in the time they have remaining.

This prospective study is the first to explore the lived experience of occupational engagement for working-aged adults living with advanced cancer and examine how participation in everyday activities changed over time as their disease progressed. A pragmatic qualitative approach informed the design of this longitudinal, hermeneutic phenomenological study. Eight working-aged adults between the ages of 40 and 64 participated in multiple semi-structured, in-depth interviews in their own homes over a span of 19 months. Findings were mapped against the Model of Human Occupation and illness experience literature.

This study found that the lived experience of everyday life for working-aged adults living with advanced cancer was one of increasing dependency, unremitting change, and loss. Losses occurred in the domains of time, space, body, and relationships. Despite these challenges, participants sought to intentionally engage in meaningful occupations. They concentrated on doing things they enjoyed within the context of their environment and valued relationships, prioritising activities that facilitated their goals irrespective of cancer progression. Maintaining the roles of worker and parent were of particular importance for this cohort. Occupational adaptation occurred through continued engagement in everyday activities, facilitating a sense of occupational identity as function declined. The person's volition (values, interests, personal causation) was the motivator for occupational adaptation in order to continue engaging in valued occupations. A unique finding of this study is its explication of occupational adaptation when competency is not a stable construct, furthering the Model of Human Occupation’s existing conceptualisation of this phenomenon. Participants’ narratives revealed a dynamic relationship between occupational adaptation, volition, and occupational identity. Findings identified that it is the meaning behind activities that motivates the person to intentionally pursue their valued activities.

Optimal care for adults living with advanced cancer should ensure access to opportunities to facilitate continued occupational engagement amid increasing dependence. This thesis contends that the motivation behind occupational engagement (volition) plays a central role in occupational adaptation whilst contending with cancer progression. Intentionally engaging in meaningful occupations is a key component of maintaining a sense of self and meaning at the end of life for working-aged adults living with advanced cancer.

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# DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university;
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Julie Brose

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# GLOSSARY

| | |
|---|---|
| End-of-life | The final months, weeks, or days of a person's life when living with a terminal illness. |
| Habituation | A person's habits, routines, and roles. |
| Hospice | A residential place where an individual can stay for respite or in the last few weeks or days of life, where palliative care is provided (Canada). This definition differs in other countries. |
| Occupation | "Occupation refers to groups of activities and tasks of everyday life, named, organised and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves" (Canadian Association of Occupational Therapists, 2002, p. 34). The term *activity* is used interchangeably with *occupation* in the vignette and findings chapters, as this is the language spoken by study participants. |
| Occupational adaptation | Defined by the Model of Human Occupation as "the development of a positive occupational identity, coupled with the experience of occupational competence over time within the context of one's environment" (de las Heras de Pablo, Fan, et al., 2017, p. 116). This can be the process or the outcome. |
| Occupational competence | Defined by the Model of Human Occupation as "the degree to which one is able to sustain a pattern of occupational participation that reflects one's occupational identity" (de las Heras de Pablo, Fan, et al., 2017, p. 117). |
| Occupational engagement | The participation or involvement in occupations. |
| Occupational identity | Defined by the Model of Human Occupation as "a composite sense of who one is and who one wishes to |

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|---|---|
| | become as an occupational being generated from one’s history of occupational participation” (de las Heras de Pablo, Fan, et al., 2017, p. 117). |
| Palliative care | Care provided to a person living with an incurable condition, usually in the final year to 6 months of life. Palliative care can occur in hospital, home, or hospice settings. |
| Performance capacity | A person’s physical, emotional, and cognitive abilities (subjective and objective). |
| Terminal stage | The final days or hours of life. |
| Volition | A person’s values, interests, sense of self-efficacy and capacity. |

# CHAPTER 1: INTRODUCTION

The ability to participate in everyday activities is fundamental and profound yet often taken for granted amid life's familiar habits and routines—until it is lost. When a life-limiting illness challenges a person's sense of normalcy, they may feel lost and vulnerable, as if a significant part of their world has been irrevocably changed. Family life, work, or social events may be severely impacted, and many activities that once gave meaning and purpose are no longer accessible. The inability to participate in valued activities negatively impacts how capable and confident a person feels in their everyday life; their sense of identity is shaken. The ordinariness of everyday life becomes increasingly significant, and its loss is often only grieved when the ability to participate in routine activities is compromised. Engaging in activities that give meaning and foster relationships provides a sense of well-being amid functional decline. This study aims to examine the lived experience of everyday life for working-aged adults living with advanced cancer and to map their experiences of declining function and priorities as they shift over time.

Two current issues in Canada serve as timely reminders about the importance of the phenomenon under investigation in this study. Both focus on the importance of participation in valued activities and the impact that the inability to do so has on quality of life and well-being. The first, medical assistance in dying[1], was legalised in Canada five years ago. Since then, the number of people choosing to end their life in this manner has grown significantly each year: from 1,018 people in 2016 to a total of 7,595 people in 2020 (Health Canada, 2021). The two primary reasons given by people who chose medical assistance to end life were the *loss of ability to participate in meaningful activities* (84.9%)[2] and the *loss of ability to participate in activities of daily living* (81.7%). The loss of their ability to engage in meaningful activities—or the threat of loss—made life unbearable for these individuals.

The second issue is currently being experienced on a global scale. The inability to participate in everyday activities has significantly impacted well-being during various stages of lockdown throughout the COVID-19 pandemic (Every-Palmer et al., 2020; Hammell, 2020a; Kamalakannan & Chakraborty, 2020; Rotenberg et al., 2021). Along with social

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[1] As Canada uses the term *medical assistance in dying*, this term will be used to refer to all forms of assisted death. However, other jurisdictions use alternate terms, such as euthanasia or voluntary assisted dying.

[2] People receiving medical assistance in dying can choose more than one reason for intolerable suffering, so the total exceeds 100%.

distancing and legal restrictions on indoor gatherings, the yearning to access and participate in meaningful activities in lockdown has increased public awareness of the value of participating in everyday life activities. While the COVID-19 pandemic did not have a significant impact on the current study, this global issue is a timely reminder that confirms the need for a deeper understanding of the universal desire to engage in everyday life. What is ‘normal’ can change rapidly. When the ability to engage in everyday activities is challenged, a person’s sense of self is affected, and how they attribute meaning to everyday life is turned upside down.

In occupational therapy theory and clinical practice, *occupation*, or everyday activities, is defined as all the activities and tasks a person does during the day; and *occupational engagement* is the ability to participate in everyday activities (Canadian Association of Occupational Therapists, 2002). These concepts are central to this thesis and will be discussed in greater detail in coming chapters. This chapter introduces the study by describing the context of the research, the situatedness of the current study, the research question and aims, the significance of this research, and my experience in this field. It will conclude with an outline of the thesis, identifying the purpose of each chapter.

## 1.1 Context of the Research

Cancer is the leading cause of death in Canada. Almost half of the Canadian population will develop cancer and nearly one in three Canadians will die from it (Canadian Cancer Society’s Advisory Committee, 2019). The Canadian Cancer Society’s Advisory Committee (2019) predicts that by 2028-2032, the number of new cancer cases in Canada will increase by 79% compared to 2003-2007. People who have cancer are living longer due to medical advances, resulting in a greater number of people alive with advanced cancer at any given time (Brenner et al., 2020; McTiernan & O'Connell, 2015; Nissim et al., 2012). This will result in increasing numbers of people requiring palliative care.

Although the Canadian government declared that quality palliative care is a right for all Canadians and should be a core value of health care, there are insufficient palliative care resources available nationwide to meet this need (Canadian Cancer Society’s Advisory Committee, 2019; Canadian Hospice Palliative Care Association, 2013; Canadian Senate, 2000). Only an estimated 15% of individuals with a life-limiting illness receive palliative care services at home in Canada (Canadian Institute for Health Information, 2018). Concerns about limited resources for palliative care services are not restricted to Canada. In 2015, 19 million adults required palliative care services globally, and of those, 34% had cancer (Busolo & Woodgate, 2015). It is expected that these numbers will continue to grow (Brenner et al., 2020). The Way Forward National Framework for palliative care in Canada recognises that palliative care should be accessible to all, focusing on the whole person and not only their disease (Canadian Hospice Palliative Care Association, 2015). However, symptom management is often the primary focus in both clinical and research palliative care settings rather than the whole person and their priorities for engagement in everyday activities (Black, 2011; Canadian Hospice Palliative Care Association, 2015; von Post & Wagman, 2017).

As advanced cancer progresses, engaging in everyday activities becomes more challenging, and deterioration in function can occur rapidly (Cohen et al., 2017; Morgan et al., 2017; Rasmussen et al., 2010). Factors such as dwindling energy levels, breathlessness, and reduced strength impair the ability to participate in meaningful occupations (Hammell, 2014; Keesing & Rosenwax, 2011; Lindqvist et al., 2006; Morgan et al., 2017; Park Lala & Kinsella, 2011). As the number of people living with advanced cancer rise, there is also a corresponding increase in the number of people who have difficulties engaging in everyday activities. Cross-sectional studies have established that this increasing difficulty in occupational engagement at the end of life impacts not only the person’s dignity and well-being but also their identity and quality of life (Eriksson et al., 2016; Maersk et al., 2017; Rasmussen et al., 2010; Vrkljan & Miller-Polgar, 2001).

While 42% of Canadians still die in hospitals (Canadian Institute for Health Information, 2018), a noticeable and growing preference among those living with advanced cancer is to die at home, and there is an increasing shift from hospital to home-based care (Alberta Health Services, 2014; Canadian Hospice Palliative Care Association, 2013; Kealey & McIntyre, 2005). There is an imperative, therefore, to better understand what it is like for people with advanced disease to live and die at home and how we can best support their choices and quality of life. What is the experience of everyday life, living at home with an advanced cancer diagnosis? The majority of occupational therapy research regarding occupation and palliative care occurs within in a hospital or hospice context and not in the home (e.g., Ashworth, 2014; Cotterell, 2008; Eriksson et al., 2016; Jacques & Hasselkus, 2004; Jeyasingam et al., 2008; la Cour et al., 2007; Marston et al., 2015; Robertson, 2015).

This imposes a limit on our understanding of how people with advanced cancer experience deterioration and how they adjust to deterioration and death in the home setting.

The voices and firsthand experiences of people with advanced disease are often obscured in palliative care research (Bloomer et al., 2018). Studies may extrapolate experiences of people living with advanced cancer from their caregivers or health care professionals, rather than foregrounding the voices of the individuals living with terminal illnesses for reasons that may be methodological, ethical, or due to other concerns (García-Rueda et al., 2016; von Post & Wagman, 2017; White & Hardy, 2010). An exploration of emerging research that does investigate the phenomenon of occupational engagement for people living with advanced cancer reveals that findings routinely group all adults together. Few studies differentiate between adults 18 to 64 years and over 65 years when reporting findings, regardless of important life stage and occupational differences (e.g., Eriksson et al., 2016; Hammill et al., 2014; la Cour et al., 2007; la Cour, Nordell, et al., 2009; Lindqvist et al., 2006; Marston et al., 2015; Peoples, Brandt, et al., 2017). The voices of people living with advanced cancer are also under-represented in occupational theoretical frameworks. Moreover, in Canada, there is limited focus in current scholarship on furthering existing occupational therapy theory and clinical practice in palliative care. In the Model of Human Occupation (MOHO) and the Occupational Adaptation model, adaptation to illness is primarily described in relation to transitions or non-progressive illnesses, assuming that, unlike advanced cancer, a relative degree of stability or improvement will be made following the medical event (de las Heras de Pablo, Pépin, et al., 2017; Grajo et al., 2018; Mills & Payne, 2015; Schkade & Schultz, 1992; Schultz & Schkade, 1992).

Given the above-identified gaps in research and patient care, this study specifically focused on working-aged adults (who may have different occupational needs than older adults) living at home (the preference of the majority). It sought to explore their lived experience of engagement in occupations (often overlooked in the medical model) as their cancer progressed and functional decline occurred over time (there are limited longitudinal studies), mapping their experiences against existing MOHO theory (no longitudinal studies in advanced cancer have been mapped against MOHO).

## 1.2 Setting of the Research Study

This study took place in the Bow Valley Corridor of the Alberta Rocky Mountains, Canada. The Bow Valley Corridor is a mountain ecosystem that includes three towns

(Cochrane, Canmore, and Banff), acreages, and small farms on the outskirts of these towns. The population of 15 to 64-year-olds in these communities is higher than average in Alberta by up to 12 percentage points (e.g., 68.5% in Alberta; 80.7% in Banff), and these communities continue to grow (Statistics Canada, 2016). Recruitment for this study occurred via the rural home care team in Alberta Health Services. The interdisciplinary team in this catchment area visits individuals of any age and any diagnosis, and includes nurses, occupational therapists, physiotherapists, social workers, and a clinical nurse specialist in palliative care.

## 1.3 Research Question and Aims

This study sought to answer the question: What is the lived experience of occupational engagement for working-aged adults living with advanced cancer, and how does this change over time?

The overarching goal of this study was to deepen and inform the current understanding of engagement in everyday life for working-aged adults living with advanced cancer as their disease progressed. The study aimed to:

- explore the lived experience of occupational engagement during disease progression for community-dwelling, working-aged adults living with advanced cancer,
- track how occupational engagement is experienced over time, and
- examine how these experiences map against MOHO (Taylor, 2017).

A hermeneutic phenomenological approach informed the design of this longitudinal study. This provided a framework to privilege the voices of adults living with advanced cancer and explore how these experiences map against MOHO and illness experience literature. To meet the aims of this study, a series of monthly, semi-structured interviews were conducted with participants who had a prognosis of approximately six months, continuing until participants could no longer take part, died, or after they completed 14 months of interviews.

## 1.4 Significance of the Research

The current study furthers existing scholarship in occupational therapy theory and practice about the lived experience of occupational engagement for working-aged adults living with advanced cancer. This in-depth longitudinal study sought to track how these individuals experienced everyday activities as their cancer progressed and death approached. The unique aspects of study design will inform the following:

1. *A longitudinal approach will increase the understanding of the experience of occupational engagement over time.*

   The complex downward trajectory of living with advanced cancer as function declines often results in difficulty engaging in meaningful occupations due to factors such as loss of ability and confidence, fatigue, and breathlessness (Hammell, 2014; Keesing & Rosenwax, 2011; Lindqvist et al., 2006; Morgan et al., 2017; Park Lala & Kinsella, 2011). Despite increasing scholarship focused on occupations or symptom management for people receiving palliative care services, limited research has examined the lived experience of occupational engagement *over time* among the subgroup of *adults (18-64) living at home* with a diagnosis of *advanced cancer* (e.g., Eriksson et al., 2016; García-Rueda et al., 2016; Haug et al., 2015; Keesing & Rosenwax, 2011; Park Lala & Kinsella, 2011). By examining occupational engagement over time, study findings will inform our understanding about how people change and adapt their participation in everyday activities and how this affects their occupational identity, well-being, and sense of control as their disease progresses.

2. *A hermeneutic phenomenological approach will elicit the lived experience of people living with advanced cancer.*

   This study focused on the *lived experience* of people living with advanced cancer within their *lived world*. A hermeneutic phenomenological approach privileges the voices of participants as their cancer progressed, enables examination of both the whole person and their context rather than merely their symptoms or physical status, and provides opportunity to identify how participants' experiences informed or were informed by current scholarship and theory (Dowling, 2007; Dowling & Cooney, 2012; van Manen, 1990; Walton & Madjar, 1999).

3. *A focus on working-aged adults will provide an in-depth understanding of the lived experience of adults between the ages of 18 and 64.*

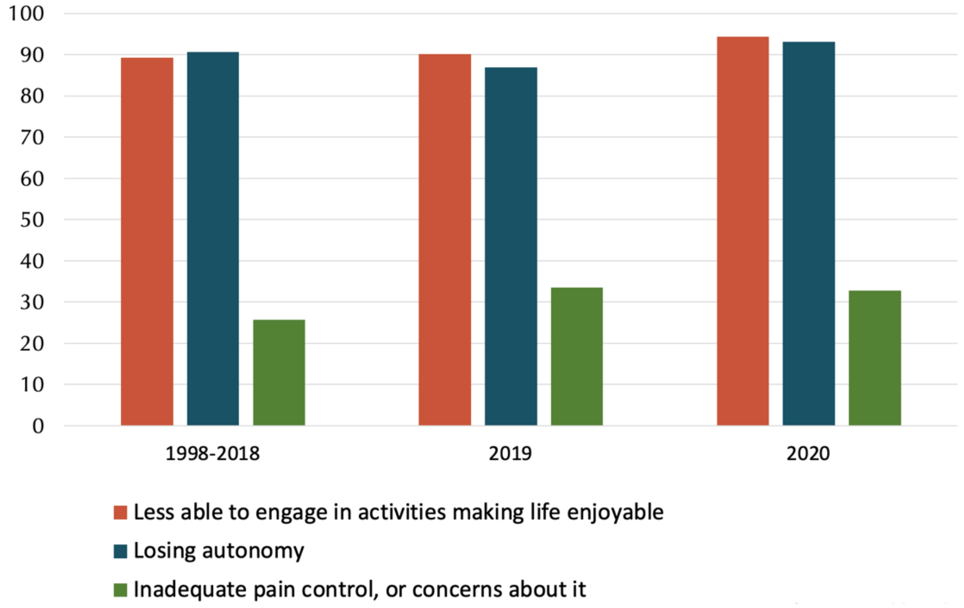
   This age distinction is important, particularly as there is a paucity of research examining everyday life experiences for working-aged adults with palliative care needs. Generally, adults under 65 may have children and careers, have been relatively healthy or active, and do not expect to die before they turn 65. Thus, the illness experience of living with advanced cancer differs between people 18 to 64 years and those 65 years and older.

4. *Findings will build on occupational therapy theory and the palliative care evidence base.*
   Current theory regarding occupational engagement, occupational adaptation, and occupational identity has limited clinical relevance for people living with advanced cancer. There has been minimal attention focused on the unremitting and unexpected changes that occur for those living with a life-limiting diagnosis, such as advanced cancer (e.g., Åberg et al., 2005; Cotton, 2012; Nizzero et al., 2017; Scalzo et al., 2016; Walder & Molineux, 2017a, 2017b; Williams & Murray, 2013). This study will explore how this cohort adapts to their continually changing abilities as time passes and will map these findings against MOHO, thus seeking to extend MOHO theory (Taylor, 2017). Examination of the lived illness experience is consistent with MOHO theory, and findings will shape our understanding of the interplay between occupational engagement, adaptation, identity, volition, and the environment.
5. *Study findings will inform clinical practice.*
   This study may have significant ramifications for the growing number of people receiving palliative care services and their support systems, palliative care clinicians, and policy makers. A greater understanding of this population's unique needs can inform client-centred care, policy decisions, and theoretical frameworks underpinning clinical practice. This study will continue the existing conversation by identifying the voiced concerns and priorities of people receiving palliative care services.
6. *Undervaluing the importance of engagement in valued activities for people living with advanced cancer can have significant consequences.*
   The capacity to participate in everyday activities at the end of life has a significant impact on well-being and quality of life. The state of Oregon (United States of America) collected over 20 years of data on concerns of those choosing to control the timing of their death with medical assistance (Oregon Health Authority, 2021). Similar to Canada, the primary reason people reported for choosing to end their life was the loss of ability to engage in valued activities (89.9%). This has remained the primary concern since 1998 and overrides concerns about symptom management as

per Table 1.1. A greater understanding of the significant impact that the inability to engage in meaningful occupations has on an individual living with a life-limiting illness is warranted. This study seeks to extend this knowledge.

**Figure 1.1**

*Concerns at End of Life: 1998-2020*



*Note:* People receiving medical assistance in dying could choose more than one reason for intolerable suffering, so the total exceeds 100%. Data adapted from “Oregon Death with Dignity Act,” by Oregon Health Authority, 2021, p. 11 (https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf). In the public domain.

## 1.5 Experience of the Researcher

Qualitative inquiry requires the researcher to be aware of the impact of their beliefs, underlying assumptions, and life experiences on the research process. My training, experience, and prior knowledge provided insight into the experiences of people at end of life, and thus, needed to be explored at the outset. It is impossible to completely bracket individual experiences and knowledge. Reflexivity is required, which is consistent with the hermeneutic phenomenological approach used in this study (Wright-St Clair, 2015).

All research has a beginning, and mine began from a young age at the time of my older sister’s childhood death. Since then, palliative care and oncology have been a passion of mine, consolidated by my experience as a hospice volunteer in the late 1990s and growing as an occupational therapist since 2002 (in hospitals, outpatient clinics, hospice, and home care settings in Australia, Canada, and China). More recently, I worked as a palliative occupational therapist in home and community health settings. As the number of clients on my caseload increased and time available decreased, attending to clients' needs became challenging. Referrals related primarily to addressing the client's self-care and mobility needs and prescribing appropriate medical equipment. Due to time constraints, staff often did not assess nor address concerns unrelated to basic activities of daily living, despite clients' strong desire to continue engaging in everyday activities. Clinically, I observed that people who continued participating in activities were better at adapting to their declining function. It appeared that engagement in everyday activities positively impacted their sense of self and brought meaning despite bodily deterioration and approaching death. This study was borne out of a desire to listen to and give voice to people living with advanced cancer as their function declined, exploring their experiences, and through this, coming to a more nuanced understanding about what influences the process of adaptation and how this knowledge can inform future patient care.

## 1.6 Thesis Overview

The thesis aims to explore the experience of occupational engagement for working-aged adults living with advanced cancer and how this experience changes as their disease progresses. Chapter 2 situates the study within conceptual and theoretical frameworks and highlights both existing knowledge and gaps in theory about the illness and occupational experiences of the advanced cancer cohort. Chapter 3 explores current scholarship on occupational engagement and disengagement within the experience of living with advanced cancer. It confirms the evidence gap in which this study sits. The fourth chapter describes the methodology and methods used to study the lived experience of occupational engagement. Chapter 5 provides a vignette of each participant, revealing the longitudinal experiences of functional decline and the adaptation required to continue participating in valued activities. Inductive thematic analysis constructed themes from the data and findings are presented in Chapters 6 and 7. Themes 1 and 2 (Chapter 6) explore the intentional pursuit of everyday activities and the impact of the environment on occupational engagement. Theme 3 (Chapter 7) discusses the lived experience of functional decline, loss, and adaptation. The eighth and final chapter synthesises theory, relevant literature, and key findings and proposes advances in occupational theory and clinical practice to facilitate quality of life through occupational engagement and adaptation.

## 1.7 Conclusion

Even towards the end of life, people seek continued engagement in their valued activities, as it fosters a sense of self, normalcy, and meaning amid functional decline and cancer progression. Thus, greater insight into occupational engagement at the end of life is required to maximise well-being and quality of life. The increasing number of people living longer with advanced cancer globally calls attention to the growing need for such scholarship. In order to address this gap, the current study explored the experience of participation in everyday life of working-aged adults living with advanced cancer as their disease progressed. It employed a hermeneutic phenomenological approach to understand the meaning behind their illness experiences, and findings were evaluated against MOHO (Carel, 2016; Taylor, 2017; van Manen, 1990).

This research contributes to existing knowledge through its longitudinal exploration of the lived experience of occupational engagement for working-aged adults living with advanced cancer. This thesis argues that while changes in occupational engagement occur over time, the role of volition in occupational adaption plays a far more significant role than previously understood for this cohort. The consequences of not addressing occupational needs at end of life can be significant, as seen in the COVID-19 pandemic lockdowns and in the reasons why people choose medical assistance to end their lives. This study contributes to our understanding of the lived experience of occupational engagement for adults living with advanced cancer, thereby illuminating possibilities for improving client-centred care.

# CHAPTER 2: THEORETICAL CONCEPTS

An interdependent relationship exists between theory, research, and practice, whereby each area informs, shapes, supports, and sometimes challenges the other. Theoretical frameworks are not static; they develop and are refined over time as knowledge advances (Taylor & Kielhofner, 2017). One of the significant, original contributions of this study is furthering existing theory on occupational adaptation for working-aged adults living with advanced cancer. This study argues that the current understanding of occupational adaptation as defined by the Model of Human Occupation (MOHO) is insufficient for this population group. The current definition views occupational adaptation as an interdependence between occupational identity and competence (de las Heras de Pablo, Fan, et al., 2017). However, a consistent level of competence for people living with advanced cancer is not feasible due to ongoing physical decline and disease progression. This thesis argues that the motivation behind occupational engagement (volition) plays a central role in occupational adaptation for this study cohort when contending with advanced cancer progression. This study contributes to the understanding of the lived experience of everyday life for people living with advanced cancer by focusing attention on and exploring the role of motivation behind *why* individuals *intentionally* chose to participate in certain occupations within their context of illness.

In order to explore the experience of occupational engagement, the study needed to situate itself in the relevant theories and concepts that affect everyday experiences for adults living with advanced cancer. Two key conceptual frameworks provided insight into these experiences: the illness experience and MOHO, a well-established theoretical framework of occupational therapy. Scholarship on the illness experience emphasises the importance of understanding and being guided by the perspective of the person living with illness, including awareness of how these individuals experience loss and ascribe meaning during everyday life. The study also adopted an occupational perspective to guide research, given its central focus on occupational engagement. The primary theoretical model framing the study was MOHO due to its emphasis on meaning and motivation, occupation, occupational adaptation, and the lived body (Taylor, 2017). The conceptual and theoretical frameworks of both the illness experience and MOHO aligned with the hermeneutic phenomenological approach employed by this study, as phenomenology seeks to understand the meaning and essence of a person’s lived experience of everyday life (van Manen, 1990). A longitudinal approach provided additional insight into changes over time, tracking how occupational engagement shifted as function declined and death approached. An understanding of both the illness experience and theoretical concepts regarding occupational engagement provided the foundation for this research, underpinning the literature review, study design, implementation, findings, and analysis.

Illness impacts participation in everyday life. Examined from the perspective of the individual living with advanced cancer, the illness experience is one of loss, increasing dependency, and the desire for normalcy. It encompasses the unique meaning an individual ascribes to their advanced cancer and how the experience of cancer affects their lived world (Carter et al., 2004; Etkind et al., 2017; McCaffrey et al., 2016; McKechnie et al., 2007; Vehling et al., 2018; Willig & Wirth, 2018). Understanding these concepts from the individual’s perspective can inform person-centred clinical practice, optimising quality of life at the end of life. The purpose of this chapter is twofold: to explore how the concept of illness experience shapes a person’s everyday life while living with advanced cancer and to examine factors surrounding participation in activities that impact the illness experience through the lens of and in relation to MOHO theory. These two frameworks—the illness experience and MOHO—complement one another, providing a deeper lens from which the experience of occupational engagement is understood.

## 2.1 The Lived Experience of Illness

Phenomenology examines the lived experience of a phenomenon (Finlay, 2011). In this study, the phenomenon under investigation is the lived experience of occupational engagement within a cohort of working-aged adults living with advanced cancer. As this chapter focuses on the frameworks of illness experience and the meaning underpinning occupational engagement, discussion in this section centres around hermeneutic phenomenology. A more detailed examination of phenomenology as it relates to methodology and method is provided in Chapter 4. This section begins with a discussion on the lived world as understood by van Manen’s (1990) hermeneutic phenomenology, followed by an examination of the illness experience, both foundational concepts framing this study. It concludes with a brief examination of the lived experience of illness across the complex trajectory of advanced cancer.

### *2.1.1 Phenomenology and the Lived World*

A hermeneutic phenomenological approach focuses attention on the *essence* or the meaning behind an individual's lived experience within the context of their lived world (Finlay, 2011; van Manen, 1990). Building on Merleau-Ponty's (1962) work on the meaning of a person's lived world and Heidegger's (1962) work on being-in-the-world, van Manen (1990) coined the term *existentials* to describe four interconnected dimensions of a person's experience of the lifeworld: spatiality, temporality, relationality, and corporeality. van Manen (1990) used the term *lifeworld* to describe the "world of lived experience" (p.182), so this term will be used interchangeably with the term *lived world* in this thesis. Existentials can significantly shape how a person experiences their world. Individuals often experience existentials subconsciously but rarely reflect on them at the time. For example, trying to leisurely (temporality) find a set of keys in a tidy room (spatiality) is a different experience to that of urgently (temporality) trying to find them in a cluttered and messy room (spatiality). The four existentials are part of and applicable to every person's experience of their lifeworld and are also valuable tools for phenomenological reflection for the researcher (van Manen, 1990).

Spatiality is the first component of van Manen's (1990) lifeworld and refers to the physical space that an individual inhabits. Spatiality extends beyond the presence or absence of physical environmental attributes and includes how lived space shapes the individual and their experience of the world. Recognising its impact on our being, van Manen (1990) states, "we become the space we are in" (p. 102). For example, a person may find being in a hospital destabilising. Not only is the environment unfamiliar, but the individual experiences hospital routines and equipment as unsettling. They may internalise their role of patient after extended periods of time in the hospital, with restrictions on what they can do and in which locations. This then affects their sense of well-being (Lee & Kielhofner, 2017a). Contrast this to feeling at home when a person receives medical care in their own house. The presence of familiar objects and routines, often unnoticed, provides a sense of meaning and identity. In this space, people engage in everyday activities without the constraints of an unfamiliar environment (Maersk et al., 2018). Thus, spatiality impacts how people perceive their illness experience and how they engage in occupations.

Temporality refers to a person's lived experience of time (van Manen, 1990). Temporality may include the sensation that time passes quickly or that time seems to drag by slowly. The perception of time affects how a person experiences their day or illness. Two examples that demonstrate different interpretations of time are parents of young children and people living with advanced cancer. Days seem to go by so slowly with a newborn, but the years disappear quickly following that initial new baby phase and as the child grows. Time may feel short and uncertain, yet meaningful, for people living with advanced cancer as they hope to live until Christmas or until a loved one's birthday. It is not uncommon for time to be remembered as more predictable before their cancer diagnosis, yet now they also experience time as fluctuating and unstable in both the present and future (Ellingsen et al., 2014). The awareness of time passing is one reason people intentionally engage in valued occupations.

A third aspect of van Manen's (1990) lifeworld is relationality. Interactions with people shape the experience of everyday life. van Manen (1990) argues that meaning is ascribed to events based on the people that are present and the nature of their relationship. For example, a workday is a vastly different experience depending on the type of interactions with colleagues or customers. Navigating social relationships within the context of illness is challenging. People living with advanced cancer may wish to be near the people they love yet also experience a sense of loneliness in their midst or have a fear of becoming a burden (Rainsford et al., 2017; von Post & Wagman, 2017).

Corporeality, the experience of the lived body, is the fourth component of van Manen's (1990) lifeworld. Rather than viewing the body as a separate entity, corporeality acknowledges the self in conjunction with the person's physical experience of their body (Kielhofner, 1995; Leder, 1990). For example, a person's hand is not simply a body part. With their hand, a person explores their world through touch and can express themselves through what activities they do. When a person's body changes due to an illness or disability, their body may feel foreign, giving rise to difficulties doing everyday tasks. Thus, following an upper limb amputation, the person begins to experience challenges using only one hand, and they may no longer feel like themself. Similarly, someone requiring assistance with intimate hygiene tasks may feel distressed by a caregiver's attitude or assistance that reduces their body to an object. The distress experienced may arise due to the disassociation felt between their physical body and self (Chochinov et al., 2009; Eriksson et al., 2016; García-Rueda et al., 2016; Lindqvist et al., 2006; Morgan et al., 2017; Morgan et al., 2021). The experience of the lived body as a barrier or facilitator of participation in everyday life is unique to the individual and context. Reminiscent of other existentials, corporeality can also profoundly impact a person's sense of meaning and well-being.

van Manen's (1990) four lifeworld existentials (spatiality, temporality, relationality, and corporeality) provide a valuable lens to examine the phenomenon under investigation, the lived experience of occupational engagement in advanced cancer. To understand this experience, the context of illness will now be explored.

### *2.1.2 The Illness Experience*

Philosophers, psychologists, sociologists, and medical researchers approach and define the illness conversation from varying perspectives. Considered together, they provide a multifaceted picture of the illness experience. Given the assumptions made about the two concepts of illness and disease and the range of opinions in the literature, this section defines the concepts of illness and disease at the outset (Boyd, 2000). A more precise understanding of the terms is also relevant for the current study as its focus is on the lived experience of advanced cancer, not the disease process. An explication of the illness experience follows, highlighting the differences between the two concepts, the importance of the person's lived perspective, and exploring some of the meanings ascribed to the illness experience. Given the limited research on the concept of illness experience in palliative care, this section relies on insights into the illness narrative from within the chronic medical condition literature.

The concepts of disease and illness have developed over time. When considering how disease affects daily life from the individual's perspective, the focus has shifted from the social impact of the sick role to the impact of the illness experience (Pierret, 2003). Historically, *disease* has described the objective aspects of medical conditions, such as the pathology of the disease process and the impact of disease on the physical body (Boyd, 2000; Svenaeus, 2019). *Illness*, on the other hand, encompasses more than disease symptomology; it is the experience of living with the disease. Illness asks questions such as how is the disease experienced? What does living with a health-limiting condition entail, and how does it affect daily life? How is meaning found and reshaped in the illness experience? From the 1950s to the 1970s, an increasing number of researchers sought to explore the conceptual differences between the sick role and disease. Research into the illness experience of numerous conditions developed further in the 1980s (Pierret, 2003). The shift in focus from disease to illness is attributed to Bury's (1982) exploration of the lived experiences of rheumatoid arthritis. Bury (1991) argued that illness impacts daily life from the onset of the initial symptoms. Viewing illness as a significant disruptor of a person's assumptions and beliefs about life, he also noted its impact on the individual's sense of self. Bury's (1991) later research on chronic illness conceptualised the shift in the meaning given to illness as both the consequences of the illness (e.g., difficulty ambulating) and its significance as reflected in positive or negative meanings attached to it (e.g., deep disappointment arising from my inability to go to my grandchild's house because I cannot walk up the stairs). A more nuanced development of the concept of illness experience is found in the work of Carel (2016), Frank (2002), Kleinman (2020), Pierret (2003), and Toombs (1987). Kleinman (2020) defined the illness experience as how an individual and their social network "perceive, live with, and respond to symptoms of disability" within the context of everyday life (p. 2). Will I still have the freedom to read books to my children without back pain while sitting on their bed? Do I feel frustrated when unable to multitask due to 'chemo brain'? Why do I feel the need to explain to others that I have no energy to walk from my car to the grocery store and that, although I may look well, I need a disabled parking pass? Illness is pervasive and sometimes obscured or hidden, yet affects every aspect of life.

There are differences between how health care providers and people who are unwell describe illness and disease. The illness experience is often re-interpreted within a medical framework (Frank, 2013; Kleinman, 2020). Thus, the disease becomes central, separate from the person's additional illness concerns. Frank's (2002) account of living with cancer highlighted the importance of and distinction between his illness experience and the disease. He observed that his body was often referred to as a diseased object during medical appointments, a separate entity as if it were a vehicle needing repairs. The experience of living in his body—his illness experience—was rarely considered or spoken of, despite the inseparability of his mind and body. Wrestling with the question of "what is happening to *me*? Not *it*, but *me*" (p. 13), Frank (2002) described how his cancer diagnosis affected him. His perspective shifted significantly due to living with cancer (i.e., how he viewed life through his illness experience). He valued the medical care received that addressed the cancer sequelae, yet astutely commented that "doing *with* the body is only part of what needs to be done *for* the person. What happens when my body breaks down happens not just to the body but also to my life, which is lived in that body. When the body breaks down, so does the life" (Frank, 2002, p. 8). If the person's physical symptoms are the primary concern of the health care system, other areas of life affected by cancer may not be addressed (Frank, 2002). The distinction between illness and disease is vital. Due to the significant impact that the illness experience has on the individual, this study focused on the person's lived experience of everyday life rather than specific physical domains of their body.

The illness experience shapes the meaning a person ascribes to their illness and their way of being-in-the-world (Carel, 2016). For many, there is a need to reconfigure how to make sense of their disrupted lives following the intrusion of a significant medical condition. How do they define themselves? Do they feel capable? How is their sense of self affected? (Pierret, 2003). Speaking about an experience often facilitates the creation of meaning (Frank, 2002; Kleinman, 2020). Listening to the perspective of the individual experiencing illness can identify how they attribute meaning to their illness. In order to listen well, health care providers must temporarily suspend their clinical biases and assumptions about what contributes to the individual's sense of well-being (Carel, 2016). More than simply listening, this should shape the assessment and interventions provided by the health care team.

Meaning varies from person to person, as noted in Carel's (2016) example of an individual with significant functional limitations (e.g., quadriplegia) who may experience a greater sense of wellness than another individual with a lesser degree of impairment (e.g., lower back pain). Carel (2016) and Hammell (2020b) argued that a person's objective health status does not necessitate well-being. A significant finding from a longitudinal study on chronic illness by Charmaz (2006) reported that people living with chronic illness often gauged their health or sense of self by what they could or could not do during their everyday life. The centrality of the impact of everyday life on well-being was also supported by Lindqvist et al. (2006) in a study focused on the illness-wellness experience of men living with prostate cancer. The illness experience changed how participants interpreted and ascribed meaning in their daily life.

To understand the *meaning* behind the lived experience of illness and everyday life, this study chose a hermeneutic phenomenological approach. Carel (2016) argued that a phenomenological approach could facilitate a deeper understanding of the illness experience. Independent of the source of chronic illness, phenomenology and the illness experience both focus on how chronic illness shapes the experience of everyday life and is situated within a given context in their lifeworld. Both concepts presuppose a view of the *whole* person and explore the nature and centrality of meaning in their world (Carel, 2016; Frank, 2002, 2013; Kielhofner, 1995; Kleinman, 2020; Toombs, 1987; van Manen, 1990). Illness significantly changes how a person inhabits their world, regardless of other contextual factors. Carel (2016) stated that "viewing illness as transforming one's being-in-the-world, including one's relationship to the environment, social and temporal structures, and one's identity, has helped capture the pervasive nature of illness" (p. 37). Although the illness experience is unique to the individual and depends on their social and cultural context, commonalities encompassing various chronic conditions exist (Carel, 2016; Kleinman, 2020; Toombs, 1987).

Space and time are experienced differently in all illnesses experiences due to the person's changed abilities (Carel, 2016; van Manen, 1990). Negotiating space can become increasingly challenging when living with an illness (Carel, 2016). In her illness narrative, Toombs (1995) described how her perception of the environment shifted following her multiple sclerosis diagnosis. Spaces that once seemed close now appeared further away, as distances in the physical environment took on new meaning. She reflected on the tiring necessity of learning and relearning how her body interacted with her environment, an experience not uncommon in many chronic illnesses. van Manen (1990) argued that the perception and response to lived space and lived time could significantly shape how a person experiences the world, all the more so when facing the challenge of any chronic illness.

Another commonality of the illness experience is the ways in which chronic illness is marked by loss. Toombs (1987) characterised this loss as the "loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the familiar world" (p. 229). Carel (2016) and Toombs (1987) explored these five losses in relation to people living with chronic illness; many of these losses are also experienced by people living with advanced cancer. The first loss, the loss of a sense of wholeness, describes the impact of bodily dysfunction. Awareness of the body may dominate consciousness rather than existing in the background. A common challenge for those with progressive chronic illness is that the physical body alters what the person is able to do. They may need frequent rest breaks or recognise the necessity of changing plans. The person may feel as if they are no longer a whole person but have lost part of their self. Concerns for the body may take a more primary role in daily life (Carel, 2016; Leder, 1990; Toombs, 1987). As a result, the person feels increasingly uncertain–the second loss. The loss of certainty introduces feelings of vulnerability as the fragility of life is intimately experienced. Daily routines are no longer stable and achieving normalcy may feel uncertain. Third, the person's world may feel outside of their control. This feeling is reinforced in chronic illness when the medical system cannot return their bodies to a sense of wholeness. The person may also experience a loss of control if it becomes necessary to receive assistance for self-care tasks due to increased dependency. The experiences of uncertainty and loss of control are recurrent themes in research involving people living with advanced cancer and are discussed further in the literature review chapter (Arantzamendi et al., 2020; Black, 2011; McKechnie et al., 2007). Life is no longer predictable.

Toombs (1987) described the fourth loss as the loss of the freedom to act, referring to the complexities of relying on a medical team for treatment decisions. However, a more apt and alternate interpretation of this loss of freedom in advanced cancer is found in Frank's (2002) experience of his future evaporating when he received his cancer diagnosis. He no longer had the freedom to plan and live out his desired future. Carel (2016) argues two additional points on the concept of loss of freedom. First, the loss of freedom is dependent on the cultural context. Some cultural settings may accept the loss of independence and resultant loss of freedom in chronic illness more readily than others. In some contexts, the value of independence is so great that certain individuals may view their loss of future freedoms as intolerable. Second, Carel (2016) furthers Frank's (2002) discussion on the loss of future freedoms to include the loss of the present freedom to do what the individual currently wants to do. Linked with this concept is the fifth loss described by Toombs (1987). The loss of the familiar world describes the loss of the ability to engage in routine habits or activities. This loss of some ability to participate in everyday life activities is significant in chronic illness and can lead to a loss of sense of self or identity (Hammell, 2004).

These five significant losses (the loss of wholeness, certainty, control, freedom to act, and the familiar world) are found within all the seminal texts on the illness experience and are particularly relevant to chronic illness and advanced cancer (Carel, 2016; Frank, 2002, 2013; Kielhofner, 1995; Kleinman, 2020; Toombs, 1987). The ability to participate in routine activities is also referred to as occupational engagement and is the focus of this study (Black et al., 2019; Morris & Cox, 2017). While the theoretical framework of occupation (MOHO) follows in this chapter, the current literature about occupational engagement is explored in Chapter 3 (Literature Review).

The concept of *illness experience* provides a valuable foundation for understanding the current study's investigation into the lived experience of occupational engagement in advanced cancer. Carel (2016) and Kleinman (2020) offer important insights from the lived world of chronic medical conditions. Many of their contributions are relevant to the current study: the distinction between disease and illness, the importance of the person's own perspective, the impact illness has on meaning, and recognition of the losses experienced. However, both authors limit discussion of the dying experience to the terminal or active dying phase, rather than presenting dying as a continuum occurring over months or years of living with a life-limiting condition. This may reflect an earlier time when palliative care services were primarily for people imminently dying rather than for people living with life-limiting illnesses as it is today. Despite this, the concept of illness experience frames the discussion on the experience of everyday life for working-aged adults living with advanced cancer. The following section explores the illness experience of people receiving palliative care services, focusing on the disease/illness dichotomy and the shifts between wellness and illness amid a declining disease trajectory.

### *2.1.3 The Illness Experience at End of Life*

Prioritising the disease process (treatment of physical symptoms) over the illness experience (impact of illness on the self) often occurs within the medical system (Frank, 2002). This may be due, in part, to a subconscious assumption of the separation of body and self, with greater value placed on the treatment of the physical body in illness or injury (Black, 2011; Canadian Hospice Palliative Care Association, 2015). Similarly, management of the disease process and symptoms are often the primary focus in palliative care services, despite the assertion of holistic, comprehensive care (Black, 2011; Eriksson et al., 2016; García-Rueda et al., 2016; Lindqvist et al., 2006; Mills & Payne, 2015; Morgan et al., 2017). Addressing the physical concerns of the person living with advanced disease is crucial as poorly controlled symptoms can be debilitating. However, it is important to avoid a disconnect between medical interventions and the person's goals (Frank, 2002). Clark (2007) noted that it should not be assumed that improved quality of life is inevitable once physical concerns are addressed. Rather, effective symptom management is a starting point towards enabling valued participation in everyday life at the end of life (Morgan et al., 2017). It is the illness experience of the whole person that must be addressed, not just their diseased body.

The experience of disease for people receiving palliative care services often follows a downward trajectory and changes can appear relentless (Murray et al., 2005; Svidén et al., 2010). Many adults with advanced cancer experience a continual movement between health and illness, shifting between feeling well and then unwell (Lindqvist et al., 2006; Morgan, 2012). This differs from the general experience of chronic illness, which has a relative level of stability, although fluctuations do occur (Carel, 2016; Kleinman, 2020). A commonality shared by both population groups is the experience of a changed body and the impact of disease on everyday life; however, *how* advanced cancer impacts daily life is different due to more rapid, frequent fluctuations and decline than experienced by those living with many other chronic diseases. An emerging body of evidence demonstrates that bodily changes accompanying advanced cancer often result in progressive functional decline with disruption to occupations, roles, and routines (la Cour & Hansen, 2012; la Cour, Johannessen, et al., 2009; Lindqvist et al., 2006; McKechnie et al., 2007; Morgan, 2012; Ngwenya et al., 2017; Rasmussen et al., 2010; Vrkljan & Miller-Polgar, 2001). These shifting experiences of disruption to everyday life require further exploration. Most of the research in this area is cross-sectional at a single point in time. Research that explores phenomena at a single point in time provides valuable information about the illness experience; however, nuances in how changes occur in a person's lived experience over time may be missed. This current study employed a longitudinal approach in order to understand how the lived experiences of everyday life changed *over time* for working-aged adults living with advanced cancer. The lived illness experience provided a valuable conceptual framework; however, it is only part of the story. The theoretical frameworks pertaining to occupation provided another lens through which to investigate the lived experience of occupation.

## 2.2 Theoretical Framework: Occupation

The previous section explored the concept of illness experience, highlighting the meaning ascribed to these experiences, the centrality of the emic or insider perspective on illness, and the losses experienced. As noted earlier, illness also affects participation in the activities of everyday life (i.e., occupational engagement). An occupational lens provided a framework to examine the experiences of occupational engagement in everyday life for people living with advanced cancer. This section begins by exploring the key occupational concepts of occupation, meaningful occupation, and occupational engagement. The remainder of the discussion will focus on the Model of Human Occupation (MOHO) and its central tenets as it applies to a person's lived experience of everyday life. MOHO was selected as the primary theoretical framework for this study as it focuses on the motivation behind occupational engagement and the concept of occupational adaptation. It is also the only occupational therapy model that has a central focus on the subjective, lived body experience, which aligns with the illness experience literature and the phenomenological approach used in the current study.

### *2.2.1 What Is Occupation?*

The concept of *occupation* is a fundamental tenet of the occupational therapy and occupational science professions. Occupation is comprised of all that a person does to occupy and structure their time. More specifically, the Canadian Association of Occupational Therapists (1997) defines *occupation* as "groups of activities and tasks of everyday life, named, organised and given value and meaning by individuals and a culture" (p. 34). Consequently, humans are considered to be occupational beings (Polatajko, Cantin, et al., 2013). Despite their continuous presence in our lives, occupations and the ability to engage in daily occupations are often taken for granted. Seemingly invisible, many daily routines are performed on autopilot. Because the term occupation incorporates everything a person does, including those activities that bring meaning and purpose to a person's life, occupation can be considered as "a basic need essential to living" (Laliberte Rudman et al., 1997, p. 647). Occupation's link with health and well-being is well established (Christiansen, 1999; Howie et al., 2004; Law et al., 1998; Stewart et al., 2016; Yerxa, 1998). Participating in occupations is central to a person's lived experience of their daily life.

Despite the common use of the term occupation within occupational therapy research and clinical practice, this construct has multiple definitions and conceptualisations. Categorisation of occupations is a popular and helpful way to conceptualise occupation. Groupings such as self-care (e.g., bathing, dressing tasks), productivity (e.g., home maintenance duties, work), and leisure (e.g., reading, cycling) are commonly used in clinical practice and research (Polatajko, Davis, Stewart, et al., 2013), or doing, being, belonging, and becoming (Wilcock, 2007). However, these commonly held categories have been questioned. Hammell (2009) suggested that occupation should be defined as being "restorative" (p. 110), "fostering belonging" (p. 110), doing occupations, or "reflecting life continuity” (p.111). She argued that the emphasis on self-care, productivity, and leisure as broad occupational categories is more applicable to the able-bodied, independent individual with defined leisure activities and the capacity to work. There is a paucity of literature that examines the relevance of category delineations for the person living with advanced cancer who is unable to work or the person who is no longer able to participate in previously enjoyed leisure activities due to declining health. Categories do not always align with or reflect individual perceptions. Individuals differ in the meaning placed on the value of everyday activities or occupations. One person may consider a specific occupation to be leisure, while it may be viewed as productivity by another. This is consistent with the illness experience literature that highlights the personal, social, and broader cultural meaning that each person brings to the conversation (Carel, 2016; Kleinman, 2020). Academic debate about the relevance of occupational categorisation and a critical review of these concepts has resulted in a significant change to the upcoming edition of the Canadian model of occupational therapy to be released in 2022. The focus on categories of self-care, productivity, and leisure will be removed in order to establish a greater focus on the meaning, purpose, and life stage of the individual (Restall et al., 2021). The lack of a consensus among researchers on how occupations should be categorised highlights the complex nature of occupation and the unique meanings ascribed to it by individuals and communities. Thus, reflexivity on the part of the researcher or clinician is required when seeking to understand the personal meaning an individual gives to an occupation.

This study focused on the lived experiences of participating in occupations for people living with advanced cancer rather than on occupational delineations. The motivation and personal meaning behind the occupation (volition) are essential aspects of a person’s lived experience. For example, going to a child’s soccer game is more than a leisure pursuit; it can represent an expression of the valued role of parent. It can also involve relational aspects of socialising with other soccer moms or dads, or indicate the desire to give back to the community through bringing the snacks (Hammell, 2004). From the person’s perspective, their values, interests, sense of self-efficacy, habits, roles, and abilities motivate them to participate in occupations. This will be discussed further in Section 2.2.5. This current study’s focus on meaning in everyday life is congruent with the theoretical and conceptual frameworks underpinning this study: MOHO and the illness experience (Carel, 2016; Charmaz, 2006; Kleinman, 2020; Taylor, 2017).

### *2.2.2 What Constitutes a Meaningful Occupation?*

The term *meaningful* is a key phrase routinely employed by occupational therapists and occupational scientists in relation to occupation, describing the meaning an individual ascribes to the activities they participate in. Despite the relevance and centrality of the word meaningful in the context of occupation, what the term entails is rarely defined or discussed in occupational therapy research or clinical practice. Hammell (2004) sought to clarify its definition in her article on the meaning of everyday occupations. She examined the impact of biographical disruption on the meaning ascribed to occupation. *Biographical disruption* is defined in this context as a health crisis impacting a person's body, sense of self, and sense of time. This term was first used in the illness experience literature when describing the early onset of a chronic illness (Bury, 1982, 1991). However, it also relates to the concept of occupational engagement since illness affects how a person participates in everyday life. As noted earlier, existing categorisations of occupation are inadequate for people who cannot independently engage in self-care, work, or leisure occupations; they do not address the experience of biographical disruption (Hammell, 2004). Meaning, on the other hand, is a central concept of the illness experience for all (Bury, 1982, 1991; Carel, 2016; Charmaz, 2006; Kleinman, 2020). Hammell (2004) proposed that a focus on meaning rather than task category provides an alternate lens through which to view occupation that is inclusive of the illness experience. She argues that a meaningful life or "a life worth living" is comprised of four aspects: a life that has "meaning, purpose, choice/control and self-worth" (Hammell, 2004, p. 302). Although her article did not focus on degenerative conditions, these concepts have relevance for people with advanced cancer who may experience the loss of function, normalcy, a sense of self, and a sense of control.

The first key aspect of Hammell's (2004) life worth living is the *meaning* that results from participating in occupations. She argued that the term *meaningful* is often assumed to have positive connotations, presupposing that meaningful activities are valued and enjoyed. However, the meaning a person ascribes to an occupation could be positive or negative. A person, for example, may feel embarrassed when receiving assistance with toileting. Rather than presume positive implications for the term meaning, Hammell (2004) suggested that another way of defining 'meaningful occupation' is to describe it as an *occupation of significance*, whether positive or negative. This is consistent with Bury's (1991) findings that people living with rheumatoid arthritis linked a sense of meaning to the consequences and significance of their chronic illness. The second component of a life worth living identified by Hammell (2004) pertains to *living purposefully*. Engaging in occupations can give an individual a sense of purpose in life, particularly when the activities are of value to the individual. However, when the occupation is not of interest to the person, participation in the activity does not necessarily represent meaningful or purposeful living. A third characteristic of a meaningful life is having a sense of *control* and *choice*. An individual can gain a sense of control when they are able to pursue that which is important to them. This is significant for people experiencing a shift in abilities due to a transition, illness, or injury. Continued occupational engagement provides a valued sense of control at a time when many other life circumstances seem out of their control.

Hammell's (2004) fourth component of a life worth living is a *sense of self-worth* or *competence*. She noted that participating in meaningful occupations shapes a person's sense of self-efficacy and identity. A diminished sense of self-worth or feeling useless is often evidenced following an injury or illness, particularly when a person may have difficulty engaging in previously enjoyed occupations. Changes in a person's sense of self are also observed in the illness experience literature when describing losses associated with illness, such as the loss of control, the loss of function, and the loss of the familiar world (Charmaz, 1983; Toombs, 1987). The description of the loss of the familiar world is consistent with concepts in the illness experience related to the inability to engage in meaningful, everyday occupations. However, when that same person is then enabled to participate in an occupation of choice, they may feel capable and perceive that they are of value (Hammell, 2004; Lee & Kielhofner, 2017b).

Scholarship on the illness experience is consistent with the centrality of meaning ascribed to occupations (Hammell, 2004). Carel (2016) proposed that "illness is a breakdown of meaning in the ill person's life. Because of the disruption of habits, expectations, and abilities, meaning structures are destabilized" (p. 14). The person may no longer be able to do the activities they previously found meaning in, such as their work (too physically demanding) or family responsibilities (insufficient strength to do many home maintenance tasks). These markers of self shift with the illness experience (Charmaz, 2006). Despite the disruption experienced by illness, Carel (2016) also queries whether able-bodied individuals focus on the primarily negative interpretations of illness due to their etic or outsider perspective and propensity to give attention to the person's lack of abilities instead of their strengths. This is also seen in health care settings, where the end-product (e.g., task completion, discharge home) has greater value than the process of participation. This thesis contends that the meaning a person places on an occupation is not limited to the actual doing of the activity but may include the *process* of engaging in that occupation and the entire volitional cycle (anticipating the participation in an occupation, choosing what occupation to do, engaging in the occupation, and the interpretation of it afterwards) as discussed further in 2.2.5.1. Setting aside presumptions and giving conscious attention to the meaning ascribed to illness by the person living with advanced cancer is essential to understanding their everyday life experiences. Hammell's (2004) proposed components that make life worth living are important to consider when looking at meaningful occupational engagement. In this current study, they informed the understanding of what is meaningful to the individual at the end of life. These aspects of a life worth living provide a more nuanced understanding of why engaging in meaningful occupations is so important for people living with advanced cancer, rather than simply focusing on the broader concepts of categorisation and task completion (Hammell, 2004). Having explored the constructs of meaningful occupation, the following section will investigate the concept of occupational engagement.

### *2.2.3 What Is Occupational Engagement?*

Why is the ability to participate in everyday activities—occupational engagement—so important? "Engagement in occupation, rather than being trivial, is an essential mediator of healthy adaptation and a vital source of joy and happiness in one's daily life" (Yerxa, 1998, p. 417). The opportunity to engage in meaningful occupations has also been described as a right for all people, given the crucial role occupation plays in a person's life and its link with well-being (Christiansen, 1999; Howie et al., 2004; Law et al., 1998; Stewart et al., 2016; Yerxa, 1998). This is affirmed by the World Federation of Occupational Therapists (2019) who argue that people have the right to "participate in a range of occupations that support survival, health and well-being so that populations, communities, families and individuals can flourish and realise their potential" (p. 1).

What is meant by the term *occupational engagement*? This term has been defined in numerous ways across the occupational therapy and occupational science fields (Black et al., 2019). Common characteristics in definitions of occupational engagement include the active participation in an occupation, the value or meaning placed on it, the link to occupational balance, and the role the environment plays in occupational engagement.

The most frequent definition of occupational engagement in the literature was the active participation in an occupation (Black et al., 2019). Although occupational engagement is often referred to as the ability to take part in occupations, this engagement may be as a passive observer, a more active participant, a novice, or with a high level of competence (Townsend & Polatajko, 2013). The term *engagement* is more comprehensive than the terms *performance* of or *participation* in occupations. More specifically, Townsend and Polatajko (2013) assert that occupational engagement does not have to include the *performance* of an occupation as traditionally defined. The authors used the example of a boy being pushed in a wheelchair while his father runs a marathon. Although the boy is not physically running in the marathon, he is still participating through being pushed by his father. Occupational engagement in both its active and passive forms is important to consider when looking at a person's experience of everyday life, especially for those living with advanced cancer. The passive state of certain occupations (such as observing an activity) may not be as easily recognised as the more active version of the occupation, yet these less recognised occupations are also significant, shaping their remaining months, days, and hours.

A second definition frequently used for occupational engagement is contingent on the *meaning ascribed to the occupation* by the person engaging in it (Black et al., 2019; Morris & Cox, 2017). The use of the term *meaningful occupational engagement* here implies a positive meaningful involvement in a valued occupation. Morris and Cox (2017) furthered the discussion on what meaningful occupational engagement entails, arguing that the definition should also include the *perceived value* and the *consequences of* engaging in an occupation. The value of an occupation can be positive or negative, ranging from a sense of absorption or 'flow' to a sense of repulsion. The consequences of participating in an occupation are an infrequently considered aspect of occupational engagement, despite their influence on what people choose to do. Morris and Cox (2017) use the example of a teenager experimenting with drugs as an occupation which can have negative consequences (e.g., affecting grades, getting grounded, or health consequences). Bury (1991) also linked the meaning of an illness experience to consequences and significance, as described earlier.

The value of an occupation is unique to the individual, highlighting the *subjective* nature of the experience (Black et al., 2019; Morris & Cox, 2017).

The two aspects of occupational engagement discussed above are central to all experiences of occupational engagement. However, additional contextual factors such as the link with occupational balance and the role of the environment were also included in many definitions of occupational engagement in Black et al.'s (2019) scoping review. *Occupational balance* was defined as having an appropriate mix of routine and varied occupations, as well as a balance between rest and activity. Both the person's *social and physical environment* have a direct influence on occupational engagement. A person may be able to participate in an occupation if the environment matches their needs, but that same individual may not be able to do the same activity in a different location or if barriers impede their function. An awareness of the impact of the physical environment on a person's lived experience of everyday life is an important component of the phenomenological understanding of lifeworld (Carel, 2016; Toombs, 1995; van Manen, 1990).

Black et al. (2019) concluded that seminal sources in occupational therapy literature should be considered when defining occupational engagement. These sources include the "transactional interaction of the mind, body, and spirit" described in the updated *Occupational Therapy Practice Framework* (American Occupational Therapy Association, 2020, p. 6); a focus on objective and subjective aspects of occupation (Wilcock, 1993); and the physical, emotional, and cognitive components (including volition, habituation, and performance capacity) involved in occupational engagement (Taylor, 2017).

This study was informed by the constructs of occupational engagement as described by Black et al. (2019), including the *active or passive* involvement in an occupation that is *subjectively meaningful* or *valuable* to the individual within the *context of their environment*. The concept of *occupational balance* was not considered a defining component of occupational engagement in this study since balancing the *types* of occupations was not a primary focus for this cohort living with advanced cancer. However, the focus on *being in balance* (i.e., the person's level of activity versus rest across their day) was deemed relevant as this directly affected participants' experiences of occupational engagement. This study privileged participant voices, who focused on being able to prioritise and balance their day-to-day lives, and the meaning participants ascribed to their occupations, rather than the types of occupations described in the categories of self-care, productivity, and leisure.

This study's position on occupation is consistent with MOHO's concepts of occupational engagement. MOHO includes the "doing, thinking, and feeling" aspects of occupation, seen in the continual interaction between volition, habituation, performance capacity, and environment (Kielhofner, 2008c, p. 184). However, in order to understand the meaning an individual attributes to an occupation, it is essential we also understand the motivation behind and organisation of occupation. The centrality of meaning in this phenomenological study aligns with both the illness experience literature and MOHO.

### *2.2.4 Rationale for the Use of the Model of Human Occupation*

MOHO is an evidence-based, person-centred, and occupation-focused model that seeks to understand the whole person within their wider context (Taylor & Kielhofner, 2017). It differs from other occupational therapy models in its descriptions of the person, the environment, and their occupations. Table 2.1 provides a comparison between MOHO and the Canadian Model of Occupational Performance and Engagement (CMOP-E), another occupational model often used in clinical practice. It highlights the variations in central concepts between both models.

MOHO was chosen as the primary theoretical framework for this study for three reasons: the emphasis on the motivation behind occupational engagement, the concept of occupational adaptation, and the focus on the lived body. MOHO emphasises the motivation for and organisation of occupations: *why* and *how* people engage in occupations. The focus on motivation for occupational engagement aligns closely with the centrality of meaning within the illness experience literature (Carel, 2016; Frank, 2002; Kleinman, 2020; Toombs, 1987). Meaning and motivation are not static, independent constructs; they exist within a dynamic system. MOHO employs a systems approach that incorporates the intersection of the person, environment, and occupation, the three interconnected components of occupational engagement (O'Brien & Kielhofner, 2017). The interplay between these three variables affects a person's motivation to participate in occupations. For example, an individual (person) may choose not to participate in an activity (occupation) if their friend is not present (social environment) or if they do not have the right equipment (physical environment). In contrast to MOHO, this dynamic system approach is not present in CMOP-E. The authors explicitly state that CMOP-E was not designed to address the interplay between the person, environment, and occupation (Polatajko, Davis, Cantin, et al., 2013, p. 209) although they identify variables relevant to occupational engagement (e.g., physical, affective, cognitive, and spiritual aspects of a person and the occupational categories of self-care, productivity, and leisure). Instead, the construct of enablement is central to CMOP-E.

**Table 2.1**

*Key Concepts of Occupational Therapy Models: MOHO and CMOP-E*

| Model Title | The Model of Human Occupation (MOHO) | The Canadian Model of Occupational Performance and Engagement (CMOP-E) |
|---|---|---|
| History | Developed in 1980; currently on the 5th version (2017) | Sequel to the Canadian Model of Occupational Performance (1997) |
| Components of the Person | • Volition (values, interests, personal causation)<br>• Habituation (habits, roles)<br>• Performance capacity (subjective and objective abilities, lived body) | • Physical<br>• Cognitive<br>• Affective<br>• Spirituality |
| Components of the Environment | • Physical<br>• Social<br>• Occupational<br>• Context (global, local, and immediate) | • Physical<br>• Social<br>• Institutional<br>• Cultural |
| Occupation | Occupational participation:<br>• The doing of occupation (work, play, self-care)<br>• Occurs through the interaction between the volition, habituation, and performance capacity of the person and their environment (dynamic systems model)<br>• Results in occupational adaptation and its components (occupational identity and occupational competence)<br>• MOHO focuses on the person's experience of occupations | Occupation is the primary domain and is comprised of:<br>• Self-care<br>• Productivity<br>• Leisure<br>Occupational performance and engagement:<br>• Within the context of the person, environment, occupation<br>• CMOP-E focuses on the occupational therapists' skills for enablement |

Enablement is described as the skills the occupational therapist uses to assist their client to participate in occupations (Townsend et al., 2013). This privileging of the occupational therapist's perspective rather than the voice of the person receiving occupational therapy services (Polatajko, Molke, et al., 2013) does not fit well with the research question or phenomenological approach of the current study. This study explored the lived experiences of occupational engagement for people living with advanced cancer. It examined *their* motivation to modify or to adapt how or when *they* participated in occupations amid the context of bodily decline as their cancer progressed over time.

A second rationale for choosing MOHO as the theory underpinning and giving structure to this study was MOHO's focus on occupational adaptation. This longitudinal study investigated how people living with advanced cancer adapted as their function declined and how their experiences of living with advanced cancer changed over time. The experience of advanced cancer is challenging. People adjust physically, emotionally, and occupationally: first, to a new diagnosis; then to multiple acute health crises; and also to the progression of their cancer. MOHO theory aligns with Carel's (2016) premise that adaptation must occur for people living with a chronic illness, but the concept of adaptation is only briefly addressed in the illness experience literature (Bury, 1991; Carel, 2016). Occupational adaptation as a concept is more nuanced in MOHO theory, aligning the construct of adaptation with both occupational competence and occupational identity. Thus, MOHO provides a framework to explore and understand an individual's ability to adapt to ongoing challenges (Taylor, 2017). However, although MOHO does apply theoretical constructs (e.g., goal setting) to people with palliative care needs, it does not apply the concepts of occupational adaptation to the cohort of people living with life-limiting conditions. This study mapped the themes constructed from the interviews onto existing concepts of occupational adaptation, explored further in Chapter 8 (Discussion).

Finally, MOHO was selected as a theoretical framework in this study because of its focus on the lived body experience. The world is lived and experienced through the body. People are often unaware of many of the routine, daily tasks they participate in until their sense of meaning is shaken by the progression of a disease that eventually limits function (Kielhofner, 1995; Toombs, 1995). Advanced cancer brings the body to the fore when the body limits what the person can do. The individual must then re-evaluate what is and is not possible. Within the context of one's world, the lived experience of the body and self shapes a person’s sense of meaning. Meaning is central to understanding a person’s illness experience and a key concept in MOHO (Carel, 2016; Fisher et al., 2017; Kleinman, 2020). In addition, MOHO’s focus on concepts such as the subjective performance capacity of the lived body, the sense of self-efficacy, and the sense of control highlights the interconnected, dynamic nature of occupational engagement. These are important aspects of daily experiences in MOHO and, therefore, sources of meaning (Taylor, 2017). MOHO as a theoretical model aligns with the phenomenological approach of this study. Both share a mutual understanding of the lived and object body. Both seek to decipher the meaning behind the phenomenon under investigation: occupational engagement. MOHO aligns well with the current study’s research question, design, and methodology, providing space for participant voices. The following section will expand on the concepts developed in MOHO.

### *2.2.5 The Model of Human Occupation: Concepts*

MOHO characterises people as occupational beings, comprised of the synergistic relationship between their volition, habituation, and performance capacity within the context of their environment. *Volition* denotes the individual’s values, interests, sense of self-efficacy, and sense of capacity, while *habituation* encompasses their roles, routines, and habits (Yamada et al., 2017). *Performance capacity* refers to the person's abilities (physical, emotional, and cognitive, both subjective and objective). These three key components—volition, habituation, and performance capacity–exist within a person’s physical, occupational, and social context (their environment). Together, they comprise the individual’s occupational identity (de las Heras de Pablo, Fan, et al., 2017; Yamada et al., 2017).

Volition, habituation, and performance capacity shape a person’s experience of everyday life, including illness. Occupational engagement may become more challenging in illness, and the desire and ability to participate in certain activities may fluctuate. For example, if an individual has a wound on their leg due to cancer yet needs to cook dinner, their experience of meal preparation and decision-making is influenced by their volition (e.g., do they enjoy or feel competent cooking?), habituation (e.g., is cooking dinner their usual role in the family or does their spouse habitually assist as needed?), and performance capacity (e.g., are they allowed to weight bear on the leg with the wound, or is pain preventing them from ambulating?). Given the importance of these factors and their impact on occupational engagement, a closer examination of the roles of volition, habituation, and performance capacity is warranted. The centrality of MOHO concepts (such as the meaning ascribed to functional decline within their lived world context) is supported by the frameworks of both MOHO and the illness experience. These align with the phenomenological approach employed by this study.

#### 2.2.5.1 Volition

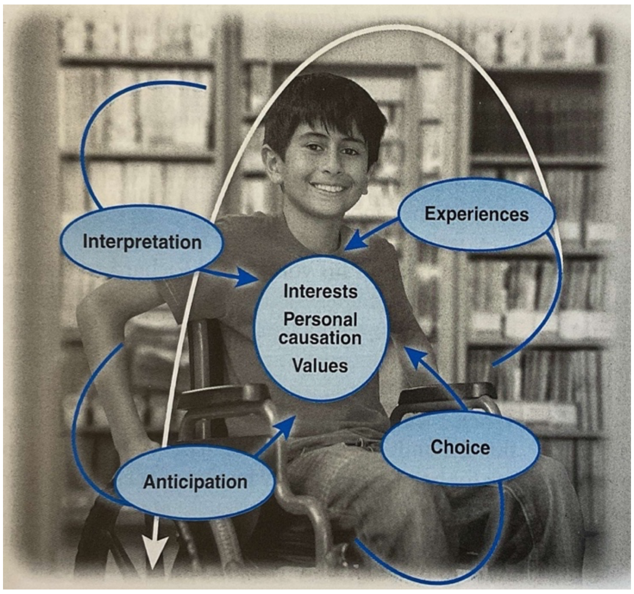
Volition refers to the motivation behind *why* a person engages in a given occupation. Three integral components underpin occupational motivation: the individual's unique interests, values, and personal causation (feelings of capacity and self-efficacy). These factors are shaped and reinforced by how they choose and engage in occupations. MOHO describes *volition* as “a pattern of thoughts and feelings about oneself as an actor in one’s world which occur as one anticipates, chooses, experiences, and interprets what one does” (Yamada et al., 2017, p. 14). A person’s preferences may be heightened yet also threatened when experiencing significant life changes. An example of this experience is observed in research on parenting while living with advanced cancer (Loiselle & Santerre-Theil, 2017; Lundquist et al., 2019; Park et al., 2017). Given the dynamic relationship that exists between the three components of volition, it is important to consider a person’s interests, values, and personal causation in relation to one another.

**Volitional Cycle*.*** The volitional cycle is an essential aspect of occupational engagement and is visually presented in Figure 2.1. The three components of volition interact and are reflected in the four stages of the volitional cycle: the anticipation of participating in an occupation, choosing what to engage in, the experience of the occupation, and the interpretation of what was done (Lee & Kielhofner, 2017b, p. 51).

The first stage is anticipation. Anticipation involves looking ahead to what the day entails or preparing for the occupations that the person will participate in. The person’s interests, values, and personal causation influence the process of anticipation. Noticing the world around them, they seek out occupations congruent with their volition. The second stage, making choices, involves choosing when to commence an occupation, how long to participate in it, and when to cease engagement in an activity. The third stage of the volitional process, the actual lived experience of the occupation, includes feelings such as excitement or anxiety while participating. Interpretation is the final stage of the volitional cycle and relates to the person’s reflection on their own experiences of occupational engagement. They may subconsciously ask questions such as: Did it meet their expectations? Did it reflect who they believe themselves to be?

**Figure 2.1**

*The Process of Volitional Change Over Time*



*Note*. From "Volition," by S. W. Lee & G. Kielhofner, 2017, in R. R. Taylor (Ed.), *Kielhofner's Model of Human Occupation: Theory and application* (5th ed., p.39), 2017, Wolters Kluwer. Copyright 2017 by Wolters Kluwer. Reprinted with permission (Appendix D).

The volitional cycle reflects, and is inseparable from, a person's volition. Despite the strong presence of the volitional cycle throughout a person's day and its impact on future choices, MOHO's volitional cycle has not been systematically researched within the advanced cancer population. This thesis argues that this dynamic cycle warrants closer examination when exploring the lived experience of occupational engagement due to its significant impact on the person's everyday life (Lee & Kielhofner, 2017b).

**Interests**. Interests are an integral aspect of volition, the motivation behind occupational engagement. A person's interests often translate to what they choose to do. Interests attract the individual's attention and bring joy or satisfaction. They often follow patterns, such as being interested in various pursuits related to sports or languages (Lee & Kielhofner, 2017b). If frustrated while encountering difficulty completing an activity, interest levels may wane. An emerging body of evidence demonstrates that functional decline associated with illness requires people to adapt or find new interests to pursue in order to optimise quality of life (Deckert et al., 2018; la Cour et al., 2007; Morgan et al., 2017; Tse et al., 2020). Engaging in meaningful occupations that reflect a person's interests is a significant contributor to a sense of wellness and enjoyment in life.

**Values.** A person's values influence how they experience their world, impacting which occupations they engage in and how they perceive their illness or disability. Cultural norms and values shape our worldview, impact familial obligations, affect our expectations, and influence what is deemed important (Lee & Kielhofner, 2017b). A person can express their values through the occupations they engage in (Maersk et al., 2017). When a person experiences functional changes due to a health condition and can no longer do what is important to them, values may feel threatened. Values are an important aspect of volition in the lived experience of advanced cancer.

**Personal Causation**. Personal causation relates to the individual's feelings of personal capacity (beliefs regarding their physical, cognitive, and social abilities) and self-efficacy (effectiveness in using their abilities). This includes a person's sense of confidence or hesitation regarding what they believe they are capable of doing or their perceived sense of what they can control. If a person views themselves as incapable of completing a task, this can be more debilitating than their actual functional disability (Lee & Kielhofner, 2017b). For example, if a person is afraid of heights and, therefore, assumes they are not able to hike along the ridge of a mountain, there is a good chance they will not be able to engage in the activity. This may occur despite having sufficient physical and cognitive abilities to complete the task safely. The loss of confidence in one's body is common for people living with chronic illnesses and advanced cancer; it affects their experience of the lived world (Kleinman, 2020; McKechnie et al., 2007; Morgan et al., 2017; Rasmussen et al., 2010). Personal causation shifts and changes over time, impacting present participation and future goals. As Lee and Kielhofner (2017b) state, "the search for efficacy involves knowing disappointment, realising what one cannot control, and finding and emphasising what one is able to influence" (p. 45). Personal causation is closely tied to a person's experience of their lived body, as it is not simply their physical abilities and functional status, but their perceived sense of capacity and effectiveness which are also crucial to well-being (Tham et al., 2017).

**Volition and occupational engagement.** As discussed earlier, MOHO's concept of volition explores the motivation behind engaging in occupations, including interests, values, sense of capacity and self-efficacy. Given this study's focus on the experience of and motivation behind occupational engagement, this section will examine existing research on volition and occupational engagement.

Despite the centrality of volition in a person's life, there is a general paucity of studies investigating the role of volition in the experiences of occupational engagement following a life transition or while living with a medical condition. This is particularly evident within the advanced cancer population. This may be due to the limited clinical uptake of MOHO in many physical hospital or tertiary rehabilitation settings, where the primary emphasis is on functional tasks and independence in the basic activities of daily living such as self-care tasks or mobility (Harel-Katz & Carmeli, 2019).

Existing occupational therapy and occupational science research on volition and chronic illnesses recognises the link between volition and engagement in occupation, consistent with MOHO concepts. Garachana Carpintero and Santamaría-Vázquez (2017) and Pritchard et al. (2014) examined this relationship between volition and participation in their studies involving people living with mental health concerns and dementia, respectively. They found that these two cohorts sought to participate in occupations related to their sense of self-efficacy, values, or interests (i.e., volition) and that participation reinforced a person's volition. The inverse was also noted. Increased institutionalisation and resultant reduced participation led to a reduction in volition (Garachana Carpintero & Santamaría-Vázquez, 2017; Pritchard et al., 2014). Occupational engagement or disengagement can either reinforce or diminish a person's volition.

The dynamic relationship between personal causation, interests, and values has profound implications for occupational engagement and the motivation behind why people engage in occupations. In exploring the experience of occupational engagement for people living with advanced cancer, this study sought to understand the meaning and motivation behind the desire to engage in certain occupations, exploring how this changed over time. The emphasis on the dynamic, evolving concept of volition is unique to MOHO and was a significant contributor to the choice of MOHO to frame this study. In addition, the focus on the meaning ascribed to a person's illness experience as shaped by their values, interests, self-efficacy, and sense of capacity is consistent with the illness experience literature (Carel, 2016; Kleinman, 2020). Despite the significant role of volition in everyday life, thus far, no studies have addressed volition and occupational engagement within the working-aged, advanced cancer cohort.

#### 2.2.5.2 Habituation

Habituation, as defined by MOHO, is another integral component of a life lived as an occupational being. The construct of habituation pertains to how people organise their lives. This includes the habits and routines people create within the structure of their days and weeks and the importance of valued roles in prioritising these patterns. Habits and roles often organise the way a person interacts with and participates in their lived world. Lee and Kielhofner (2017b) argue that there is a link between the lived experience of occupational engagement and quality of life due to the importance of how their day is organised (habituation) with valued occupations (volition). Therefore, if a person experiences a loss of abilities because of an illness or injury, their sense of the familiar and dependability of their previous life can be shaken (Aoun et al., 2016; Bury, 1982; Lee & Kielhofner, 2017a).

***Habits.*** Habits are the consistent performance of an activity in a routine manner and environment, where minimal effort and conscious attention is required. Habits may include how occupations are done (e.g., donning socks before donning the rest of their clothes), how time is used (e.g., activities at set times), and how a person operates in their environment (e.g., routinely rushing or taking things slowly). “Habits organise our use of underlying performance capacity so that we can perform within our environment. The fit of our habits to our performance capacity and our environment will determine how effective we are in our everyday routines” (Lee & Kielhofner, 2017a, p. 63). For example, a person living with advanced cancer may experience increased difficulty performing habitual activities, such as bathing. Home care aides may come to the house at the same time each day (similar time use) but may rush the individual through tasks (a faster way of conducting what was once a leisurely task prior to cancer progressing). The environment can also impact a person’s routines. The individual may no longer be able to have a bath, hindered by difficulty getting in and out of the tub and home care policies that do not allow staff to assist with bathtub transfers. This changes their daily bath habit to a sponge bath in bed. Disruption to habits can be destabilising following disability or illness, as new patterns need to be established (Bury, 1982). This disruption often leaves a person feeling lost due to the changed structure of their days. Challenges may include navigating the particularities of receiving assistance from another individual, learning new skills, or incorporating adaptive devices into daily routines (la Cour, Nordell, et al., 2009; Lee & Kielhofner, 2017a; Morgan et al., 2021). However, rebuilding habits and routines can be complex yet rewarding when living with advanced cancer (la Cour, Johannessen, et al., 2009).

**Roles.** The second aspect of habituation pertains to the roles a person plays within the context of their social environment. These roles may include worker, spouse, sibling, athlete, or student. Each role has predetermined expectations regarding behaviour and approach to life. Roles shape a person's identity and how they view the world. It is not only the presence of the role but how it is internalised that impacts an individual's motivation for occupational engagement (Lee & Kielhofner, 2017a). For example, one employee may inhabit their worker role but solely as a means to an end: to have money to spend during non-work hours. Their values and interests relate to their leisure pursuits and role as a soccer coach for a community team. Another person may internalise their role as a worker, which shapes their identity. They may introduce themselves to others as being in a specific profession or behave in a certain way based on values inhabited as part of that role. Not all roles are well-defined. Poorly defined roles are often misunderstood, such as the role of a young adult living with advanced cancer. This may impact not only the person's sense of identity, but also how this role is inhabited and how others interact with them. For example, if a person identifies strongly with their cancer diagnosis and inhabits the sick role, then they may experience adverse effects such as increased hopelessness and distress (Gökler-Danışman et al., 2017).

The significance of roles should not be underestimated when examining the lived experience of advanced cancer. Internalised roles impact occupational engagement. They create a daily and weekly rhythm, influence how the world is inhabited, and impact on which occupations an individual participates in (Lee & Kielhofner, 2017a). In the role of parent, a person may wake early to get their children ready for school, pack lunches, and walk the children to the bus stop. Their other role as a worker may also dictate that they spend their morning hours getting ready for work: donning work clothes, stopping for a coffee at the local café after a school drop-off, and then catching the train to the office. When a person is living with advanced cancer, their roles and habits will change. Going to work may no longer be possible, or parental responsibilities may have changed (Lundquist et al., 2019; Lundquist, 2017; Park et al., 2017). When roles shift, people often experience loss as their sense of occupational identity and purpose change. Continuous re-evaluation of habits, routines, and roles is inescapable for people experiencing changes due to disability or illness (Bury, 1991; Lee & Kielhofner, 2017a).

#### 2.2.5.3 Performance Capacity

Performance capacity is the third component of an occupational being in MOHO theory, alongside volition and habituation. Performance capacity incorporates the concept of the lived body by focusing on the whole person from both an objective and subjective perspective. Adopting the phenomenological concept of *lifeworld* and the term *lived body,* as described by Leder (1990), MOHO uses the term *lived body* to describe a person's subjective experience of their world through their body. Lifeworld is the world, often unnoticed, that a person lives in (van Manen, 1990).

People usually view themselves as an integrated self and physical body. They often take their bodies for granted, only conceiving their physical self as separate when impairments exist or when learning new skills. A person's integrated self thus experiences the world through their physical body, emotions, and intellect, such as recognising that water they are drinking is cold, the glass they hold is smooth, or that the dog they are patting has coarse hair. This is the lived body that MOHO speaks of (Kielhofner, 1995; Leder, 1990).

Performance capacity thus relates to the objective and subjective abilities a person has that enables them to engage in occupations. This component of MOHO is significant for the purposes of this study that examines lived experience. It differs from the medical model and the other occupational therapy models such as CMOP-E and Person-Environment-Occupation (PEO) model that focus on the objective abilities of the person (Kielhofner, 1995; Kleinman, 2020; Tham et al., 2017; Townsend & Polatajko, 2013).

An individual's objective and subjective skills affect their ability to engage in everyday life within their lived world (Kleinman, 2020; Morgan et al., 2017). The current study focused on the perspective of the working-aged adults living with advanced cancer in order to understand their motivation for occupational engagement (volition), how they organised their days (habituation), and their changing ability to participate in occupations (performance capacity). Understanding their illness experience was central to this study, which included their lifeworld. Having explored the unique, person-specific factors of volition, habituation, and performance capacity, this next section will focus on the context of occupational engagement: the environment.

#### 2.2.5.4 The Environment

In MOHO, the environment is an essential mediator of well-being through its ability to facilitate or hinder occupational engagement. The nuanced role of the environment as defined by MOHO will now be discussed. MOHO conceptualises the environment as comprising the person’s physical, social, and occupational environments within immediate, local, and global contexts. The physical environment consists of both physical spaces as well as the objects used within that location. The social environment encompasses the relationships between individuals and includes how people interact within this space. The occupational environment considers the factors and context of the occupations a person engages in. It takes into account the occupational opportunities given to an individual, the flexibility to adapt an occupation, the support available, or whether or not sufficient time is provided to complete the task (Fisher et al., 2017). The inclusion of the occupational environment is unique to MOHO (Polatajko, Backman, et al., 2013).

There is a dynamic relationship between the environment, the person, and the occupation they wish to participate in, similar to the dynamic relationship between the three components of the person (volition, habituation, and personal causation) (Fisher et al., 2017; Yamada et al., 2017). Changes in any one of the three domains will impact a person’s ability to participate in occupations. The environment can influence occupation in various ways, including the motivation to engage in occupations, how occupations are structured, and whether it is even possible to engage in an occupation. First, the motivation for participation depends on the environment, such as the presence or absence of a supportive social network (Fisher et al., 2017). Whether friends recognise fatigue's impact on a person living with advanced cancer shapes that person’s motivation to engage in occupations with those friends. Staff may be required to modify an occupation or provide cues so that a person living with dementia is able to participate in the occupation (Raber et al., 2010). Second, how the environment is structured impacts occupation. The presence of a raised toilet seat or supervision from home care aides may facilitate independence in personal hygiene, providing a sense of “comfort and security” (Badger et al., 2016, p. 227). Third, is it even possible to engage in a given occupation, or is the choice taken away due to the mismatch between the environment and the person or occupation? For example, it is not possible to go snowshoeing in Australia in summer or to independently enter a restaurant that has stairs at a point of access if a ramp is required.

It is crucial to consider the impact of the environment from the individual's perspective, as the same environment may affect each person differently. The presence of a home care aide to support a morning self-care routine may cause anxiety for one person due to a stranger being in the house, relief in another because they feel safer while showering, and increased feelings of dependency for a third person. It is impossible to separate a person's occupational engagement from their environment, so taking into account the environmental impact is essential (Fisher et al., 2017). In addition, the presence of a 'just-right challenge' between the person's volition, habituation, performance capacity, environment, and the task can facilitate continued occupational engagement. This then results in the person being set-up appropriately in their environment to successfully participate in an activity that does not result in too high or low a demand (Rebeiro & Polgar, 1999).

### *2.2.6 Occupational Adaptation*

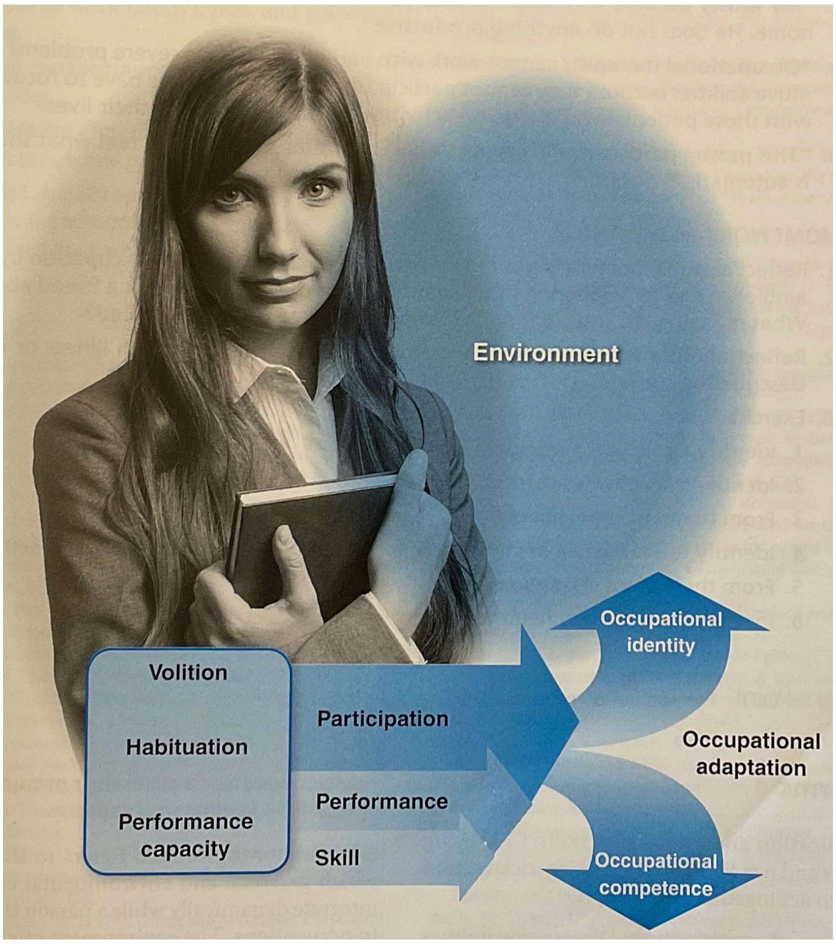
Occupational adaptation, the ability to adapt in order to continue engaging in occupations, is a key concept that differs in theory and practice depending on the theoretical framework used. The Canadian Model of Client-Centred Enablement describes the ability to adapt as a skill the occupational therapist uses to enable continued occupational engagement (Townsend et al., 2013). This differs from MOHO, which uses the term in relation to the client adapting their occupations, linking it with their occupational identity and occupational competence (de las Heras de Pablo, Fan, et al., 2017). Alternatively, the Occupational Adaptation model by Schkade and Schultz (1992) and Schultz and Schkade (1992) frames occupational adaptation as both an internal process of the individual and an intervention strategy of the occupational therapist. Given that the primary occupational model used in this study is MOHO, an exploration of occupational adaptation and its related concepts will follow.

MOHO defines *occupational adaptation* as "the development of a positive occupational identity, coupled with the experience of occupational competence over time within the context of one's environment" (de las Heras de Pablo, Fan, et al., 2017, p. 116). This connection between occupational adaptation, occupational identity, and occupational competence is unique to MOHO, and is visually represented in Figure 2.2. de las Heras de

Pablo, Fan, et al. (2017) describe occupational identity as who a person is and would like to be within their lived experience of their body, volition, and habituation. Occupational competence is a person's ability to put their occupational identity into action through engaging in meaningful occupations (de las Heras de Pablo, Fan, et al., 2017). According to MOHO, occupational identity and occupational competence are developed through participation in occupations and occupational adaptation (Christiansen, 1999; de las Heras de Pablo, Fan, et al., 2017; Howie et al., 2004).

**Figure 2.2**

*The Process of Occupational Adaptation*



*Note*. From “Dimensions of Doing,” by C.-G. de las Heras de Pablo, C.-W. Fan, & G. Kielhofner, in R. R. Taylor (Ed.), *Kielhofner’s Model of Human Occupation: Theory and application* (5th ed., p. 119), 2017, Wolters Kluwer. Copyright 2017 by Wolters Kluwer. Reprinted with permission (Appendix D).

Limited studies have explored the role of occupational adaptation at the end of life or within the chronic illness experience literature. Carel (2016) briefly touched on this topic in her book, *Phenomenology of Illness*, describing how the person's ability to adapt is crucial to their well-being. She proposed that if a person can adjust to the changes experienced due to chronic illness, it will permit them to have a greater level of well-being than their objective state of health. Interestingly, exceptions were made for people experiencing pain or incontinence, and the author cautioned that adaptation requires time. Carel (2016) described a period of challenging transition during the year following a diagnosis of chronic illness and before stabilisation occurred. However, her examination of adaptation to illness does not explore the concept of adaptation for people with advanced cancer who do not have the luxury of stabilisation. The adaptation process for those who experience continual bodily decline with advanced cancer is significantly different to that of people with chronic illness. Frank (1996) first conceptualised that adaptation is facilitated through participating in occupations. Morgan et al. (2017) confirmed this in their study on the embodied experience of functional decline due to advanced cancer and argued that people adapt to functional decline through the process of occupational engagement (Morgan et al., 2017). However, a question remains: what constitutes occupational adaptation if a central component—occupational competence—is not possible nor sustainable in advanced cancer due to a person's ongoing deterioration in body and function? This is explored further in Chapter 8 (Discussion).

## 2.3 Conclusion

This chapter examined the concepts of the lifeworld, the illness experience, and occupation, and explored the theoretical framework of MOHO as it pertains to occupational engagement. Each of these concepts or theories inform the other, supporting and shaping our understanding of the significance of occupational engagement and contextual factors at the end of life. Illness affects every aspect of everyday life, and its impact is significant, resulting in numerous losses and destabilising a person's experience of what is meaningful or valued (Carel, 2016; Charmaz, 2006; Frank, 2013; Kleinman, 2020). Existing scholarship on phenomenology, the illness experience, and MOHO affirms the centrality and importance of everyday life in the illness experience. Although awareness of the disease and symptoms is an important consideration, the illness literature views the experience of illness as separate from the disease process. (Carel, 2016; Kleinman, 2020). People with progressive disease experience multiple losses including the loss of wholeness, control, certainty, freedom, and the loss of a familiar life (Carel, 2016; Toombs, 1987). However, the process of adaptation to these losses for the chronic illness cohort may be different than for the advanced cancer population.

The changes experienced by those living with advanced cancer are often reflected in a disruption of their daily activities. Understanding the importance of occupational engagement when living with advanced cancer is facilitated by appreciating how and why people ascribe meaning to occupations. MOHO provides a logical and coherent framework that informs understanding of how a person's values, interests, and roles impact their sense of self and affect their manner of being-in-the-world, or how their self-perceived performance capacity and sense of self-efficacy alter how and when occupational engagement occurs (Kielhofner, 2008b; Lee & Kielhofner, 2017a, 2017b). As the person experiences changes in their abilities due to a disability or illness, their illness experience shapes their lived world. The person living with advanced cancer is also affected by contextual factors in their lived world: the space a person inhabits shapes their sense of well-being (Fisher et al., 2017). MOHO's key concepts provide a valuable lens through which we can examine the role of occupational adaption for those with advanced cancer. Taken together, these person and environmental factors shape how a person with advanced cancer adapts as their function changes. MOHO's framework provides an understanding of the motivation behind occupational engagement, the importance of adaptation to continuing participating in everyday life, and the role of the lived body in this adaptation.

This chapter highlighted key gaps in existing theory: Specifically, how do people engage in their occupations and adapt to functional decline whilst living with advanced cancer, particularly when a stable level of competence is not possible? The following chapter will build on the conceptual and theoretical foundations of the lived illness experience and MOHO by examining contemporary literature on the experiences of occupational engagement for people living with advanced cancer.

# CHAPTER 3: LITERATURE REVIEW

Illness is pervasive, affecting all aspects of a person's life and disrupting the meaning ascribed to everyday experiences. The impact of illness on occupations, the everyday activities that occupy a person's time, goes beyond disrupting the simple doing of a task. Illness shapes the person's lived experience of their world, their well-being, and their sense of self. An awareness of the illness experience and its impact on occupation provides the context for and enriches the understanding of the research question: What is the lived experience of occupational engagement for people aged 18 to 64 living with advanced cancer? Chapter 2 provided the foundation and knowledge base for this literature review as it explored the conceptual and theoretical frameworks of the illness experience, the Model of Human Occupation (MOHO), and the concept of occupation (Carel, 2016; Kleinman, 2020; Taylor, 2017; Toombs, 1987, 1995).

This chapter seeks to critically review relevant literature, focusing on current research findings and highlighting significant gaps or limitations in the literature, theory, and existing clinical practice as it pertains to advanced cancer. It builds on the concepts of occupation and the illness experience by exploring the significance of occupational engagement for the advanced cancer cohort. The philosophical, non-occupational understandings of suffering, meaning, or adaptation are concepts beyond the scope of this study. More specifically, Chapter 3 provides an overview of the experience of health-related shifts in occupational engagement and examines the experiences of living with a life-limiting illness. The chapter concludes with a discussion of the current scholarship on the significance of occupational engagement within the palliative care context.

## 3.1 Shifts in Occupational Engagement

This section employs an occupational lens to examine the importance of occupational engagement. It examines illness-related shifts in participation, subsequent adaptation needed for continued participation, and occupational disengagement.

### *3.1.1 The Centrality of Occupational Engagement*

Occupation encompasses all that a person does during their day. It gives structure to life, shapes a person's occupational identity, and is a medium by which people relate to others. A person often identifies with aspects of the occupations they participate in, such as running ("I am a runner"), playing with their grandchildren ("I am a grandparent"), or working with spreadsheets (“I am an accountant”). It is also the medium by which they are identified by others (Walder & Molineux, 2017a). By choosing to participate in occupations they enjoy, people reinforce their occupational identity and maintain their sense of self and well-being (Hammell, 2017; Howie et al., 2004; Law et al., 1998; World Federation of Occupational Therapists, 2010).

The centrality of occupation and its strong link to well-being and quality of life is not only noted in the fields of occupational therapy and occupational science (Christiansen, 1999; Cotton, 2012; de las Heras de Pablo, Pépin, et al., 2017; Laliberte Rudman, 2002; Laliberte Rudman et al., 1997; Nizzero et al., 2017; Walder & Molineux, 2017a), but there is also increasing recognition of the value of occupation in evidence-based standards for global health (Coulter, 2017; Organisation for Economic Co-operation and Development, 2017). An intergovernmental organisation of 38 countries, the Organisation for Economic Co-operation and Development, recommended that health care should be more person-centred. Recognising the significance of engagement in everyday activities to well-being, they proposed the broader use of outcome measures that focus on quality-of-life factors such as participating in valued activities and living independently. As indicated in the previous chapter, engaging in valued occupations at all levels of health is a basic need for all people and a significant contributor to a person’s quality of life (Aldrich, 2011; Laliberte Rudman et al., 1997). Ultimately, “how we spend our days, of course, is how we spend our lives. What we do with this hour, and that one, is what we are doing” (Dillard, 2016, p. 75). The impact of involvement in meaningful activities is far-reaching. Who you become is often a reflection of what you do.

### *3.1.2 Disruptions to Occupational Engagement*

Following an illness or disability, engagement in routine occupations can be challenging. The impact that an illness or disability may have on an individual can vary widely depending on the type of impairment, but commonalities in the illness experience exist. A person’s objective and subjective abilities (performance capacity) can decline due to physical, cognitive, or emotional impairment, requiring assistance with specific tasks (Tham et al., 2017). Subsequently, their sense of time and space may shift as daily habits, routines, and the environment change and take on new meaning (Appelin et al., 2005; Carel, 2016; Maersk et al., 2018). A person may be at home more often if unable to work at the office, medical equipment may affect the look and feel of their familiar rooms, or stairs may prevent them from accessing the shower. The multifaceted impact of the illness experience on occupational engagement varies with the individual and the condition, but illness affects a person's experience of their lived world. The impact illness has on daily life is consistent with the illness experience literature (Carel, 2016; Frank, 2002; Kleinman, 2020; Toombs, 1987; van Manen, 1990).

A growing body of literature recognises the destabilising nature of increasing difficulty engaging in everyday life due to illnesses such as advanced cancer (Carel, 2016; Hammell, 2020a; Keesing & Rosenwax, 2011; Kleinman, 2020; Nizzero et al., 2017; Raanaas et al., 2019; Toombs, 1995; Vrkljan & Miller-Polgar, 2001). A person's sense of self may be shaken, as participation in occupations is often an expression of how they define themselves. For example, when a person chooses to no longer attend their knitting group due to residual upper limb impairments which precludes the independent use of knitting needles, their role within their knitting community shifts, and their routines change. They experience the "loss of the familiar world" (Toombs, 1987, p. 229). Furthermore, their confidence may decrease and their sense of competence may decline, resulting in changes to how they view themselves. Contending with a deteriorating body and increasing dependency also affects a person's identity (Christiansen, 1999; Morgan et al., 2017). Individuals who undergo a significant life event due to illness may experience undesired shifts in the roles, habits, and occupations that they previously engaged in (Scalzo et al., 2016; Tse et al., 2020; Walder & Molineux, 2017a). Such changes may lead to increased uncertainty about what the future holds or their 'new normal' will be. The experience of loss of certainty is confirmed in both occupational and illness literature following significant life events such as an injury, illness, or life transition (Aldrich, 2011; Carel, 2016; Scalzo et al., 2016; Toombs, 1987; Walder & Molineux, 2017a). Shifts may also occur in the meaning a person ascribes to an occupation. Specific activities may increase in value while others decrease (Park Lala & Kinsella, 2011). Examining the motivation behind occupational engagement gives insight into the impact of disruptions in occupational engagement, as described in MOHO and in this chapter (Harel-Katz & Carmeli, 2019; Lee & Kielhofner, 2017b).

### 3.1.3 *Occupational Adaptation Following Injury or Illness*

The need to participate in meaningful occupations, even in a modified form, is increasingly important when daily activities are disrupted due to a life-limiting illness.

Occupational therapy and occupational science researchers have explored how individuals with certain medical conditions adapt to change in occupations and how occupational adaptation impacts their occupational identity and competence (Åberg et al., 2005; Cahill et al., 2010; Morgan et al., 2021; Paley Altit et al., 2019; Schkade & Schultz, 1992; Schultz & Schkade, 1992; Vehling et al., 2018; Walder & Molineux, 2017a). Studies focusing on the process of adaptation are often specific to diagnostic groups, such as people living with a traumatic brain injury or stroke (Cotton, 2012; Klinger, 2005; Williams & Murray, 2013); older adults living with a variety of physical disabilities (Bontje et al., 2004); or people living with and without attention deficit hyperactivity disorder (Paley Altit et al., 2019).

Research focusing on significant disease-related transition points provides additional insight into adaptation following illness or injury. If an event has an eventual plateauing of function (e.g., stroke, spinal cord injury, or brain injury), its impact on occupational adaptation is significantly different than following a progressive condition (e.g., dementia, amyotrophic lateral sclerosis [ALS], or advanced cancer). The disease trajectory of the first group is often characterised by a sudden initial decline in abilities that routinely eventuates in a general stabilisation of bodily function (Cotton, 2012; Tse et al., 2020; Williams & Murray, 2013). This trajectory contrasts with that of a progressive, degenerative condition where function declines concurrently with bodily deterioration, such as multiple sclerosis (Cahill et al., 2010; Månsson Lexell et al., 2010). People in this latter cohort experience an ongoing decline in their ability to engage in occupations as their bodies deteriorate further. To maintain engagement in certain occupations, they must continually accommodate or modify their participation to match their newest limited capability or changing environment. A common thread in both functional trajectories was the gradual process of adaptation in response to changed abilities (Bury, 1982; Cotton, 2012; Grajo et al., 2018; Klinger, 2005; Morgan et al., 2017; Scalzo et al., 2016; Thorén-Jönsson, 2001; Williams & Murray, 2013). As people learn what their bodies can or cannot do, they fluctuate between doing too much and then withdrawing from activities, as demonstrated in a longitudinal study involving people living with poliomyelitis sequelae (Thorén-Jönsson, 2001). Engagement in valued occupations, however, assists with rebuilding a sense of identity following a significant life event (de las Heras de Pablo, Pépin, et al., 2017; la Cour et al., 2007). Regardless of whether the person experienced a sudden reduction in abilities (e.g., spinal cord injury or stroke) or a more gradual decline (e.g., dementia or multiple sclerosis [MS]), occupation is the context in which adaptation occurs (Bontje et al., 2004; Thorén-Jönsson, 2001).

Having provided a brief overview of the literature on how illness disrupts occupational engagement, the remainder of this section will explore shifts in occupational engagement and resultant adaptation in different cohorts. Given the limited research about occupational adaptation in advanced cancer, we need to examine literature outside palliative care to better understand this concept. Research pertaining to how people adapt to changes due to a variety of medical conditions provides a starting point for exploring shifts in occupational adaptation over time for working-aged adults living with advanced cancer.

#### 3.1.3.1 Shifts in Occupational Engagement: Non-Progressive Medical Conditions

A defining characteristic of the experience of a non-progressive medical condition (e.g., traumatic brain injury or stroke) is that of a single event associated with a sudden disruption of function, followed by a transition period that leads to relative stability. The initial decline in abilities disrupts the person's sense of their familiar lived world. They recognise the changes in their body and realise that everyday life will no longer be as it was prior to the injury or illness (Bury, 1982; Williams & Murray, 2013). Changes in occupational engagement vary significantly depending on the person's capabilities (e.g., a reduction in their physical, emotional, or cognitive skills), environmental changes (e.g., inability to drive, no longer working, support available, or changing residence), or temporal needs (e.g., requiring additional time for rehabilitation; Tse et al., 2020). Individuals with a non-progressive medical condition also experience grief and uncertainty, not knowing their future limitations or how to define themselves (Cotton, 2012). The person must re-evaluate what they are able to do as they attempt to participate in occupations. When the person has difficulty doing a familiar activity, they often choose to substitute one activity for another or modify how or when they do that task to optimise their success (Åberg et al., 2005; Bontje et al., 2004; Klinger, 2005; Thorén-Jönsson, 2001; Williams & Murray, 2013). For example, a study on occupational engagement post-stroke found that participants often gave up activities such as travelling, driving, and going to work, replacing them with more sedentary occupations such as reading or watching television. They sought to participate in activities related to how they now defined themselves or what made them feel competent and independent (Tse et al., 2020). Another study involving a post-stroke cohort noted that a person's acceptance of their new functional level and reframing of their priorities grew over time (Williams & Murray, 2013). A new sense of normal had begun.

An awareness of *what* and *how* occupational engagement changes after an illness or injury is only one component of a person's lived experience. Understanding the motivation behind *why* people choose or cease to participate in certain occupations is necessary. Tse et al. (2020) argued that the desire to continue participating in everyday activities was a key component fuelling the motivation to adapt after experiencing a stroke. Exploring how people adapt following a single event such as a stroke informs our understanding of changes to occupational engagement following illness or injury. However, understanding how the lived experience of occupational engagement changes over the trajectory of a progressive, degenerative medical condition provides us with additional insights into this phenomenon.

#### 3.1.3.2 Shifts in Occupational Engagement: Progressive Medical Conditions

"To be ill means to be not at home in one's being-in-the-world, to find oneself in a pattern of disorientation, resistance, helplessness, and perhaps even despair, instead of in the homelike transparency of healthy life" (Svenaeus, 2013, p. 103). People experience the world through their bodies, and when the body changes due to a progressive medical condition, everyday life is significantly impacted. Although there may be some level of stability for a while before their body changes again, functional decline continues, either slow and steady or fast and unpredictable. Individuals living with a progressive medical condition experience continued loss and disrupted ability to engage in valued occupations. This section will discuss the shifting experiences of occupational engagement and the ways in which two cohorts living with progressive medical conditions—ALS and MS—adapt to changes in functional abilities (Cahill et al., 2010; Foley et al., 2014a, 2014b; Månsson Lexell et al., 2010). Although their trajectories differ from advanced cancer, similarities exist regarding how occupational adaptation occurs.

The significant, unremitting loss experienced by people living with ALS due to disease process is highlighted in a study by Foley et al. (2014b) which examined their experiences of health care. Participants in this study spoke of the specific losses experienced: loss of a sense of normalcy, independence, hope, and identity. To regain a sense of control in life, individuals living with ALS resorted to exerting control over their health care where possible. Foley et al. (2014b) concluded that taking charge of another area of their life (specifically, their health care services) was how individuals adapted to their unremitting functional losses due to disease progression. In a second article exploring these experiences with the same cohort, the authors noted differences in life stage and adaptation (Foley et al., 2014a). The study found that younger adults living with ALS faced greater challenges adapting to the changes resulting from ALS than older adults, mainly due to not meeting certain milestones (e.g., young children at home) and the perception that death should not occur in younger adults (Foley et al., 2014a). In both articles, the social environment (i.e., health care services or parenting younger children) affected the person's motivation to adapt to the changes they experienced (Foley et al., 2014a, 2014b). The deteriorating functional trajectory of ALS resulted in experiences of progressive loss. Their losses of function, their future, and their familiar world shared similarities with losses described in the illness experience literature (Carel, 2016; Foley et al., 2014a; Frank, 2002; Kleinman, 2020; Toombs, 1987).

A second example of the shifting experience of occupational engagement for people with progressive conditions relates to women living with MS. A MOHO-informed study by Cahill et al. (2010) explored how women with MS adapted to frequent changes in their lives. Study participants experienced varying degrees of bodily deterioration resulting in reduced occupational competence, challenges to participating in activities of interest, and shifting roles. In the midst of these difficulties, they sought to continue participating in activities related to their sense of self and family life. The authors noted that "when the participants lost some roles and interests, they adapted occupationally by engaging in alternative satisfying occupations that were congruent with their physical capabilities, strengthening their occupational identity and competence and, consequently, facilitating their occupational adaptation" (Cahill et al., 2010, p. 112). The women strove for occupational competence (the objective ability to participate in an occupation successfully) *by* participating in activities that matched their abilities. Another study on the experiences of occupational adaptation for women living with MS confirmed participants' desire for competency, defined here as both the objective and subjective abilities to complete the activity (Månsson Lexell et al., 2010). Both studies found that these adults also intentionally engaged in activities related to their sense of self, as doing so maintained their sense of well-being (Cahill et al., 2010; Månsson Lexell et al., 2010). The physical and social environment also significantly impacted the occupational competence of adults living with MS, as it allowed or prevented certain occupations from occurring. The findings from these two studies support MOHO's assertion that the environment is a key component of occupational adaptation, along with occupational competence and occupational identity when looking at occupational adaptation (Cahill et al., 2010; de las Heras de Pablo, Fan, et al., 2017; Månsson Lexell et al., 2010). Women with relapsing-remitting MS were more likely to view changes due to disease progression as temporary occupational disruptions, thereby having less disruption to occupational identity and competence than women with progressive MS. Biographical disruptions significantly impacted the person's experience of their lived world, similar to people living with chronic illness (Bury, 1982; Cahill et al., 2010).

Taken together, studies on progressive degenerative conditions identify key features of the experiences of occupational engagement, loss, and adaptation (Cahill et al., 2010; Foley et al., 2014a, 2014b; Månsson Lexell et al., 2010). Bodily deterioration is inevitable due to ongoing degenerative illness or disability. It significantly impacts what and how occupational engagement occurs. Participants in these studies described the social (Foley et al., 2014a, 2014b; Månsson Lexell et al., 2010) and physical (Cahill et al., 2010) environmental factors that influenced their ability to adapt. They expressed their desire to regain a sense of control (Foley et al., 2014b) and indicated that adapting in order to continue engaging in valued occupations shaped their identity (Cahill et al., 2010; Månsson Lexell et al., 2010) and sense of competence (Cahill et al., 2010). Participants wanted to engage in occupations related to their volition (values, interests, personal causation), as volition is the motivation behind occupational engagement in MOHO. Other studies involving cohorts experiencing functional changes corroborate findings such as the significance of volition or environment (e.g., Harel-Katz & Carmeli, 2019; Pritchard et al., 2014; Raber et al., 2010), but this has not been comprehensively explored in the advanced cancer population. Factors influencing participation (e.g., the environment) provide valuable information on the experience of occupational engagement while living with life-changing medical conditions. However, understanding the individual's *motivation for participating* in certain occupations (i.e., their volition) and their *motivation for adapting* provides a deeper understanding of the lived experience of occupational engagement following a significant disease-related transition (de las Heras de Pablo, Fan, et al., 2017; Lee & Kielhofner, 2017b).

#### 3.1.3.3 The Construct of Occupational Adaptation

Having explored adaptation subsequent to shifts in occupational engagement experienced by specific disease cohorts, the following section will explore adaptation through the lens of occupation. Building on existing theoretical knowledge of occupational adaptation and examining studies on specific medical conditions, it will examine how adaptation impacts people living with various health-related concerns. As discussed earlier, occupational choices typically reflect a person's sense of identity (Christiansen, 1999). Therefore, when an illness or bodily limitation results in loss of abilities and difficulty doing everyday tasks, a person's sense of self is challenged (Walder & Molineux, 2017a). Qualitative studies echoed the literature on the illness experience and occupational frameworks, arguing that the experience of health-related concerns resulted in increased feelings of inadequacy, a sensed loss of control, or an impaired sense of self (Åberg et al., 2005; Carel, 2016; Christiansen, 1999; de las Heras de Pablo, Pépin, et al., 2017; Laliberte Rudman, 2002; Schkade & Schultz, 1992; Schultz & Schkade, 1992). Conversely, these studies found that resuming familiar occupations and habits following an injury or illness facilitated the person regaining a sense of control, identity, and well-being. Early conceptualisations on adaptation highlighted the significance of occupational engagement in facilitating adaptation (Frank, 1996; Schkade & Schultz, 1992). Building on this, George-Paschal and Grajo (2019) proposed that actively participating in occupations enables adaptation to occur, thus leading to the development of a new occupational identity.

A systematic review on occupational engagement and adaptation by Walder and Molineux (2017a) employed grounded theory to explore how people engaged in occupations after a health-related trauma. This review of 37 studies found that individuals with chronic conditions experienced changes to their roles, habits, and abilities, which impacted their experience of occupational engagement. The meaning people ascribed to occupations shifted, and their diminished sense of competence shook their identity. However, when a person actively pursued occupational adaptation, it enabled the individual to reconstruct their identity after the health event. Adaptation occurred through the process of developing a new degree of *competency*, *confidence*, and *motivation* for continued engagement. The authors argued that these three concepts closely link to a person's experience of occupation and occupational identity. Strategies such as redeveloping habits, re-evaluating their values and priorities, and goal setting facilitated adaptation. Adapting well then enabled the shift from a sense of loss and reduced abilities to a sense of well-being and competence. This occurred in a non-linear fashion the majority of times. Walder and Molineux (2017a) concluded that adapting well to chronic or significant illness produces a renewed occupational competence and occupational identity, which is consistent with MOHO’s description of occupational adaptation. From the perspective of a person who experienced a life-changing event eventuating in a general level of stability, this conclusion may be applicable. However, from the perspective of a person living with a life-limiting illness, a cohort excluded from the study, the ability to adapt ‘well’ may not be possible. Due to the ongoing, deteriorating nature of life-limiting conditions, attaining mastery or competence is consistently challenged. The difference between the experience of adaptation in life-limiting illnesses versus chronic illnesses is that the former needs to continually reconfigure goals as their body deteriorates and function progressively declines. Occupational competence may be elusive. In contrast, those with chronic illnesses can work towards competence in occupational engagement. This is a significant distinction and one this study will examine further as it relates to working aged adults living with advanced cancer.

In addition to individual studies and systematic reviews on occupational engagement and adaptation, two models outline the concept of occupational adaptation: MOHO and the Occupational Adaptation Model (de las Heras de Pablo, Fan, et al., 2017; Schkade & Schultz, 1992; Schultz & Schkade, 1992). MOHO’s concept of occupational adaptation pertains to the development of a person’s occupational competency and occupational identity. MOHO describes *occupational competency* as a person’s ability to match their volition, habituation, and performance capacity to an occupation, successfully participating in that occupation. *Occupational identity* is defined as “a composite definition of the self, including roles and relationships, values, self-concept, and personal desires and goals” (de las Heras de Pablo, Fan, et al., 2017, p. 117). As noted, occupational identity is closely linked with a person’s volition (values, interests, and personal causation).

The Occupational Adaptation model explores the interaction between a person’s occupational environment (defined in this model as the context of occupational participation) and their bodily components (psychosocial, cognitive, motor, and sensory). The concept of mastery is a central assumption in the Occupational Adaptation model and is relative to the individual’s efficiency, effectiveness, and satisfaction. The individual desires mastery (internal motivation), the environment demands mastery (external motivation), and the resultant interaction between the two results in a “press for mastery” (Schkade & Schultz, 1992, p. 831). When faced with an occupational challenge, an adaptive response is required in order for the individual to experience mastery. This model assumes that all people have a desire for competency. Therefore, if competency is not possible due to an impairment, dysfunction occurs (Schkade & Schultz, 1992; Schultz & Schkade, 1992).

Walder and Molineux (2017a) concluded that "adjustment can be defined as the process of regaining occupational well-being through occupational engagement and construction of an occupational identity, supported by a process of developing competence, motivation and confidence" (p. 240). However, the question remains: When there is no hope of mastery due to the disruption of constant and progressive functional losses from advanced cancer, what does a new occupational identity look like? The majority of studies regarding occupational adaptation, identity, and competence pertain to occupational adaptation following a non-progressive medical event or life transition (Bontje et al., 2004; Christiansen, 1999; Cotton, 2012; Grajo et al., 2018; Howie et al., 2004; Johansson et al., 2018; Klinger, 2005; Paley Altit et al., 2019; Raanaas et al., 2019; Schkade & Schultz, 1992; Schultz & Schkade, 1992; Vrkljan & Polgar, 2007; Walder & Molineux, 2017a, 2017b; Williams & Murray, 2013). In this scenario, a person can rebuild and reconfigure their occupational narrative into something stable following a period of adjustment (Åberg et al., 2005; Bontje et al., 2004; Cotton, 2012; Klinger, 2005; Nizzero et al., 2017; Scalzo et al., 2016; Vrkljan & Polgar, 2007; Walder & Molineux, 2017a, 2017b; Williams & Murray, 2013). However, existing studies often actively exclude people living with terminal conditions or those receiving palliative care services. Apart from studies on degenerative neurological conditions such as those involving people living with ALS or MS (Cahill et al., 2010; Foley et al., 2014a, 2014b; Månsson Lexell et al., 2010), there is little discussion on how to maintain occupational identity when a person's narrative is not a stable construct. For adults living with advanced cancer, there is significant fluctuation and variation in the levels of occupational competency, which affects their occupational identity.

The concept of occupational adaptation as it changes over time has yet to be tested within the cohort of adults living with advanced cancer. If competence continues to decline due to disease progression, how does this affect a person's occupational identity and ability to adapt? Whether people living with advanced disease can maintain their occupational identity and well-being over time remains unknown. Unfortunately, when people are not afforded the opportunity to adapt, occupational disengagement may occur.

### 3.1.4 *Occupational Disengagement*

Occupational disengagement and occupational deprivation refer to the degree to which a person cannot participate in their valued occupations due to external limitations or ongoing restrictions. More specifically, *occupational deprivation* is defined as "a state of preclusion from engagement in occupations of necessity and/or meaning due to factors which stand outside the immediate control of the individual" (Whiteford, 2000, p. 201). For example, although an individual may be able and willing to assist in their morning self-care routine, a health care professional or caregiver may take over and complete self-care tasks to be 'helpful' or 'save time.' The result of the occupational disengagement for the individual may be an increase in their feelings of dependency and a reduction in their sense of capacity. The impact of occupational deprivation is currently seen on a global scale in the COVID-19 pandemic. A common theme amid various stages of lockdown was the devastation experienced by many people being unable to participate in meaningful activities outside the home or within their usual social context. The impact of changes to routines and restrictions that limited how and what occupations people could do was devastating, as occupational deprivation occurred on a global scale (Hammell, 2020a; Kamalakannan & Chakraborty, 2020). Occupational deprivation negatively impacts a person's health and well-being, restricting their autonomy and control (Durocher et al., 2014; Polatajko, Molke, et al., 2013). For the person with progressive advanced cancer, occupational deprivation can be catastrophic.

This first section of the literature review situated the current study within occupational therapy and science literature related to occupational engagement. However, these concepts are also found in the literature of other disciplines using non-occupational terminology to describe these everyday activities (occupations). Descriptions related to maintaining a person's independence and involvement in everyday activities reflect occupational engagement, while distress, suffering, or the loss of a person's sense of self may reveal occupational disengagement and its effects (e.g., Beng et al., 2014; Cotterell, 2008; García-Rueda et al., 2016; Ngwenya et al., 2017; Nilmanat et al., 2010; Philip et al., 2014; Rainsford et al., 2017). Although the terminology used to describe people's distress due to occupational disengagement differs across disciplines, the concept is the same; this will be explored further in Section 3.3.2.

There is increasing recognition of the significance of occupational disengagement for people living with a range of health conditions. When participation in occupations become difficult due to the disease process and functional decline, failure to adapt can lead to further dependency and decreased quality of life. Factors outside the disease process can also result in occupational disengagement or deprivation, such as being a new migrant mother (Kielsgaard et al., 2018) or experiencing intimate partner violence (Ballan & Freyer, 2020). Current understanding of occupational disengagement for people living with advanced cancer is lacking.

## 3.2 Living with Advanced Cancer

Understanding internal and external contextual factors in the experience of living with advanced cancer provide the foundation for this study on occupational engagement for working-aged adults living with advanced cancer. As palliative care services are often the setting in which advanced cancer research takes place, and should be considered, a brief overview of the history of palliative care is warranted to commence this section. An analysis of existing research on experiences of living with advanced cancer follows. It will then examine the role of the environment when receiving palliative care services and conclude with an overview of the value that an occupational lens brings to the study of everyday life.

### 3.2.1 *The Canadian Palliative Care Context*

The field of palliative care strives to provide comprehensive care for people living with life-limiting illnesses, including symptom management and emotional, practical, and spiritual support (Health Canada, 2018). Dame Cicely Saunders pioneered the modern hospice movement in the mid-20th century by focusing on the multi-dimensional components of the person living with a life-limiting illness. This was a significant shift in focus away from active medical interventions aimed at a cure, towards a focus on symptom management earlier in the disease trajectory (Brooksbank, 2009). Balfour Mount, a Canadian palliative care physician, coined the term ‘palliative care’ in 1974 as he sought to further the quality of life and care provided to people living with terminal illnesses in Canada (Clark, 2007). Over the years, palliative care shifted from a primary focus on end-of-life care in oncology to encompass a broader range of practice that included community settings earlier in the course of illness. The World Health Organization (2020) reaffirmed the goal of Mount and Saunders for palliative care to maximise the quality of life in all areas of a person’s life, stating:

> Palliative care is an approach that improves the quality of life of persons and their families facing the problem associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (para. 1)

However, whether palliative care services in Canada are achieving this aim is contested (Health Canada, 2018; Ryan et al., 2020). A Health Canada (2018) report stated that hospital-based physician-driven symptom management of life-limiting conditions remains the primary focus of palliative care services in Canada. The report argues for a more patient-driven, integrated palliative approach to care within the community and earlier in the course of the disease. Although this has been slowly changing, gaps in care provision still exist. For example, referrals to palliative care continue to occur later in the disease trajectory (Ryan et al., 2020). In a recent retrospective Canadian study, the decedents' family physician only considered a palliative approach for 25% of deceased patients in their final year of life (Gallagher et al., 2021). Gaps still remain in care provision for those who are able to access palliative care services. One study noted the infrequency of identifying and addressing client-centred goals; less than a third of patients living with glioblastoma had conversations with their medical team about their quality of life or personalised end-of-life goals (Miranda et al., 2018). Although goal setting may have occurred, differences existed between the focus on symptoms by the health care professional versus the focus on activity from the perspective of the person receiving care (Boa et al., 2019).

To address existing gaps in the provision of comprehensive palliative care services, the Canadian Government created a "Framework on Palliative Care in Canada," which affirmed that a greater emphasis is needed on "holistic" palliative care services that "address[es] the physical, psychosocial, spiritual, and practical concerns of the person and their family" (Health Canada, 2018, p. 26). Effective symptom management is considered the cornerstone of palliative care provision; however, it should not be the end goal of palliative care in and of itself. The purpose of symptom management should be for the ultimate goal of optimising functional abilities so that adults living with advanced cancer are enabled to engage in meaningful occupations, particularly with the people they love (Boa et al., 2019; Morgan et al., 2017). Ideally, comprehensive, person-centred care would not be appended to medical care but be an inherent part of palliative care provision, bringing interventions into line with the Health Canada (2018) recommendations to address the whole person.

### 3.2.2 *Experiences of Living With Advanced Cancer*

People living with advanced cancer often experience nausea, breathlessness, fatigue, or weakness, which may compromise their ability to participate in everyday activities (Canadian Association of Occupational Therapists, 2002; Hammell, 2014; Keesing & Rosenwax, 2011; Lindqvist et al., 2006; Morgan et al., 2017; Park Lala & Kinsella, 2011). The multifaceted nature of advanced cancer impacts their sense of normalcy, leaving the person with feelings of uncertainty. They recognise that their body would continue to deteriorate over time, wondering whether they would be able to participate in specific tasks due to their body's unpredictability, what the future may hold, or when they will die (McKechnie et al., 2007; Shilling et al., 2017).

Qualitative studies that examine the experiences of people living with advanced cancer often focus on supportive care needs (e.g., accessing information, communication, continuity of care), quality-of-life domains (e.g., physical, social, cognitive), or how the experience of everyday life is affected by cancer (e.g., desire to live while dying, seeking a sense of normalcy). An example of how end-of-life experiences are explored through quality-of-life domains was described in a systematic review of 24 qualitative studies (McCaffrey et al., 2016). Authors identified eight domains related to quality of life at the end of life from the perspective of people receiving palliative care services. Significant overlap and interconnectivity of domains were noted. Although not described in occupational terms, the centrality of occupational engagement was evident in the descriptors of different quality-of-life domains, including those categorised as social (e.g., engaging in occupations with loved ones), physical (e.g., the desire to continue gardening with sufficient strength), or cognitive (e.g., reading or watching television). While generic quality-of-life domains may be used to inform service allocation or resource distribution, they do not capture the lived experience of participants, nor do they give sufficient attention to nuances in the illness experience. Carter et al. (2004) argued that generic quality-of-life tools are insufficient to explore the experiences of everyday life at the end of life.

The number and quality of studies focused on experiences of living with advanced cancer is steadily growing. This is evidenced by the increase of these studies included in systematic reviews; four articles in 2011 that met inclusion criteria grew to 13 studies in

2016 (Black, 2011; García-Rueda et al., 2016). Despite the growing number, few studies specifically explore the unique experiences of specific demographic groups. For example, only five articles on the experiences of 18- to 39-year-olds living with advanced cancer were included in an integrative literature review by Lundquist and Berry (2019).

The importance of everyday priorities of people living with life-limiting conditions is a recurrent theme in end-of-life literature. Priorities for this cohort include living well while dying (e.g., Arantzamendi et al., 2020; Carter et al., 2004; Morgan et al., 2017; Vig & Pearlman, 2003; von Post & Wagman, 2017), seeking a sense of normalcy (e.g., Black, 2011; Lee, 2018; Lundquist et al., 2019), maintaining meaningful relationships, and desiring to continue with existing valued roles or responsibilities previously held (e.g., Doumit et al., 2007; McCaffrey et al., 2016; Park et al., 2017). Multiple descriptions of occupational engagement are used by these studies to depict what it was like to live life with semblances of normalcy amid cancer progression. Although many studies did not use occupational terms, the concepts identified are consistent with occupational engagement (Appelin et al., 2005; Arantzamendi et al., 2020; Bates et al., 2018; Carter et al., 2004; Dewhurst et al., 2020; Doumit et al., 2007; García-Rueda et al., 2016; Johansson et al., 2006; McCaffrey et al., 2016).

Living well while dying is a priority shared by people with advanced cancer (Arantzamendi et al., 2020; Jacques & Hasselkus, 2004; Morgan et al., 2017; Vig & Pearlman, 2003; von Post & Wagman, 2017). Participants in Vig and Pearlman's (2003) study described how they could facilitate a sense of living while dying when they continued to do everyday activities, engaged in regular routines, or planned what they wanted to do. More than simply subsisting, these individuals "believed that they were still whole people engaged in living their lives … [such] as going out for meals and maintaining enjoyable hobbies. Continuing to engage in these activities gave a sense of meaning and normalcy to participants lives" (Vig & Pearlman, 2003, p. 1598). Similarly, Arantzamendi et al. (2020) described the process of living well while dying. This study found that people living with advanced cancer experienced a delicate balance between being alive and feeling like they were also dying. They struggled with approaching uncertainty and death yet also had moments of acceptance of their approaching death.

McKechnie et al. (2007) explored the experience of uncertainty for people living with advanced cancer at end of life and identified the strategies used to continue living well in the midst of uncertainty. This included adjusting what they did to maintain a good balance between maximising independence in the midst of increasing dependence, having a positive attitude, focusing on what they felt was 'normal,' and maintaining a sense of hope. At times, participants chose to push cancer into the background in order to actively pursue living. Another study highlighted a range of strategies used to facilitate a sense of living, such as focusing on being present in the moment and maintaining social connectivity with loved ones (Arantzamendi et al., 2020).

Living well while dying was identified as an overarching priority of people living with advanced cancer in another exploratory study by Carter et al. (2004). Participants took control through active involvement in planning their day which facilitated the desire to live well, including adapting their choices or activities as required. Taking charge occurred amid a range of challenges such as functional decline, managing symptoms, or shifts in their relationships. Symptom management facilitated continued occupational engagement (Morgan et al., 2017; Vig & Pearlman, 2003). This pursuit of normalcy and the ordinariness of life was often facilitated through maintaining routines or valued roles, as evidenced in other literature (Appelin et al., 2005; Johansson et al., 2006; Peoples, Nissen, et al., 2017). The significant value placed on living and doing everyday life extended throughout the cancer trajectory and was a priority even in the final week of life (Dobrina et al., 2016).

Maintaining important relationships, valued roles, and responsibilities was also a priority and highly valued by people living with advanced cancer. These priorities are consistent with MOHO theory which describes the social environment (relationships), volition (the person's values), and habituation (their roles and responsibilities) as central components in a person's motivation to participate in everyday life (Kielhofner, 2008a). The meaning ascribed to relationships, roles, or responsibilities shifted as cancer progressed, either increasing in value and importance or taking on less significance. Although participants enjoyed their independence, being present with their loved ones was also a priority (Vig & Pearlman, 2003). Their sense of well-being was also linked to their ability to do things for others and maintain valued relationships (Bates et al., 2018; Doumit et al., 2007). Two studies that explored the experiences of people living with advanced cancer illustrate the importance of valued roles and relationships. Both involved a younger cohort—33 to 66 years (Bates et al., 2018) and 21 to 71 years (Doumit et al., 2007)—and recognised the importance of the worker, family member, or homemaker role for these individuals. The loss of involvement in productive roles due to functional decline significantly affected participants' sense of meaning. Another study affirmed the importance of valued roles and relationships within the working-aged adult cohort, where all but one participant was under 65 (Dewhurst et al., 2020). Participants believed that remaining physically active would allow them to return to work or maintain their parental role. In each of these studies, participants placed a high value on occupational engagement which was associated with maintenance of well-being.

Although younger adults (18 to 64 years) and older adults have much in common, the experience of living with advanced cancer for working-aged adults is different in many respects from the experience of older adults. This younger cohort focused on their work and parenting roles more so than older adults who have grown children and are retired (Bates et al., 2018; Doumit et al., 2007). These unique experiences of the under 65-year-olds have been described in a number of studies (Bates et al., 2018; Doumit et al., 2007; Hanna et al., 2019; Knox et al., 2017; Lundquist et al., 2019; Lundquist et al., 2020; Lundquist & Berry, 2019; Lundquist, 2017; Park et al., 2017). They did not expect to be diagnosed with cancer and die at a young age. They felt a sense of isolation and loneliness, believing that their peers did not fully understand what they were going through. In a study involving adults between the ages of 18 to 39 with an advanced cancer diagnosis, one-third of the participants had small children, which added to the difficulty of living with cancer (Knox et al., 2017). Study findings indicate that these parents experienced a greater sense of isolation compared to those who did not have children, describing the struggle to coordinate their children's needs as well as managing their own symptoms and medical schedules. Another study identified that the maintenance of the parental role was of paramount importance to a group of women in their thirties who had advanced breast cancer who sought to continue this role for as long as they could (Lundquist et al., 2019). This was evident in their desire to continue caring for their children despite challenges that arose from illness. Participants in the Park et al. (2017) study all had at least one child under the age of 18 and all sought to be present with their children while maintaining related responsibilities. They held this desire in tension whilst grieving the losses experienced due to cancer and feeling as if they were "missing out" (p. 234) on their children's childhoods due to cancer progression. Parenting children while living with advanced cancer significantly shaped participants' experience of everyday life. Although these studies provide insights into specific aspects of the parenting experience whilst living with advanced cancer, there is limited research surrounding the broader experience of everyday life and contextual factors for this age cohort.

### 3.2.3 *The Environmental Context of Living With Advanced Cancer*

The environment plays a significant role in a person's illness experience, as the physical space a person inhabits shapes their everyday life (Carel, 2016; van Manen, 1990). The phenomenological concept of being-*in*-the-world includes the meaning people ascribed to their environment or lived space (Heidegger, 1962; van Manen, 1990). Svenaeus (2013) described this as the *unhomelikeness* or *homelikeness being-in-the-world*. MOHO positions the environment in everyday life as a central component of occupational engagement (Fisher et al., 2017). The environment affects a person living with an illness or injury through factors such as narrowing the perceived size of their world, the over medicalisation of the person's home, or by fostering a sense of normalcy and the feeling of being at home (Madsen et al., 2019; Rasmussen & Edvardsson, 2007).

Following an injury or illness, environmental limits on mobility may become an issue. A person may experience their world as shrinking as they discover challenges to leaving their home environment. This may be due to their residual functional impairments, physical barriers, or insufficient social supports. For example, wheelchair users in Canada may have difficulty accessing the community in winter due to the snow (Ripat et al., 2015). Research about the experiences of people who have sustained a stroke demonstrates that the loss of the ability to access their environment can lead to a sense of hopelessness and lack of purpose (Williams & Murray, 2013). Instead of recognising the environment as a barrier, people may attribute their inability to do a task to their physical limitations (Carter et al., 2004). Conversely, the ability to leave the home environment can have a positive, significant impact. The opportunity to get out of the house and access the community contributed positively to a feeling of normalcy for adults and older adults living with advanced cancer (Maersk et al., 2018). The outdoor environment is also recognised and experienced as a place that fosters spiritual quality of life for people living with advanced cancer (McCaffrey et al., 2016).

Consideration of the environment as the context in which care is provided is an area that is garnering increasing attention in palliative care research (Madsen et al., 2019; Rasmussen & Edvardsson, 2007; Rigby et al., 2010). The preferred place for care for many is the home environment due to its familiarity and sense of normalcy it brings, as the individual can retain their place in the family unit as a parent, grandparent, or spouse (Appelin et al., 2005; McCaffrey et al., 2016). The presence of personal objects within the home provided participants with a sense of continuity with who they were in the past (Maersk et al., 2018). The significant impact that modifying the environment can have on participation was demonstrated by a participant in a study by Bentz et al. (2021) who used a device (tweezers) to facilitate function (picking up items in the wood shop). However, a cohort of people receiving community palliative care saw assistive medical devices as symbolic of the limited time remaining before they died. This equipment also made the home resemble a more hospitalised environment, thus interfering with this sense of normalcy (Appelin et al., 2005; Maersk et al., 2018). People attach meaning to their environment, and thus the persons home can both foster and "threaten identity in the context of living with advanced cancer" (Maersk et al., 2018, p. 16).

A small body of research about the experience of dying in a hospital environment found that being in the hospital contributed to an increased focus on the swiftness of time passing and awareness of approaching death (Doumit et al., 2007). In the same space, time in the hospital can also be experienced as monotonous (no structure, each day being the same). Individuals in the hospital experienced an altered sense of spatiality, desiring to be outdoors yet feeling 'stuck' indoors without the freedom to leave (Eriksson et al., 2016).

The centrality of the environmental context for a person's health is evident in occupational therapy theory (Fisher et al., 2017) and affirmed in the *Ottawa Charter for Health Promotion*:

> Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love. Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances. (World Health Organization, 1986, p. 4)

The occupations a person engages in shape their everyday life within the physical and social environment. However, what remains unclear is how the environment impacts a person's ability to engage in occupations within the context of a continuously changing, deteriorating body and advanced cancer.

### 3.2.4 *The Value of an Occupational Focus*

Outside of occupational therapy or occupational science literature, the role of occupation for people living with advanced cancer is rarely characterised as an independent construct. The intrinsic value, impact, and significance of occupation is diluted when categorised as a coping strategy of “everyday pragmatism” (Walshe et al., 2017, p. 9) or discussed as a general concept (e.g., McTiernan & O'Connell, 2015; Pasman et al., 2009; Rasmussen et al., 2010; Walshe et al., 2017). However, understanding the nuances of occupation and the priority placed on specific occupations at the end of life can enhance recognition of the individualised nature of the experiences living with advanced cancer. By using an occupational focus to understand a person’s perspective on living with advanced disease, the motivation behind occupational engagement can be explored, thus providing insight into how people choose and participate in meaningful occupations at the end of life. This is crucial to their well-being and quality of life.

Occupational therapists are uniquely positioned to research the lived experience of everyday life from the perspective of the person living with advanced cancer due to the profession’s core competency of occupational engagement (the ability to participate in everyday life). Employing an occupational lens such as MOHO, which accommodates the nuances of the person, environment, and occupation, can enhance the inquiry into the lived experience of everyday life. The following section will explore the current understanding of occupational engagement in palliative care settings, including the significance of occupational engagement and adaptation for people living with advanced cancer and how this changes with disease progression.

## 3.3 Occupation at the End of Life

The lived experience of advanced cancer is characterised by uncertainty, loss, bodily deterioration, and functional decline. However, in the midst of these losses, the illness experience is one of actively seeking a sense of normalcy, a sense of self, and well-being through continued involvement in the ordinariness of everyday life.

### 3.3.1 *Occupational Engagement and Advanced Cancer*

The number of studies examining the significance of occupation for people living with advanced cancer has steadily increased over the past few decades, primarily from a group of occupational therapy researchers in Australia, Denmark, and Sweden. Study settings vary across the continuum of care, including residential care (la Cour et al., 2005; la Cour et al., 2007), hospice (Jacques & Hasselkus, 2004; McKechnie et al., 2007), day hospice (Lyons et al., 2002), inpatient hospital settings (Ashworth, 2014; Eriksson et al., 2016), and at home (Bentz et al., 2021; Hammill, Stewart, et al., 2019; la Cour & Hansen, 2012; la Cour, Johannessen, et al., 2009; la Cour, Nordell, et al., 2009; Maersk et al., 2018; Maersk et al., 2021; Maersk et al., 2017; Morgan et al., 2017; Peoples, Brandt, et al., 2017; Peoples, Nissen, et al., 2017; Unruh et al., 2000; Vrkljan & Miller-Polgar, 2001; Wæhrens et al., 2020). The focus of the research ranges from engagement in creative activities, to developing a sense of belonging, the experience of time, or identifying which occupations foster joy. However, a common thread throughout all studies is the desire to continue participating in valued occupations to the end of life for as long as they are able, despite functional decline and approaching death. The prioritisation of occupational engagement by adults living with advanced cancer is often attributed to the link between occupation and well-being (Svidén et al., 2010; von Post & Wagman, 2017). Having explored the general concepts of occupation, occupational engagement, and occupational disengagement earlier in this chapter, the discussion will now turn to the impact and meaning of occupational engagement as it pertains to adults living with advanced cancer.

A scoping review by von Post and Wagman (2017) on the priorities of people living with a life-limiting condition identified the centrality of occupation at the end of life as an overarching theme. Participating in valued occupations is often underpinned and intensified by the desire to maintain social relationships through helping and being around others, leaving a legacy, maintaining previous routine occupational patterns, and taking control of the life that was left. The drive to actively support loved ones in the midst of approaching death highlights the importance of reciprocity at this time of life (Park Lala & Kinsella, 2011). Studies on occupational engagement amid advanced cancer sequelae demonstrated how participation in valued activities can facilitate a sense of meaning at end of life (Mills & Payne, 2015; von Post & Wagman, 2017).

Occupational engagement shapes the person's occupational identity and self-efficacy, enhancing their sense of self (de las Heras de Pablo, Fan, et al., 2017; Hammill et al., 2014; Jacques & Hasselkus, 2004; Laliberte Rudman et al., 1997; Law et al., 1998; Mills & Payne, 2015; Morris & Cox, 2017; Polatajko, Davis, Stewart, et al., 2013). The impact of occupation on well-being and quality of life is far-reaching in the final stages of cancer. Recognising the role of occupation in the facilitation of well-being, Mills and Payne (2015) concluded that that "occupation allows individuals at the end of life to adapt, cope, reflect, learn, live, do, appreciate, contribute, prioritise, and fulfill [sic] their potential within this special time they have left to them" (p. 1762). An emerging body of literature affirms that the ability to engage in occupations helps people living with advanced cancer feel like they are 'still living,' preserving feelings of mastery and control in everyday routines (Badger et al., 2016; de las Heras de Pablo, Fan, et al., 2017; la Cour, Johannessen, et al., 2009; Peoples, Brandt, et al., 2017). Participation in routine occupations and habits facilitates a sense of normalcy despite disease progression (García-Rueda et al., 2016; la Cour, Johannessen, et al., 2009; Lindqvist et al., 2006; McKechnie et al., 2007; Ngwenya et al., 2017; Rasmussen et al., 2010; Vrkljan & Miller-Polgar, 2001).

The lived experience of advanced cancer is subjective and affects a person's sense of meaning in their everyday life while contending with inevitable and unremitting change and loss (Frank, 2013; McKechnie et al., 2007; Vehling et al., 2018). Importantly, although the once-familiar world becomes foreign, the act of continued engagement in routine or new occupations creates new meaning in the midst of experiencing a changing world (Lindqvist et al., 2006; Mills & Payne, 2015; Svidén et al., 2010). Specific valued occupations are reinterpreted with a greater sense of significance, whereas other occupations start to lose their value as time grows short (Park Lala & Kinsella, 2011). The experience of occupational engagement is unique to the individual, affected by the person's motivation for doing (volition), habits and roles (habituation), and their abilities (performance capacity; de las Heras de Pablo, Fan, et al., 2017; von Post & Wagman, 2017; Yamada et al., 2017).

### 3.3.2 *Occupational Disengagement and Advanced Cancer*

Occupational therapy and occupational science use the terms occupational disengagement or occupational deprivation to describe the sudden or progressive removal of valued occupations due to external factors (Hocking, 2017). Discussed earlier as a general concept, it is now applied to the advanced cancer cohort. Occupational deprivation in this thesis refers to the lived experience of the loss of ability to engage in an occupation due to the progression of advanced cancer. Peoples, Brandt, et al. (2017) studied how people manage occupations at home whilst living with advanced cancers and found that 34% of participants experienced the loss of occupations they were previously involved in. The inability to participate in meaningful activities due to advanced cancer and impaired performance capacity can have significantly detrimental consequences (Hammill et al., 2014; Keesing & Rosenwax, 2011; Morgan et al., 2017; Park Lala & Kinsella, 2011). The person may no longer inhabit valued roles they previously held (e.g., 'worker,' 'dancer,' or 'wife who used to host dinner parties every week'). Occupational disengagement at the end of life is linked to reduced quality of life, increased hopelessness, and a personal sense of suffering (Durocher et al., 2014; Hammill et al., 2014; Keesing & Rosenwax, 2011; Rasmussen et al., 2010). The ramifications of occupational disengagement are significant for the person living with advanced cancer. To understand this further, an exploration of suffering in palliative care is required.

The term *suffering* has been used in medical and nursing palliative care literature to describe distressing concerns at the end of life (Beng et al., 2014; Boston et al., 2011; Nilmanat et al., 2010; Pasman et al., 2009; Sacks, 2013). In both clinical practice and research, there is often a presumption that suffering is related to poor symptom management. However, these symptoms themselves are often a sign of something more profound that is being masked: difficulties that originate in losing a sense of control and normalcy in everyday life (in other words, the loss of occupational engagement at its core; Black, 2011). A systematic review by Gruenewald and White (2006) on end-of-life experiences for older adults noted that:

> Good symptom management is essential, although not sufficient in itself to ensure a sense of hope and adequate quality of life near the end of life. Comprehensive assessment and palliative care for older people near the end of life should go beyond symptom management to include an assessment on the possible causes of suffering. Hospitalised and institutionalised older people are particularly vulnerable to a sense of loss of control, isolation, and hopelessness near the end of life. (p. 176)

A study on euthanasia in the Netherlands also reported similar findings. Pasman et al. (2009) explored differences between how Dutch physicians defined suffering compared to the people in their care who wished to end their lives. The physicians defined suffering in very physical terms, primarily pertaining to pain or other uncontrolled symptoms. However, for those who requested euthanasia, their definition of suffering related to their changed identity and sense of self-efficacy: their inability to engage in meaningful roles, increased dependency, or the difficulties doing their routine, meaningful everyday activities (i.e., occupational engagement). This study identified a strong link between unbearable suffering, increased dependency, and resultant occupational disengagement and is consistent with data from other jurisdictions where physician-prescribed medication to end life is legal. However, emerging evidence affirms that the reasons why people with advanced disease choose to end is consistent: the actual or anticipated fear of suffering due to difficulties engaging in everyday life (Health Canada, 2020, 2021; Oregon Health Authority, 2021; Pasman et al., 2009; Washington State Department of Health, 2018).

Health Canada (2021) recently released its second annual report on medical assistance in dying, which includes statistics on who chooses to end their life, where it is undertaken, and why they made this decision. To be eligible, people must state that they are experiencing “intolerable suffering” and the nature of this suffering. The data collected reports that the two main reasons for suffering are the inability to engage in valued occupations: the “loss of ability to engage in meaningful activities” (84.9%) and the “loss of ability to perform activities of daily living” (81.7%)[3] (Health Canada, 2021, p. 20). This is consistent with the 22 years of data from Oregon and the past decade in Washington (Oregon Health Authority, 2021; Washington State Department of Health, 2018).These reports point to the significant impact occupational disengagement has on the quality of life for the person living with advanced disease. It also highlights the potential gap in service provision reflected by individuals experiencing this level of intolerable suffering. However, there is a paucity of literature that examines the meaning and experience of occupational disengagement or deprivation in palliative care research.

The concept of suffering is explored outside of the literature on medical assistance in dying. An integrated literature review by Boston et al. (2011) identified key factors contributing to existential suffering. These included a loss of meaning or purpose, increased dependency, fear of being a burden, a loss of dignity, and a loss of roles; all aspects related to occupational engagement. The inability to participate in everyday activities as a cause of suffering is reinforced in a study by Dobrina et al. (2016) on the concerns and needs of adults living with advanced cancer in which fifty five percent of people in their last week of life described themselves as ‘suffering’ or feeling ‘bad’ to ‘very bad.’ However, on closer examination, the cause of their suffering pertained to their inability to engage in occupations such as walking or lawn bowling rather than symptoms such as pain. Beng et al. (2014) also explored the experience of suffering in people living with advanced cancer, identifying ten themes and corresponding causes of suffering: differential, dependent,

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[3] People could choose more than one option for how they defined intolerable suffering in the Canadian and American data sets; thus the numbers add up to more than 100%.

empathic, terminal, interactional, environmental, sensory, emotional, cognitive, and spiritual suffering. For example, dependent suffering pertained to depending on others for care needs, whilst environmental suffering described the distress due to a hospital environment. The authors stated that there should be a greater focus on addressing causes of suffering such as dependency.

Many aspects of suffering described above relate to the ability to engage in valued occupations. However, what does that look like amid functional decline and bodily deterioration? The above studies did not consider the importance of addressing *how* to adapt to increasing dependency or fluctuating abilities. This is essential, as the inability to engage in occupations affects a person's sense of self and, at times, the desire to live. "Not being able to participate in everyday life may imply suffering, and … a feeling of hope and participation resulted from easing their suffering through some form of occupation" (von Post & Wagman, 2017, p. 3).  The following section will explore existing scholarship on adaptation at end of life.

### 3.3.3 *Occupational Adaptation and Advanced Cancer*

Discussed earlier as a general concept in disease progression, occupational adaptation is now considered in the context of advanced cancer, where a consistent level of occupational engagement is not possible and many individuals experience occupational disengagement (Peoples, Brandt, et al., 2017). People living with advanced cancer must adapt in order to continue participating in their valued occupations (la Cour & Hansen, 2012; von Post & Wagman, 2017). However, for people living with a progressive life-limiting illness, developing new habits, adapting roles, and creating new ways of being in the world is a continuously changing experience. There is a repeated shifting between a sense of wellness and illness over the cancer trajectory (la Cour, Johannessen, et al., 2009; Lindqvist et al., 2006; McKechnie et al., 2007; Morgan, 2012; Ngwenya et al., 2017; Rasmussen et al., 2010; Vrkljan & Miller-Polgar, 2001). Ongoing adaptation is required in order to accommodate the continual decline in abilities and shifting needs (Morgan et al., 2017; Park Lala & Kinsella, 2011).While an emerging evidence base has examined the broader experience of occupational adaptation at the end of life, the experiences of occupational adaptation for working aged adults with advanced cancer are underrepresented in the literature. There is an imperative to better understand the process and outcome of occupational adaptation for this cohort given the increasing numbers of people living with advanced cancer and the significant link between occupational engagement and experience of intolerable suffering (Brenner et al., 2020; Health Canada, 2021; Pasman et al., 2009).

Importantly, people living with advanced cancer have been excluded from concept development or systematic reviews around occupational adaptation. For example, a grounded theory synthesis on adjustment to injury, illness, or chronic disease by Walder and Molineux (2017a) excluded studies involving people receiving palliative care services or living with cancer in order to avoid conflation with issues at the end of life. Even in studies that do not exclude this cohort, minimal research exists on occupational adaptation of working-aged adults who have palliative care needs. For example, there were no studies on occupational adaptation involving people living with advanced cancer or receiving palliative care services included in a recent content analysis study of occupational adaptation by Walder et al. (2021), nor in the integrative review by Scalzo et al. (2016), nor the scoping review by Grajo et al. (2018). Reasons for the lack of studies are not articulated, despite the importance of adaptation for this cohort. Although no conceptual model specifically addresses or guides occupational adaptation in advanced cancer, studies involving these individuals acknowledge the primacy of occupational engagement, highlighting the importance of modifying activities and adaptation to functional decline.

As discussed earlier, theoretical perspectives on occupational adaptation are beneficial for understanding adaptation in people who are experiencing a health event that will eventually plateau to a ‘new normal’ as seen following a stroke, amputation, or brain injury (e.g., de las Heras de Pablo, Fan, et al., 2017; Schkade & Schultz, 1992; Schultz & Schkade, 1992). The underlying assumption in these models is that successful adaptation results in a plateauing of identity and competency. However, the theoretical models of MOHO (Taylor, 2017) and the Occupational Adaptation Model (Schkade & Schultz, 1992; Schultz & Schkade, 1992) do not sufficiently explore the process of occupational adaptation when there is no plateauing of identity, nor of competence, due to continued decline in disease and functional trajectories as found in advanced cancer.

#### 3.3.3.1 Adaptation Over Time: Advanced Cancer

Given that the experience of occupational engagement and adaptation in advanced cancer is different from that of someone with a more stable disease trajectory, this raises an important question. What is the nature of the significant changes in roles, habits, occupational identity, or sense of capacity as cancer progresses over time? A greater focus on the longitudinal aspect of occupational adaptation and engagement is warranted, particularly in progressive conditions. The current study builds on previous research by Morgan (2012), who concluded that it is through occupational engagement that occupational adaptation occurs. Unless otherwise specified, the studies quoted in this chapter were cross-sectional, where the experience of occupational engagement, adaptation, or identity was only examined at one point in time. Functional decline was, therefore, not tracked over time.

This thesis challenges the assumptions currently underpinning occupational adaptation as it is a changing construct for working-aged adults living with advanced cancer. There is a paucity of longitudinal studies in palliative care and no longitudinal studies exploring occupational engagement and adaptation for this cohort. A longitudinal study can build on and extend the existing knowledge of experiences of occupational engagement and adaptation, as it can provide a more nuanced and accurate lens on the shifts in meaning that may occur. "Studying everyday life experience over time may enable new insights into individual adaptation by enabling assessment of meaningful activity simultaneously with the experience of loss" (Vehling et al., 2018, p. 11).

## 3.4 Conclusion

People living with advanced cancer want to actively engage in valued occupations until the end of life; however, they are not always given the opportunity or support to do so. This chapter built on the theoretical concepts raised in Chapter 2 and provided the research context for the current study, highlighting gaps within existing scholarship. This chapter foregrounded the value of occupation for people following a life transition due to a medical event, outlining the disruption illness causes and the resultant adaptation required to continue participating in valued activities. It examined occupational engagement and occupational adaptation and explored the current status of the Canadian palliative care context and literature regarding the experience of living with advanced cancer. This included the desire to live whilst dying, seeking normalcy, and maintaining valued roles and relationships. Although studies in other disciplines used non-occupational terminology to describe participating in occupations, they indirectly affirmed the value of occupational engagement and the negative impact of occupational disengagement. Recognising the significant impact of occupation on well-being and quality of life underscores the importance of using an occupational lens when researching people living with advanced cancer. Finally, this chapter examined the significance of occupational engagement while living with advanced cancer. This was particularly important to consider in the current study due to the link between occupational engagement, well-being, and a sense of identity.

The Canadian palliative care context highlights the need for more comprehensive care to address the priorities of people living with a life-limiting illness. Facing limited time, resources, and constantly changing patient abilities, palliative care services primarily focus on symptom management rather than the illness experience and adaptation in the face of occupational losses (Health Canada, 2018; Ryan et al., 2020). However, medical assistance in dying data demonstrates that people are increasingly choosing to end their lives due to inability to engage in valued occupations, not the escalation of symptom burden (Health Canada, 2021). Although the ethical issues of medical assistance in dying may be controversial, *the root cause of intolerable suffering, inability to engage in meaningful occupations, needs to be better understood in order to inform care*. Thus, the experience of occupational engagement for people with advanced cancer requires further examination, in order to identify how people adapt during this time and how their well-being and occupational identity is affected as a result.

An emerging body of research suggests that adaptation to occupational losses occurs through occupational engagement, even when challenged by disease progression and a deteriorating body, (la Cour et al., 2007; Morgan et al., 2017; Park Lala & Kinsella, 2011). However, existing theory regarding occupational engagement, adaptation, and identity is insufficient to inform our understanding for the advanced cancer cohort, as it does not address or track the lived experience of unremitting and unexpected changes that occur for people living with advanced disease. There is a paucity of research involving the under 65-year-old cohort, particularly regarding their unique experiences of occupational engagement and identity due to their life stage. As the numbers of adults facing advanced cancer continue to rise worldwide, a more nuanced understanding of occupational engagement, quality of life, identity, and meaning over time is required for this cohort. The current study fits within the broader scholarship on occupational engagement. The next chapter outlines the methodology and methods used for this study to answer the questions: What is the lived experience of occupational engagement for working-aged adults living with advanced cancer, and how does this change over time?

# CHAPTER 4: METHODOLOGY AND METHOD

The research design and methods of this study are the focus of Chapter 4. It builds on the previous two chapters, which established the theoretical framework underpinning this research (Chapter 2) and identified how this study fits within current scholarship (Chapter 3). The current chapter focuses on the study's design, outlining the methodology and methods used to examine the experiences of occupational engagement for working-aged adults living with advanced cancer. Following an overview of the research aims and questions, the background and rationale for the research methodology are described. This includes the methods used for recruitment, data collection, and analysis. Chapter 4 concludes with a discussion on rigour, ethical issues requiring consideration, and methodological considerations.

## 4.1 Research Questions and Objectives

This research answered the questions: What is the lived experience of occupational engagement for community-dwelling, working-aged adults with advanced cancer, and how does this change over time?

The objectives of this study were to

- explore the lived experience of occupational engagement during disease progression for community-dwelling, working-aged adults living with advanced cancer,
- track how occupational engagement is experienced over time, and
- examine how these experiences map against current occupational therapy theoretical frameworks.

## 4.2 Research Design

A qualitative design was used to study the experiences of people aged 18 to 64 years who were living with advanced cancer. The chosen methodology had implications for how the study was designed and data analysed, and thus, the rationale for the use of a qualitative research design is described below. As phenomenology was used as both methodology and method, an overview of the phenomenological approaches informing this study is provided. The application of the longitudinal, hermeneutic phenomenological design will then be described.

### *4.2.1 Qualitative Approach*

Qualitative research seeks to comprehensively understand a person's experience, observations, or perspectives on a phenomenon within its context. Approaches in qualitative research range from understanding how systems work and their consequences to exploring the meaning people give to an experience (Patton, 2015). A variety of study designs may be employed in qualitative research, including ethnography, phenomenology, and grounded theory. The design selected is informed and determined by the research question, the method, and the study's goals. This study used a phenomenological approach due to the centrality of the meaning behind the phenomenon under investigation, as noted in Chapter 2 (Theoretical Concepts). Its focus was to explore the impact of advanced cancer on participation in daily activities and to examine how this experience changed over time as cancer progressed. The experience of living with advanced cancer is very personal and complex, and qualitative research can be used to effectively explore how meaning is constructed during disease progression. Furthermore, the occupations people value and engage in are often unique and individualised. The individual experience of participating in daily activities can differ significantly between people with advanced cancer and often changes over time as health deteriorates. A phenomenological approach provided the space and flexibility required to deepen the current understanding of the longitudinal experience of occupational engagement for working-aged adults with advanced cancer.

Finlay (2011) stated that "phenomenologists are interested in embodied lived experience and the meanings held about that experience. The aim is to describe the phenomenon (i.e., an event, object, situation, process) as it is known through our everyday experience of it" (p. 16). Phenomenology provided the framework to capture the individual meanings participants ascribed to their experiences of everyday activities (Finlay, 2011; Liamputtong, 2013; Patton, 2015; van Manen, 1990). The research approach involved an in-depth, systematic analysis of participants' descriptions of everyday life with advanced cancer. This approach enabled their voices to be heard in detail, honouring their narratives. A phenomenological approach also gave participants the opportunity to provide context to their lived experience as they shared their perspectives on everyday life from within their homes and community environments (Kendall et al., 2007). This study chose a pragmatic approach because of the emphasis on participants' context-specific experiences and the meaning they gave to these experiences. A pragmatic paradigm seeks to understand practical aspects of a topic, emphasising the interconnectivity of theory and practice (Hartrick Doane & Varcoe, 2005; Morgan, 1994; Patton, 2015). This approach informed the design of the study and supports practical application of the findings—an important consideration, given that the study findings have the potential to inform clinical practice and development of theory. The qualitative design and pragmatic paradigm used in this study allowed for a comprehensive understanding of each participant's lived experience of the phenomenon of occupational engagement in advanced cancer and the "practical consequences" (i.e., impact on clinical practice) of the findings in an individual's context (James, 1907/1997, p. 94). The following factors also contributed to the chosen phenomenological approach:

1. *Phenomenology explores everyday life experiences and seeks to uncover the essence hidden behind the doing (van Manen, 1990).*

   A phenomenological approach seeks to elicit a person's lived experience from their perspective. This experience is understood through the fundamental domains of temporality, relationships, the lived body, and the space inhabited (van Manen, 1990). A person experiencing pain illustrates this concept. Rather than asking participants to describe the physical aspects of their pain, phenomenological research would ask the questions: How is pain experienced? How does it impact daily occupations? How do social relationships and meaningful roles shape how pain is experienced or tolerated? Are there temporal considerations? How does a person view themself because of their pain experience? This current study conducted an in-depth exploration of the lived experience of occupational engagement for adults living with advanced cancer, asking questions that sought to uncover and understand the meaning behind their everyday activities.

2. *Phenomenology helps to understand the depth and breadth of a person's lived experience within their context.*

   The experience of occupational engagement is situated within the complex nuances of the lived world, as discussed in Chapter 2 (Toombs, 1995; van Manen, 1990). Phenomenology takes lived world factors into account, such as the physical, social, and occupational environments. The environment has a significant impact on the experience of occupational engagement, and therefore, it is crucial to consider this contextual aspect for people living with advanced cancer in their own homes.

3. *Phenomenology encourages the reflexivity of the researcher.*

   As discussed in Chapter 1, it is impossible to completely bracket over 18 years of experience working as an occupational therapist with this population group and my personal life experiences. Reflexivity ensures rigour in the data by continuously examining any assumptions or biases that may influence the study. Hermeneutic phenomenology was chosen, as the difficulty with bracketing is acknowledged and reflexivity is encouraged (Dowling & Cooney, 2012; Frank, 1997).

This study was informed by both descriptive and interpretive phenomenological approaches, defined by van Manen (1990) as hermeneutic phenomenology. After expanding on components of descriptive and interpretive phenomenology as philosophy, a discussion on this study's hermeneutic phenomenological approach follows.

### *4.2.2 Descriptive Phenomenology*

Phenomenology was developed in the early 1900s through the work of Edmund Husserl, a German philosopher. Husserl explored the meaning of phenomenon from the individual's perspective, attempting to make known the lived experience of a phenomenon (Dowling & Cooney, 2012; Husserl, 1931/2012). He believed that participation in everyday life occurred with limited awareness or reflection at the time of experiencing it. Therefore, he aimed to explore the essential components of a person's experiences by extracting the *essence* of a phenomenon under investigation through suspending preconceived ideas, beliefs, or biases surrounding it. Husserl believed doing so allowed the researcher to focus on and describe the essence of the individual's lived experience. This approach became known as descriptive phenomenology. Proponents of descriptive phenomenology assert that the researcher should also 'bracket' previous experiences, assumptions, or knowledge pertaining to the subject in order to allow the data to speak objectively. Conducting literature reviews prior to commencing data collection is discouraged by some descriptive phenomenologists, as they consider bracketing to include prior knowledge of the subject. Husserl's descriptive phenomenology became the precursor to various other phenomenological approaches[4], including interpretive and hermeneutic phenomenology (Dowling, 2007; Liamputtong, 2013; Lopez & Willis, 2004).

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[4] Multiple other branches of phenomenology have also arisen; however, it is not within the scope of this study to continue the debate regarding different forms of phenomenology such as what constitutes 'purist'

### *4.2.3 Interpretive Phenomenology*

Martin Heidegger, a student of Husserl, was the father of interpretive phenomenology. He believed that the experience of a phenomenon was to be understood through a deeper inquiry into its meaning, not solely by its description. The researcher examines and interprets the participant's experiences within the context of their lived world; the participants do not interpret their own experience in interpretive phenomenology (Lopez & Willis, 2004). The meaning ascribed to a phenomenon—such as the experience of occupational engagement in this study—is central to interpretive phenomenology.

Heidegger emphasised the importance of recognising and acknowledging the researcher's preconceived ideas through reflexivity in order to understand the phenomenon under investigation. He believed that complete bracketing is not possible when interpreting others' experiences as the researcher is in the world, not separate from it (Dowling & Cooney, 2012). Acknowledging the impossibility of completely separating myself from the world and those with whom I work or study, I adopted an interpretive and reflexive approach in this study. This required continual self-reflection and evaluation of any pre-existing beliefs or assumptions arising from my familiar role as an experienced palliative care occupational therapist (Chapter 1: Introduction). Ongoing reflexivity supported the privileging of participants' voices and understanding of their lived experience: their *being-in-the-world* (Finlay, 2009; Frank, 1997).

Gadamer built on Heidegger's work and emphasised the importance of understanding the contextual "horizon" from the participant and the interviewer's perspective: what they see from their point of view (Dowling, 2007; Gadamer, 1975/2004; Lopez & Willis, 2004). An acknowledgement of the situatedness of both the researcher and the participant is important. Thus, a contextual understanding is crucial in exploring the lived experience of a particular phenomenon; in this case, occupational engagement for working-aged adults living in rural communities in the Canadian Rocky Mountain ecosystem.

Interpretive phenomenology seeks to understand a person's lived experience within the context of their everyday life, including their physical and social world (Lopez & Willis,

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phenomenology, van Manen's hermeneutic phenomenology, or Smith's Interpretive Phenomenological Analysis (Smith, 2018; van Manen, 2017, 2018).

2004). The concepts of *dasein*, *being-in-the-world,* and *being-towards-death* are central concepts in interpretive phenomenology (Heidegger, 1962). Dasein, translated as being or existence, is an essential part of life as a human being. *Being-in-the-world* is how the lived body is situated, within and inseparable from the physical world. *Being-towards-death* describes the awareness of the certainty of death. Authentic being-towards-death recognises the reality and possibility of our own death, while an inauthentic being-towards-death pertains to viewing death as something that only exists in the future (Farcus, 2012; Heidegger, 1962). In the current study, experiences of living with cancer were explored through the phenomenological lens of being-in-the-world and being-towards-death. These concepts are examined in a study exploring the experience of people who underwent surgery for gastrointestinal cancer (Khatri et al., 2012). Their experience of being-in-the-world whilst living with cancer was shaped by multiple factors, including a changed perspective of how time passes and an increased awareness of being-towards-death. This research lends support to Heidegger's notion that "when Dasein [existence] concerns itself with time, then the less time it has to lose, the more 'precious' does that time become" (Heidegger, 1962, p. 418). Acutely aware of the sense of being-towards-death, participants' anxiety increased, and they feared cancer recurrence, irrespective of the curative intent of the surgery. The use of interpretive phenomenology as a methodology and method was a useful tool, enabling the researchers to explore the lived experience of participants with gastrointestinal cancer following curative surgery (Khatri et al., 2012).

Interpretive phenomenology often employs theoretical frameworks to guide research, as existing knowledge can focus and inform the research inquiry (Clarke, 2009; Dowling, 2007; Dowling & Cooney, 2012; Lopez & Willis, 2004; Wright-St Clair, 2015). Occupation-centred frameworks informed this study's research questions and method, thus deepening the inquiry (Kielhofner, 1995; Tham et al., 2017). The Model of Human Occupation (MOHO) and the illness experience literature (Chapter 2: Theoretical Concepts) also informed analysis and discussion of participants' lived experiences of occupational engagement whilst living with advanced cancer.

This study also employed a hermeneutic phenomenological approach, informed by both descriptive and interpretive phenomenology (van Manen, 1990). This will be discussed in detail in the next section.

### *4.2.4 Hermeneutic Phenomenology*

Hermeneutic phenomenology extends beyond a simple description of events; the researcher interprets experiences described by the participants. van Manen (1990) defines hermeneutic phenomenology as

> a descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena. (p.180)

In order to understand the human experience more comprehensively, hermeneutic phenomenologists believe that it is essential to consider the context of the lived world, as discussed in Chapter 2 (Theoretical Concepts) and expanded below for the advanced cancer population (Walton & Madjar, 1999). van Manen (1990) describes the human experience in the world as being part of, or within, the context of the "four fundamental existentials of spatiality, corporeality, temporality, and relationality" (p.102). First, spatiality not only incorporates the lived physical space where an individual finds themselves, but it also has an impact on the person's occupational experience. For example, sitting on the patio to read whilst fatigued is a different experience from reading while sitting on a busy train, with fatiguing visual and auditory stimuli. How a person feels about the difference in lived space shapes the sense of meaning they ascribed to the activity. Second, corporeality captures the experiences of the lived body. It includes both the individual's encounter with their changing physical body due to progressing cancer and their view of self as "not me" (e.g., the experience of the body as separate to themselves in cachexia, extreme weight loss due to the disease). Third, the subjective experience of time—temporality—highlights the various ways in which time is experienced. This may include a sense that time is slowing down, an encounter with memories about the past which shape the present, or the experience of hope for the future whilst being aware of limited time. For example, feelings of breathlessness may be linked to an awareness that one's remaining time is short, as each breath drawn is interpreted as time running out. Fourth, relationality describes experiences with other people. Relationships impact how a person experiences their world and are crucial to consider when examining the lived experience of a life-limiting disease. This is exemplified by the person living with advanced cancer recalling the experience of last week's walk with their beloved child and dog in the woods. Reflecting on this event involves subconsciously giving meaning to this experience, and the person experiences intense emotions while thinking about leaving their children behind when they die. In hermeneutic phenomenology, the researcher extracts the essence of that experience. Thus, time seems to slow down when recalling precious moments such as walking and conversing with your child and dog, while the shared physical space whilst walking in the forest may result in a sense of calm.

Understanding a person's lived experience is central to phenomenological research. It includes the experience of their bodies, as well as how they feel, their perspective on life, and the meaning they ascribe to an event. The strong connection between the physical body and the self is crucial to understanding lived experience in illness (de las Heras de Pablo, Fan, et al., 2017). When the body does not work as anticipated due to a medical condition, the person's sense of self is affected. The works of Leder (1984, 1990, 1992) and Gadow (1982, 1983) complement the hermeneutic phenomenological approach and further the discussion about the lived body. They describe how a sense of meaning from being-in-the-world is possible through the lived experience of one's body (Gadow, 1982, 1983; Leder, 1984, 1990, 1992). This experience varies depending on factors such as a person's age or abilities. For example, working-aged adults have a different experience at end-of-life than older adults due to many of the contextual factors described by van Manen (1990) and MOHO (Taylor, 2017). The interconnection of contextual factors such as lived space, physical bodies, experiences of time, and the impact of relationships shapes each unique experience of occupational engagement and complements MOHO's emphasis on the interplay between the person, environment, and occupation (Chapter 2: Theoretical Concepts). In summary, this study used a hermeneutic phenomenological approach to understand the lived experience of occupational engagement for working-aged adults living with advanced cancer within their physical and social context.

### *4.2.5 Longitudinal Design*

People living with advanced cancer experience continual—and often unexpected or sudden—changes in everyday life as their cancer progresses. Cross-sectional studies provide limited information regarding longitudinal health and occupational changes, as fluctuations in abilities due to disease progression may not be evident at a single point in time. Longitudinal research in palliative care tends to focus on trajectories of disease progression and patterns of specific characteristics associated with these trajectories, such as functional decline and prognosis (Beernaert et al., 2016; Lynn & Adamson, 2003; Morgan et al., 2019) or health service utilisation and health economic implications (Cohen-Mansfield et al., 2017; Fassbender et al., 2009; Luta et al., 2020; Seow et al., 2018). Cross-sectional trajectory studies tend to be quantitative rather than qualitative in design and provide limited insight into the longitudinal nature of the experience of living with advanced cancer. Illness trajectories at the end of life have also been mapped (Lunney et al., 2003; Morgan et al., 2019). Murray et al. (2005) and Sercu et al. (2018) furthered the understanding of trajectories and their clinical implications, including preparing clients for future disease progression, recognising that individuals may not follow a distinct trajectory, and being intentional with the terms used to reflect the level of care provided.

Longitudinal studies on the experiences of living with advanced cancer examine how aspects of everyday life change over time, how a person adapts, and identify changes as participants' cancer progresses. They can also identify specific trends not evident in cross-sectional studies. For example, researchers who conducted a longitudinal study involving people expressing a desire for hastened death anticipated that suffering and loss would be a recurrent theme throughout the study. However, findings demonstrated that this was not a significant theme; rather, themes such as regaining a sense of control and resiliency were more common as time passed (Nissim et al., 2012). Increased insight into a phenomenon through a qualitative, longitudinal study design is valuable; however, challenges exist due to factors such as time limits or attrition rates in palliative care longitudinal research (Bloomer et al., 2018; Steinhauser et al., 2006; White & Hardy, 2010). As a result, there is limited research tracking the experiences of people living with advanced cancer.

As this current study sought to examine changes in occupational engagement over time, the combination of a longitudinal and hermeneutic phenomenological approach was employed. The qualitative, longitudinal design facilitated investigation into how, when, or what occupations participants engaged in changed as death approached (Saldaña, 2003). Fluctuations in the value placed on certain occupations were also examined through the use of multiple interviews. As cancer progressed and health declined across the course of participants' interviews, their lived experiences of occupational engagement were also mapped against current occupational theoretical frameworks and illness literature. A longitudinal design enabled the research question to be addressed more comprehensively than a cross-sectional study, thus giving a deeper understanding of changes in lived experiences of occupational engagement for these participants.

### *4.2.6 A Longitudinal, Hermeneutic Phenomenological Approach to Data Analysis*

In keeping with a longitudinal, hermeneutic phenomenological approach, this study privileged the voices of people living with advanced cancer as they experienced changes due to disease progression. Two different data analysis methods were combined and used to analyse participant interviews (Colaizzi, 1978; Saldaña, 2003). Although Colaizzi (1978) is associated with the descriptive school of phenomenological thought, his thematic data analysis method was chosen for this study due to its well-defined, structured yet flexible framework for analysing phenomenological data. Colaizzi (1978) emphasised the primacy of the participant's voice in his methods, and his stages of thematic analysis provided rigour, credibility, and structure. Colaizzi (1978) notes that "the listed procedures and their sequences should be viewed flexibly and freely by each researcher, so that, depending upon his [sic] approach and his phenomenon, he [sic] can modify them in whatever ways seem appropriate" (p. 59). This is in line with the flexibility afforded by van Manen's (1990) hermeneutic phenomenology, which proposed that the phenomenon under investigation should drive the selection of research methods and techniques. My experience, theoretical lens, occupational perspective, and interpretive skills also informed data collection and analysis. Consequently, minor modifications to Colaizzi's (1978) stages of thematic analysis were made to ensure that the data analysis method was congruent with this study's approach. Saldaña's (2003) data analysis methods informed the longitudinal aspect of the research. Longitudinal modifications to Colaizzi's (1978) stages of thematic analysis are highlighted below in italics. These modifications also allowed for the inclusion of an occupational framework to deepen the inquiry in the second-to-last step and were consistent with the interpretive lens and hermeneutic phenomenological approach of the study. The identification of significant statements and layers of meaning occurred prior to mapping findings against the theoretical frameworks. This was to ensure the meaning behind the participant's experiences was heard first. Consistent with hermeneutic phenomenology, continuous reflexivity occurred throughout the research process (Finlay, 2011; Msiska et al., 2014).

Colaizzi (1978) articulates the data analysis steps as follows, with modifications in italics to accommodate a longitudinal, hermeneutic focus:

1. Read the interview transcripts in-depth to get a sense of the participant’s voice.
2. Identify and isolate significant words, phrases, or sentences.
3. Identify layers of meaning within the transcripts.
4. Repeat steps 1-3 with all transcripts, then organise the formulated meanings from individual transcripts into themes common to all. This includes validating themes back to the original transcripts, noting when themes may differ between transcripts. *This also includes noting when themes differ between various stages of disease progression.*
5. Compile a comprehensive description of the themes raised that address the research question.
6. *Review the themes from the perspective of disease progression, noting how the participants’ voices change at various points in time. Saldaña (2003) recommends the following questions can assist with recognising changes that occur as time progresses:*
    a. *What increases?*
    b. *What has a cumulative effect?*
    c. *Do any epiphanies occur for the participants, and if so, what happens?*
    d. *What ceases?*
    e. *What remains consistent?*
    f. *Is there anything idiosyncratic?*
    g. *Is there anything missing?*
7. Formulate the above into a fundamental structure *and note how the themes interact with theoretical frameworks underpinning the research question.*
8. Review the individual transcripts with participants to validate the themes identified thus far.

Flexibility was an important consideration during the data analysis. For example, as this was a longitudinal study, preliminary data analysis and member checking occurred during the months of data collection. This enabled validation of topics with participants prior to their final interview and death. Having outlined the research methodology above, the following section describes the research setting, recruitment, participants, data collection and analysis, questions of trustworthiness, ethical considerations, and methodological challenges.

## 4.3 Research Setting

The study was undertaken in the rural communities west of Calgary, Canada, including the towns of Cochrane, Canmore, and Banff (an area also known as the mountainous ecosystem of the Bow Valley Corridor). Situated in the Rocky Mountains and the Foothills, there are numerous small towns, acreages, and farms in this area. Many people live near green spaces, such as rivers, lakes, mountains, forests, and walking paths. Because of the mountain and foothills topography, seasonal changes from summer to winter significantly impact people living in these communities. For example, snow in winter can make travel difficult and bears coming out of hibernation in the spring impact the ability to go for walks in some communities. Due to the climate and geography, homes in this area are often two storeys above ground with a basement (three storeys in total) and have steps at the front and rear entrances. The toilet, kitchen, dining, and living rooms are often on the main floor, with the bedrooms and a full bathroom on the top floor.

The communities in this study are served by the Rural West area of the Calgary Zone, Alberta Health Services. The primary medical centres for this region are located in the nearby City of Calgary, with all towns in this study within a 90-minute drive. Generalist home care teams provide services to people of all ages and diagnoses for communities outside Calgary city limits. No dedicated palliative home care team exists. The generalist home care team recruited participants for this study, a team consisting of health care professionals such as nurses, occupational therapists, physiotherapists, and social workers.

## 4.4 Research Participants

### *4.4.1 Sampling and Selection Criteria*

Purposive sampling enables the intentional investigation of a particular phenomenon for a particular population group. This method was employed in the current study to ensure the selection of working-aged adults with advanced cancer living in their homes in the community, as their lived experience of occupational engagement was the phenomenon under investigation (Patton, 2015). The research question and aims informed the inclusion and exclusion criteria. The rationale for each criterion is recorded in Table 4.1. The inclusion criteria were

- adults (between 18 to 64 years old),
- diagnosed with advanced cancer,
- living at home,

- able to participate in interviews, and
- an Australia-Modified Karnofsky Status (AKPS) Status score of 80 or less, indicating at least some difficulty doing everyday tasks (Abernethy et al., 2005).

**Table 4.1**

*Selection Criteria*

| Criterion | Rationale |
|---|---|
| Adults (ages 18 to 64 years) | As discussed in Chapter 3 (Literature Review), limited research has focused on this age group (18 to 64 years old) living with advanced cancer. Multiple studies address adolescents and young adults (15-39 years old) or adults (18+, including older adults). Adults have different needs to children or older adults, as they are in a different stage in their lifespan. For example, adults between 18 to 64 are often employed and have a mortgage or a young family. They may also be dealing with their own aging parents and do not expect to receive a terminal diagnosis. Adults between the ages of 18 to 64 were the focus of this study. |
| Advanced cancer | People living with advanced cancer were included in this study due to the unique aspects and experiences of advanced cancer that differ from other conditions, such as multiple sclerosis, heart disease, or chronic obstructive pulmonary disease. In addition, different diagnostic groups have a variety of trajectories at the end of life. Homogeneity of diagnosis was chosen rather than inclusion of individuals with any terminal diagnosis. |
| Community-dwelling | The experiences of adults living in their own homes and communities can be vastly different from those living in assisted living facilities or nursing homes. As the phenomenon under investigation was occupational engagement in an independent living environment[5], participants were considered for recruitment if they resided independently in a private home environment. |
| Some difficulty with occupational engagement | An AKPS score of 80 or less was chosen as a criterion for inclusion in this study. This score indicates that the individual can complete regular activities with some effort. In occupational language, a score of 80 or less corresponds to some difficulty with occupational engagement. The AKPS score was a requirement to exclude people who have no difficulties with everyday tasks, as this study explored changes in occupational engagement over time that occurred for working-aged adults living with advanced cancer. |

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[5] This study excluded institutional or congregate care settings, as individuals living in independent living settings were the focus of the study. Residing in an independent living settings does not preclude an individual from receiving home care assistance if required.

Participants were excluded from the study if they were under 18 or over 64 years old, residing in an assisted living facility, nursing home, or hospice at the time of referral, had a palliative diagnosis other than cancer, were not able to participate in interviews, or received an AKPS score of 90 or 100.

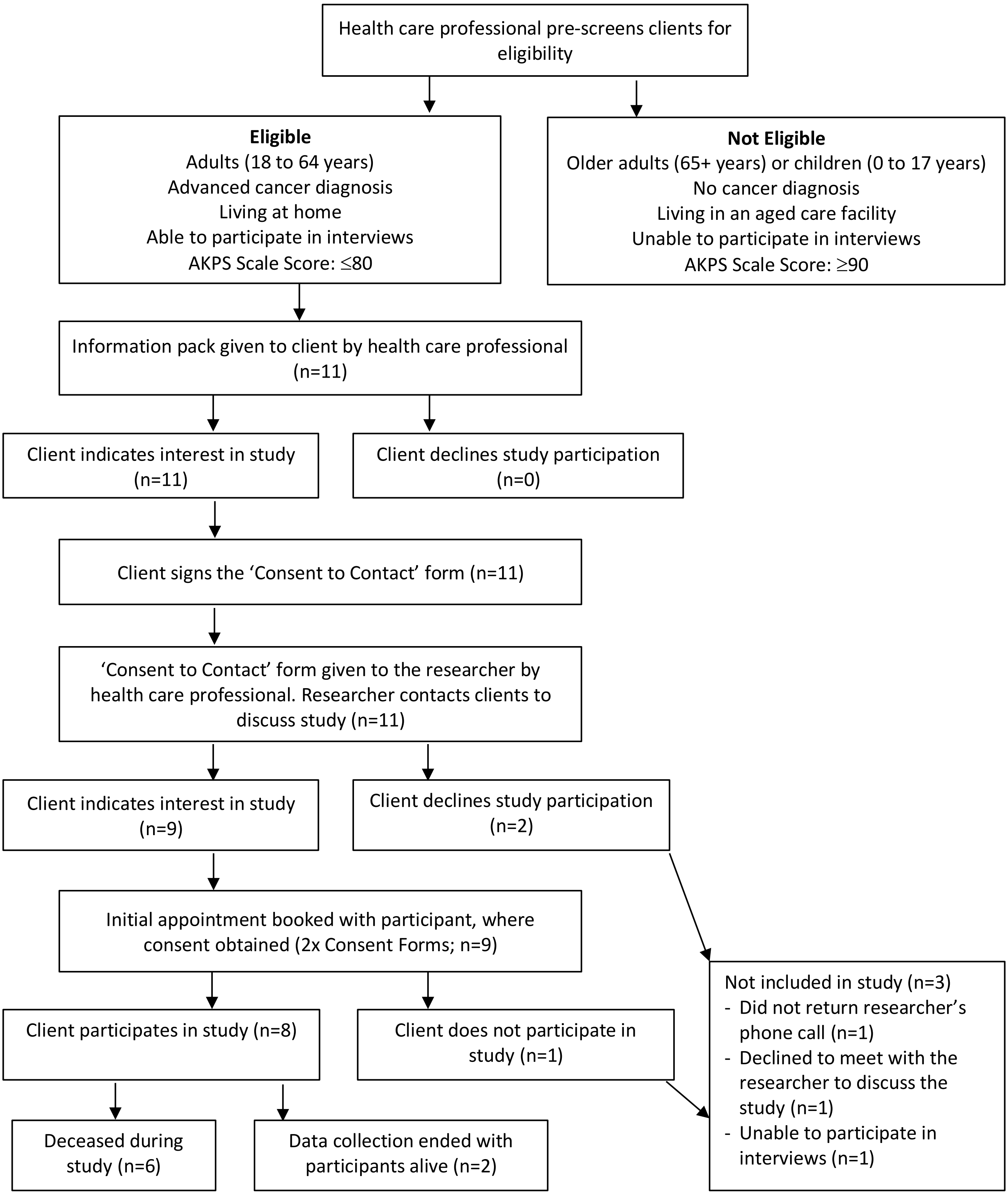
### ***4.4.2 Recruitment***

Recruitment occurred through the home care team in communities west of Calgary, Canada, including the towns of Cochrane, Canmore, and Banff. Figure 4.1 outlines the recruitment pathway. Permission was obtained to recruit participants for the study through Alberta Health Services and the manager for the home care teams in Cochrane, Canmore, Banff, and surrounding communities. Multiple presentations were given to the home care teams regarding the study and recruitment. I also attended monthly staff meetings to develop relationships with the staff and provide reminders about recruitment. This was required due to the reticence of some staff to approach potential participants. Recruitment increased following my attendance at the monthly meetings. If a client met the inclusion criteria, the health care professionals discussed the study with the potential participant and provided the information pack (an information sheet and a letter of introduction) as noted in Figure 4.1. All recruitment forms are provided in Appendix B.

The home care team approached eleven clients about study participation between February 2018 and May 2019. After the signed ‘Consent to Contact’ form for each potential participant was given to me, I contacted each person via telephone. Out of these 11, one person did not want to meet to discuss the study, and another did not return the telephone messages that were left. Nine potential participants consented to an initial home visit to discuss the study further. One potential participant met for the initial appointment but was not eligible to participate in the study; this person had difficulty communicating in the interview as a result of the disease process. The remaining eight participants consented to join the study and met all eligibility requirements.

**Figure 4.1**

*Recruitment Pathway*



This study aimed to recruit eight to ten participants due to the longitudinal and in-depth nature of the collected data and the practical limitations of a PhD study. Longitudinal changes were captured as intended. Recruitment and data collection spanned 19 months (February 2018 to August 2019), capturing seasonal differences that impacted occupational engagement. The completion of data collection occurred due to a combination of thematic data saturation for some participants (e.g., those with nine or more interviews with no new themes) and pragmatism regarding time available for data collection (Fusch & Ness, 2015). Data collection ceased just prior to the impact of the COVID-19 pandemic in our area.

In summary, eight participants were eligible for and consented to participate in the study, and 33 interviews were completed. Six participants died over the course of the study, and two participants were still alive when the data collection period ended. These two participants were in the study for over one year when data collection ceased. This is consistent with current trends of people living longer with advanced cancer due to medical advances (Brenner et al., 2020). A longitudinal phenomenological approach allowed sufficient data to be collected to understand the embodied experience of occupational engagement for working-aged adults living with advanced cancer in the Rocky Mountain ecosystem as their cancer progressed towards death.

## 4.5 Data Collection and Analysis

### *4.5.1 Interview Guide*

Semi-structured, open-ended interviews were used to collect data from participants (Liamputtong, 2013). Consistent with a hermeneutic phenomenological approach, the interview guide was informed by: (a) the literature review, (b) the theoretical framework (MOHO), (c) my extensive palliative care clinical experience, and (d) in-depth consultation with two experienced qualitative researchers. The open-ended questions aimed to elicit extended discussion about participants' lived experiences and explore various topics pertaining to occupational engagement. The context in which participants engaged in daily occupations was also explored, as a person's lived world plays a significant role in their experience of occupational engagement (Carel, 2016; Fisher et al., 2017; van Manen, 1990).

Open-ended questions provided an opportunity for participants to discuss their experience of what had been meaningful or important to them during the month preceding the interview and to track any changes that occurred during this time. This set the scene for ongoing discussion of their experience of occupational engagement in the lived world, consistent with a hermeneutic phenomenological approach. If the participant found answering the open-ended questions difficult, prompts were given to assist them with further elaboration. Any changes that they reported since the previous interview were explored further. Interview questions are listed below in Table 4.2, with the MOHO component listed in the adjacent column.

**Table 4.2**

*Interview Questions*

| Interview Guide | MOHO Concept |
|---|---|
| 1. How are you doing? | Subjective experience |
| 2. Can you tell me a bit about yourself? (first interview) | Subjective experience |
| 3. How has your week/month been? (since I saw you last?) - for follow-up interviews | Subjective experience |
| 4. What does a typical day look like for you? | Habituation<br>Performance capacity<br>Occupational identity |
| *(Prompt)* What activities do you do on a regular basis? | Habituation |
| *(Prompt)* What roles or responsibilities do you currently have to do or keep on top of? | Habituation<br>Participation in occupational roles |
| 5. Out of the activities you mentioned, what is most important to you? | Volition<br>Occupational identity |
| *(Prompt)* Can you tell me more about why this activity is important to you? | Volition<br>Occupational identity |
| 6. Can you talk to me about how have these everyday activities changed for you in the past month? | Occupational adaptation<br>Social relationships |
| *(Prompt)* What is that like for you? | Subjective experience |
| *(Prompt)* Has this changed how you go about …? | Occupational adaptation |
| 7. Out of the responsibilities you mentioned, what is most important to you? | Volition |

| Interview Guide | MOHO Concept |
|---|---|
| *(Prompt)* Can you tell me more about why this role or responsibility is important to you? | Volition |
| 8. How have your roles or responsibilities changed in the past month? | Occupational adaptation |
| *(Prompt)* What is that like for you? | Subjective experience |
| *(Prompt)* Can you talk to me a bit more about that? | Subjective experience |
| 9. What is the biggest concern you have about these changes? | Volition<br>Performance capacity<br>Occupational identity |
| *(Prompt)* What do you think is the biggest factor causing these changes? | Personal causation<br>Volition<br>Habituation<br>Environment<br>Occupational adaptation |
| 10. Is there anything that you would like to do but you are not able to do at the moment? | Volitional anticipation |
| 11. What is the one thing you are most concerned about no longer being able to do? Tell me more about this. | Volition<br>Personal causation<br>Occupational identity |
| 12. *(If there is change):* Has the way you manage your everyday activities/roles/habits changed how you see yourself? If so, how? | Occupational adaptation<br>Occupational identity |
| 13. Is there anything you would like to discuss about your everyday activities that we have not talked about today? | Subjective experience |

### *4.5.2 Interviews*

Interviews took place in participants' homes, with most occurring in the area of the home that the participant primarily resided in (e.g., living room, basement, bedroom). Participants were able to choose the location of the interview within their home. This was indoors for all but two, which occurred in the backyard during summer. Family or caregivers could stay for the interview if the participants requested; however, this rarely occurred. On the occasions when family or caregivers were present, they were doing an unrelated task in the room in which the interview occurred. As a result, participants were able to converse openly during the interview. Only one participant had a friend present for an entire interview. Their environmental context was an essential consideration of the phenomenon under investigation and was consistent with the phenomenological approach.

As noted previously, the longitudinal approach furthered an understanding of the experience of occupational engagement and tracked changes as cancer progressed. The semi-structured interviews occurred at approximately 4- to 6-week intervals. Frequency was determined by participants' schedules and the cancer progression. Initially, due to the variability of their medical appointment schedules, follow-up interviews were booked when participants were phoned a few weeks following their last interview. However, scheduling subsequent appointments became challenging for two participants due to difficulty contacting one participant and because of gatekeeping by the spouse of another. Therefore, follow-up interviews for these two participants were subsequently booked at the time of the current interview. Each participant had between one and ten interviews. All interviews but two were recorded at the participant's request. On the two occasions when participants requested interviews not be recorded, one interview occurred shortly after the participant experienced significant loss, and the other during the participant's final interview at a hospice. Written notes were taken afterwards.

### *4.5.3 Member Checking*

Interviews were transcribed verbatim by a professional transcriptionist in Western Canada in order to ensure nuances in the local language would be correctly understood. Interview transcription occurred immediately after each interview, allowing for verification and member checking with participants during their follow-up interviews. All interview recordings were reviewed against transcripts to ensure that they were correct. Member checking occurred, whereby a one-page summary of the most recent interview was provided to the participant and discussed at the subsequent interview. No participants requested modifications to the one-page summaries. Although offered at the time of consent, no participants in the study requested a copy of the full transcript of any of their interviews. Both a one-page summary and the full transcript were offered as an ethics requirement. A sample is available in Appendix C.

### *4.5.4 Thematic Analysis*

Following verification of the written data, NVivo was used to manage transcripts and construct themes. Data analysis employed phenomenological and longitudinal perspectives and was conducted using a combination of Colaizzi's (1978) and Saldaña's methods (2003), respectively. The specific aspects of data collection for this study are described in Table 4.3.

**Table 4.3**

*Data Analysis Method*

| Data Analysis Step | Description |
|---|---|
| 1. Reading and rereading of transcripts multiple times. | All 33 transcripts were read in-depth multiple times. Listening to audio files whilst reading transcripts provided a stronger sense of the emotional experience of the phenomenon under investigation. |
| 2. Identification of important words and sentences in the transcripts that address the research question. | Significant statements made by participants about occupational engagement were identified and highlighted in the transcripts using NVivo software. Verification with two experienced researchers followed to ensure that the significant statements pertained to the phenomenon under investigation. Important phrases identified by the participants were noted, including conversation topics frequently spoken about. |
| 3. Identification of layers of meaning within the transcripts. | Once the important words, phrases, and sentences were identified, the meaning behind the statements was explored. Active listening to the participant's voice was crucial in this step to identify the meaning for the participant. Additional contextual factors regarding the statements made were noted, such as the environment or family systems. Theoretical frameworks and existing literature were not imposed on the participant's words at this stage. |
| 4. Clustering of the identified layers of meaning into themes common to all participants. | All transcripts were subjected to the first three steps. Formulated meanings identified in Step 3 were clustered into emerging themes. Consistent with phenomenological research, the themes reflected the voices of participants. Variations between transcripts or at different stages of disease progression were noted. Once identification of themes occurred, validation ensued through comparing the themes back to the original transcripts. Two experienced qualitative researchers provided feedback on verifying and |

| Data Analysis Step | Description |
|---|---|
| | refining the constructed themes to ensure that the themes constructed pertained to the initial research question and aims. |
| 5. Compilation of a comprehensive description of the themes raised that addressed the research question and the phenomenon being investigated. | Five major themes and their subthemes were reviewed in NVivo, and a word document was created to examine them further. Each theme was separated into its subthemes, with descriptions and sample quotes for each component written out. This process refined the themes into three major themes and corresponding subthemes. The process of compiling the participants' descriptions and quotes validated their statements and demonstrated that they answered the research question. |
| 6. Identification of how themes changed over time. | Identifying how themes and subthemes changed over time included exploring factors in participants' experiences that increased, decreased, continued as is, or ceased. If participants had reflected on their experiences, these were highlighted, with any relevant contextual factors noted. As part of this process, vignettes of each participant were created to follow their narrative as time progressed (Chapter 5: Vignettes). |
| 7. Formulation of the identified themes into a fundamental structure. | The process of compiling themes, as described in Step 5, enabled the commencement of organising themes and subthemes into a structure. Following this, I identified how themes interacted with the theoretical and conceptual frameworks of MOHO, occupational engagement, occupational adaptation, and the illness experience literature. Consistent with the hermeneutic phenomenological approach used, mapping the results against theory and research deepened the inquiry. |
| 8. Validation of topics discussed. Review of the individual transcripts and confirmation of the findings thus far with the participants. | Due to the nature of this longitudinal study, this step occurred throughout the data collection and analysis. After each interview, the individual transcript was reviewed, and a one-page summary was developed, outlining the topics discussed. Participants received this one-page summary at subsequent interviews, which allowed them to verify that the summary was consistent with their experience. Follow-up interviews with participants built on topics raised in earlier interviews. This was done to highlight changes that may have occurred over time from the participants' perspectives and discuss their changing occupational engagement experience. |

Although data analysis methods are described in a linear fashion, some overlapping steps, such as validation of findings with participants (Step 8), occurred throughout the study. A longitudinal and cross-sectional analysis was completed in line with the longitudinal, phenomenological nature of the study (Grossoehme & Lipstein, 2016). A sample of significant statements, their formulated meaning, and the final themes and subthemes are listed in Table 4.4.

**Table 4.4**

*Data Analysis Sample*

| Significant statements | Formulated meaning | Themes and subthemes |
|---|---|---|
| "If I can get stronger between chemos [*sic*], that's really significant so that I can do activities. … Just getting ready and going down to the bank and then to the post office; if I can do those errands, that's what I want to do" (Jessica: Interview 2)<br>. | My sense of self was previously closely linked to what I do. | Theme: The intentional pursuit of everyday activities<br>Subtheme: Purposefully striving for independence |
| "I can't run and chase my kids anymore, using my legs anyways, so now I'll chase them in the wheelchair" (Peter: Interview 2). | I have lost the ability to walk, so I have to adapt how I play with my children. | Theme: The challenge of unrelenting change and loss<br>Subtheme: Adapting to change is an active, ongoing process |
| "We moved in the middle of February into here … everything was packed in there, and you couldn't even hardly get in, but over time stuff have been organised, shelves put in, so now there is room, and that's why the treadmill was accessible now" (David: Interview 1). | I am now able to exercise because barriers in the physical environment have been addressed. | Theme: Everyday life is contingent on my environment<br>Subtheme: Physical barriers hinder my ability to participate |

| Significant statements | Formulated meaning | Themes and subthemes |
|---|---|---|
| "I can't shut the tight lids on the leftover containers yet [crying] … oh just frustrated, because I can't do things that I want to" (Tammy: Interview 3). | I am frustrated because my physical limitations impair my ability to do what I want to do. | Theme: The challenge of unrelenting change and loss<br>Subtheme: Losing independence as I become unwell |

## 4.6 Rigour

The trustworthiness of this study was enhanced by employing the components of rigour (Lincoln and Guba (1986). These include credibility, transferability, and dependability. Research has shown that once these three components are addressed, confirmability occurs (Koch, 2006; Korstjens & Moser, 2018; Liamputtong, 2013; Lincoln & Guba, 1986).

*Credibility* refers to the trustworthiness of the research and was enhanced through "prolonged fieldwork, triangulation, member checking, peer review, and reflexivity" (Liamputtong, 2013, p. 25). *Reflexivity* is crucial for hermeneutic phenomenological research, which includes the acknowledgement that all people are culturally located and situated at a particular point in time so that complete bracketing is not possible (Dowling & Cooney, 2012; Frank, 1997; Koch & Harrington, 1998). Acknowledging the researcher's situatedness is vital; therefore, my experience as an occupational therapist in palliative home care was clearly described at the outset in Chapter 1 (Introduction). In this study, credibility was maintained through a variety of factors, including:

- The design of a longitudinal study, where participants were recruited and data collected over 19 months. Interviews averaged 52 minutes each, allowing for lengthy discussions on the topic.
- The review of methods and data analysis with two experienced qualitative researchers, one with extensive clinical and research experience in palliative care, the other an experienced social scientist. This included discussion regarding the rationale for decisions made in the study design and constructing themes.
- The use of structured and rigorous data analysis methods from a longitudinal and phenomenological perspective (Colaizzi, 1978; Saldaña, 2003).

- Member checking with participants, using one-page summaries of previous interviews.
- Reflexivity occurred through self-reflection, including checking preconceived assumptions, being mindful of any bias, and weekly to fortnightly supervisory meetings. One example is the following. Prior to commencing this study, I assumed that the primary reason people wanted to continue engaging in occupations was due to the value they placed on independence and a desire to participate in everyday life, as in my palliative care practice, where many individuals focused on desiring greater independence. In addition, in occupational therapy practice, there is often a central focus on maximising independence. However, as the interviews progressed, I noted that it was not solely the value of independence that provided the motivation behind occupational engagement, but I saw other significant factors and motivations were at play (see Chapter 6: Findings). In addition, the role of the environment proved to be crucial, yet I did not expect this to be a central theme at the outset.
- As an experienced palliative care occupational therapist, I was familiar with concepts pertaining to occupational engagement and the illness experience on a general level and, more specifically, with this population group. This experience and knowledge were assets to the study design, data collection, and data analysis process. For example, credibility was enhanced in interviews by my ability to provide prompts with sensitivity and accuracy and by remaining actively engaged in the conversation when participants explored emotionally distressing experiences.

*Transferability*, a second criterion for rigour, refers to the ability to transfer findings to other contexts (Korstjens & Moser, 2018). A thorough description of all steps in the research design and methods was provided in this chapter. This study is unique in its longitudinal exploration of occupational engagement for working-aged adults living with advanced cancer, so it is difficult to verify transferability with other studies. However, aspects of the findings reflect those found in other studies pertaining to occupational participation and engagement, as noted in Chapter 3 (Literature Review) and Chapter 8 (Discussion). In addition, the longitudinal nature of this study enabled the examination of themes within different contexts as time progressed.

The third criterion of rigour is *dependability*, which describes the consistency of the process within a study. A clear decision trail demonstrates that this criterion has been met.

Questions may be asked, such as: Does the data fit the question being asked? Are steps clearly outlined? (Koch, 2006; Korstjens & Moser, 2018; Lincoln & Guba, 1986). This chapter sought to provide detailed explanations of the research process and a background picture of the situatedness of this study. Lincoln and Guba (1986) describe the establishment of dependability through a decision trail focusing on the process; this differs from confirmability, which requires that findings are derived from the data (Korstjens & Moser, 2018). Vignettes presented in Chapter 5 and the findings chapters (6 and 7) help establish confirmability and trustworthiness.

### 4.7 Ethical Considerations

Ethics approval was obtained through the Health Research Ethics Board of Alberta Cancer Committee (HREBA-CC) in Alberta, Canada (December 2017), and the Flinders University Social and Behavioural Research Ethics Committee (SBREC) in South Australia, Australia (February 2018). Operational approval was obtained from Alberta Health Services to recruit participants through the home care teams servicing Cochrane, Canmore, and Banff, Alberta (January 2018). Ethics approval for SBREC was for three years, and HREBA-CC was for one year. An extension was granted in January 2019 to extend the HREBA-CC ethics approval for another year, with data collection completed prior to January 2020. See Appendix A for the SBREC and the HREBA-CC ethics approvals and operational approval from Alberta Health Services.

During the ethics application process, two primary concerns were raised by SBREC at Flinders University:

1. How to protect participants from a perceived power differential between participants and health care professionals during screening; and
2. The amount of information to be given to the participant following each interview.

After discussion, the following was agreed upon:

1. The first consideration was addressed by the inclusion of a third consent form—the Consent to Contact Form. The process was modified as follows:
    (a) Potential participants were to be screened by the home care health professional to determine eligibility for the study and willingness to be contacted by me.

    (b) The potential participant who expressed interest in the study would sign a ‘Consent to Contact for Research Purposes’ form with the health care professional from home care. This form would then be given to me. This ensured that the health care professional did not know whether or not the client agreed to participate in the study following contact by me. It also allowed me to contact the client directly to provide further information about the study.
    (c) I was to contact the potential participant and obtain written informed consent prior to the individual joining the study. Multiple opt-out points were built-in to the study design if participants wanted to withdraw due to their disease progression or any other reason. Participants were informed that opting out would not impact the health care services they were receiving.

These changes were accepted by the HREBA-CC and by the SBREC.

2. The second consideration pertained to the proposed member checking of transcripts. The SBREC requested that all participants be given the full transcript of each interview. However, it was argued that requesting participants with advanced disease to review monthly, multiple page interview transcripts as their disease progressed would significantly increase the burden of participation. The ethics committee chair concurred that a one-page summary would be sufficient for member checking. If the participants wanted to receive a copy of the full transcript, they would be made available on request. The information sheet was updated to include this change and was accepted by the HREBA-CC and the SBREC.

There was no discrimination of participants based on gender, racial, cultural, sexual, educational, socioeconomic, or religious backgrounds. Due to the nature of living with advanced disease, the participants’ potential vulnerability was considered. The primary risk for participants was one of distress due to the interview subject matter. No feedback or concerns were reported during the study duration; rather, only positive feedback was received from several participants about the opportunity for study inclusion and the therapeutic value of the interviews. Participants stated that they could share their thoughts and feelings about current experiences during their interviews that they did not feel they had space to do so in other arenas (e.g., Jessica, Melissa, Tammy, Chris). Other feedback was from spouses of participants who reported that the interviews were the highlight of the participant's day (e.g., David, Peter). Another participant wrote a thank you note at the end of their interviews, stating:

> Firstly, thank you for doing this unique and important study. I hope … that it reaches the right people's desks! Secondly, thank you for your professionalism and for being a smart and compassionate 'interviewer.' I appreciate the way you conducted the sessions. … And thirdly, human to human, thank you for being you. For giving me a space to thoughtfully hash out my priorities and think about my daily life and future. You are a special person. (Melissa, personal communication, August 14, 2019)

This supports the notion that people receiving palliative care services should be given the opportunity to participate in research and speaks to the value participants placed on the opportunity to give voice to their lived experience of advanced cancer (Bloomer et al., 2018; White & Hardy, 2010).

Other considerations for conducting research with this cohort include the impact of sensitive topics and internal role conflict on the person living with advanced cancer (Dean & McClement, 2002). Sensitivity was required regarding issues at the end of life. Having worked in palliative care settings since 1999, I was aware of many concerns and sensitivities participants and their families might experience. In addition, as a clinician and researcher, it was important to ensure that my role as a researcher was at the forefront rather than responding as a clinician during the interviews (Frank, 1997). All clinical inquiries were directed to the appropriate health care professional following interviews, with participant permission (Sivell et al., 2019).

Confidentiality was adhered to throughout the study, and all identifiable information was stored in a secure location. Transcripts and recordings of all interviews were stored using participants' pseudonyms in an encrypted password-protected computer. In addition, a backup of all data was stored on a secure, encrypted backup drive. The Australian Code for the Responsible Conduct of Research (2018) and the Canadian Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans (2018) were adhered to.

### 4.8 Methodological Challenges

Challenges arose during the study's recruitment and data collection phase, consistent with the literature regarding research involving people living with life-limiting conditions (Bloomer et al., 2018; White & Hardy, 2010). This pertained to gatekeeping at the point of recruitment and during the data collection phase, and on the death of participants.

The primary issue regarding the recruitment of participants was gatekeeping, where access to participants was controlled by the health care professional. The health care professionals had good intentions, wanting to “protect” a vulnerable population (i.e., working-aged adults living with advanced cancer), particularly in the early stages of recruitment. Multiple clients met the criteria for the study; however, the health care professional did not always inform them about the study. Gatekeeping was identified as an access issue following discussions with those recruiting participants. This was evident through statements such as “this client is eligible, but the client is feeling really anxious” or “the client has young children.” Consequently, this resulted in the recruitment of participants taking significantly longer than planned, more than 1 year instead of the anticipated 6 months. To overcome this challenge, trust was proactively developed and fostered with the team, and a significant amount of education was provided to the home care teams. The education included discussion around (a) my education as an occupational therapist and training to address complex situations that might arise; and (b) my extensive clinical experience working with clients living with terminal illnesses, including complex or mental health conditions. I attended team meetings regularly in order to build rapport with staff and discussed current literature on experiences of people in palliative care settings being involved with research. This included findings of an integrative review on research in palliative care settings concluded that “participants affirmed that it was indeed ethical for dying patients to participate in research, and in fact, it was unethical not to include dying patients” (Bloomer et al., 2018, p. 854). Regular attendance at clinical meetings and providing ongoing education over the recruitment period decreased the amount of gatekeeping. However, it was not possible to collect the number of potential participants who were eligible but not informed of the research due to gatekeeping.

The second methodological challenge pertained to the unpredictability of the illness trajectory. Although the study design was longitudinal, collecting longitudinal data was not achievable with two participants due to spousal gatekeeping and death. During a follow-up phone call, one participant’s family member would not let me speak with the participant, saying, “don’t you know he has cancer?” This prevented booking a second interview, despite the participant previously indicating that he wanted to participate in the study. Another participant was only able to complete one interview as she died shortly thereafter. Although this is one of the limitations of a longitudinal study involving participants living with advanced disease—the inability to predict the length of time a participant will be part of the study—single interviews with these two participants were not a reason to exclude them from the study. The interviews with these two participants covered current and previous experiences of occupational engagement and included discussions about their hopes and concerns related to occupational engagement in the future.

### 4.9 Conclusion

This chapter discussed the longitudinal, hermeneutic phenomenological approach and methodology used in this study. The pragmatic focus on the lived experience of individuals within their context was central to this research. A phenomenological approach enabled an in-depth exploration into how adults living with advanced cancer experienced occupational engagement. The longitudinal design identified how these individuals adapted as their disease progressed and death approached. Rigour and ethical considerations were outlined, emphasising how trustworthiness was upheld throughout the study design and implementation. The occurrence and management of methodological challenges were also discussed. The constructed themes reflect the shared meaning that participants ascribed to their experiences and are explored further in Chapters 6 to 8. The next chapter, Vignettes, begins the findings section of this study, documenting each participant's experiences of occupational engagement and the changes they encountered over time while living with advanced cancer.

# CHAPTER 5: VIGNETTES

The focal point of this hermeneutic phenomenological study was to understand the meaning behind a person's lived experience of occupational engagement while living with advanced cancer. A longitudinal design was employed to capture the changes in everyday life as participants' cancer progressed and death neared. The previous chapter outlined the rationale for the study design and chronicled the methods used to collect data in a rigorous, ethical manner. Consistent with the methodology chosen, participants' perspectives and the meanings they attached to their everyday lives, within the context in which they lived, were key considerations of this study.

This chapter presents a series of vignettes of the working-aged participants in this study who were living with advanced cancer. Beginning with a brief demographic overview, this chapter proceeds to explore the individual participants' unique experience of occupational engagement amid cancer progression. Participants talked about what they found meaning in, and how their priorities changed over time, often leading to shifts in what occupations they participated in. Functional changes and contextual factors, such as environmental barriers, resulted in increasing difficulty with occupational engagement. The vignettes also outline *how* participants adapted to changes they experienced and the beneficial impact of addressing environmental barriers to facilitate continued engagement in everyday life. Due to the longitudinal nature of this study, each vignette presents participant narratives chronologically in order of their interviews to map experiences as their disease progressed, unless otherwise specified.

## 5.1 Participants

Recruitment and data collection occurred over a period of 19 months, resulting in 33 interviews involving eight participants. The time between interviews varied from 3 to 8 weeks due to hospitalisations or being out of town. The longest duration between an initial and final interview (with multiple interviews in between) was 14 months. Some participants phoned to reschedule appointments and discussed their hospitalisations, upcoming medical appointments, or holiday plans. These phone calls were not recorded or counted as interviews. Interviews ranged in length from 31 minutes to 75 minutes; most interviews were between 50 and 65 minutes. There was a bias towards women who were married with children and pets. Three men and five women participated, all between the ages of 40 and

61. Six participants were married and two lived alone. All participants lived in their own homes and had a diagnosis of advanced cancer. Initial interviews were conducted between 2 and 12 days after completing the ‘Consent to Contact’ form. There were one to 10 interviews per person; variability was due primarily to gatekeeping and differences in disease progression. Two participants were alive when data collection ceased, which is consistent with the growing numbers of people living longer with advanced disease in Canada (Brenner et al., 2020).

This chapter highlights changes experienced in occupational engagement over the span of participants’ interviews. The Australia-Modified Karnofsky Performance Status (AKPS) Scale was used to screen for recruitment and to monitor functional status over time (Abernethy et al., 2005). Participants scored between 50 and 70[6] in their initial interviews. Final interview scores for participants were between 20 and 60. It is important to note that participant-reported functional abilities were not always reflected in their AKPS score, which, as a screening tool, has limited sensitivity. For example, two participants improved functional status due to adaptive strategies, but their score did not change. However, these discrete changes in functional status, occupational engagement, and well-being over time were captured in the interviews. Table 5.1 presents additional demographic data about individual participants. Pseudonyms were used for confidentiality.

Consistent with the hermeneutic phenomenological design of this study, participant voices were central to understanding the meaning participants ascribed to occupational engagement. Thus, participant voice and language are prominent in these vignettes. To reflect this, participant vocabulary such as “activity” instead of “occupation” was used in narratives. Vignettes were drawn from participants’ interviews and descriptions of their lived experiences and set the scene for the findings chapters (Chapter 6 and Chapter 7) and the discussion chapter (Chapter 8). Each vignette commences with a brief synopsis of the participant, then summarises their experiences of living with advanced cancer and how this changed over time.

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[6] An AKPS Scale score of 70 indicates an ability to conduct self-care tasks yet difficulty with other everyday activities, 60 denotes an ability to complete most tasks yet occasional assistance needed, and 50 indicates the individual requires considerable assistance (including medical care). A score of 20 indicated the individual was bedfast and required extensive care.

**Table 5.1**

*Demographic Information*

| Name | Gender | Age | Marital Status | Living Situation | Diagnosis | AKPS at Each Face-to-Face Interview | | | | | | | Time Range of Interviews | Number of Interviews | Status at End of Study |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | 1 | 2 | 3 | 4 | 5 | 6-9 | 10 | | | |
| Peter | Male | 40 | Married | Wife, two children, dog | Colon cancer, multiple metastases | 60 | 30 | 40 | | | | | 5 months | 3 | Deceased |
| Lisa | Female | 49 | Single | Alone | Metastatic melanoma, breast cancer | 60 | | | | | | | 1 interview | 1 | Deceased |
| Melissa | Female | 41 | Married | Husband, two children | Metastatic breast cancer | 70 | 60 | 60 | 60 | 60 | 60 | 60 | 14 months | 10 | Alive |
| Jessica | Female | 56 | Married | Husband, son, dog | Metastatic rectal carcinoma | 60 | 50 | | | | | | 2 months | 2 | Deceased |
| Amanda | Female | 60 | Divorced | Dog | Malignant neoplasm of the pancreas | 70 | 60 | | | | | | 3 months | 2 | Deceased |
| Tammy | Female | 55 | Married | Husband, cat | Metastatic breast cancer | 50 | 60 | 60 | 60 | 60 | 60 | | 13 months | 9 | Alive |
| David | Male | 60 | Married | Wife, daughter, son-in-law, cat | Adenocarcinoma of the sigmoid, multiple metastases | 70 | 50 | 40 | 30 | 20 | | | 5 months | 5 | Deceased |
| Chris | Male | 61 | Married | Wife, dog | Metastatic retroperitoneal cancer | 60 | | | | | | | 1 interview | 1 | Deceased |

### *5.1.1 Peter: Three Interviews Spanning 5 Months*

*Peter described himself as a citizen of two countries, a police officer, a family man, and a husband to his wonderful wife. His function declined significantly over the 5 months of his interviews, necessitating a move from a manual to an electric[7] wheelchair. Peter attributed his adaptability to the constant changes of cancer to his work in law enforcement, where he always had to be ready to shift or adapt to sudden change. His ability to adjust and move forward was a central theme in Peter's interviews. He continually adapted how he lived his life in order to maintain his valued relationships, primarily the roles of dad and husband. Cancer progression did not stop Peter from wanting to continue participating in activities important to him. He sought to live his life as fully as possible until he died. However, the environment affected his ability to engage in daily life. This shifted significantly during the interviews due to the assessments and interventions provided by his occupational therapist. Ongoing monitoring and making changes as required to his surroundings ensured that his physical environment matched his current skills as his function declined due to cancer progression.*

Just 2 years earlier, Peter had been diagnosed with advanced cancer. His life changed significantly in the 2 months prior to his first interview when his cancer spread to the spine, compressing his spinal cord and reducing his ability to walk. Peter had always been reasonably healthy and did not expect that, at 39, he would suddenly need a wheelchair to do simple tasks such as moving around the house or going to the bathroom. Peter spoke about the physical changes from the cancer, and said that pain relief was difficult to achieve. Spinal surgery had been unsuccessful as the inserted rods broke. In addition, Peter explained that he had swelling and open wounds in both his legs, requiring regular nursing care to manage the oozing. However, he still referred to himself as a strong and healthy person despite having cancer and difficulty using his legs well.

Peter lived with his wife and two young children in a two-storey home with a basement and nine steps to enter the house from outside. The bedrooms and a bathroom with a shower were upstairs, the kitchen, toilet, and living room were on the main floor, and Peter's 'man cave' was in the basement. Peter's physical surroundings were very important to him. For example, the man cave did not have a television, as he intended the space to be

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[7] Peter referred to his power wheelchair as an electric chair or wheelchair.

where friends could gather and socialise. He had designed this space to reflect who he was: an immigrant, a worker, a history buff, and a family man. During his first interview, Peter described how he could no longer use the stairs due to the weakness in his legs. This meant he could not get to his man cave or the upstairs bedroom; he was confined to the main floor of his house. His life primarily revolved around the open-plan kitchen and living room area, where his hospital bed was set-up next to the couches and television. Peter described how confined he felt, limited to only this area. Despite these challenges, he spoke about making the most out of whatever situation he was in. This included ensuring he could still do things he wanted to, such as setting up a little station next to his hospital bed with colouring pens and paper to draw with his children and other "bits and bobs."

Peter's frustration about physical barriers in his home was not solely limited to the inside of the house. He could not manage the stairs at the front and back entrances of his home or get out to enjoy his back porch. For example, Peter had to call friends for help to get to medical appointments; he required assistance to be lifted down the front stairs and into the car in his wheelchair. On returning home, he had to phone the same friends and get their help to lift him back into the house. Peter described his experience of living with advanced cancer as a lonely existence on multiple occasions during his first interview; these challenges were difficult for him as a self-identified social person. The hardest part of living with these barriers in his home was the lack of freedom to drive to meet a friend for coffee or go to the park to play with his children. Peter said he felt he was going "stir crazy" being stuck at home in one area.

At the second interview, Peter's outlook on the house had changed. He spoke about the hope he felt, despite being increasingly bedbound and having significantly decreased abilities due to cancer progression. His function had changed from the first interview when he could walk short distances with assistance on one floor of his house. He was now primarily confined to the hospital bed on the main floor, as he was unable to walk and fatigued quickly when using his manual wheelchair. The occupational therapist had arranged for three lifts to be installed, although this had not occurred at the time of the interview: one at the front steps of the house, another on the flight of stairs going up to the bedrooms, and a third from the main floor to his man cave in the basement. Peter eagerly anticipated the freedom these modifications would afford him. He shared that he was looking forward to the physical intimacy with his wife that would come from sleeping together in their bedroom upstairs. Peter spoke about the sense of hope he felt as he looked forward to these changes.

Peter described the time between his second and third interviews as a rollercoaster ride. He was in and out of the hospital due to significant leg wounds, and his ability to do simple everyday tasks, such as walking or bathing, fluctuated during this time. He had been prescribed and fitted for a power wheelchair which had arrived, and the porch and stairlifts had been installed; both of which increased his independence. As a result, while he was still in bed much of the day, he was not primarily confined to it. His power wheelchair and the lifts meant the world to Peter. He could now go down to his man cave, up to the upper floor bedrooms, out onto the back porch, and to leave the house through the front door. The weather had also warmed up over the past three months since the previous interview[8], and with the beginning of summer starting, Peter excitedly shared how wonderful it was to now be able to sit on the back porch in the sunshine. He talked about increased freedom, as he could now get up to his children's bedrooms for bedtime routines and take items down from shelves in the kitchen using his tall power wheelchair. Even though Peter's cancer was progressing, his strength decreasing, and his energy levels waning, he said he felt more independent and freer with the equipment in place. He could do a lot more as it required less energy and physical strength to operate his power wheelchair than manoeuvring his manual one. As a result, Peter could now move and collect items with greater ease, such as fetching a board game from another room to play with his children. This meant a lot to him.

More than anything, Peter saw himself as a father. Being a dad was central to how he described himself, and he spoke about this in all three interviews. Peter's children became his priority. He wanted to continue playing with them, having meals together, and helping with their daily routines for as long as possible, even if he needed to now use a wheelchair. He described how he previously considered routine activities such as eating dinner together as mundane, but he now considered them incredibly significant, these little, everyday activities mattered the most. Peter used to play sports and other active physical activities with his children; however, being confined to a wheelchair meant he had to adapt by participating in less physically demanding play. He described working on puzzles, playing board games, and colouring together as important to him as a father. Peter kept a variety of

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[8] There was a 3-month gap between the second and third interviews as Peter was in hospital.

games and play activities within easy reach on the station he set up next to his hospital bed so that there were always things he could do with his children. However, he became tearful when he spoke about how his children just wanted him to be ‘normal’ or asked him why things kept changing. He recounted the explanation he gave to his children – that there is no such thing as normal, and every person was different. He described how this motivated him to leave a written legacy for his family of an autobiography so his children would know more about him and his family history. He planned to email a copy to his parents and leave a hand-written copy for his wife and children.

Peter wanted to maintain his professional identity whilst living with advanced cancer, as this was a key part of how he saw himself. His work in law enforcement required him to travel, and mementos from his working days and related travel were on display in his man cave. Peter did not want to quit his job when he knew he was dying; he chose to go on sick leave from work so he could continue to identify himself as working in law enforcement. Peter attributed his ability to adapt to the frequent and multidimensional changes of living with cancer to skills he learnt on the job. He spoke with great pride in his work and how this adaptability was crucial to his current well-being.

Throughout Peter’s interviews, a recurrent theme was his desire and ability to adapt to whatever came his way. This attitude was consistent regardless of circumstances, whether he could walk, required a manual wheelchair, power wheelchair, or was confined to his bed. He recognised and grieved his losses but did not dwell on them. Whenever Peter had difficulty or found himself unable to do something, he always sought to find alternative ways of achieving the goal he set out to reach. Peter explained that his ability to adapt was a skill he attributed to both his job and something that came naturally to him. He frequently said that “If you were not willing to adapt, you might as well give up.” This attitude helped Peter maintain his valued roles and relationships over the 4 months that the interviews spanned, despite progressive deterioration. Peter died shortly after the third interview.

### 5.1.2 Lisa: One Interview

*Work was a central theme for Lisa, providing her with a sense of stability and identity in the midst of the uncertainty of living with cancer. Her work community was important to her. She attributed her ability to push through difficult circumstances, intentionally living one day at a time, to her German heritage. Lisa managed her low energy days by focusing on* *what she could do and not what she could not. She described living out her day, week, and month by taking it one step at a time: "you've got to do what you've got to do."*

Lisa had moved to her small, mountainous community right after high school; now, in her 40s, she felt as if it was home. She worked just outside of town and had a good circle of friends who lived nearby. In 2011, Lisa had a small melanoma excised; however, she did not think much about it until cancer returned a few years later. In the meantime, she was also diagnosed with breast cancer, but this seemed relatively minor to her compared to the news of her other cancer spreading.

Lisa spoke highly of her workplace and the support she received there. Her employer willingly made changes to her job due to her cancer progression so she could continue working. Lisa's functional ability had been stable for 15 months, but she described a sharp deterioration in her health over the past 3 months. She had recently reduced her hours at work from full-time to part-time due to her low energy levels. Lisa's employer allowed flexibility with her office hours, so she could come in a bit later if she had a difficult start to her morning. She expressed her thankfulness that her employer continued to pay her at a full-time salary. This took a lot of pressure off Lisa since she was concerned that she would not be eligible for disability payments due to working part-time and the rental rates in her mountain town were high. The ability to work was very important to Lisa, and as long as it was possible, she preferred to be employed part-time rather than cease employment and receive government benefits. Lisa emphasised that working gave her purpose in life and a sense of meaning. Lisa shared how being in the office was the most important part of her day; her responsibilities at work were more than mere tasks to fill her schedule. She felt that she was an integral part of her workplace team. Lisa reflected on the flexibility she was afforded to accommodate the physical changes she experienced. She really appreciated the thoughtfulness and practical assistance her workmates offered when she was not feeling well, such as driving her home on occasion. Lisa described the disappointment and loss she would feel if she could not work anymore but also acknowledged the reality that, at some point, she would have to stop working. Noticing the recent decline in her functional abilities, Lisa had joined a clinical trial, hoping that the new drug would extend her life and thus allow her to continue to work.

Outside of work, Lisa described the importance of spending time with friends. She was unmarried and did not have any children nor family in the area, so these friendships were significant. She appreciated how local friends not only spent time socialising with her, but also assisted with practical tasks such as driving her to appointments. Her sister's recent visit from Vancouver was also encouraging to Lisa, as she enjoyed having her older sister check in on her. Lisa was very concerned about the impact of her deterioration on her social life. She was worried about becoming a hermit and hoped that her friends would still visit her if she eventually became housebound. Spending time with friends was a strategy Lisa had implemented so she would (as she put it) not just sit at home and feel sorry for herself.

Lisa's key priorities were to continue to work and maintain important friendships; she recognised adaptations were required to facilitate these goals. She spoke of not wanting things to change yet acknowledged that they already had, and that her abilities would continue to decline as her cancer spread. Lisa described needing to accept these functional shifts and to modify what she could. For example, it took her a while to get used to cutting down her work hours. The way she travelled to and from work changed from cycling to taking public transport then walking the remainder of the way. As the weeks passed, she began using a taxi service or accepted rides from workmates so that she could conserve her energy for work tasks. Taking cabs or accepting lifts to and from work frustrated her, as ordering a taxi was expensive and she did not want to become a burden on her colleagues.

Lisa recognised that she needed to make an effort to go out and participate in activities within her community. If she did not, she said she would just stay home and her motivation to do everyday tasks would decrease. As she explained, she would prefer to participate in activities and not feel well rather than be at home alone not feeling well. Despite her desire to stay as independent as possible in her work and social relationships, Lisa acknowledged that she did have physical limits and could not force herself to do activities that were too demanding. For example, Lisa enjoyed going for walks but found that she could not walk far on days when her energy levels were low. Winter had just begun when Lisa was interviewed, and she described her concern about walking on slippery, snow-covered roads and sidewalks. On days when she was unable to get out of the house easily, Lisa enjoyed reading at home, a meaningful activity she was still able to do.

Cooking was an important and deeply satisfying activity for Lisa; however, she found it increasingly difficult as her energy levels began to dwindle. Lisa adapted to her fatigue levels by exploring ready-made foods. On weekends when she did not have to go to work, she would use her energy to cook a large batch of food such as chilli or spaghetti. Lisa froze it into smaller containers to reheat when she wanted some home-cooked food. However, as her appetite waned, she began drinking meal supplements to ensure that her body was getting all the nutrients it needed. Lisa recognised that her low appetite and food intake impacted her energy levels and, therefore, the remainder of her day.

A significant concern for Lisa was the change in her function—it was getting worse. She described an increasing need to rely on others for self-care tasks or home maintenance duties. While she found it difficult to acknowledge her increasing dependence, she also realised she did need assistance with some tasks. Initially resistant to hiring a cleaning service, she described the peace of mind she felt when they began to help. Lisa started feeling better about outsourcing this task when she noticed the joy she felt from having a cleaner home. However, Lisa remained staunchly independent in some tasks, declining laundry or showering assistance. She did not want too much involvement from home care services but was willing to meet the staff so that she would be familiar with who would be involved if required at a later stage.

Living with uncertainty was emotionally taxing for Lisa. Every day was different; some days more difficult than others. She scoffed at the idea of living each day as if it was her last and spoke more about just carrying on and living one day at a time. She sought to do as much as she could by focusing on what needed to be accomplished. Her goal was to make each day the same as the previous day. Lisa described these strategies as a mental challenge. Completing items on a bucket list was not feasible for Lisa, as certain activities on this list, such as visiting Africa, were no longer possible. She explained that she needed to hold hope and reality in tension to live life as normally as possible.

Lisa described herself as a person living with cancer. She did not want to be defined as someone dying of cancer, even though she spoke of the downward trajectory she was currently experiencing because her cancer was progressing. Her philosophy was to just keep doing as much as possible and be willing to adapt as required since every day was different. Lisa expressed the hope that maintaining a sense of normalcy would assist with longevity, demonstrated by continuing everyday activities such as working. Living with cancer was not easy for Lisa, but she explained how she tried to prepare herself as best as possible for the changes she knew she would experience. Although the clinical trial had initially given her an additional sense of hope, she was disappointed that it did not seem to be lengthening her life. Lisa was in the hospital at the next scheduled appointment time, and she died shortly after.

### *5.1.3 Melissa: 10 Interviews Spanning 14 Months*

*At 41, Melissa could not imagine having stage IV breast cancer that had spread to her bones. As the cancer progressed, it caused far-reaching changes to her everyday life; this included resigning from work and no longer volunteering in the community or at her children's school. Melissa lived with her second husband and four children. Before receiving her cancer diagnosis, being a mom and her work at the school were vitally important to her, defining her place in the world. However, as the months passed, her priorities and goals changed. The importance of being a mother intensified, and her work and volunteer life became less central. How Melissa engaged in everyday life shifted over time, and the changes she experienced over the course of the 14 months of interviews are outlined below. Given the number of interviews, Melissa's vignette has been arranged around the central themes that arose.*

The most important thing for Melissa was to be with her children, husband, and friends. She spoke about how much she cherished her deep relationships with her children. A social person with many deep friendships, Melissa wanted to be remembered well. She wanted her children to know that she made them a priority, as they brought her so much joy and happiness. For example, Melissa wanted to ensure that her youngest did his homework, hoping he would be okay when she was gone and on his way to a career. However, for Melissa, being a mother was more than being remembered well. Although she did not enjoy cooking, she made this activity a priority, regarding it part of her role as a mother. She described how cooking fostered relationships within her family unit, where everyone sat down around the table and spent time together. Even though tasks such as making a cake were exhausting, Melissa considered that the result—everyone enjoying it and being together—made the task worthwhile. She also valued more passive activities, such as watching television together. Preparing her family for her death and ensuring that her children would be okay was a common theme raised repeatedly by Melissa over the 14 months of interviews. Melissa confided that she would feel hopeless if she lost social connections with others and envisioned that she would still feel connected with friends and family if they visited her when she was confined to bed. She missed seeing friends at work and in her volunteering positions, yet at the same time was thankful she had given those activities up to prioritise spending time with her family and being in the mountains.

As her cancer progressed, Melissa described the importance of prioritising how she spent her day in order to ensure she had sufficient energy to do all that she wanted to accomplish. She could no longer simply run errands and meet up with friends, as she did not have the strength or energy. Melissa described some of the modifications she had to make, including shifting the time of day and location she met with friends. Getting together for breakfast instead of joining friends for dinner parties better suited her energy levels. However, sitting on certain types of chairs was difficult, particularly when the chair did not have an option to recline. This significantly impacted her ability to sit when going out with friends, as Melissa could not sit for long periods of time if no recline feature was available. She also went out dancing less frequently, as this became less of a priority. Adjusting how tasks were done and receiving assistance with specific ones were other modifications she found necessary to incorporate in her life. Melissa described how she took more shortcuts, such as hiring a cleaner. Although she said that this initially made her feel like a bit of a failure, she made these modifications in order to concentrate on other activities that were more of a priority within her limited energy levels. Similarly, she found that pushing the grocery cart was quite painful to manoeuvre, so she made it a priority to never go to the grocery store alone; her children or husband were always present to assist with the cart.

Melissa had to rethink her involvement and limit what activities she pursued as her cancer progressed. She had been going to yoga classes, but explained that she chose to stop doing this and started going to the pool for water aerobics classes because it was less painful. She previously showered whenever she wanted to, but even this task became less frequent as it fatigued her, so she often showered after being in the pool. Melissa loved shopping but became an online shopper when going to the stores became too challenging for her to do in person. As her cancer progressed, other valued activities became so difficult that she could not continue doing them at all. Melissa missed having sex with her husband but could not find a way to make it comfortable. Some losses she accepted, while others were a struggle. The first summer that she was unable to play golf, she was quite frustrated and angry whenever golfing was mentioned by anyone close to her. Over time, Melissa gradually accepted that this was the way life was going to be for her and did not mind hearing about friends going golfing. Sometimes she felt that it was not worth modifying some activities to continue doing them so she chose to do an entirely different activity. Melissa said that she would rather not play golf than simply practice putting. She talked about how she needed time to process and to accept what her ‘new normal’ was becoming, continuing to adjust activities as needed. However, her idea of what this ‘new normal’ was kept shifting as her cancer progressed.

Another important activity that Melissa missed doing was hiking. She had always been an avid hiker, but as her cancer spread, she was unable to do this activity anymore due to fatigue and pain. Melissa lived in a mountain town and was surrounded by forest, with her house situated immediately below a mountain peak. Being in nature was very important to her, and she described feeling a bit lost when unable to go for long hikes. Melissa still wanted to be outdoors, even if she could not hike in the mountains, so she began walking in the local neighbourhood or down by the river, taking easier walks. Although this was better than not walking altogether, it was not the same as walking in the middle of the woods. She explained how being in the forest was calming and cleared her mind in a way that rarely happens when walking on the street or on a busy pathway. Unfortunately, due to a bear sighting in the area, she could not get out as much in the summer. Melissa found walking increasingly challenging over the 14 months of interviews, so she started spending more time sitting on her porch in order to enjoy the forest around her home and take in the mountains.

A big struggle for Melissa was navigating social relationships; in particular, figuring out how to have conversations with friends and acquaintances about her declining health as her cancer progressed and she deteriorated. Melissa described fielding comments from others regarding how she lived with advanced cancer, observing sadly that there was significant pressure from friends and acquaintances for her to be positive. Others minimised her losses, telling her, “oh, but think of the things you can do” or “but at least you can do this or that,” “but it could be worse, look on the bright side” or “you won’t get better if you think negatively.” Another person informed her that if she changed the way she thought, she would get better. Melissa found these comments very frustrating and wished that others would just say, “that must be hard,” or “this sucks.” In great frustration, Melissa said that it made steam come out of her ears, and she found that she became increasingly blunt in responding to these comments. Melissa also disliked it when cancer was used to define who she was, particularly when people identified her as “that person with cancer.” She wished that others would identify her as “that’s my friend” or “she worked at a school,” or “she is a mom” or is fun or likes to read books.

It was not just navigating comments from friends that was challenging for Melissa. She felt judged when others did not think she needed help, such as when travelling in airports. Melissa recognised that she did not look sick, so staff and friends did not understand when assistance was needed. She confessed that although she regretted it afterwards, from time to time, she joined activities such as yoga despite the significant pain it caused because she did not want to be judged or was worried about what others might think of her. She said she initially found it difficult to set boundaries and give herself permission to listen to her own body and make adjustments as needed. These experiences were really frustrating and impacted how and when she participated in various activities and related to friends that she previously enjoyed spending time with.

Melissa’s experience of everyday life shifted with the seasons, as seasons played a significant role in how and what she could do. She appreciated the transformations in the countryside that occurred with the changing weather. She enjoyed the busyness of summer when her children were on school holidays and looked forward to low-key family vacations. Multiple forest fires occurred in the first summer of interviews, and there were reported bear sightings and warning signs posted in the neighbourhood during the second summer of interviews. Both the fires and the presence of bears limited Melissa’s ability to go for walks. When summer turned to fall, Melissa described how she enjoyed the quieter house and routines as the children returned to school, as fewer family activities were going on. Winter was an enjoyable (although exhausting at times) season for Melissa due to the lead up to Christmas and many family and social gatherings that happened during this time. She recognised how she would sometimes overexert herself in order to be part of social activities. For example, her family often did a puzzle at Christmas, and she found it very tiring standing over a puzzle. However, she would push through the pain in order to continue doing this with her family, as she valued ‘puzzle time.’ Spring was another time of enjoyment for Melissa, as she sat on her porch and watched buds developing on trees and flowers opening.

Melissa explained that family, friends, literature, and her mind were the most important things to her, and she reflected on this throughout her 10 interviews. She shared the difficulty and frustration she experienced in figuring out some crosswords or remembering a book that she had read recently as medications made her mind less sharp. Reflecting on her life, Melissa said that she was a person of routine, and she noticed that she became even more scheduled as the months passed. She described herself as a young person living like a senior. Melissa appreciated the increasing amount of time spent planning her days, as having a routine that she could set herself allowed her a sense of control and agency despite challenges and losses along the way. She described her dislike for uncertainty about the future, which she held in tension with learning to live more in the present. Not worrying about the future was often Melissa's way of dealing with unpredictability; her goal was to live in the moment and be more fully present with what she was doing and with her family.

Melissa's 10 interviews spanned 14 months, and only one interview was postponed due to a snowstorm resulting in unsafe driving conditions to reach her community in the mountains. A decision was made to cease interviews after 14 months as the study's data collection time period was coming to an end.

### *5.1.4 Jessica: Two Interviews Spanning 2 Months*

*Jessica was a very focused and resilient person, living life purposefully to meet the needs of her family while aware of her own health limitations. Although she wanted to be intentional in planning her time, how her days were spent was more often dictated by her symptoms and environment (due to her frequent need to be near a bathroom). Jessica's son had autism, and she described the increased fervour to arrange for his long-term care prior to her death and before he turned 18. Despite increasing fatigue, she pushed through her exhaustion, not wanting to burden her husband with organising their son's affairs. At the same time, Jessica's care needs increased, and she had to rely more on friends, which was overwhelming for her. Putting things in place to prepare her family for her declining health helped Jessica feel a sense of control in the midst of change.*

Jessica lived just outside a small hamlet in an older home shared with her husband, son, and pet dog Max. Now in her mid-fifties, Jessica's only child was born later in life, and was now in his final year of high school. Jessica was his primary caregiver. It had been a difficult few years for Jessica, not just because of her cancer diagnosis the previous year and the challenges of caregiving for her son, but also due to the devastation of a flood that had recently swept through their house. Jessica still experienced post-flood anxiety whenever she smelled mud. Exhausted, she felt her home had a revolving door, with people regularly coming in and out to assist her or her son and repair the house following the flood. Jessica described the significant (and challenging) lesson she learnt during this time: to accept help from others, rather than relying on her usually resourceful self.

Jessica explained that her goal for a typical day was to simply get through the hour, the morning, and the day. Her physical symptoms, including rectal pain, were challenging to live with at times, but it was the emotional toll that concerned Jessica. She felt as though she never fully gained control, despite her best efforts to manage her symptoms. Waking around 7 am, a painful and exhausting hour in the bathroom was followed by a return to bed. To ensure that she had sufficient nutrition to maintain her strength, Jessica made an effort to join her family for breakfast every day. She made frequent trips to the bathroom and constantly monitored her extensive medications throughout the rest of the day. Jessica lived in a rural area, and it took considerable effort to coordinate the large number of prescriptions she had from her local pharmacy. Recording all medication doses ensured she would not forget any, but more importantly, it helped Jessica feel that she was actively involved in taking care of her physical self. Other self-care tasks included coordinating with rural paramedics for intravenous hydration and setting up home care and other services.

Inherently an organised and proactive person, Jessica was also constantly aware of her son's schedule and what needed to be done to support him. It took a lot of energy to stay on top of her son's paperwork for government funding (e.g., care and after school programs), plus deadlines for tax and guardianship administrative tasks. Jessica found this increasingly difficult in her last months, as her own needs grew, and her cancer progressed. She also found it frustrating when people told her to "just rest" instead of doing multiple other tasks. Jessica explained that it did not matter if she was experiencing significant pain; she had to push through the symptoms in order to fulfil her responsibilities and ensure that her son would be okay both now and after she passed away. Her husband was self-employed, but due to the recession, had limited income. This financial stress also weighed heavily on Jessica. Despite the significant amount of coordination required, she wanted to remain at home as long as possible to support and care for her husband and son.

During her second interview 2 months later, Jessica described the uncertainty she felt about planning for the future. She was not certain about her prognosis, so sought to be more intentional and prioritise her time. Her goal was to be able to pick up her son from school or the day program after school, and she hoped for a 'good day' when she could do this. Increasingly, Jessica recognised that she did not have the energy levels to engage in all the tasks she wanted to do, so she sought to identify what was most important to her. Less important tasks, such as bookkeeping for her son's care needs, were delegated to others. Trying to figure out and manoeuvre what was best for herself and her family was a movable target; it kept changing as her needs changed and time passed.

Before her cancer diagnosis, Jessica walked a lot – walking home from work, walking Max, the dog, and going for walks with her son. Walking was therapeutic for Jessica, being out in nature and enjoying the sunshine. Now, if she was having a good day, Jessica would go for a walk in the neighbourhood, an activity she recognised she had previously taken for granted. As she lived in a forested location just outside the town, when she went for a walk, Jessica checked in with friends along the way for safety reasons and enjoyed the interaction with others from her community. Walking from the pharmacy to her home or to a nearby store to fax documents now gave her a great sense of accomplishment. Going for a walk became an increasingly important priority for Jessica, even if she only went down the road. By the second interview, Jessica's walks were limited by increased swelling in her legs. Attempting to control this, she monitored what she did (e.g., limiting standing in one spot) and obtained assistive devices (e.g., compression socks). She spoke of the delicate balance between being able to continue walking to maintain her leg strength and emotional energy without overdoing it.

Jessica was cognizant of not just looking after her physical self but also her spiritual and emotional self, and her sense of well-being. She explained that only after looking after these aspects of herself could she then focus on others around her. Near the end of the day, she would do a guided meditation from a CD, which helped her focus and not think about all the devastation happening in the world. She would often fall asleep doing this and found it very helpful.

Spending time with her dog Max was life-giving. Jessica described him as her soulmate, someone who needed her, a companion who she could pet or hug as needed. If she was having a rough night and not sleeping, Max would jump onto the bed and be with her without being asked. Jessica felt frustrated on days that she was unable to take care of her dog or be outside with him, even just looking at the flowerbed. However, she tried to adjust her perspective, hoping that she would be able to do it tomorrow. She was thankful for the days that her son took the dog for a walk, as it meant that he was accepting responsibility for something. Jessica insisted that pets should never be underestimated or devalued, as they stabilise people.

Maintaining friendships was also important to Jessica's well-being, but it became more difficult as her function declined. Even simple tasks such as sending emails became tiring. She felt stuck on her acreage and often wished she was living in town with others she knew. She continued to invest in these relationships and spoke of the joy it brought when receiving photos of her nieces and nephews.

Jessica described one unexpected aspect of living with advanced cancer: her need to re-examine who she felt herself to be, including her feelings, self-perception, goals, and hopes in life. Jessica expressed how she felt destabilised after the cancer diagnosis; her entire world was shaken, her sense of self lost. Re-engaging in everyday life was a significant challenge, and she struggled with her belief that others who had a 'normal,' non-cancerous life would not understand. She described how she sought to maintain a sense of control in all that she did, although this became increasingly difficult as her cancer progressed and she became more dependent.

Despite acknowledging her increasing dependence, Jessica described herself as very independent, capable, and efficient. However, functional changes over the last 2 months of her life meant she could not do certain tasks anymore; this was hard for Jessica to accept. She reflected on how she had always been very handy around their rural property, but now she was unable to even lift the hood of the car due to reduced strength in her arms. It also discouraged Jessica when finishing other activities took longer than intended or she repeatedly had to ask others for help grocery shopping or running errands. However, she described an experience of going for a walk with a former workmate, who told Jessica that she was missed at work due to her ability to complete tasks in a timely manner. As she recounted this recent event, Jessica said hearing this "energised" her and that this was so important to her as she also strove to do the same in her personal life. Jessica talked about how she sought to be on top of tasks as much as possible, despite limitations of pain, weakness, and reduced activity tolerance.

Doing small, everyday tasks, such as washing the dishes or sweeping the floor, took on new meaning. She described feeling grateful when able to complete a task independently. On the days that Jessica was unable to go for a walk, she experienced a sense of competency by independently mopping the bathroom or putting food away after a meal shared with her family. Jessica said it was these little things that were important to maintain her sense of self and family relationships.

Some days Jessica felt overwhelmed—particularly as her cancer advanced, her pain increased, and her resources dwindled—but she said that she kept persevering with her main goals in sight: to be a good mom to her son and to manage her physical and mental health needs. She recognised, that like her son, she needed to have a regular schedule in order to feel a sense of control and certainty. Jessica attempted to maintain a routine to combat her fluctuating emotions. Having a schedule helped her feel as though she was living her own life and allowed her to plan important tasks during optimal windows of opportunity when she knew she would be at her best. At times this meant taking medication to take the edge off her bowel pain. At other times, it meant lengthening the time between chemotherapy cycles, so she could feel more energy and, as she described it, more life. Jessica set up services for her son so that they would not always have to rely on people in her community. She recognised that the combination of her own needs and her son's needs were becoming more significant as time progressed. She also arranged for someone in town to look after her son one night a week to provide respite from caregiving duties. Everything was in place for his long-term care. Aware of her dwindling strength, putting all of these strategies in place was very important to Jessica as she adapted to the progression of her cancer. Not everything was in her control. Jessica talked about how thick smoke from wildfires that summer made it difficult to go for walks. She said she felt frustrated and depleted of energy, made worse by the wildfire smoke or heat, but she also explained how taking even short walks with Max had helped her to maintain her sense of self. Jessica spoke about the days feeling long, and she described feeling more emotionally fragile when unable to put her strategies in place due to limits in the seasonal environment and her declining health. Over her final 6 months, we spoke by phone, as Jessica was unable to do any further interviews in person due to hospital admissions or time spent with her friend following chemotherapy rounds. These phone conversations were not included as interviews, and conversations primarily revolved around her chemotherapy schedule, when she would be at home versus at her friend's house, and coordinating her son's schedule.

### *5.1.5 Amanda: Two Interviews Spanning 3 Months*

*Amanda's life centred around her dog. He was her most valued relationship and her constant companion. She was devastated when he died, which occurred between her first* *and second interviews. Feeling lost and without a sense of purpose in life, Amanda became increasingly symptom focused. She began to disengage from occupations that gave her life meaning. There were moments when she sensed that things could be good, such as a friend coming to visit, but discouragement was a dominant theme of conversation. Tasks were completed with minimal enjoyment; she considered them as merely things to fill her time.*

Amanda lived with her companion dog, Frankie, in a basement suite. She did not work, subsisting on disability payments from the government. Her social contacts were limited, although she had extensive family living in the province. Amanda had married young and, at age 60, had three children and seven grandchildren in neighbouring towns and cities. Her mother, sister, and niece lived next door; however, Amanda’s primary visitors were the home care team. She had expected that her family and the government would take care of her, assisting with tasks such as cleaning. She was very disappointed when this did not happen as she had hoped. Amanda was classified as high risk for overdosing due to past drug abuse so nurses would visit three times a day to supervise her medications. One of the nurses that dispensed her night-time medication also took the time to tuck her into bed, and this kindness was highly valued by Amanda. This became the most important time in her day—when others took care of her. Even so, she also was fiercely independent. She insisted on managing tasks such as bathing, dressing, and cooking herself, as it gave her the sense that she was doing okay. Getting dressed at the start of her day helped her feel more like herself. Amanda explained that even if she did need help, she would try to get by and do it on her own. She did not want to rely on others for help.

During the first interview, Amanda described how her daily life primarily centred around her service dog, Frankie, and the pain she was experiencing. Amanda referred to Frankie’s official role as providing pressure therapy for her osteoarthritis and cancer. Whenever she felt pain, Amanda would call Frankie over to her. Hearing “paws up,” he would instinctively lean against the area where she felt pain. This deep pressure was very comforting to Amanda throughout the day. She also took medication to assist with pain management, describing her pain as something that no one could understand if they had not been through it. Visibly upset, Amanda believed that medical staff did not understand what it was like to live in pain and with cancer. Although she initially looked forward to the home care team visiting and enjoyed the nurses’ companionship during the day, she also felt frustrated with the number of supervised visits needed for medication management.

She wished she could be more independent in this area, and not require supervision. Amanda felt that pain control was hard to achieve under their strict scheduling. She explained it was difficult to plan to go away for the weekend due to the number of medications she was on. Constant monitoring of pain was an important yet challenging part of her day, but she said she was grateful this entitled her to a service dog.

Amanda had always loved animals and had previously owned horses. She found them to be great friends and a source of comfort. She recalled a time when her horses lay down in the field next to her, and as she read, one horse would put its head on her lap. The horses had to be housed elsewhere when Amanda was first diagnosed with cancer; this loss of companionship was difficult for her. At the time of her first interview, Frankie was the only pet Amanda had. As a service dog, Frankie was allowed in restaurants and accompanied her to other places. She described how his presence relaxed her and made her feel less lonely. Frankie was a dearly beloved companion, and he meant everything to her. She described Frankie as another part of herself, similar to a husband. Amanda was able to sleep at night because he was near. When sleep was elusive, it meant so much that Frankie kept her company. Previously, Amanda took Frankie for daily walks outdoors. However, she explained that these walks occurred less often as the cancer progressed due to the pain she experienced. In cold weather, she did not miss dog walks, preferring to snuggle with Frankie on the couch while crocheting or watching a movie. Amanda rated this time together as the same quality time as going for a walk with him. Amanda assumed that Frankie loved dog movies and commercials. She enjoyed watching him become excited when she played a movie she expected he would like. In the first interview, Amanda disclosed that she believed her life would not be worth living without him. He was more important to her and much closer to her than family.

Two days before the first interview, Amanda had sold her car as she could no longer safely operate a motor vehicle. She said that she missed the freedom of being able to drive as it represented independence and not relying on others to get milk and groceries. Without a vehicle, she could no longer volunteer at the children’s hospital with her service dog, an activity that she missed. Apart from Frankie, there was no one else Amanda could take care of, something she had done to a large extent before having cancer. By the second interview, Amanda had not driven for 2 months. She was teary as she explained how awful it felt to lose her driving independence. Amanda had planned to walk more now that she did not have a car, but her walking tolerance was declining due to the disease process. She talked about the prospect of using a walker or wheelchair to help with her ability to get around. Amanda felt torn with these options, as she also felt she would be less self-sufficient if mobility aids were required. She described how important her ability to get around independently was to her. The loss of a car was momentous for Amanda.

Amanda experienced a more significant loss by the second interview. She wept as she shared that Frankie died between the first and second interviews. She cried as she described his decline during his last few days and how difficult his death was on her. Amanda was lonely without her faithful companion. However, she expressed relief that he died before she did, as she was worried that he would be inconsolable if she died first. Amanda recognised that her own health was declining and realised she might not have enough time left to qualify for another service dog. She sorely missed being a dog owner. Consequently, she purchased a large plastic dog that was missing a leg at a hardware store. Amanda planned to make him a new leg from papier mâché. She named him Stan and said that caring for him gave him—and her—a new lease on life.

As her cancer progressed, Amanda increasingly reflected on the role she had played in others' lives. She placed a high value on the reciprocity of caring for others when they were ill, and she longed to be cared for by another now she had advanced cancer. In Amanda's second interview, she spoke about how she had always been a caretaker of others throughout her life. She believed that it was now her turn to be taken care of. She was tearful and disappointed that her family did not visit more frequently or support her. She believed it was because they were afraid, not knowing what to say or do. She had looked after her dying uncle until his death and remembered that other family members stopped visiting him at the end. Without Frankie, Amanda was lonely, and she missed the company of both family and friends. Amanda's boyfriend had passed away a year earlier, and she missed him considerably. She discussed wanting to join a dating service in her community, hoping to meet someone to do things with. If possible, this person would be someone who understood what it was like living with cancer. Amanda longed to be understood and felt that this was missing in many of her relationships. She maintained that her requests for increased pain medications were rejected by medical staff due to their lack of understanding of the significance of her pain. Constant monitoring and treatment of pain were significant aspects of her experience, as was her desire for support, love of her dog, and strong desire for independence. She had multiple hospital admissions for uncontrolled pain following the second interview. Amanda passed away less than 2 months following her final interview; spending her final month in the hospital, she died in hospice.

### 5.1.6 Tammy: Nine Interviews Spanning 13 Months

*Tammy was a very independent 55-year-old who lived with her husband and cat in a one storey home. Her ability to use her hands was impaired by a spinal cord compression, but she had full use of her legs. Over the 13 months of interviews, Tammy's function improved as she learned strategies for everyday tasks, which helped her compensate for the limited physical abilities in her hands. She continuously strove for increased independence, regardless of how big or small the task was. Tammy enjoyed helping friends and family, despite the personal challenges she herself experienced.*

From the first interview, Tammy was committed to finding ways to improve her health, including keeping as physically fit as possible and eating a healthy diet. A passionate person, she continually described her love of natural products and her desire to help others in their life. She hoped she would be cured of her cancer—despite its advanced status—and had plans to study to become a cancer coach. She spent much of her time learning about healthy living, essential oils, and how toxic relationships impacted health. Keeping active was another goal for Tammy, as she believed this would also improve her health. However, despite her desire to be as independent as possible, Tammy described certain tasks that she could not do independently. She expressed considerable frustration about having to rely on others for driving and felt trapped in her own home. Consequently, friends coming to visit was a reprieve from being at home alone, particularly when she could not go out unaided to meet them for coffee. Tammy placed a high value on helping others, so being present with friends and listening to their stories meant a great deal to her. She spoke about being thankful that she could help her friends, even though she was not yet able to study to be a cancer coach.

Tammy said she felt at home in nature. She enjoyed going for walks and hikes and described the hope she felt when experiencing the outdoors. She found it peaceful to be in a natural environment, smelling trees, hearing birds, and looking at flowers. Tammy confessed that she often felt more connected when spending time in nature than being with other people in her life. She spoke about how the length of her walks decreased as her cancer progressed and fluctuating fatigue impacted her ability to walk. Despite this, even short walks were life-giving to Tammy. One unexpected issue she encountered when the weather became cooler, was that she could not do up zippers. This limited her ability to walk as she could not put on a warm winter coat independently. However, Tammy said she was determined not to let her zippers stop her from going on walks, so she developed a strategy to get around it. Zipping up her jacket halfway, she then stepped into it and, holding the lower part of the jacket between her legs, she could finish zipping up the rest of the way. Tammy excitedly described how much joy she felt the first time she was put on her coat independently. This strategy allowed Tammy to continue to go for walks in the winter, often the highlight of her day.

After 10 months of interviews, Tammy began to complain of pain and weakness in her legs. To compensate, she did specific tasks for shorter periods of time. She was avidly committed to continuing to maintain her independence as much as possible. By this time, her hand function had improved to the point that she could attach a leash onto a friend's dog, which she often took care of, so she focused on this positive improvement instead of the discomfort of her legs. Tammy actively sought to maintain her mindfulness and positivity practices and tried to reframe her challenging attempts at engagement in daily activities as "I will try to do this" rather than "I can't do this." She also attempted to let things outside of her control go, recognising that life was short.

Tammy's ability to persevere and continue seeking strategies to modify difficult tasks was evident throughout her nine interviews. She purposefully sought to engage in pastimes that brought her joy and be as independent as possible throughout her day. She was determined to do as much as she could, regardless of the challenges she encountered. Her love of swimming meant initially accepting help to put on her bathing suit, but she slowly made progress and eventually was able to do this independently. In her first interview, Tammy had demonstrated how the pain and lack of muscle tone in her hands prevented her from doing simple tasks such as holding a glass or brushing her hair. By the second interview, she reported having regained minimal wrist control so could now hold onto a glass using both hands. At this stage, Tammy was able to shower independently but still required and valued home care assistance for dressing and other home duties, such as making breakfast. By the third interview, Tammy described the frustration of still requiring assistance to open containers, do zippers up, and make breakfast. Eventually, she excitedly demonstrated during an interview how her hand function improved to the point that she could pick up an iPad, do up large buttons, and use large-handled scissors. She described how she regularly practised putting on her seatbelt in the hopes that she would be one step closer to being able to drive again. Tammy also prioritised keeping her house tidy—small tasks given greater meaning and no longer taken for granted as her cancer progressed. She spoke of how these minor improvements in hand function made a significant difference in how she felt about herself. As the months passed, Tammy recognised her need to keep doing as much as possible for her own mental health. She described how she was a problem-solver, and that her perseverance and having a plan helped her achieve some of her goals.

Both Tammy's brother and daughter died unexpectedly between the third and fourth interviews. Tammy found their absence from her life very difficult. For example, being unable to get together with dear friends over Christmas was made harder as these friends knew her daughter very well. However, spending time reminiscing and enlisting their help to go through her daughter's possessions after the funeral was both emotional and meaningful to Tammy. Over the following months, she comforted and took care of her daughter's friends as if they were her own. Supporting these friends brought a lot of meaning to Tammy and helped her through her grief.

Tammy's experience of living with advanced cancer was filled with ups and downs, from gaining improvement in hand function to experiencing a decline in her lower limb abilities and the loss of family members. She attempted to maintain as much independence as possible through problem-solving to modify activities, positive thinking, and perseverance throughout it all. Sometimes Tammy's progress was slow, such as being able to hold a pen one month but not able to write lines until the next month. However, even small functional gains significantly bolstered her sense of wellness and sense of self. Tammy participated in nine interviews over 13 months. A pragmatic decision was made to cease interviews after this time due to cessation of the data collection period.

### 5.1.7 David: Five Interviews Spanning 5 Months

*David's philosophy was simple: the longer he could keep doing things, the better. Staying involved in everyday life was a regular topic of discussion in all his interviews. At times, this meant prioritising what he wanted to do, but what he prioritised changed over time. A social man, David found ways to use technology to continue his valued relationships when he could not leave the house. He adapted his activities to maintain involvement in all* *that was important to him and sought to accept his cancer diagnosis with as much peace as possible. He realised that there were limited things he could do to change the course of cancer, so David wanted to just make the best of the situation. As his cancer progressed, David had everything set up for him in the basement, which enabled him to have visitors, sit and watch television, have a drink or snack, or take his medications. He was content to sit quietly, remaining involved in his community by simply looking out the window, watching the world go by.*

David lived at home with his wife, daughter, son-in-law, and his cat Simba. David, his wife, and cat had moved over 1000 km from their mobile home into his daughter and son-in-law's newly built house in a new community 4 months earlier. At age 60, David retired sooner than he anticipated due to cancer. His biggest challenge in the months prior to the first interview was moving provinces. He and his wife needed a large amount of help from friends to pack up and sell items. David described how hard it was to accept that his strength and energy levels were not as good as they always had been. He felt the loss of not being able to complete multiple projects in the yard before leaving, including fixing his boat. David felt encouraged that he had already lived past the first timeline after the oncologist told him he had 2 weeks to 3 months left to live. At the time of the first interview, it had been 6 weeks since that initial appointment.

David and his wife set-up their space in the basement of his daughter and son-in-law's new home. He preferred the basement over the upstairs floor, as it was a cooler temperature and darker for sleeping than rooms on the main or upstairs floors. This was an ideal location to have a nap or watch television. Initially, David spent much time during the day on the sofa in the living area of the main floor where he could watch new houses being built in neighbouring yards. David talked about previously enjoying tinkering with building projects in his own backyard, so watching neighbours build their sheds, back porches, or fences gave him much enjoyment. During the first interview, he described this as the most exciting and important part of his day.

David had few responsibilities around the house. A typical start for the day usually involved waiting for his wife to make his breakfast and watching television in the mornings. He was unfamiliar with where dishes and other items went in this new home environment, and the rest of the family completed all the home duty tasks. David was independent with his own personal care routine, including bathing, dressing, and grooming tasks. He tried to be as active as possible, which meant walking on a treadmill for about 10 minutes was a priority. His oncologist had told him this might help him live longer, and David took this to heart. Initially, he was quite fatigued, but he discovered that he felt a lot better after walking on the treadmill for the first couple of months.

David was proud of his creativity in modifying aspects of his life so that he could be more confident, independent, and maintain a sense of dignity. For example, to protect his ostomy bag from damage when he went swimming, he made a bag with a fibreglass insert to fit over his ostomy bag. He felt more confident having a trendy looking bag over the ostomy bag instead of the ostomy on its own. Another way David became more independent was by purchasing Google Home devices for himself and his family to use upstairs. As time progressed, David's voice grew weaker, and he could not communicate with his family if they were in other areas of the house without using the new Google equipment. Whenever he needed something, he could use his device and broadcast his request to others on the main floor. He also set up Google Home to remind him to take his medications, increasing his independence for this task by not needing to rely on others to remind him to take his prescriptions. David and his wife shared a cell phone, so the cell phone was also connected to the same Google technology. This enabled David to make calls to friends without having to buy a second cell phone. David found the recent installation of this technology made an enormous difference, enabling him to connect with others and maintain his independence with specific tasks. Most importantly, he talked about how he regained the freedom to communicate, which he felt he had lost when his voice and body became weaker.

David enjoyed the many friends who came to visit him. Between two of his interviews, a group of friends had arranged an anniversary party for him and his wife. This meant a lot to David. He described himself as a simple man and said that for others to have arranged this event was such a blessing. In reflecting on having such good friends, he recognised that he, too, had been a really good friend to them over the years. As the cancer progressed, he found his energy levels declined and priorities changed. David spoke about beginning to need a break from visitors. When this happened, he would excuse himself from the conversation and go downstairs to his bedroom. Despite waning energy levels, David sought to maintain a positive attitude, as he believed that his happiness in life was mainly due to the ability to make the most of any situation. Both he and his wife had cancer, and they sought to live well in the midst of it all. David spoke about accepting where he was in life rather than focusing on losses experienced, noting that there would be many more things that he would not be able to do. David described that it was important for him to accept things as they came and to graciously recognise when he could no longer do something.

During the second interview one month later, David described how the tumour had progressed in size and was coming out of the ostomy. As a result, he had to adjust his activities and be more careful about how he moved. He began to receive more frequent visits from home care nurses. He was only able to tolerate sitting upright on the couch upstairs for about half an hour before needing to lie down. David said he could still bathe and dress himself independently but needed assistance from his wife to set things up (e.g., setting out fresh clothes, putting worn clothes in the laundry) and help towel dry after his shower. The shower was upstairs, and David was still sleeping in the basement area. He was able to walk up the stairs at this time, but he recognised that this might soon change. He mentally prepared himself for the need to have a sponge bath on his bed in the basement when no longer able to manage the stairs.

As his strength and energy levels continued to decrease, David described how his activities and priorities changed from going out into the community to staying at home. For example, he considered himself a handyperson and previously enjoyed going to the local shops or hardware stores to look around. However, he no longer had the activity tolerance to do this, so to stay involved, David read printed catalogues, browsed online stores, or watched videos online to keep updated with the latest and greatest in the plumbing or hardware world. He was also saddened that he was not able to attend his faith community as often, as he was a devout follower of his religion. David arranged with his faith community to access the church services through the phone (and, therefore, the Google Home device, which also amplified the service). At that time, his faith community would also send an individual to his house, so he had company while listening to the broadcasted message. Talking with others about his faith was a highlight of David’s day. His faith organisation had a television channel that shared work being done overseas. Although no longer able to attend meetings, David felt that connecting to the meetings by phone and watching their television channel maintained his involvement in his faith community and strengthened his faith. In his fourth interview, David described how watching television also helped manage his pain, as it took his mind off his physical body.

By the third interview, David found the flight of stairs very challenging. Adjusting to the new circumstances, he set himself up in the basement with a table next to his hospital bed holding all his needed items: his water, medication, books, Google Home, and television remote. Accepting his physical decline, he spent his days sitting on the recliner chair next to his hospital bed, watching television. David had a stationary commode and a little handwashing basin placed in another corner of the basement with a rug underneath it, which he called his ‘bathroom station.’ It was easier accessing the commode in the basement than going upstairs to the bathroom, and the rug kept his feet warm when sitting on the commode. He was thankful his wife did not mind emptying the commode bucket as needed, as David had difficulty climbing the stairs to the closest bathroom on the main floor. As he had predicted, he described how sponge baths were his new way of showering, but sometimes he felt discouraged at how incomplete the sponge bath felt compared to having a shower.

David’s strength and energy levels decreased as the interviews progressed. However, David continued to actively and creatively find ways to adapt to his declining abilities. He had friends visit him in the basement rather than the main living area. He chose not to take his pain medications when people were visiting as it made him feel tired, and conversing with others was a higher priority for him than managing pain. He continued to limit the length of friends’ visits, as he fatigued quickly but still valued their company. As David spent more time sitting and less time with friends, he increasingly appreciated the presence of his cat, Simba, when no one was around. Simba was a constant source of strength for David. He described her as faithful and affectionate. Having Simba rest on his lap when he was in bed encouraged him, and he described how this experience made him feel loved. When others in the house were busy, Simba was a regular presence, content to spend her day sitting on his lap.

David always had the best interests of his family at heart. Thinking about dying was no different. His primary concern centred around leaving his wife in a new town without their old community to support her. Because his family did not want him to die in their house, David planned to go to a hospice in a nearby city to spend his final days. The uncertainty of when that would be was stressful for David. He worried that he might have less frequent visitors at the hospice and wanted to stay involved with others as long as possible.

By the second to last interview, David could no longer sit upstairs to watch the building of nearby houses just outside their home, so he sat in the basement with his son-in-law talking about what was being done. David could identify how many bags of cement workers were carrying or what was happening by listening to the different sounds made outside. He described the satisfaction he felt when he was able to help his son-in-law build a fence by talking it through with him, carefully explaining the fence building process. Although not as meaningful as standing outside and physically assisting with the building progress, David felt that he had an important role to play by ensuring continued involvement in a modified way.

David's fifth and final interview took place in a hospice, and he passed away less than a month later. He spoke about the kindness of the hospice staff but how he missed having his cat sit on his lap. David was thankful when his family or faith community members visited him and appreciated the television in his room, which provided him with something to do while confined to the bed. His wife phoned after he died, expressing her and David's gratitude that David was included as part of this study, as it had provided a source of meaning and purpose in his final months.

### *5.1.8 Chris: One Interview*

*The primary theme woven throughout the interview with Chris was loss. He observed that living with cancer was living in continuous transition and dealing with multiple losses in everyday life. Every day felt different, and every week things became more challenging. Chris became emotional as he described how he used to walk his dogs around the local lake, pausing to watch beavers at work or geese nesting. Now, Chris felt lucky if he could walk to the end of the driveway with his dogs. He described the change as a loss of the ability to do what he wanted to do. Cancer, he said, makes your walls narrower and your life smaller; it shakes your whole world, and it does not cease—the loss is continual.*

At 60, Chris was looking forward to his retirement years with his wife. With no extended family nearby and no children of his own, his wife and dogs were extremely important to him. However, life changed significantly when he discovered that he had cancer after a routine colonoscopy. The diagnosis of metastatic retroperitoneal cancer occurred the year before his involvement in the study. Chris prepared himself for cancer treatment and anticipated what living with cancer would look like. However, he was not prepared for the depth of the losses he would feel, nor how cancer and subsequent losses would impact his family and everyday life. The theme of loss was intertwined throughout the entire interview. Chris observed that it is impossible to separate the losses experienced from the reality of living with cancer. He wished that everyone understood that there would be losses when fighting cancer or facing any chronic disease.

Chris described how the losses occurred daily and were both big and small. Significant for Chris was the loss of his ability to choose, as he was no longer able to do as much as he previously could. For example, Chris grieved his inability to go hiking, explaining that his legs could no longer carry him long distances. As an avid hiker, the loss of the capacity to be active in this manner was difficult for him. With winter approaching, Chris also reflected on the need to cancel the family ski vacation for the first time in many years. Skiing was important to Chris for two main reasons: the chance to connect with his wife while engaging in a shared recreational activity and the opportunity to physically challenge himself with difficult ski runs at high speeds. Choking back tears, Chris described his first two significant losses as not being able to ski and not being able to go hiking.

Previously, an important part of Chris' day was taking his dogs for long walks, which provided him with an opportunity to process his thoughts from the day. He enjoyed being in nature and appreciated the time alone on these outings—just him, his dogs, and nature. Unfortunately, one of their two dogs had passed away 2 months earlier. As walking became increasingly difficult for Chris, the walks shortened to taking the dog down the steps to the end of the driveway—another significant loss. Living near a lake, he also felt the secondary loss of not being able to watch local animals on these walks, as there were often geese, muskrats, coyotes, or beavers to be seen. Chris wished for a good day, which he described as a day when he would be able to take his dog for a longer walk.

Chris' biggest fear was leaving his wife unprepared. He could not assist with all the household responsibilities anymore and increasingly relied on his wife. Chris recognised that his roles in the home had changed, such as doing the banking and home maintenance tasks. As he approached death, Chris felt the urgency to pass these tasks over to his wife. He explained that she needed to be taught how to budget, pay taxes, and do all the tasks required around a large house and rural property. When they considered all that would be required of her on her own, they decided to sell their home—another substantial loss.

Preparing the house for sale took a significant amount of time. Chris became tearful as he described the worry he had for his wife, recognising that his most important job was to prepare his wife for life after he was gone.

Large parts of Chris' day were spent talking to people, watching television, and dealing with his medical needs, such as monitoring his medications. He described how he felt that time had become condensed, and the size of his world was shrinking. Chris became emotional as he spoke about his time on earth coming to an end, feeling the accelerating loss and compression of time for him and his wife. On good days, he had the energy and strength to do many tasks around the house. However, when he was not feeling well, just being able to get dressed and watch television became his goals for the day. Chris described the days between the good and more challenging days as transition days, where anything could happen. Before he died, he hoped for one really good day in which he and his wife did not think about cancer, a day where he felt fully alive.

Even though loss was a repeated theme throughout the entire interview, Chris described the importance of adapting to life's changes. Chris attributed his success at adapting to the constant change of cancer to his work background, noting he had helped many others manage difficult times of change. He acknowledged that dealing with end-of-life losses would be significantly more challenging for those with limited experience dealing with significant change. Chris described his adjustment as the need to recognise that life was going to be hard and could get harder. There will be grieving and crying ahead, he said, but it was important to Chris to hang on for the future good times, as he hoped these would still be there in the midst of everything.

Unfortunately, Chris's wife did not want him to participate further in the study, sensing his approaching death, and he passed away just over 2 months following the interview.

## 5.2 Longitudinal Considerations

### *5.2.1 Shifts Over Time*

All participants experienced relational changes in their life as their cancer progressed. Some described how they changed the way they spent time with others (e.g., meeting during the daytime instead of evenings, having people over instead of going out as had been their routine in the past, meeting others for shorter visits rather than extended outings, or retiring to the bedroom when a visitor stayed too long). Others noted an increase or decrease in the importance placed on specific family or workmate connections. Some of the parents prioritised time spent with their children as their cancer progressed and death approached, while other participants mourned the loss of certain relationships or looked back on unmet social expectations when their function declined. As death approached, increasing emphasis was placed on the importance of pets as a source of physical touch, grounding, companionship, and comfort. One participant emphasised the importance of keeping connected with his faith community, modifying how he engaged with his community using technology. Shifts in how participants experienced and invested in relationships were evident over the course of the interviews, particularly as participants' cancer progressed and function declined.

In the midst of functional decline, participants desired to do as much as they were capable of doing. Some participants sought to achieve this by modifying how tasks were completed, such as by playing with their children on the main floor instead of upstairs in their bedrooms. Most pushed through symptoms to continue doing what was important to them. Some participants modified their environment to facilitate independence, whether it be choosing a specific type of winter coat (easier to put on), having a stairlift installed to get up the stairs, or moving to be closer to family. Others accepted assistance in certain areas to preserve energy for other tasks. These adaptations were necessary to facilitate their continued independence, and how or what they adapted continued to change as time passed and their cancer progressed. This will be discussed further in Chapter 7 (Findings).

### ***5.2.2 Conclusion***

Consistent with the phenomenological approach used in this study, these vignettes described the lived experience of occupational engagement for eight working-aged adults whose lives were disrupted by cancer. Throughout this longitudinal exploration of their cancer journeys, participants experienced multiple changes in their abilities and involvement in valued activities, including both deterioration and occasional improvement in function. They all experienced significant losses and felt the resultant need or desire to cease specific occupations. However, when participants were able to modify their activities in order to keep on participating in what they wanted, this affected their sense of normalcy and well-being, thus fostering continued relationships with those they loved. This intentionality in how they lived their lives occurred within the constraints of their cancer progressing, declining function, and the resources or barriers in their environment.

It was often smaller, routine moments of daily life that were the most meaningful for participants. The longitudinal aspect of this phenomenological study allowed the exploration of these significant, valued moments in everyday life. Privileging the voices of people living with advanced cancer allowed their lived experiences to be shared. The ability to adapt in order to maintain valued activities allowed participants to live as fully as possible to the end, enabling them to define themselves as they always had been and still were: a parent, spouse, friend, pet owner, or worker.

The following two chapters (Chapter 6 and Chapter 7) will discuss the themes identified in the study, highlighting the desire for independence, the impact of the environment, and the experience of constant change.

# CHAPTER 6: FINDINGS THEME 1 AND 2

The lived experience of occupational engagement for working-aged adults living with advanced cancer is central to this longitudinal, phenomenological study. Vignettes in the previous chapter documented the personal nature of occupation and how life changed over time for participants, demonstrating that *how* people spend their days impacts how they view themselves. Chapters 6 and 7 present the findings of this study. The first two themes are explored in this current chapter, and Chapter 7 will discuss the third theme.

Theme 1 foregrounds the importance of occupational engagement: *The intentional pursuit of engagement in everyday activities.* In the midst of functional decline and cancer progression, participants intentionally sought out meaningful activities related to their sense of self, interests, valued roles, and relationships with others. Theme 2 examines the close relationship between occupations and the environment: *Everyday life is contingent on my environment.* Participants identified significant barriers or facilitators of occupational engagement, including the physical environment, assistive technology, and seasonal changes. Theme 3, *The challenge of unrelenting change and loss*, is discussed in Chapter 7, highlighting the longitudinal nature of changes that participants experienced as time passed and cancer progressed. Participants described the experience of unremitting loss and increasing dependence.

By privileging participants' voices, these findings make explicit what may be taken for granted or hidden in the routines of everyday life, consistent with the hermeneutic phenomenological study design. The vignette and findings chapters use participant language such as *activity, doing,* and *task* instead of *occupation* to reflect their voices.

## 6.1 Theme 1: The Intentional Pursuit of Engagement in Everyday Activities

As their health declined, participants sought to intentionally engage in activities important to them, despite the functional changes and complex losses experienced as their cancer progressed and health declined. Their ability to participate in valued activities increasingly played a critical role in maintaining their sense of self and well-being as they approached the end of life. Due to the nature of progressive cancer, *how* they did tasks changed for some participants, but the *desire* to do was persistent and did not diminish. Although there were unique individual differences in what they valued and enjoyed, as well as their goals, relationships, and roles, notable commonalities existed among participants. Table 6.1 provides an overview of Theme 1.

**Table 6.1**

*Themes and Subthemes*

| Theme | Subtheme | Minor Themes |
|---|---|---|
| The intentional pursuit of engagement in everyday activities | Purposefully striving for independence | Being independent means the world to me |
| | | I want to live purposefully |
| | | Pushing through symptoms in order to keep doing what I want to do |
| | Reprioritising relationships | Doing things with others means the world to me |
| | | Doing things for others is so important |
| | | Leaving a legacy |
| | | Navigating social relationships |
| | | My pet companion |
| | Doing things I enjoy makes me feel alive | It was really fun |
| | | My work is important to me |
| | | I love to move; it gives me energy |

### *6.1.1 Purposefully Striving for Independence*

Participants highly valued independence, irrespective of whether they could complete an entire task or only components of it. They expressed satisfaction on successful participation in an activity and profound sadness or frustration when unable to do what they wanted to do. Participants prioritised important activities and planned out their day. Setting goals allowed them to live purposefully. As their disease progressed and health deteriorated, shifts occurred in how their purposeful pursuit of independence was expressed. At times, the ability to do valued activities was more important than the exacerbation of symptoms. Although the activities participants valued were unique to the individual, the desire for purposeful participation was common to all.

#### 6.1.1.1 Being Independent Means the World to Me

*Interviewer: Why is that important to you, to be independent?*

*Lisa: Because it's everything. (Interview 1)*

Independent engagement in valued activities brought a sense of satisfaction and well-being to all participants. When asked what being independent meant, participants described various meaningful daily activities they could do. Chris spoke about enjoying “walking the dog” (Interview 1), while Melissa shared, “I’ve always been a big reader, and I can still do that, so that is something … that doesn't need modifications. It’s wonderful” (Interview 2). Lisa valued her ability to cook independently, saying that preparing meals was satisfying (Interview 1). Jessica explained how wonderful it was to do specific household tasks:

> For me, just to be able to do a couple of dishes, put my hands in the warm water, and to be able to do that function … I’m grateful for that at that point. … And just Swiffering[9], being grateful that I can just Swiffer a patch up. … I can go, yeah, that looks clean and sanitary, and I feel good about it. (Interview 1)

The ability to independently engage in meaningful activities was satisfying for participants as it provided a sense of normalcy in the face of increasing losses.

The *desire* to engage independently in meaningful activities continued as their cancer progressed, regardless of their declining function that limited their *ability* to participate independently. Peter illustrated this, as he enjoyed hiking in the mountains. During his first interview, Peter explained that he could no longer go on hikes due to limited mobility but was hopeful that he could find a way to access the outdoors even though his physical function had deteriorated. Participants no longer took independence for granted and intentionally sought to continue participating in their valued activities. Peter and his occupational therapist made plans to install a porch lift so that he could bypass the stairs and leave the house using his wheelchair. He looked forward to its completion, saying, “I’ll be able to get out of the house, which is probably the biggest thing. … It will be nice to have that freedom again and getting some independence back” (Peter: Interview 2). By the third interview, Peter’s cancer had progressed, and he had developed serious wounds on his legs and feet, yet this did not stop him from being active. He was intentional in his search for ways to be involved in the daily routines of everyday life.

The ability to independently engage in small daily tasks—once taken for granted when able-bodied—took on increasing significance for participants as their disease progressed over weeks and months. Like other participants, Tammy experienced

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[9] Swiffer is a brand name of a broom in Canada.

fluctuations in her abilities as her cancer progressed over course of 12 months. A spinal cord compression resulted in an upper extremity motor impairment which significantly impacted her level of independence. As the months passed, Tammy regained minimal hand function, and she developed compensatory strategies for other deficits. Tammy excitedly described how much this independence meant to her:

> I'm able to do more. I'm able to get out more. I'm feeling better. I'm up all day and not sleeping all day. … I can turn my toothbrush off and on again, and I can brush my own hair! … [It makes me feel] really good, and I'm showering myself again. … I can shower and dry. Not do everything for dressing myself, but a lot of things. Gaining some of my independence back feels really good! (Tammy: Interview 2)

Tammy experienced joy whenever she could complete a task independently, regardless of how small or mundane. She diligently persevered towards her goals and developed strategies that enabled her to shower independently. It felt "wonderful! Wonderful! And to brush my own hair–wonderful! I'm really thankful to be able to do that again" (Tammy: Interview 3).

A consistent theme in Tammy's interviews was the significance of independence, regardless of whether she could complete the task in part or the whole, whether it was a simple or complex activity. She described the joy she felt: "I'm so happy, right, because the little things do matter, they do!" (Tammy: Interview 6). She continuously sought to do as much as she could and spoke out whenever family or friends suggested that she could not do something (Tammy: Interview 9).

The importance of intentionally pursuing independence was a recurrent theme across participant interviews. The ability to engage in valued activities grew in importance over time, despite the functional deterioration they experienced due to disease progression. Melissa explained that going to the grocery store could be "empowering … it just makes you feel like you're still a functioning human that can still do things for myself; I'm not totally helpless" (Melissa: Interview 10). For Melissa and other participants, it was not simply the ability to do an activity independently that was significant. It was the sense of personal agency and feelings of competence that resulted which provided a sense of meaning as they approached death.

#### 6.1.1.2 I Want to Live Purposefully

> *Lisa: The more I stay at home and don't do things, the less inclined [I feel to do other things]. I feel better when I get out and do things, so that is why it is important to get out and walk or go to work or something because once I'm there and sort of get into it a little bit, I do feel better than I would I think than if I were just staying at home feeling crappy. I still feel crappy, but at least I'm out doing something. (Interview 1)*

Participants were considered and purposeful in their quest for independence. Three recurrent aspects of intentional living were identified. First, participants became *increasingly focused on the daily goals* they wanted to achieve to maintain independence in everyday activities. As their cancer progressed, goals often changed in order to meet their abilities, needs, and wishes at that point in time. Second, participants *prioritised what was most important* based on their goals. To do so, they created a plan for what their day or week entailed. These priorities shifted as their function declined. At times this meant *accepting assistance* for specific tasks so that participants could conserve energy to participate independently in other activities that were important to them. This third element—accepting and receiving assistance—enabled participants to be purposeful in how they wished to live their life. Examples of these three aspects demonstrate how they sought to live purposefully and will now be discussed.

The first aspect of living purposefully—developing goals—supported participants' desire to continue living despite cancer progression. For some, this was an overt process. Chris was an avid goal-setter, in part due to his previous role as a project manager. His main goal was to prepare his wife for life after he died. They lived in a large home in a rural community, and a significant concern was the upkeep required for the house and sizable yard. To lessen future burdens on his wife, they decided to sell their home. In his interview, Chris described the steps taken thus far to achieve his goal and some of the tasks that remained:

> I really started to work with [my wife] on we've got to do this, we've got to do this, we've got to do this. That is when we put the house up for sale, cleaned it up, painted, touched up and did things like that. So that was about a month ago and since it has been a real focus on keeping things looking very good, so that when somebody shows the house. So, everything has been really around that. (Chris: Interview 1)

Peter also identified the significance of living intentionally by setting goals. Goals gave him a purpose, something to look forward to and focus on. They helped Peter feel like he was actively living, not just waiting to die. Goal setting also provided a sense of control and agency. Peter's two primary goals were making the front entry wheelchair accessible and writing an autobiography to leave as a legacy for his young children:

> It's not a little thing, it's fairly big being able to access the house, but I mean, it just gives you something to look forward to. You set these goals. That's another reason why I did the book and why I want to do the videos; I want to give myself goals. I want to set achievements ahead and not just sit around and wait to die. So, whether it be something like waiting for a chairlift to be installed, although it's not me physically doing it, it's still a goal to be able to have it installed and go upstairs or downstairs. Being able to complete the book as much as I can, and maybe leaving a space in the back to put their own stories in. That gives me that goal, doing something like that. It just setting those goals and those milestones, it gives you a purpose is the word I guess I'm trying to say. (Peter: Interview 1)

Peter proceeded to describe how hard it was to be housebound, but he reassured himself, saying, "I also know that it's not permanent and at the end of the day I will get out. Again, goals and things that you focus on to get you through some of those bad days" (Peter: Interview 2). Peter achieved some of his goals, such as getting out of the house. Once accomplished, his sights shifted onto other goals, such as purchasing a modified vehicle with hand controls so he could visit friends and family (Peter: Interview 3). The latter goal gave him a sense of hope for the future, even though he did not achieve it before he died. As his cancer progressed over the five months of interviews, it became harder for Peter to take part in self-care tasks or help around the house. He described how he focused on smaller and more achievable daily goals:

> I say to myself, I'm going to build this model today, or I'm going to paint this part of this, or I'm going to draw this picture, or I'm going to do that, just something to do. Trying to set goals and focus on those rather than focus on what's going on with me so much, because I mean it can be tough. (Peter: Interview 2)

Like other participants, intentionally setting goals assisted Peter to get through the days, weeks, and months of functional decline and increasing dependence. In his final interview before he died, when asked about how to live well while dying, Peter responded that this "is part of setting those goals and being there and trying … not just moping around feeling sorry for yourself" (Peter: Interview 3). Living purposefully meant maintaining involvement in important, albeit modified, activities, even as death approached. Lisa stated that setting goals is "important. It gives you a bit of a purpose" (Lisa: Interview 1). The intentional pursuit of independence was supported and made easier by setting daily goals that were meaningful and brought satisfaction when planned and undertaken.

The second aspect of purposeful living, as described by participants, was how they prioritised and spent their time. Participants had to decide which activities they wanted to accomplish in order to accommodate their fluctuating energy levels—a common experience of living with advanced cancer. Doing too much in one day could exacerbate their pain, reducing their ability to do much the following day. Melissa described the importance of planning her schedule, commenting that she "would never plan for more than one thing in a day, whether it's an appointment or something fun, so that is something that mitigates the risk that I'll not feel up to something, is knowing that is the one thing" (Melissa: Interview 5). However, multiple events occasionally arose on the same day, which meant reorganising the following day, particularly if additional recovery time would be required. "It's that balance of still doing things but not overdoing it" (Melissa: Interview 8). At times, this balancing act worked well. At other times Melissa was uncertain. "I knew I shouldn't, and I still did it anyway. The consequences of it aren't severe; I had a couple days afterwards where it was quite a bit more painful, but then I was back to my normal level" (Melissa: Interview 4).

Goals and priorities that followed a set daily routine often provided motivation, structure, and purpose for the day. Melissa described this as "I have something on my schedule, which is nice, so I can have a routine of some sort. Then also, it just makes me feel like I'm doing something" (Melissa: Interview 3). Tammy also recognised the importance of structuring her day, stating,

> I have a plan, even if it's a plan to spend my day alone: oh I'm going to spend tomorrow alone, and I'm going to watch my show, and I'm going to do my laundry, and I'm going to go for a walk and play my bowls, or meditate or whatever, having a plan. I think, okay, tomorrow I'm doing this … having a plan and knowing that I'm going to get up in the morning and eat healthy and have my tea and start my day off happy and have the people that I want around me. (Tammy: Interview 9)

Prioritising tasks allowed participants to live purposefully when time and energy were in short supply. It encouraged the pursuit of that which was meaningful.

The third recurrent aspect of intentional living pertained to receiving physical assistance from others. This was crucial as health declined and dependency increased. Participants recognised the need to be flexible and to accept help when needed. Receiving support for certain activities conserved energy for other tasks that were a higher priority. For example, home care staff assisted Tammy to get out of bed and helped her with her morning routine (Tammy: Interview 1). She described how she would feel if she was unable to have support for her personal care needs. “Lost. What would I do? I’d be lost. I wouldn’t know what to do. I don’t have anybody to turn to, to ask to help, you know, for full-time care” (Tammy: Interview 2). Tammy also received help with grocery shopping. Friends drove her to the shops and assisted with carrying items. In her usual expressive manner, she exclaimed, “it means the whole world because I can’t survive without it! … I have to get out and get my shopping done. How would I do that if I didn’t have the people in my life to take me?” (Tammy: Interview 3). More than providing basic personal care, accepting assistance with daily and weekly routines was crucial to Tammy. It enabled her to save her energy to intentionally pursue independence in those meaningful tasks she was still able to do on her own.

These three aspects of intentional living were exemplified by Tammy, who embodied the concept of living purposefully in order to achieve independence amidst functional decline. As her cancer progressed over many months, she actively worked on the ability to do things important to her. She *focused on daily goals*, prioritised how her time was spent, and accepted assistance when required. During the first interview, Tammy shared her initial goal of engaging in activities with greater ease. “I’m trying, I’m just brushing my kitty again, and I’m getting some strength doing that, so that’s a good thing. I’m trying” (Tammy: Interview 1). *The proactive choice and scheduling of activities* were “so important, you have to look forward to things. … I didn’t use to be [so proactive], but I’m starting to be” (Tammy: Interview 2). Tammy sought to live purposefully in both big and small things in life. Doing up buttons was one example of the small things that became increasingly important. Tammy exclaimed that she was “so thankful. It was very difficult, but I did it. … [It means] everything, like I was like, wow I did that without even thinking about it today! … Usually, it’s such a struggle for me” (Tammy: Interview 6). Minor improvements in function were so significant to Tammy, *even if she still required assistance* for part of the task. “I got help with the zippers on my boots. Other than that, I facilitate all of my own clothing, and I felt very independent and very wonderful” (Tammy: Interview 6). Receiving assistance was crucial to meet her goals. One momentous functional improvement Tammy noted as “a funny one … [I could] pluck the chin hairs out of my chin” (Tammy: Interview 8). Although the activities participants valued were unique to the individual, the intentional pursuit of independence was common to all.

#### 6.1.1.3 Pushing Through Symptoms in Order to Keep Doing What I Want to Do

> *Interviewer: How do you know when it’s worth pushing through the pain versus not? What is that distinction in your mind?*
>
> *Melissa: That’s a good question. Probably the amount of joy that I’m going to get from the situation, so meeting up with a friend that I really enjoy or that would be worth it. Well, tonight I’m going to the school to watch my son in a play … [there are] horrible bleachers [that cause pain] but it is super fun, so that’s totally worth it. Something like that really is joyful. (Interview 8)*

From time to time, participants chose to push through symptoms in order to engage in valued activities. This included doing things for others or themselves. At such times, they preferred a degree of pain over taking medications that impaired their ability to participate. This was illustrated by Melissa, who loved going to the theatre with friends despite experiencing back pain due to sitting for long periods of time in ill-fitting chairs. “It’s painful, but it also gives me energy … makes you feel like you are part of something. I really enjoy it” (Melissa: Interview 8). The choice to endure symptoms during activities was often related to participants’ desire to foster meaningful relationships. They often described their decision to push through symptoms as a benefit-versus-burden scenario. Some activities were worth it in order to maintain these valued relationships, whereas others were not. Melissa believed that spending all day making cookies was worth the pain experienced, because of the joy she saw on her father’s face when he ate them. Conversely, despite being an avid puzzler, doing a puzzle was not worth the pain as it was a solitary activity, not relational. Melissa explained that on

> the cookie day, I spent all day making them, and I was in a ton of pain at the end of the day, but I was happy. I was like, that was worth it. The puzzle was not worth it. The cookies were worth it, yeah, I would do that again. My dad goes so crazy over

> them that it makes me feel so good. He's like, "these are my favourite." He eats like 20 … it brings joy to someone else, and I get to enjoy their joy, and they're tasty, whereas the puzzle is just like [shrugs] "Okay. I did a puzzle." (Melissa: Interview 5)

Similarly, David chose not to take his pain medication when he wanted to focus on a task or be present with friends visiting. He said his medication affected his ability to focus and stay alert, limiting his capacity to engage in occupations and relationships he particularly valued (David: Interview 4). Jessica's nauseousness did not preclude her from doing things for her husband and son; rather, she preferred to push through symptoms in order to manage her son's care or cook dinner for her family (Jessica: Interview 1). Providing care for her family was as important as receiving care to Jessica. The choice of when to push through symptoms in order to engage in meaningful activities was unique to each individual, dependent on the activities they enjoyed and the people they valued.

### *6.1.2 Reprioritising Relationships*

> *Peter: Relationships are [important]. I mean, who wants to be lonely, really, at the end of the day. It definitely is important to me, those relationships and friendships and whatnot. It is. You really do find out who your friends are, and there have been a few surprises. It's quite funny actually, but not in the negative way, but the surprise was people who stepped up I never thought would, which is kind of nice because I wasn't expecting that and neither was my wife.*
>
> *Interviewer: What does that mean to you then?*
>
> *Peter: It means the world. (Interview 1)*

The context for connecting with others was activities. Doing things with and for others was highly valued by participants. They intentionally chose to engage in activities where they could spend time with those they loved. What this looked like varied, as each person was unique. Some participants lived alone, others had partners and no children, some were married with young children, and others married with children who were adolescents or young adults. Engaging in activities together built, fostered, and maintained significant relationships. Friendships were mutually beneficial. Participants described how doing tasks with and for others—in the context of valued relationships—was a substantial source of meaning and strength for them.

#### 6.1.2.1 Doing Things With Others Means the World to Me

> *Interviewer: You said before that it's the little things that matter the most. Can you tell me more about that?*
>
> *Peter: Yeah. When the kids come home and they run upstairs and they give you a big hug and a kiss and they just say, "hey Dad, I love you" and that out of the blue, things like that, they just, those little things mean so, so much. Having a friend text you, "hey how are you doing?" or family members giving you a call or whatever it might be. That's probably where I find most of that strength. (Interview 3)*

Participants expressed a desire to connect with others in the context of daily life. This ranged from visits with friends to telephone calls or text messages, watching a movie together, or spending time at the dinner table with family. Participants recognised that shared activities fostered valued relationships; this was more significant to them than to simply do an activity on its own. The motivation behind participating in shared activities—maintaining meaningful relationships—was a priority for all participants. Peter explained how the moments of connection with his children or friends were a source of strength as his health deteriorated (Peter: Interview 3). Participants spoke about connecting with others within the context of activities.

Normally unremarkable, daily routines shared with others took on increasing significance for participants as they approached death. They intentionally participated in activities that others were also doing. The relationships fostered through this time spent together in daily activities took on a deeper meaning and new significance. These routine tasks included activities such as talking about the day with family, tasks that they said were previously taken for granted or viewed as mundane.

> It is nothing to do with activities [per se], it's nothing to do with anything specific, it's just being there for them. Honestly, that's the most important thing, and being able to answer the questions and just to be their dad. … Your outlook on life changes, so it's those little things that matter the most. The sit down at the dinner table and being able to talk about the day. Before, it was just kind of eh, it's part of the day, but it means a lot now. (Peter: Interview 1)

Peter described how his outlook on life changed, as it had for all participants. Everyday activities took on increasing significance when doing things with others. He spoke about this change, saying, "it's the little things. I mentioned it before … little things matter the most" like spending time having dinner with his family (Peter: Interview 2). For all the participants, everyday activities were given significance when doing them with others they loved.

Participants with children reported that being a parent was their prime consideration and the central—if not the most important—role they played at this stage of life. Although they wanted to maintain their role and activities as a parent, this became increasingly challenging due to cancer progression. Participants described how their parenting changed and the ways in which they needed to adapt in order to continue engaging in activities with their families. This was exemplified by Peter when he described how he modified how he played with his children when he could no longer walk (Peter: Interviews 2, 3). Similarly, Tammy described the importance she placed on doing activities with her young adult sons:

> It means so much to go out and watch them play. … It's nice to go watch my boys. I don't spend a lot of time with them. They work full time. They have girlfriends. They have their own life. So, to go out and watch them play ball, that's great. I've watched them play sports their whole life growing up, so now that they don't live at home, being able to go watch them play is great. (Tammy: Interview 3)

All participants wanted to participate or be present during meaningful activities with others, particularly when these events defined who they were, such as being a friend or a parent.

#### 6.1.2.2 Doing Things for Others is so Important

> *Melissa: I am still a good friend because I text or I chat with them, I can still participate in some things, or I can still buy presents, I can still be involved in different ways. (Interview 10)*

Participants valued doing things for people who were important to them. They wanted to care for others, not just be a recipient of care. This reciprocity was important to Melissa and Tammy, as they sought to be present for friends experiencing hard times. During Melissa's 14 months of interviews, the son of a friend died, and the same friend's home burnt down. Melissa said that sometimes just sitting together and visiting was meaningful for both Melissa and her friend. "We just hung out and had coffee and talked. It was nice to be with her. She is having a tough time. But it was good, like to be with her" (Melissa: Interview 5). Although Tammy was also grieving the unexpected death of her daughter, she intentionally sought to support her daughter's friends during this difficult time. Tammy said,

> one of [my daughter's] friends is coming and spending a lot of time with me. … It is nice. It is wonderful. They were best friends as they grew up, and she came last Wednesday and spent the full day with me and we went out for lunch and then we came back here and played crib. It was awesome … [it means] everything, everything, it's just beautiful. It means everything. And [my daughter's friend] is a beautiful girl, so I'm very thankful. I'm thankful to be able to be there for these kids and do what I'm doing right now. (Tammy: Interview 6)

Participants also spoke about their desire to support their families, even when doing so was an emotional struggle. The specifics varied depending on individual circumstances. For Melissa, this meant letting her son go overseas to visit his father instead of staying home for Christmas (Melissa: Interview 3). Similarly, David continued receiving chemotherapy longer than he desired because his wife wanted it. She felt that if he stopped chemotherapy, he would be giving up. To support his wife, he agreed. Jessica expressed a desire to do things for her husband, despite experiencing significant symptoms of fatigue, nausea, and diarrhoea. She described this active care of her husband as an important part of being married, saying,

> little things that you learn as a relationship, like he really wanted some paper towel … I was able to pick up on sale at the pharmacy and carry it back. … Just little things that we need to recognise that are important, and thinking about somebody else and ourselves, that's important. (Jessica: Interview 1)

Doing things for one another was highly valued by most participants. Sustaining reciprocal relationships became increasingly important even when functional decline significantly limited a person's abilities. Being mindful of loved ones continued throughout the interview series.

#### 6.1.2.3 Leaving a Legacy

> *Interviewer: What does that mean to you, to have [time with people you love]?*
>
> *Melissa: I think it means a few different things. One is I just really enjoy connecting. I really enjoy being a part of people's lives. That's one of the things. Another of the things is I'd like to be remembered, and I would like there to be a lot to remember, and I wouldn't like to leave and then have anyone say, "oh I wish I'd had more time with them." I mean, obviously, the kids probably would say they wished they'd had*

> *more time, but not in the day to day, but to say like she took time for us, that would be the most important thing. (Interview 1)*

Declining health prompted participants to reflect on how others would remember them. They wanted to leave a legacy for their loved ones, including making treasured memories with their children or teaching life skills to family members. In addition to writing an autobiography to be remembered by, Peter shared his desire to create a social legacy for his children. During his interviews, he described how he sought to impart knowledge to his family, teach and model morals, and pass on a love for the outdoors to his children. He explained that he wanted to create positive memories, knowing "that when [death] does happen I have at least left that legacy and those positive memories of 'Dad always used to read stories' and used to help them with the homework" (Peter: Interview 2).

Leaving a legacy through teaching their children or spouses independent living skills was important to Melissa and Chris. Melissa wanted to prepare her children for life after she died. She described how she supported her family's well-being and also encouraged her husband to develop healthier habits. Melissa's husband smoked and had a poor diet. She explained, "I want him to be healthy to be able to look after me, and then also to be around for as long as possible for the kids" (Melissa: Interview 8). To facilitate this, she began leaving a legacy of healthy meal planning and encouraging the habit of regular exercise. She also invested time teaching her children independent living skills, as this helped her feel "that they will be capable of living a life and looking after themselves … it makes me just feel more confident that they'll be okay" (Melissa: Interview 5). Similarly, Chris' primary concern was how his wife would manage the household tasks, paperwork, bills, and taxes once he died. Chris wanted to ensure that his wife was able to live independently after he passed away, disclosing, "what I'm afraid of is making [my wife] unprepared. It's my greatest fear" (Chris: Interview 1). He sought to help her transition well after he died, including

> teaching [her] how to do it on the bank [web]site. Big deal? No, but if you've never done it before, [it is]. And there are a lot of things that need to be done around the house. … There are bills you need to be prepared for, like city taxes. People don't think about those who have never owned a house, that every 12 months you get a whopper of a bill. So [my wife] is learning about that too. (Chris: Interview 1)

Preparing to leave a legacy was on the minds of participants and they sought to identify how they would leave their personal mark on those they loved. This became an area of increasing importance for participants as they approached the end of life.

#### 6.1.2.4 Navigating Social Relationships

> *Interviewer: With all these changes and difficulties in the last month or so, what is the biggest concern that you have? …*
>
> *Jessica: I'm a people person, and I'm finding—and I'm not one to sit on the phone all day—and lately I find to sit and chat with my sisters, I can't do a lot anymore because the one sister is going through a really hard time and I can't be her shoulder right now, and I find it very difficult when I am [her shoulder to cry on]. (Interview 2)*

As participants' abilities, needs, and outlook on the world changed due to advancing cancer, this shaped how they fostered social relationships. They had to navigate their own personal expectations, the expectations of others, as well as shifts and challenges in their intimate relationships.

The first significant change identified by participants was the need to *alter their own social expectations*. They outlined changes in how they participated in activities with friends. Setting boundaries or adjusting how time was spent with others became necessary as their function declined due to the cancer. When friends visited, David found it challenging to balance his two conflicting desires: his instinct to be "positive and encouraging" (David: Interview 1) and also his need to be assertive when fatigue levels were mounting, which necessitated asking friends to end their visits early (David: Interview 3). Similarly, Chris enjoyed socialising with those important to him but as his cancer progressed, he became more articulate about what and whom were a priority for him (Chris: Interview 1). Peter also navigated and changed the manner in which he related to friends. He was no longer able to participate in physically challenging, enjoyable activities such as hiking with friends. There were also fewer in-person meetings over a cup of coffee or tea due to difficulty leaving the house. He described how he changed his expectations and began phoning, texting, and FaceTiming others more frequently (Peter: Interview 2). Peter modified how he fostered relationships with friends, workmates, and even within his family unit. "The same as relationships with friends can change, relationships with your wife [change] … you find other ways of connecting. I've probably learned more about myself and [my wife] than I would have done if this hadn't happened" (Peter: Interview 2).

Melissa noted changes in how she spent time with her young family: less physically active connections and more routine activities like helping with homework. For example, cooking was a task she did not particularly enjoy; however, the end result—sitting down together as a family at the table to eat dinner together—was something Melissa cherished:

> It's one thing that I can do that they enjoy that we can sit around the table and be together. … I find often like if I have cooked, everyone is more likely to sit around the table with it, rather than just something that people can just heat up or if we ordered pizza, everyone would just grab a piece and go to their room or. So, I feel like when I've made an effort in the kitchen, they are more likely to hang out. (Melissa: Interview 2)

As their abilities declined, participants described other changes in their experiences of how they related to others, due to shifts in the context wherein relationships were fostered: activities.

*Navigating the expectations and assumptions of others* regarding activity engagement was a second relational challenge identified by participants. For example, Tammy often spoke about how diligently she worked on her hand function with the goal of doing valued tasks, but she was also acutely aware of her own limitations due to her spinal cord compression. She felt disheartened when others assumed she could do more than she could. Saddened, she said,

> I'm getting more frustrated with the things that I can't do because I want to do them … [like] putting the lid on this container last night. Just frustrated, really frustrated. My husband kept saying, "just try it, try to here." I'm like, "no, I know I can't." Very frustrated and I got upset. I'm like, "leave me alone, quit telling me to try it. I know my capabilities and I try every day to see what I can do and what I can't do, because I don't want to lose my capabilities." It's not a good place to be. … But I can't shut the tight lids on the leftover containers yet. [crying] … [I'm] just frustrated, because I can't do things that I want to. (Tammy: Interview 3)

Similarly, a recurrent theme in Melissa's interviews involved friends who made incorrect assumptions regarding how she was doing while living with cancer. On a weekend away, friends thought she could tolerate doing more than she could. Melissa described how she felt compelled to participate in social events to comply with these expectations, which caused her considerable pain as she overextended herself. After repeated similar events, Melissa began doubting others' judgement of what she could do. She described her discouragement when friends did not take her concerns seriously. She believed that they thought that because she was young and did not look sick, she did not require assistance or longer rest breaks (Melissa: Interviews 2, 4, 5, 9). Melissa also grappled with how to be honest with others about her symptoms. She struggled to speak about her pain with friends "because either they just get sad and then I feel sad, because I don't want to make people sad, or they say, 'oh you should do this, you should do that'" (Melissa: Interview 5). As the year progressed, Melissa recognised the importance of herself choosing to accept or decline invitations, rather than have others make that decision for her. She described her strategy: to frame her pain in a different way, saying, "that's too tiring for me" – a more socially acceptable answer (Melissa: Interview 5). Friends would then respond sympathetically to her, saying, "you've got cancer, you must be tired." The fact is I'm hardly ever tired, so I'm kind of not helping the narrative" (Melissa: Interview 5). Melissa described the struggle she felt when others were vocal about alternate views regarding how to heal her cancer. A few friends told her that if she changed certain things, such as the way she thought or if she used a natural deodorant, her health could improve (Melissa: Interview 4). Navigating social relationships was exhausting for Melissa.

> With different friends, either they see you as strong, or they just want to fix it, so you don't want to talk to them about it, or they think you should be positive all the time, so they get mad when you say something negative because they feel like you're not going to get better if you're not positive. (Melissa: Interview 5)

David's experience differed from Melissa's. Some of his friends assumed he would be in much worse shape than he was. Trying to act as normally as possible to combat this, he stated, "I try and be like I don't have cancer. Because people … expect me to be all withered and not much hair and stuff like that, and they say oh, I was expecting for me to be looking a lot worse" (David: Interview 1). The navigation of social relationships was a difficult balancing act for all participants.

*Navigating spousal relationships* was a third relational shift that affected the participants' experience of living with advanced cancer. Capacity for intimacy changed for couples as cancer progressed and their physical abilities declined. Peter and Melissa both confided that sexual intercourse had ceased, and they had to focus on other forms of physical intimacy such as hugs and kisses. Peter described how this resulted in a greater focus on bonding emotionally. Rather than focusing on the physical aspects of his relationship with his wife, Peter stated, “I’ve learned more about my emotional relationship and how close to [my wife] I am. I’ve learned more about myself as well than I probably ever would have done if this hadn’t have happened” (Peter: Interview 2). Peter was able to see a positive benefit in the midst of the challenges experienced. Chris described the difficulty he faced with changes in his spousal relationship. With his voice breaking, he said,

> your time is coming to an end and because your time is coming to an end, it seems everything becomes more compressed. Everything. The size of your world shrinks, and that is impossible to have that occur without affecting your spouse. … It comes back to that again, where it’s a condition that the entire family has. … There is a compression in everything that is occurring and it’s accelerating and it’s affecting [my wife] too. (Chris: Interview 1)

Not all participants had spouses or partners. Amanda, a more socially isolated participant, grieved the loss of significant relationships. Her boyfriend had died the previous year, and she missed him. She longed for the ability to do things together within the context of a meaningful relationship. She reminisced over his death and also desired to meet other people, saying, “that is what I want, companionship. I’d like a male companion because I miss that. … Just to get together and watch a movie” (Amanda: Interview 1). Amanda missed doing things with others, and like many other participants, found navigating relationships difficult at times.

These three relational shifts—adjusting their own expectations, managing assumptions of others, and spousal relationships—were spoken about by participants within the context of activity.

#### 6.1.2.5 My Pet Companion

> *Amanda: Oh god, if someone said I had to get rid of [my dog] and go somewhere else, to a facility, I think I’d, confidentially, I think I’d want to end my life, end things, because I wouldn’t have anything to live for anymore. I mean I’ve got my [adult] kids but they’re all fine now, they’re all happy; this is a good time. They’re happy, they’re doing good. He’s more important that way. So yeah, for sure, the dog. (Interview 1)*

The six participants who had pets all expressed the importance of being with them as their cancer progressed. This relationship was meaningful to all involved. Participants described their pets as more than a companion. Jessica shared that her dog was “my soulmate, and she’s very important to me and she needs me” (Jessica: Interview 1). Amanda explained emphatically that her dog was “the other part of you … he’s just everything, he means everything” (Amanda: Interview 1). Participants indicated that caring for pets, such as taking the dogs for a walk or brushing their pets’ hair, gave them a sense of meaning (e.g., Chris: Interview 1). Tammy spoke about the significant meaning she placed on these activities, for example brushing her cat’s hair (Tammy: Interview 1). A sense of satisfaction and affection arose from simply enjoying the pet's companionship sitting on their lap or the ability to talk to them (e.g., Amanda: Interview 1; David: Interview 4). Participants also remarked that the pets seemed to just know when their presence was needed when distressed or symptoms escalated, snuggling up on their bed or lap. “[My dog] is very important for me just knowing she is here, I have company. … She is my little buddy and she’s very important to me. So, pets, they shouldn’t be undermined. … They stabilise people and I think we seem to forget that” (Jessica: Interview 1).

Amanda spoke about the importance of her relationship with her dog and the meaning attributed to this relationship. She acknowledged that she was more socially isolated than she would like, so being with her dog and doing things together was a notably important part of her day. She described how this significant relationship was her primary source of comfort and joy. Unfortunately, Amanda’s dog passed away between her first and second interviews, and this loss reduced her desire to engage in other everyday activities. Recognising that she was dying, Amanda did not want to get another dog. Instead, she purchased a plastic dog statue, allowing her to maintain her valued role as a pet owner. Amanda described how she felt about her new purchase: “It was great. He was just sitting there, and no leg and I felt sorry for him, and … he really did help. I was inconsolable, and then I got him, and he’s just, it is almost like he is real” (Amanda: Interview 2).

As cancer advanced, participants intentionally sought out activities that included others, including pets. The presence of pets provided a sense of joy and peace in the midst of constant change and a distraction as symptoms progressed and death approached. Being a pet owner provided purpose and a sense of meaning. Whether they walked their dog, brushed their cat’s hair, or simply sat with their pet, all participants with pets enjoyed their sense of connection and their comforting companionship.

### *6.1.3 Doing Things I Enjoy Makes Me Feel Alive*

> *Tammy: I said to the kids, I said you need to come and get me and take me out, so the kids took me rafting even though they capsized. … There I was floating down the river in my life jacket … it was amazing!*
>
> *Interviewer: Was it worth it?*
>
> *Tammy: Absolutely, wouldn't have given it up for nothing. Take me floating again please. I love floating the river, I always have! (Interview 1)*

Participants sought to do activities that they were interested in and brought enjoyment. Depending on their priorities and perspectives, the specifics of what this looked like varied from person to person. Activities included those that were just pure fun, valued activities such as work, and other activities that involved moving their bodies.

#### 6.1.3.1 It Was Really Fun

> *Melissa: It was good, yeah, it was fun, it was really fun. (Interview 8)*

The ability to do things that they really enjoyed made participants feel alive and reinforced the sense that they were still themselves. For some, it brought a sense of normalcy, and for all, it provided distraction amid the challenges of living with advanced cancer. Whether the activity was working, going to the theatre, watching their children play, or going on a walk with their dog, participants wanted to do things that inherently brought them joy. As discussed earlier, they enjoyed nurturing relationships while doing routine tasks or fun activities with their friends, spouses, and children. Pet owners found pleasure in spending time with their pets. Participants also described the joy they felt when doing activities on their own, such as reading a book or watching Netflix or television. Each participant was unique, and what they enjoyed doing was unique to the individual. Participating in an activity they enjoyed made them feel alive.

#### 6.1.3.2 My Work is Important to Me

> *Lisa: [Work] is important. It gives you a bit of a purpose. Plus, I like my job and I like the people I work with, so I'd rather be there than sitting around at home not feeling well or whatever. (Interview 1)*

As a younger cohort of adults under the age of 65, participants talked about their ability and desire to continue working. Participants had contrasting views on the role of work at this stage in life, influenced by the context of their current health concerns and priorities. For some, continuing to work was very important as it helped them feel a sense of purpose.

Others were thankful to give up their position and responsibilities at work due to deteriorating health. How participants defined work varied and included paid work, volunteering, and household tasks. For Tammy, it was housework. She sought to live intentionally in all that she did. The ability to do housework gave her a sense of meaning and purpose and helped her feel more like herself. "Do your dishes, get your laundry up, fold your tea towels. Check the plants. Check to see what needs to be cleaned. … A big part of me is coming back because I like things nice" (Tammy: Interview 9). Other participants felt conflicted about returning to work. When Melissa received her cancer diagnosis, she experienced tension as she wanted to return to work but realised it was not feasible to do so. She hoped for life to go back to normal:

> like you just want to go back to the way it was, and part of that is going to work. When I was first diagnosed, it was, yeah, I want to go back to work, I'll be back after spring break. Then it was really quickly apparent that that wasn't going to happen. I was like well back after the summer. Then it was it was like well no you won't. Now I'm kind of at peace that I won't go back to work. (Melissa: Interview 7)

In contrast, one of Lisa's most valued roles was that of being an employee of a local company. Without a spouse or children, she described how her work community was an important source of meaningful connections. Lisa regarded work as the most important part of her day and was thankful that she was still able to contribute to her workplace. She shared her uncertainty about how long she could continue working before her cancer would progress to a point when this was no longer possible. If unable to work, Lisa said, "I'd be disappointed. I'd be very disappointed. … There is a certain amount of reality that you have to face when given this diagnosis; … it's not automatically just going to turn around and get better" (Lisa: Interview 1). Contributing to work responsibilities and socialising with workmates were important for Lisa. Her work environment gave Lisa purpose and meaning. It enabled her to have a life apart from cancer, and she sought to continue with this valued activity for as long as possible.

#### 6.1.3.3 I Love to Move; It Gives Me Energy

> *Interviewer: Out of all those different activities that you mentioned, what is the most important to you?*
>
> *Tammy: Walking. When it's nice out, yeah. Yeah, I love to hike and walk.*

> *Interviewer: Can you tell me why it's so important to you to be able to keep walking and keep hiking?*
> *Tammy: Well, because it's good for my body, right. I need to keep my strength, but I love to be outside, I love to move, I love to walk. I just love it. I've always walked. I love to ride bikes, I love to cross country ski, I love being outside; I think it's good to move your body.*
> *Interviewer: How do you feel when you are outside walking or you're outside hiking?*
> *Tammy: When it's nice out, wonderful! … Generally, I love summer; it's beautiful, right. (Interview 1)*

Staying physically active invigorated and energised participants. In addition to the physical and mental health benefits of participating in such activities, it also fostered relationships with others. Like many other participants, Jessica shared the importance of walking, which included how it made her feel alive and that she could connect with others along the way:

> Out in nature and having that sun absorption and you feel like you've gotten out and you just interact with people in your community, [as you] walk past somebody, nature is very good energising-wise, and so that is very important to me because I used to walk and never think anything of it. I walked to work, I quickly walked home, I walk with my son and my dog, and so things we take for granted that I just want to do again, so walking is very important. If I can carry a bag of toilet paper from the pharmacy, just those activities you've got to keep going. (Jessica: Interview 1)

Similarly, Melissa described the benefits she received from participating in her aquatic exercise classes at the community pool. "It's me and all the old ladies. That started again once a week, so I've been enjoying that. It wipes me out, but it's so good in the water. It's kind of a social thing, so I've been happy" (Melissa: Interview 3).

At times, bad weather and slippery sidewalks made it difficult to get out and move for both Melissa and Lisa. Despite the risk, Melissa was motivated and made an effort to continue walking, as "being outside is good for the mind, so I need to, so I do like being out. I never regret it. Even if I do too much and I end up in pain, I never regret that I've gone" (Melissa: Interview 4). The impact of the weather and the physical environment will be explored further in Theme Two, *Everyday life is contingent on my environment.*

Regular reference to and description of the importance of continuing to be physically mobile was a recurrent theme throughout the interviews. Valued activities were wideranging and included exercise, being outside with their children, or going for walks to enjoy nature and the outdoors. Staying physically active gave participants energy, a sense of normalcy and made them feel alive. It provided space in which they could continue fostering meaningful relationships with those important to them. Participants loved to move and intentionally sought it as part of their routines, even as their health declined and physical activity became more challenging.

### *6.1.4 Theme Summary*

Theme 1, *The intentional pursuit of everyday activities,* highlighted the value and importance that working-aged adults living with advanced cancer placed on engaging in meaningful activities. Findings demonstrate that participants *purposefully strove to maintain independence* and maintain their involvement in valued activities as long as possible, despite the constant changes and challenges they experienced over weeks and months. To do so, they purposefully prioritised their goals each day. At times this meant pushing through symptoms or delaying treatments. Participants also described the *significance of relationships* as cancer progressed and health declined, and focused on *engaging in activities with and for others.* Meaningful activities were the context in which relationships were fostered. Although the activities preferred differed among participants—whether it be walking the dog, going to work, meeting friends for coffee, or playing with their children—all activities shaped their sense of meaning and sense of self at the end of life. *Engaging in enjoyable activities* made participants *feel alive*.

## 6.2 Theme 2: Everyday Life is Contingent on My Environment

Disease progression was inevitable for all participants, but the individual experience of involvement in everyday activities at the end of life varied and was contingent on their environment and changing abilities. The interplay between the person, their environment, and the chosen occupation was often raised by participants in their interviews. From their perspective, the environment's impact on quality of life was significant. The centrality of the environment in shaping the lived experience of occupational engagement for working-aged adults living with advanced cancer was a recurrent theme, playing a central role in their sense of self and well-being at the end of life. An overview of this theme is noted in Table 6.2.

**Table 6.2**

*Themes and Subthemes*

| Theme | Subtheme | Minor themes |
|---|---|---|
| Everyday life is contingent on my environment | Physical barriers hinder my ability to participate | |
| | Reducing the impact of environmental barriers helps me do what I want to do | |
| | Seasonal changes | |
| | Occupational environment | Altered relationship with time |
| | | Receiving support helps me do what's important |
| | | The space I am in shapes my emotional landscape |
| | | The importance of freedom to choose |

### *6.2.1 Physical Barriers Hinder My Ability to Participate*

> *Peter: It is hard. … I mean I haven't been up to my own bedroom for over a month as well, so not being able to utilise any of the rest of the house, it's not easy. … One of the things I don't like is I don't sleep with my wife anymore because our bedroom is upstairs. She sleeps up there and I sleep down here. So not being able to be with the person that you love, that's difficult. It's hard. So that's another little thing that people don't really think about. It's that physical separation. Even though you're in the same place, you're not. That is really tough. (Interview 1)*

Participants identified barriers within their physical home environment that made routine daily activities difficult or impossible to do. Peter and David spoke of their inability to access their bathrooms, preventing them from taking a shower. Typical homes in their communities had two to three levels, with a full bathroom and bedrooms on the upper level accessed by an internal staircase. They felt discouraged by the incompatibility between their physical abilities and the layout of their homes, which meant they had to settle for sponge bathing on the level of the house where they resided (David: Interview 2, 4; Peter: Interview 2). The internal physical environment of homes limited how, or even if, they could engage in certain valued activities. Inaccessible parts of the house that were no longer usable for certain valued activities like playing with children, pursuing hobbies, or socialising with friends diminished quality of life. As Peter said,

> it's been hell. It really does suck, I'm not going to lie. It's not even just being stuck in the house, it's literally being stuck on one level of the house. I have a man cave in the basement, and … I can't even go down there and enjoy being relaxed in my own home. (Peter: Interview 1)

The inability to leave the house due to physical environment limitations (e.g., external stairs) was also a challenge for some participants. This was illustrated by Peter's "cabin fever" and sadness about the sense of isolation he felt, in part due to his inability to engage in meaningful outdoor activities with his children (Peter: Interview 1). During the second interview, Peter became very emotional as he talked about feeling "stir crazy being stuck on one level of the house. It's been going on three months now, and that's a long time to be stuck in one place" (Peter: Interview 2). Physical barriers to the outdoors, which disrupted routine activities in the community, impacted participants' mental health and sense of well-being. They were deeply affected by their ability to engage in occupations outside the home environment. Melissa had considered leaving her beloved mountainous community to move to a new single-storey home in the city, one without stairs from the house's central area to the bedroom and bathroom. However, this was not feasible, so they decided to stay where they were and live with the challenging stairs (Melissa: Interview 2).

For participants who were able to leave their homes, issues arose at times when fatigue or weakness made it difficult to access and use transportation systems on their own, whether it be their own vehicle or the public bus system. Lisa's cancer-related fatigue resulted in her gradual inability to walk the distance from the bus stop to her workplace. She became increasingly reliant on others for transport (Lisa: Interview 1). Other participants, such as Peter and Jessica, could not independently travel to medical appointments, visit friends, or go into town. This environmental barrier increased Peter's feelings of isolation (Peter: Interview 2). Jessica found it frustrating that difficulties with transportation made it difficult to run errands or connect with friends (Jessica: Interview 2). Difficulty accessing modes of transportation were complicated by living in a rural environment, where public transportation was not readily available, so there was a high reliance on personal vehicles. This was a challenge for those unable to drive. Rurality provided additional challenges for some participants, such as difficulty procuring required medications because of limited access to the nearest pharmacy. Jessica also expressed frustration at the level of advocacy she needed to provide in order to access medical programs such as the mobile laboratory and paramedic hydration services, programs that should have been routinely available to rural communities with limited transportation options into the city (Jessica: Interviews 1, 2).

Being in an unfamiliar environment made it difficult to do specific tasks, which often resulted in a reduced level of independence while in hospital or travelling. Although Peter could move from his bed or chair to the commode or toilet at home without using an assistive device, this changed when he was admitted to the hospital where unfamiliar equipment (i.e., a lift and sling) was used for transfers. He found that he stuck to everything,

> so I couldn't slide, I couldn't move, I couldn't manoeuvre, which is why I would have to use the lift. So, when I would use the lift … I lost control of my faculties and there was some pain involved and everything is hanging out for everybody to see so you have no privacy whatsoever. (Peter: Interview 3)

Staying in an unfamiliar environment limited Peter's ability to participate in daily tasks that he could do independently in his own home. Similarly, Melissa found that unfamiliar places were more unpredictable while travelling and affected sleep patterns. She described aspects of the travelling environment that were a challenge: packing, getting to the airport, and onto the airplane, were challenging due to her limited activity tolerance, the amount of walking involved, and uncomfortable airplane seats. Melissa described feeling bad when she rode the transportation cart between parts of the airport. On one occasion, there was insufficient space for both her and an elderly couple so she gave up her seat; she felt judged that she was wanting to take the transportation cart as she looked younger and "should" be able to walk longer distances, despite being unable to do so (Melissa: Interview 4).

Participants' experience of engagement in valued activities was contingent on the physical environment. They described how their level of dependence in everyday tasks increased due to environmental barriers, such as the internal or external access to their homes, the accessibility of required components to a task, or challenges due to being in an unfamiliar environment.

### 6.2.2 Reducing the Impact of Environmental Barriers Helps Me Do What I Want to Do

> *Peter: It [medical equipment] gives you a certain sense of freedom and independence that I didn't have before, and now I have it back again, and it's nice to know that I'm*

> *able to go outside if I want to, and now I don't have to wait for someone to do everything for me and call a group of friends to come and lift me out of the house or anything like that. It's made a big difference. (Interview 3)*

Addressing the mismatch between the physical environment and a person's abilities can result in greater independence and an increase in the ability to do activities in the context of important relationships and interests. Peter recognised the importance of environmental modifications to participate in valued activities as he had experienced bodily deterioration and increased dependence due to the cancer progression. An occupational therapist prescribed appropriate equipment and home modifications, which optimised his independence. A hospital bed, manual wheelchair, power wheelchair, chairlifts and porch lifts were forms of assistive technology that reduced the negative impact of environmental barriers as his disease progressed and function declined. Peter required ongoing monitoring of his fluctuating functional status and corresponding support that was responsive to his changing needs, particularly further environmental modifications to his home. One area of ongoing concern was Peter's ability to ambulate within his house. When ambulation became increasingly difficult without a mobility device, the occupational therapist prescribed a manual wheelchair. Peter described his gratitude when the wheelchair arrived and was fitted. He was now able to play with his children with greater ease (Peter: Interview 1).

A second environmental issue of concern was Peter's confinement to one floor of the house. This was a significant issue for Peter over the five months of interviews. Although other participants spoke about similar barriers, Peter's experience highlights the key issue at hand. He was restricted to the main floor, where his hospital bed was set-up so he could partake in family routines and remain on the main floor of the house, assisting his children with homework, and eating dinner together. It was a temporary solution until the stair lifts were installed (Peter: Interview 1, 2). The wait for the installation frustrated Peter, as he felt quite dependent and constrained. He described looking forward to installing the lifts so he could regain the ability to choose if he wanted to go upstairs or outside. The equipment not only reduced the impact of environmental barriers (the stairs), but it also facilitated everyday activities and routines that were an important part of his relationship with friends and family (Peter: Interview 2, 3). In response to a question on how he thought having a chairlift would change some of those things, he replied:

> Massively. I'll be able to sleep in my own bed, which will be nice. I'll be able to have a shower in my own shower, which will be good as well. I'll be able to get out of the house, which is probably the biggest thing, and off of just one level. It will be nice to have that freedom again and getting some independence back. … To now being able to just get out and get groceries with [my wife] or whatever, it will be huge. That will be the biggest thing I think, just getting that independence back and being able to get some mobility back as well, as far as the outside of the house. (Interview 2)

Over the following months, Peter's function and health continued to decline, and a third area of concern arose regarding barriers in the environment. Increasing breathlessness and fatigue resulted in difficulty mobilising in his home environment with his manual wheelchair. Peter's occupational therapist prescribed a power wheelchair[10]. Shifting to using the power wheelchair changed more than just access to the environment. Peter described how the new power wheelchair changed his relationship with the broader world; it

> has made a big difference. … I know that I've lost some of my independence and that's fine, it's going to happen, and there is not much you can do about that. But that being said, I've also been able to regain some of my independence, which has been fantastic, whether it be getting a glass down [from the cupboard] or rolling out to the porch lift and going outside, you know, out to the driveway and watching the kids paint with chalk or draw with chalk or do whatever they want to do, and be part of their lives and take it all in again, it has been great. (Peter: Interview 3)

Peter did not take his renewed ability to access the broader environment for granted. Having previously lived an active life with his work and family, he recognised that the restored ability to enjoy the outdoors helped him feel more like himself.

Addressing specific barriers in the environment did not necessarily resolve all access issues. Reducing the impact of one environmental barrier often exposed other unanticipated access issues. As his cancer progressed, new functional and environmental challenges also arose. Peter shared how he had hoped to assist with his children's bedtime

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[10] Please note: Peter refers to his power wheelchair as an "electric chair." This differs from his manual wheelchair, which he simply calls his "wheelchair."

routines when the stairlift was installed and he could go upstairs again but he had not anticipated that some of the difficulties that followed would be so distressing:

> I mean the nice thing is that I'm a lot closer, but [my kids] want me to lay down with them; I can't do that because I can't get out of their beds. If I go into their rooms, I'm sitting in a wheelchair and although I'm relatively comfortable, I can't stay in there for as long as they might like. … It's heartbreaking, it really is, I mean it really is very heartbreaking, but you explain it to them and give them a hug and sit one up for a few minutes if you want, have them cuddle that way, or I could wheel back into my bed and you can come cuddle and lay down with me for a while. When they say things like, "how come you can't?" or "I wish you could do this", it is heartbreaking because you want to be able to do the same things that they want you to do, but you just can't. (Peter: Interview 3)

While the stairlift increased Peter's ability to engage in many activities, other environmental barriers to function were amplified and remained unaddressed.

Other participants were able to engage in meaningful activities once environmental barriers were removed or altered. Tammy's children knew she loved to go river rafting, so they inflated the raft, lifted it onto the river, and managed all the tasks involved with rafting. This then enabled her to go on a rafting trip without having to set it all up. Melissa planned to decline an invitation to a friend's birthday, as it was in the evening and most people would be standing or dancing, with few places to sit. Aware that Melissa loved to dance, the friend set up a La-Z-Boy chair in the middle of the room so that she could sit comfortably, recline when she was fatigued, and yet still be a part of the fun, including chair dancing. She remembered:

> He had this lazy boy chair set up at the table for me, and so I was lying back—it was amazing—and then when he wanted everyone to dance, he moved the La-Z-Boy into the middle of living room and laid it back and said "okay, Melissa, you go in there, I'm going to turn on the disco ball, and everyone dance around you." It was awesome, it was so amazing! … It was fun! I just kind of moved my arms around. It was really good. That was a highlight for sure. It meant a lot. (Melissa: Interview 6)

For David, digital technology reduced the impact of environmental barriers and enabled him to communicate with his faith community by phoning into their meetings. They broadcast their services so he could attend virtually. He also felt that he could connect with the broader community by watching their ministry work on their global television channel. The use of technology to reduce the impact of barriers maintained his role in the community; this was significant to David as it made him feel that he was part of something larger than himself (David: Interview 2). David also used Google Home technology to communicate and interact with his family when they were in other parts of the house. He could receive medication reminders from his wife or request lunch to be brought down to his room. This regained agency meant a lot to David, as he felt he could control certain aspects of his life while limited in his physical abilities (David: Interview 1).

The use of medical equipment and other technological devices reduced the impact of environmental barriers to David's independence and his sense of home. David's function had slowly declined over time, and by the fourth interview, he described the increasing importance of using the commode in the basement due to difficulty managing stairs. He remained downstairs for toileting and to wash his hands, brush his teeth, and shave. Despite a continued need for assistance with setting up items for self-care tasks, David valued having his own space and equipment set up. The equipment in his physical environment matched his physical abilities (within the constraints of the home; building a shower or toilet in the basement area was not feasible). This match enabled David to adapt and continue doing the tasks at hand as independently as possible. Other forms of technology, such as using an electric razor, assisted with maintaining independence. The switch from using a razor with blades was small, but the impact was significant to David, as he highly valued being both independent and clean-shaven. The use of assistive technology facilitated participants' engagement in meaningful activities by reducing the impact of environmental barriers, thereby improving their sense of self and connecting them with their valued relationships.

### *6.2.3 Seasons Affect Routines*

> *Tammy: The smoke [from wildfires] was chasing all the animals this way from [British Columbia[11]], so we were getting extra bears and cougars. That is what is happening, the animals were coming this way because the smoke was so bad, so I wasn't going out by myself. I won't walk by myself. In the winter, when my husband gets home from work it is dark. (Interview 3)*

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[11] The province next to Alberta, on the other side of the Rocky Mountains.

Seasonal changes affected participants’ ability to engage in meaningful activities, often restricting or encouraging participation. During the spring months, hungry bears with new cubs coming out of hibernation provided additional risks and limited the activities participants were able to take part in, such as leaving the house to go on a hike or walk. Participants described the importance of being mindful of where they walked due to the danger of encountering bears in their rural communities (Chris: Interview 1; Melissa: Interview 2, 8). A barking dog could be perceived as a threat by bears, as could walking on a path that unknowingly separated a bear from her cubs. Melissa had to reduce her time walking in the forest and shift to more populated areas. This was difficult for her, as walking in the woods has the “calming, head-clearing feeling that you can’t really get in the house or just on the street” (Melissa: Interview 2). In the summer, she came across a mama bear and her cub during a walk, but she was able to get help from another local to avoid harm (Melissa: Interview 9). At times, Melissa began driving to another part of her mountain community to walk (Melissa: Interview 8). At other times, she adapted to the environment by simply carrying bear spray and making a lot of noise; “every time I’m out I’m like [claps loud] ‘hey bear’” (Melissa: Interview 2). Attaching a small bear bell to a backpack was another common modification to the environment that participants used when hiking.

Extreme weather patterns were also barriers to doing activities due to the physical environment for participants. Forest fires in the summer resulted in significant levels of smoke, thereby limiting the ability to leave the house. This impacted the emotional and physical well-being of participants. Jessica described how the smoke from forest fires resulted in her inability to walk outdoors; she found it “very frustrating with the smoke and the heat … it was horrible. It made for really long days. I felt my energy probably was worse, and my emotional energy, my depression of things. I was crying a lot” (Jessica: Interview 2). On hot days, some participants described how they modified their routine to walk early in the morning to avoid the energy-sapping heat of summer. Peter also shared, “we haven’t had the best of weather lately, with the smoke and everything else. With the rain and all the snow, we’ve certainly had a bit of limitation as far as being able to go out” (Peter: Interview 3). In the winter, various environmental barriers impaired going outdoors, such as snowstorms, icy and slippery sidewalks, lack of traction on roads, and snow build-up on street corners due to recently ploughed roads.

Lisa enjoyed going for walks and missed walking outdoors in the winter as she required a higher level of balance on the slippery sidewalks than she had at other times (Lisa: Interview 1). Melissa had a similar experience; “I’m also nervous now in the winter because I have fallen a couple of times” (Melissa: Interview 4). Peter desired to be outdoors with his family yet was unable to achieve this due to both the weather and the mismatch between his abilities and the physical environment. However, he found it more tolerable to be stuck at home due to the climate than because of other physical barriers. He viewed difficulty leaving the house resulting from snowstorms as normal and expected and, therefore, more acceptable than because of physical decline (Peter: Interview 2). When participants could not leave the house, they still enjoyed access to the outdoor environment by watching the world through the window. Even though Peter could not go outdoors due to both the weather and barriers at the front door during the first two interviews, he was comforted by the fact that he could still look at the mountains through the windows, an activity he enjoyed and never tired of doing (Peter: Interview 1). Melissa described the satisfaction she felt when watching the budding trees from her window, an activity she said that she would never have done before cancer limited her mobility (Melissa: Interview 8). The physical environment related to seasonal weather significantly impacted the person’s ability to participate in activities important to them.

Participants struggled to decide whether to participate in or forego certain annual cultural holidays or festivals due to deteriorating health. They looked forward to times of the year such as Christmas, mentioning feeling “super fulfilled, super excited, happy … I just love having everyone around and making people smile when they open something that they really are happy to receive or having good food all together” (Melissa: Interview 4). Lisa also described her enjoyment when spending Christmas together with her daughter (Lisa: Interview 2). Tammy excitedly decorated her home with moose figurines and ornaments, saying, “I was so happy! I was so excited! I told everybody about it, sent them pictures. … We’re not having Christmas, we’re having moose-mas!” (Tammy: Interview 6). However, at these times, participants also felt discouraged when cancer progression prevented them from going away or getting together with others for meaningful cultural events. Tammy was saddened when she could not go away with her family to celebrate the new year, their usual routine (Tammy: Interview 7). Melissa wanted to attend the opening parade for the local rodeo, which involved sitting for an extended period watching floats, horse riders, and marching bands pass by. However, she did not know if this would be a good idea or if she would regret it. She described the conflicting emotions between how much she enjoyed previous events versus acknowledging her limited activity tolerance, recounting:

> The parade is always a ton of fun and everyone always goes, but it's a lot of sitting and then afterwards, we usually do a big BBQ. So maybe it's better not to do the parade, but then they're always talking about it, and I'm like ugh, because last year I didn't go to the parade and I regretted it, but the year before I did go to the parade and I thought I shouldn't have. So, I don't know. So, I think whatever I choose, I'm going to be unhappy; that's what I'm looking forward to the least. I'm going to be annoyed either way. (Melissa: Interview 9)

Taking part in routine seasonal activities, cultural events, or important holidays was valued by all. Participants described how seasonal changes or extreme weather patterns could impair their ability to engage in activities because of factors such as environmental hazards, reduced confidence in their abilities, or feeling housebound. How this was lived out was different for the individual, depending on their abilities and their environment, but the environment impacted everyone.

### *6.2.4 Occupational Environment*

As discussed in Chapter 3 (Theoretical Concepts), the occupational environment is the overarching backdrop of the activity, and includes aspects such as the timing of activities, supports available, and the availability of the activity (Fisher et al., 2017). This context is a precursor to and requirement for doing what a person wishes to do. For these participants, having sufficient time to complete a task or ensuring that the zipper on a jacket was started were vital components for successfully conducting a task.

#### 6.2.4.1 Altered Relationship With Time

> *Tammy: If I want to go out and [the homecare workers] don't ask if I want anything else [or check if I need to get dressed] and they run out the door, then I'm not dressed … and you can't do [other things]. Yeah, it's frustrating. (Interview 3)*

Time-related components of the occupational environment significantly impacted the experience of everyday activities. This included the time of day that a task was done, whether or not there was any flexibility with timing, and if pacing of the activity was possible. Melissa and Jessica described the importance of planning what time of day a task was completed. Melissa scheduled to meet her friends for coffee in the mornings and avoided evening events, saying, “if someone asks us for a dinner party, even if it is in advance, just saying no because I’m pretty sure in the evening I won’t be up for it” (Melissa: Interview 5). Jessica described how she needed to schedule her early morning bowel routine, so she could go for early walks in the cool of the summer day when she had more energy. She was frustrated when she left her walks too late in the day and could not go out as planned (Jessica: Interview 1).

A second aspect of time pertained to whether there was an option for flexibility if required due to fluctuating or unexpected health issues. Lisa enjoyed her role at her workplace and wanted to continue working for as long as possible. However, her energy levels fluctuated as her cancer progressed, and she did not know how she would feel from one day to the next. She was thankful that she was afforded the flexibility to modify her work hours. This workplace accommodation was meaningful to Lisa and enabled her to continue working as long as she was able.

> If I show up to work, they are very happy to see me, and I’m typically there four or five hours a day, so that works out just fine for everybody. I can do a certain amount of things from home too. It is just getting up and getting there and whatever. … Originally, I was really struggling to maintain the same schedule, and it was becoming really difficult and it was just too taxing, like I couldn’t do it. I get up and shower and fiddle around a little bit and go to work for 10 or 11 o’clock, that kind of thing, and come home at four. (Lisa: Interview 1)

Pacing an activity was a third aspect that facilitated or hindered the participants’ ability to engage in activities. This included the length of time needed to conduct the activity, whether sufficient time was allotted for the task, and whether time to rest was incorporated during and following the activity. David, Tammy, and Peter shared their frustration and disappointment with the speed at which their morning self-care routine was completed. They all felt that the staff were often rushing due to insufficient time allotted. During those moments, David, Tammy, and Peter did not feel like they received a thorough wash and felt unwelcome to participate in their morning care routines (David: Interview 4; Peter: Interview 2; Tammy: Interview 1). Tammy noted that insufficient time designated for morning care prevented her from participating in other activities. She could not go out for a walk if they did not allow enough time to assist her with getting dressed in the morning. Melissa described the tension experienced when she felt “done” with an activity but did not want that knowledge to impact others around her. She often felt unspoken expectations—real or not from others.

> If I go out with friends, everyone says, "well, as soon as you're feeling tired or if you're in pain, just tell us and we'll go home." … I was doing more than I wanted to be doing, but I also felt like I didn't want to ruin it for everyone else. (Melissa: Interview 5)

Pacing included proactively setting limits within an activity, as well as ensuring rest breaks throughout the entire morning or day. Melissa shared the difficulty of travelling with others when the day involved continual doing without sufficient rest breaks to renew her energy levels:

> I don't want to stop them from doing fun things, but I also don't want to overdo it. … We have gone non-stop morning to night, do everything, see everything, eat everything, shop everything, just like go, go, go, go. … I am nervous about getting the balance right of not just staying in the hotel and doing nothing but also not affecting their fun too. I'd hate to be the stick in the mud. (Melissa: Interview 3)

Time elements were an important aspect of the occupational environment to consider and impacted participants' experiences of engaging in valued activities at all levels of functional decline.

#### 6.2.4.2 Receiving Support Helps Me Do What's Important

> *Tammy: I'm thankful that they [home care] come and do what they do. I'm thankful because it leaves me more time to do things for me, or maybe read that extra thing I need to read, and not struggle with packages and things, and not worry about cutting myself when cutting vegetables or grating the ginger for my tea. (Interview 9)*

The experience of engagement in daily activities was significantly impacted by the help and support participants received as their health declined. Tammy noted that when the home care workers assisted her to get ready in the mornings, it enabled her to do other things in her day. Helping her get out of bed provided a needed jump start for Tammy and facilitated goal attainment throughout the day. "I just make sure that I set myself up. I'm getting, I'm more situated now. This week has been a good week getting homecare come in, and it's really changed my attitude" (Tammy: Interview 1). Receiving assistance in the morning allowed Tammy to conserve her energy for other tasks during the day:

> My care workers come in and facilitate what I need for the day, which is amazing, because they come in early in the morning now, like 7:30, 8 o'clock, get me up, so I have to get up, which is fabulous. It's right. It is the way you're supposed to live and not lie in bed. So, they get me up and I get going. (Tammy: Interview 5)

Receiving and accepting support was not confined to assistance with morning care routines but also included other domains. Melissa discussed how supportive environmental factors such as available seating options at the museum enabled her to participate in an outing with her family. When tired, she was able to rest while seated without hindering her family as they explored the museum. She then had enough energy to join her children for lunch (Melissa: Interview 9). In contrast, Jessica could not engage in certain meaningful activities due to the lack of consistent transportation supports. She had an unreliable car and there was no available local public transportation from her rural property. Lacking the support to repair her unreliable car was a source of frustration for Jessica:

> It impacts your sense of self. It really knocks you down and that's why with that car I really needed, I need to go to the bank and I need to get in my car and just be able to know that I can rely upon that car just to go down to the bank and do my little errands and not be impacted by that car. (Jessica: Interview 2)

Jessica's growing fatigue eventually meant that she could not independently drive into town to pick up her son from school, meet friends for coffee, or go to the local pharmacy. The loss of the flexibility and independence that a car afforded was an ongoing struggle impacting her quality of life.

The ability to complete a valued but challenging task in the midst of progressing cancer, declining function, and increasing dependency was a challenge. It often required a combination of supports, such as home care and other physical assistance. For example, in order for Tammy to take the dog for a walk, three barriers needed to be addressed. First, she needed assistance to get dressed in the morning, which home care provided. When this did not occur because staff were rushed, it limited what she could do during the day. Second, Tammy had to attach the dog to a leash—a task that necessitated weeks of practice squeezing the clasp on the leash. Once she regained the strength in her hand to attach the leash, Tammy needed assistance to overcome the third barrier: positioning the zipper on her winter coat so she could step into it independently. Without help, all three preparatory aspects of taking the dog for a walk would become occupational environmental barriers, preventing her from participating in a significant activity she enjoyed (Tammy: Interview 3, 6, 7). Receiving and accepting appropriate support, practice, and modifications to how she put on her coat provided the occupational environment for Tammy to be involved in activities that were important to her, thus increasing her quality of life.

#### 6.2.4.3 The Space I Am in Shapes My Emotional Landscape

> *Tammy: I love sitting in my yard. It's nice and my plants are nice. I sit on the grass and soak it up. (Interview 9)*

The environmental context shaped participants' experiences of the activities that occurred within that space. For example, simply being outdoors brought great joy to all participants. All resided outside major city areas, which made this experience of lived space particularly significant. Simply being in natural surroundings with beautiful scenery was refreshing and nurturing. Even though Melissa could no longer hike, she cherished the moments she was able to be outdoors, enjoying the fresh mountain air (Melissa: Interview 8). Tammy described how being in the mountains was invigorating, as it took her worries away, gave her a sense of peace, cleared her mind, and allowed her to be mindful of the present (Tammy: Interview 1, 7).

> I'm just at home there. That's my place. It's just peaceful, listening to the river and watching the water and listening for the animals and the trees and the birds. You smell the trees and you smell the pine and you smell the cypress. You look at all the flowers and the daisies are so beautiful. It's nature, it's connection, which is great. (Tammy: Interview 1)

When spring arrived and the weather made for an easier trek outdoors, Tammy shared how being in nature made her feel alive: "I feel grounded, more grounded. The outdoors is so beautiful. Walking the river is so beautiful, and it's so peaceful and so serene. It's something that you want all the time" (Tammy: Interview 9). Peter also revelled in the thought of being outside the house, reconnecting with the natural environment. The first time he was able to access the nearby park with his children—thanks to the successful installation of a porch lift and wheelchair delivery—he described the joy he felt:

> Oh, it was amazing. It was a nice sunny day, it was beautiful out, and just being able to drive [in my wheelchair] up to the park and be out in the sunshine and breathe the fresh air was great, and just see the kids having a great time and running up to me and "watch me, daddy, watch me do this." That's something that I haven't been

> able to do for a long, long time, and being able to do that, it felt pretty good. (Peter: Interview 3)

Some participants highlighted their indoor environment as an important space. Tammy described how she felt when she could tidy her home and have it decorated to her liking: "When you're indoors, you want to try and make your environment indoors as nice as you can, so you're happy in your indoor environment" (Tammy: Interview 9). David spoke about his bathroom station in the basement, where a commode was set up. The commode was placed on a small rug, a nice reprieve from the cold concrete floor and open space in the basement. This small act of placing a rug to delineate a bathroom area made the space more personal and home-like for David. The match between the occupational environment, the person's abilities, and the task was important to maintain a sense of self, independence, and well-being in the midst of functional decline due to cancer progression.

The experience of space also pertained to being in the physical presence of others, impacting on a sense of connection to one another. Phoning friends was not as meaningful as having friends visit in the same space. Peter shared that

> it is very hard. It's not like I don't talk to friends. I'm talking to them on a daily basis, but talking to them over text or on a phone versus sitting down and having a chat and a cup of coffee or tea or whatever, is very different. They come by when they can, but I can't go to them, so I'm very reliant on them to come to us, which is difficult. (Peter: Interview 2)

The physical shift in space, actions and activities that separated work and non-work tasks was important to Jessica. She described the physicality of the routines she put into place to indicate this shift:

> You have visual things where you physically close the office, you close a binder or your list of things to do, and you go okay this is now time to, whatever it is, have your meditation or let your dog in or whatever it might be, or go stand outside and look at the flowerbed. (Jessica: Interview 1)

The space participants were in affected their experience of engaging in valued activities. Nurturing spaces enabled a feeling of connectedness, renewed energy, and restored well-being. This included being outdoors, having an ordered indoors, being physically present with others, and the delineation of space between work and non-work tasks. Lived space is an important consideration in the activities of daily life.

#### 6.2.4.4 The Importance of Freedom to Choose

> *Melissa: It does make you feel like, yeah, just that loss of "oh I don't get to choose what job I do" or "what activity I'm going to do?" or what the future might hold. (Interview 10)*

Participants felt they lost the *choice* to participate in an activity if the physical or occupational environment was not set up to accommodate their current abilities and the desired task. The impact of being deprived of choice was significant. Participants with functional limitations described feeling homebound and confined when unable to leave their home, as environmental barriers eliminated their option to leave. Their sense of discouragement was noticeable and profound. His voice breaking, Chris said, "the loss is daily. It is the loss of the ability to—not the ability—the choice" (Chris: Interview 1). Limited choices arose in both significant and more minor aspects of life, such as the more immediate loss of the ability to choose what to eat (Lisa: Interview 1) as well as the loss of choices that were farther reaching, such as being "stuck in the house" for long periods of time due to mobility and environmental barriers (Peter: Interview 2).

The ability to make choices was at times informed by participants' friends or acquaintances. For example, Melissa struggled when others decided to invite her to social events or exclude her out of fear of exacerbating her pain levels. Frustrated, she said, "I wish people were just okay with being told I'm in pain … I don't mind them saying 'oh that sucks, do you still want to do this or not?' and then you can make that choice" (Melissa: Interview 5). She was saddened when friends did not give her the choice of attending events without consulting her. Being given the option was important, as it provided a sense of personal agency and control. Melissa commented, "choosing what and how much [I do] probably does help" (Melissa: Interview 5). David described how the choice to phone into his faith meetings was only possible with the correct set up. Initially, he could only phone in when his wife was available, as he needed their shared cell phone to be downstairs for this event to occur (David: Interview 3). Alternatively, if his wife attended their faith meetings in person, another congregation member needed to be at his home to set up the connection (David: Interview 4). The choice was taken away at times when there was a poor match between the environment, the participant's abilities, and the task they wanted to participate in. The ability to choose was a vital issue for all participants, facilitated or hindered by barriers or the supports within the physical and occupational environment.

### *6.2.5 Theme Summary*

The lived experiences of everyday activities for participants—working-aged adults living with advanced cancer—was significantly impacted by their physical and occupational environments. Although its influence is often overlooked, the environment can be modified and remodified over time to match participants' changing abilities and goals. Doing so enabled participation in meaningful tasks and brought a sense of normalcy, independence, sense of self, and satisfaction. However, the environment negatively impacted participants' quality of life when it was not set up appropriate to their abilities and the activities they wished to do. While not all physical environmental barriers could be adapted—extreme weather patterns genuinely limited participants' ability to go for walks—addressing other environmental restrictions (e.g., stairs) facilitated continued engagement in activities and valued connection with family and friends. Participants also discussed the significance of their occupational environment, including their experience of time and space, in shaping everyday life while living with advanced cancer. The ability to choose what or when they participated in activities was vital for participants' well-being. Freedom to choose was either denied or made possible by the environment. A poor match between abilities and the environment meant the ability to choose was, in effect, taken away. Two significant contributions to knowledge resulted from the environment's findings: the focus on the environment as a barrier or facilitator for engagement in meaningful activities for working-aged adults living with advanced cancer, and the concept that the environment has the power to remove *choice* for these adults. The environment significantly impacted participants' quality of life and well-being at the end of life.

## 6.3 Conclusion

This chapter discussed the first two themes, exploring the high value participants placed on intentionally pursuing valued activities and the impact of the environment on their everyday life. The following chapter is a continuation of the findings. It will explore the third and final theme, *The challenge of unrelenting change and loss*, noting the longitudinal changes in the study as life keeps changing.

# CHAPTER 7: FINDINGS THEME 3

This final chapter on this study's findings focuses on the longitudinal challenge of unremitting change and loss for working-aged adults living with advanced cancer. It builds on the stories of participants (Chapter 5: Vignettes) over their interview series, and is the third of three themes identified in this study. Chapter 6 explored the first two themes. The first theme, *The intentional pursuit of engagement in everyday activities*, is essential for understanding the lived experience of occupational engagement for working-aged adults living with advanced cancer. Theme 2, *Everyday life is contingent on my environment,* expands on participant experiences, highlighting the essential role of their environmental context. The experience of advanced cancer is one of fluctuating symptoms, bodily decline, and uncertainty, whereby change can occur on a monthly, weekly, daily, or hourly basis. These longitudinal changes are explored in the third theme, *The challenge of unrelenting change and loss*.

## 7.1 Theme 3: The Challenge of Unrelenting Change and Loss

This third theme, *The challenge of unrelenting change and loss*, calls attention to the participants' longitudinal experience of living with progressive and constant change, uncertainty, increasing dependence, and their ongoing need to adapt to change in order to continue participating in meaningful activities. Each person's situation was unique, yet all participants described continuous and significant functional changes that impacted their lives over the course of their interviews. Increasing dependence and physical deterioration was a reality over the interview series. Theme 3 explores these fluctuating experiences in further detail, and Table 7.1 outlines the theme and subthemes discussed in this chapter.

**Table 7.1**

*Themes and Subthemes*

| Theme | Subtheme | Minor Themes |
|---|---|---|
| The challenge of unrelenting change and loss | Living with unrelenting change and uncertainty | Continuous change with disease progression<br>Experiencing hardships unrelated to cancer when you have cancer |

| Theme | Subtheme | Minor Themes |
|---|---|---|
| | Losing independence as I become unwell | Anticipatory grieving of future decline and loss<br>Inevitable increase in dependency |
| | Adapting to change is an active, ongoing process | I adapt by continuing to do<br>I adapt how I do things<br>I adapt how I think |

### *7.1.1 Living with Unrelenting Change and Uncertainty*

#### **7.1.1.1 Continuous Change with Disease Progression**

> *Interviewer: If you had to summarise the top three things that you would want other people to know, … what are the three most important things?*
> *Melissa: [Cancer] changes everything about your life and how you are in the world, who you are, and that there is nothing in life that it doesn't touch. … Even though you're the same person, it changes and touches every aspect of your life. … I think it changes the way people see you, and it changes your priorities, it changes your finances, it changes your career life, … it changes the relationships with everyone around you because they see you differently and you see yourself differently, … it changes your physical abilities, your mental capabilities. … I feel like it affects every part of your life. (Interview 10)*

Ongoing functional decline is a reality for people living with advanced cancer. Changes in functional ability can shift from month to month, week to week, and day to day as disease disrupts normal function. Participants in this study described these changes as "a rollercoaster" (Peter: Interviews 1-3), where "every day is different" (Lisa: Interview 1; Tammy: Interview 2, 5). Many participants described the functional changes they experienced as a general decline over time. David described his functional changes as "I know it's going downhill. There are probably not going to be too many uphills" (David: Interview 2). Chris struggled with the uncertainty and cyclical nature of some of the disease-related changes he experienced. He linked feeling well and unwell with function as he shared his experiences:

> When you are progressing through the disease, it's not just this symptom for a known period of time; you don't know. … So, be it good or be it bad, you're facing a transition from feeling well and being able to do most things to a state where you really can't, be you feeling sick or just unable. You go through that change, and you go through that change more frequently as the disease progresses. (Chris: Interview 1).

The continuous change and uncertainty participants experienced due to the cancer progression was not solely evident in their physical deterioration but was also apparent in other domains in life. Lisa described the "physical changes, work changes, mental changes" that she had experienced since her diagnosis due to the spread of her cancer (Lisa: Interview 1).

Participants experienced erratic fluctuations in their emotions while living with advanced disease, as described by Chris:

> Put on your big boy pants, get your head out of your ass, and realise it's going to be, this is what it is, and realise it's going to be hard, and it could get harder every day for a number of days. You've got to be ready for it. It's going to hurt. You're going to cry. Just because you're crying now doesn't mean you won't be laughing later. Hang on for the good times because they're still out there; we still have them. But even the swing from the hard times, the bad days to the good days, you better hang on to that too because that's not something you can predict or necessarily control. I'd say it's a lot about getting ready; it's going to be a ride. Cancer is a ride. It´s not all bad either. You learn things you never thought you would about yourself. (Chris: Interview 1)

There was constant change and no stability in daily life when living with advanced cancer. This continued as participants' disease progressed over the interview series.

#### 7.1.1.2 Experiencing Hardships Unrelated to Cancer While You Have Cancer

> *Tammy: When [my daughter] passed away, she was at a friend's house and unbeknownst to me—I didn't know what was going on [with the drugs]—and he knew and he watched it happen, [cryng] and he found me and said she was snoring. … So, when he phoned me late Sunday night at 10:30 at night and said she's snoring loudly, I thought, well she always does, that's just, you know, that's [her], she snores;*

> *I'm used to that. So, I didn't think anything of it. She passed away that night [from a drug overdose]. (Interview 9)*

In the midst of disease progression, participants experienced difficulties and adverse circumstances unrelated to their cancer journey. These included illness or disability within the family unit, flooding homes, house fires, and the deaths of pets, children, or siblings. Jessica described the challenges she faced while supporting her son with autism. He required significant assistance with daily life, so she had to deal with tasks such as coordinating regular caregivers and scheduling activities. She was also in the process of applying for guardianship and trusteeship for when her son turned 18. Complicating everything else, Jessica's house had also undergone significant flooding 5 years prior, and unresolved repair issues remained. Exhausted, she reflected on how their life was "an open platter with people coming in our life for autism and for the flood. In 2013 the river ran through our house. And now cancer. So, for our family of three, it's very difficult" (Jessica: Interview 1). For Jessica, the pressures of her non-cancer responsibilities and the weight of certain unexpected events felt unrelenting. Yet, in the midst of her pain and constant fatigue, Jessica still sought to look after and be there for her family.

A number of participants related multiple experiences of grief and loss over a short period of time that were unrelated to, but concurrent with, their cancer. These additional losses impacted their everyday life. Amanda had a strong attachment to her dog. He meant everything to her, to the point of not wanting to go into a hospice if that meant she had to leave him. Her feelings about this were so strong that she said, "I think I'd want to end my life, end things because I wouldn't have anything to live for anymore. I mean I've got my kids but … they're doing good. He's more important that way" (Amanda: Interview 1). The death of Amanda's dog after her first interview was an overwhelming loss. She shared the devastating loneliness she felt now that her primary companion and source of comfort was gone (Amanda: Interview 2). Life, over and above cancer, was changing, and the impact of additional loss was hard.

Tammy's daughter passed away unexpectedly between her third and fourth interviews from an unexpected drug overdose. Her grief was intense during the fourth interview, and she cried as she described the emotional toll it took on her family. Tammy never thought she would bury her daughter first. Shortly after this, Tammy's brother also died, and the family home she grew up in burnt down (Tammy: Interview 4). Overwhelmed by grief, Tammy wept as she spoke. “It is still hard. It’s hard. It’s still hard, and I don’t know if it is ever not going to be hard. I cry every day, not all day, but every day” (Tammy: Interview 6). Arranging funerals and all that was required following a death were additional tasks that Tammy had to do while confronting her own pending death. Other unexpected, non-cancer-related events continued to occur for participants who were experiencing their own shortened lifespan and the losses caused by cancer. This heaviness was difficult for participants.

Loss was also experienced in other ways. David had a significant life transition when he and his wife moved from their long-term community to another province to live with their daughter and son-in-law. This was a loss on many levels, such as losing a familiar home, their own possessions, a workshop, and living near to many friends (David: Interview 1). For all participants, irrespective of the stage of cancer, life continued to be full of hardships, tears, and loss due to unexpected challenging events and circumstances unrelated to, but complicated by, their cancer journey.

### *7.1.2 Losing Independence as I Become Unwell*

Losing independence and the resultant experience of increased dependency was a reality for all participants. They recognised that their functional abilities would continue to decrease over time and that they would be increasingly limited in what they could do on their own. As their ability to engage in meaningful activities increasingly became impaired over time, participants had to learn to accept a degree of support, modify their involvement, or learn to live with being more dependent. Losing independence frustrated many and their abilities kept changing as they became increasingly unwell. Participants experienced the accumulation of incremental losses which were compounded by frequent, more sudden losses.

#### 7.1.2.1 Anticipatory Grieving of Future Decline and Loss

> *Tammy: What do people do when they can’t facilitate a life? How devastating that must be, how sad. (Interview 5)*

Participants reflected on the future losses they would eventually encounter, as they anticipated and experienced ongoing decline in their functional status. Thinking about the changes yet to come saddened many. They reflected on how they would feel if when they were unable to engage in a given meaningful activity. Lisa described how she would feel if she was unable to work anymore: “I’d be very disappointed … There’s a certain amount of reality that you have to face when given this diagnosis right, and things aren't working in terms of medication. It's not automatically just going to turn around and get better" (Lisa: Interview 1). When discussing future loss and decline, emotions expressed varied among individuals from anticipated feelings of disappointment (e.g., Lisa's comment) to a future sense of devastation (e.g., Tammy's quote above). A collective sense of grief and loss was expressed by all participants when anticipating future uncertainty, change, loss, and increasing dependency as a result of functional decline. Their ability to adapt to change did not prevent participants from these feelings; they had a heightened awareness of how cancer progresses and what the future may entail.

For many participants, *being outdoors or active* such as going on hikes in the mountains, walks in their communities, or to the local hot springs held great value. It had a calming effect, clearing their minds or lifting spirits. Tammy spoke about the hope and peace she experienced being outdoors. When Tammy considered not being able to do these activities anymore due to increasing dependence, she said, "I'd be devastated. I'd feel so stuck. I would. I wouldn't know what to do with myself if I couldn't facilitate that. I would find a way somehow … I would find a way" (Tammy: Interview 5). Similarly, Melissa described the loss and grief she would feel if she was not able to attend her valued exercise class anymore at some point in the future: "I'd miss it … like another digression, like another step towards less and less. I think if I couldn't do that, then there are a lot of other things I also couldn't do, so it would be hard to accept" (Melissa: Interview 5).

The thought of no longer having the ability to *do everyday tasks* such as the ability to cook a meal or simply prepare a hot beverage was frustrating for many participants, as these were activities they valued and wanted to continue. Melissa described how any future loss of independence, such as loss of the ability to make a cup of tea, was not solely about the anticipated loss of function. It also affected those around her. "That would be very frustrating. I already feel like I'm not much use to many people already, so it would be like a whole other having to rely on someone else for something pretty simple … it would be pretty frustrating" (Melissa: Interview 3). Tammy also spoke about the frustration she felt when unable to engage in simple but meaningful tasks such as brushing her cat in the midst of a difficult day. "Just when you can't meet your challenges, it's frustrating" (Tammy: Interview 1).

Participants also reflected on what it would mean if, in the coming months, they were no longer able to do things *with others*. Lisa lived alone and was grieved at the thought of a future with increasing challenges connecting with others. She said she would be "very disappointed … hopefully, I'd still at least have visitors" (Lisa: Interview 1). Regardless of the future loss envisioned by participants due to increasing dependence—whether it was a loss of social connections, the ability to independently make their own meals, or be outdoors—the sense of approaching loss was significant and unremitting. All participants expressed anticipatory grief. Chris described how his struggle

> wasn't so much about a disease or fighting a disease or anything like that. It was more about loss, and you had to give up things, and if there is a thread I will weave through this conversation today, it's probably that because that was the most significant piece, and it's what I deal with every single day. Be the loss great, or be the loss small, it is a loss. (Chris: Interview 1)

Tammy expressed similar feelings of anticipated sorrow, stating, "it would be terrible. I'd be so depressed. That would be awful. Yeah, yeah" (Tammy: Interview 1).

#### 7.1.2.2 Inevitable Increase in Dependency

> *Melissa: That's the most annoying thing about the pain, I guess, is that it takes away the independence, more so than the pain itself. Obviously, I don't like pain, but I guess what it takes away is what is hard, and that is a lot of independence and spontaneity, and just the ability to do what you want when you want to do it, which is something I definitely took for granted for a long time. And being more reliant on others I find frustrating, which I think most people do. Nobody likes that feeling. (Interview 9)*

Losing independence as health declined was a significant aspect of the lived experience of occupational engagement for all participants throughout the interview series. Increasing dependence and the subsequent loss of ability to independently participate in meaningful activities were prime concerns for all. For some participants, dependence occurred gradually; Amanda called it a sporadic shift. For others, significant change in the need for assistance occurred within a few short weeks. Peter's ability to function unassisted changed dramatically over a short period of time. He transitioned from the ability to walk with a cane to relying on a wheelchair for mobility. When Peter described his experience of deterioration, he spoke of having changed from being a "fit, healthy young man to somebody who basically has no mobility left. I spend most of my time in a wheelchair or a recliner or on a bed because I can’t stand up. I don’t have the physical strength” (Peter: Interview 1).

Participants’ distress over losing their independence in valued activities was evident in all 33 interviews. Weeping, Amanda explained that being unable to go to the grocery store was “awful because I’m used to being independent, so I’m losing my independence. … It just feels [crying] I don’t know. … [My independence means everything] it does, and it always has” (Amanda: Interview 2). Over the previous months, Lisa had seen her functional status decline and was distressed over her growing dependence, with its perceived threat to her well-being. “Not being able to [do things], like I don’t want to be completely an invalid, yeah, that’s hard” (Lisa: Interview 1). Melissa also expressed her distress at how the inevitable increase in dependency permeated all of life:

> I just felt completely useless, like nothing in my normal life was the same, stuck in the house, couldn’t do anything for anyone, had to ask for everything. I mean, there was a time when [my husband] was wiping my butt. And just not able to shower myself. (Melissa: Interview 3)

The impact that the loss of independence had and the meaning it carried was unique to each participant, but they all shared an inherent sense of loss and distress when abilities declined over time. No one was exempt.

The increasing inability to participate in meaningful activities was discouraging for all participants. They spoke about how it felt as though they were *losing a part of themselves*. This sense of loss was more than simply being unable to do something. Chris was an active man who enjoyed hikes and regularly walking his dogs in his community. When he was no longer able to go for frequent walks outdoors due to the progression of his cancer, he felt that this change diminished him as a man. Over time, Chris had to reduce the frequency and distance he walked. Once able to complete long-distance walks, a short dog walk to the end of his driveway was all he could manage now. He lamented the changes he saw in himself: “I was always very physically active … [and] fairly large and muscular and was able to do what I wanted. I can’t do that anymore. I can’t even necessarily walk right now … down to the end of the street” (Chris: Interview 1). Similarly, Peter’s abilities continued to deteriorate over time. Like other participants, he went from being an independent person to someone requiring assistance in multiple domains. In his second interview, he described how he increasingly felt that he was “more of a burden, just because you’re physically unable to do pretty much anything. It is hard in that regard because you are not able to be the person who you were” (Peter: Interview 2).

As function declined, many participants reflected on the challenges of growing dependency in intimate tasks such as toileting. In his first interview, Peter was concerned about episodes of urinary incontinence and the need to wear incontinence underwear. During Peter’s second interview, this progressed to experiencing episodes of diarrhoea which he found embarrassing. The increasing frequency of diarrhoea limited his ability and desire to leave the house. He described this as “very hard. Not being able to wipe your own bum is very demeaning. That’s difficult, very difficult for me anyways, to take” (Peter: Interview 2). Over the course of several weeks, Peter’s intimate hygiene abilities continued to decline. By his third interview, Peter’s incontinence was complicated by a hospital admission–an environment that did not facilitate his independence. He was now wheelchair dependent, a significant change from a few months prior when he was walking independently. An overhead lift was required in the hospital, as he was unable to transfer independently onto a commode due to the hospital being set up differently than at home. Frustrated, Peter spoke frankly about how the overhead lift

> pinched everything together, and I had no control over my faculties. I would pee, or I would defecate, I would poop on the floor because I couldn’t control anything and it was just being squeezed right out of me, and there were certainly times where it was, just sitting the way that they positioned it, it pinched in the wrong areas and that was quite painful. … Yeah, when it pinches your genitals, it’s not fun. (Peter: Interview 3)

Increasing dependency often brought with it a *loss of privacy*. Peter described how he felt this loss when he was in the hospital. He found that “everything is hanging out for everybody to see so you have no privacy whatsoever and I used to be shy, and I just don’t care anymore because really, it doesn’t matter” – in contrast to “being at home, in my own private home, my bedroom, I shut the door and wheel into there [the bathroom]” (Peter: Interview 3). Tammy had always been an independent, relatively private person who loved to swim. She was hesitant about visiting the hot pools in the local mountain town due to difficulty donning and doffing her bathing suit with flaccid hands. She said she “was worried about going because … I do need help, and I do have a hard time asking people to help me …

it is awkward” (Tammy: Interview 5). Over time, her desire to swim meant her priorities changed, and she was willing to forego her privacy and ask a stranger to help put on her swimsuit.

The inescapable need to receive assistance from others was difficult for some participants to accept, particularly as they strove to retain their independence. As Tammy’s experience highlighted, giving up independence in one area (dressing) allowed independence in another area (swimming). However, it was also the *meaning attached to the loss of independence* that was a concern for participants. More than the loss itself, the loss of independence implied inevitable full dependence and pending death. Melissa described the “shortcuts” she took to feel a sense of control and to reduce dependence on significant others, such as hiring a cleaner for the house. Although thankful for the assistance, she still struggled with the change: “it still feels like a bit of failure because I’m not the one keeping the house” (Melissa: Interview 1). Melissa described how she learned to prioritise what she did in order to not overexert herself as her function declined. However, she also found this change discouraging:

> I’m just tired of not being able to do everything I want to do. I want to be able to get up in the morning and do lots of things and not have to measure like, oh, if I do that, then I won’t be able to do that. So, deciding which is the more important, like I’m just kind of tired of not doing it all. (Melissa: Interview 5)

Participants wanted to view themselves as independent and competent individuals despite changes in functional status. Jessica continued to identify herself as an independent person who required increasing assistance as her cancer progressed, yet also acknowledged that losing her independence “impacts your sense of self” (Jessica: Interview 2). Peter described how his functional decline over the previous month was accompanied by a sense of being a burden:

> I find you feel yourself as more of a burden just because you’re physically unable to do pretty much anything. It is hard in that regard because you are not able to be the person who you were and to help out and do the cleaning and the cooking and help with the kids at bedtime because I’m not able to—not through not wanting to—it’s just physically not being able to, and it puts a lot of extra pressure and stress on [my wife], which isn’t easy. (Peter: Interview 2)

Like Peter, many other participants felt that their growing inability to engage in certain activities, and increasing need to accept help from others, impacted not only how they viewed themselves but also how they viewed their relationship with others, particularly within their family unit, but also in the wider community.

Parenting is a lot of work at any time in life. When a person is also living with advanced cancer, functional decline and increasing dependency *make parenting even more complicated*. Participants described how important and meaningful being a mother or father was for both themselves and their children. However, challenges arose as they balanced maintaining their role as parent whilst looking after their own wishes and needs as their cancer progressed. Jessica spoke openly during her interviews about struggles raising a son who had autism. She described how "we just got him set up to transitioning. … We had to keep that going. … It's been very challenging as a mom being sick like this, and just kind of watching my family happen while I'm in this process" (Jessica: Interview 1). At times she had to "step away [from some caregiving tasks for her son] because I don't have the energy" (Jessica: Interview 1).

During her final interview, Jessica spoke frankly about the impact disease progression and growing dependency had on her as a parent. In addition to the fatigue felt from daily activities such as cooking and cleaning, other parental tasks complicated her lived experience of cancer. Jessica was navigating both being a carer of someone with high needs—her son—as well as dealing with her own functional deterioration due to cancer. Reflecting on the administrative tasks associated with organising her son's care, she said, "there are rules and requirements … and things that have to be done whether you're sick or not. … I'm told to rest, but I'm still expected to be a liaison, which I don't think they always get" (Jessica: Interview 2). She also still managed many household tasks for her husband and son, as her husband was working. Carer tasks increased in difficulty as her cancer progressed. Drained, Jessica described how life must go on. She put herself last to look after her family, even though she was dying of cancer. Jessica had to coordinate the employment of the caregivers for her son, which included dealing with the tax office:

> It's a payroll situation, and other people are involved and are really relied upon, and there are real serious rules of deadlines with [the tax office], and payroll payments to them, you can't ignore those rules; so I don't have a choice in ignoring those rules and just saying "oh whatever, they'll understand because I'm sick." They don't

> understand because you’re sick. … Even if I’m sitting here and writhing in pain, then I have to look at the clock, I have to take a pain med, and I have to decide okay I’ve got to get that payment in and drag myself into the bank, even if I have to walk there, to pay [the tax office] this calculation of a remittance of payroll. That is all there is to it. If I can’t walk it in, then I need to phone somebody to drive me in or to carry it into the bank, and they’ll pay it for me, but it’s got to be calculated and done. Yes, if I have to stay up until midnight to do that calculation, then I will. It is … harder and harder to do. (Jessica: Interview 2)

Roles within the family unit also changed, as deteriorating health affected everyone in the family unit. Over time, the role of a spouse shifted to include the role of caregiving. Chris describes how:

> It’s hard. [pause, tearful] And it’s not just hard on me, it just washes right over [my wife] too. … It is not limited to a person with cancer. There is only the two of us and the dog. … Cancer is a condition that affects the family. The disease is a very small part of it that necessitates certain actions at home, the clinic, and the hospital, but it is no more than that. Cancer is very small … but it gets into the family. It gets into everything. (Chris: Interview 1)

Peter’s wife became his primary caregiver, and their relationship dynamic shifted as his cancer progressed. “It completely changes, … it really does. [She] is more of the caregiver now, taking up that role more so, so it has changed our dynamic; I mean cancer in general has changed our dynamic physically and emotionally” (Peter: Interview 2). Living with advanced cancer affected how participants related to others.

As their cancer progressed, participants continued to *lose their ability to engage in certain activities*. Melissa shared frustrations of her inability to do the same activities with her husband as she previously was able to:

> It sucks to just have a lot of the things that you enjoy doing together gone. [My husband] and I used to golf all the time together. It was our couple thing. A lot of things that I like to do and a lot of the things that he likes to do are not the same, and golf was one thing that we both really enjoyed. So, cancer taking that, like sometimes it makes me really angry. I’d say that for me is harder than thinking of a shortened lifespan or the side effects or the actual pain or all the appointments or the pokes, you know, like all the physical stuff, I find that if I could find a way to have

> the same connections and feel the same, be able to be the same person, I wouldn't mind all that so much, even though it all goes together and it's part of why. (Melissa: Interview 3)

When participants lost the ability to engage in certain activities, they often lost a degree of connection to their community. David always enjoyed socialising with friends and family. This priority changed for him as his cancer advanced and fatigue reduced his stamina. In his last few months of life, David's energy levels waned, and he increasingly wanted friends to only visit for a short time or to simply get updates from his wife. Eventually, he had to abandon face-to-face catch ups and maintained these relationships via telephone conversations instead. David had become increasingly soft-spoken over the course of his five interviews. He described the difficulty and frustration he experienced when a friend could not hear him clearly due to his quiet voice. Saddened, he said that it made him feel "not good. A little bit sad. More probably disappointed that I can't talk to them anymore. If they are right close, it's fine, but over the telephone or Google, it doesn't carry as good" (David: Interview 3).

Chris similarly took stock of his loss and increased dependence up until this point. The impact of his progressive functional decline not only affected him, but also his family. Appraising all that had happened, he described the weightiness of his experience, saying,

> it's always there, sure that the hurt is always there, but there is also a numbing, and that's a loss. I never really thought about it to a certain extent, and that takes away from life. Life should be full of ups and downs. It shouldn't be a narrow band. It shouldn't be. So that's kind of how it makes you feel; it makes you feel a little numb. It hurts sometimes more than others. It is not limited to a person with cancer. There is only the two of us and the dog. I would not imagine that it would be any different with a family with 15 kids. It is going to wash over them as well. … Cancer is not a disease. Cancer is a condition that affects the family. The disease is a very small part of it that necessitates certain actions at home, the clinic, and the hospital, but it is no more than that. Cancer is very small. Cancer is a weak, sickly little cell that is one of the easiest to kill, actually. It is not a terribly strong cell. But it gets into the family. It gets into everything. It just takes time, though. So that is the point I want to make; there is a very big separation in the way I see it between the disease, which seems to

> be not the hard part … as far as medical intervention, but it’s the condition that really affects everyone. (Chris: Interview 1)

Simply put, participants had once considered themselves independent but were becoming increasingly dependent as the days, weeks, and months passed and their cancer progressed. This growing inability to independently engage in meaningful activities was difficult for all participants. The experience of relentless constant changes, ongoing losses, and increasing dependency ranged from frustrating to deeply distressing. Chris described how “the loss is daily” (Chris: Interview 1). Amanda said, “I’m having a really hard time doing the things I used to do, which really upsets me” (Amanda: Interview 1). Tammy wept as she described no longer being able to do simple tasks; it was “devastating [crying]. Absolutely! … It’s devastating to not be able to do things” (Tammy: Interview 1). Over time, participants became increasingly aware of their loss of freedom, the loss of control, and their need to give up some of their valued roles and activities. Peter described the scope of his loss, saying, “it’s about the freedom. I don’t have that freedom anymore. So that’s tough, that’s really hard. I can’t just jump in the car and go meet a friend” (Peter: Interview 1). Melissa understood that “it kind of feels like the control is taken out of your hands” (Melissa: Interview 10). Loss of independence was progressive, so individuals did not always have time to process one loss before additional, cumulative losses were experienced. The experience of relentless, cumulative losses was a recurrent theme over the course of the interviews and profoundly challenging for participants. Melissa sighed as she summed up her experience of declining function, disease progression, and successive losses with these words: “I find that tiring, just knowing that this is not going to change, this is life, this is the way it is, and sometimes I have trouble accepting that” (Melissa: Interview 5).

### *7.1.3 Adapting to Change is an Active, Ongoing Process*

Adaptation played a large role in participants’ experience of advanced cancer. Some participants spoke directly about how they adapted to change, yet others alluded to the processes consistent with adaptation. In their interviews, participants described how they adapted to functional decline through a variety of means, including an active intentionality to engage in everyday activities, modifying how they participated in activities, and reframing their perspectives when processing experiences. Finding ways to adapt gave participants the ability to continue doing activities they valued despite increasing dependence due to cancer progression. Even though they may have needed to change how they engaged in these activities from interview to interview, adaptation enabled a sense of normalcy. Adaptation helped participants feel like themselves. By way of illustration, Peter adapted how he played with his two young children on multiple occasions. He described his attempts to establish a "new normal" for them in the face of his declining health. Importantly, what Peter defined as normal continuously changed for Peter over time. Adaptation to these changes was an ongoing process and a valuable tool in Peter's life.

> It is very hard when they ask you "how come you can't do these things" or "why aren't you getting better" and "I wish you were normal" kind of thing and that's difficult and I say "well, this is my new normal, look at the bright side, I can give you guys a lift on the chair, and nobody else can do that" You try and spin these into positives and that's what I've been trying to do the whole time that this diagnosis came through, try to be as positive as you possibly can be, not only for my own sake but for the kids and everybody else as well. (Peter: Interview 3)

In addition to the adaptations Peter made that affected how he played with his children, he revamped his and their expectations when needed and focused on what could be done rather than what was not possible. Peter revisited these adaptations as needed over a period of five months and as his function declined.

#### 7.1.3.1 I Adapt by Continuing to Do

> *Tammy: When this happened to my nerve, I was sitting here, and my hand was ten times the size. It was all inflammation, and it was black, and I was so sick. [My friend] comes and she had a coon hound, [says] "let's go walking." So, we walked every day. She got me back on my feet. (Interview 2)*

Participants sought to keep engaging in valued activities, so when their abilities began to decline and tasks became difficult, they needed to adapt. Motivation to adapt tasks was stronger when they participated in those meaningful activities related to their interests, roles, and relationships. Intentional, active, and continued participation in everyday life supported a sense of capacity for the individual, facilitated a sense of normalcy, and assisted with maintaining a sense of self amid their seemingly unstable world and deteriorating function. In the earlier example, Peter described the adaptations he made to play with his young children. Over time, he reframed how he thought and spoke about his diminishing abilities in order to maintain his valued role as father. Living with cancer as a father of young children was hard for Peter, yet his ability and willingness to adapt had an impact on him as an individual, as well as his family unit. His declining functional abilities made playing with his children incredibly difficult. However, *through* play, he experienced a sense of competence in his relationship with his children even as function declined. Peter observed that

> the kids hate seeing me like this too; they want me to be up and want me to be like a normal dad who can run and chase them, but I can't do it. I tell them I can chase them in the wheelchair, so it's like I've got a car. So, we try to make the most of it and look on the positive side of things. (Peter: Interview 1)

Peter's ability to adapt to declining abilities through continued participation in everyday family activities helped him to maintain his meaningful relationships with his children.

All participants experienced ongoing decline in their bodies and abilities as their cancer grew. Never static, adaptation was an evolving process due to the progressive nature of the disease. Melissa illustrates this in her role as a mother of four children. She considered adaptation to be a balancing act, knowing how much to do versus what not to do. She shared the gradual nature of adaptation over time, saying,

> it's pretty gradual. I still have moments of frustration, but they're probably fewer and maybe last a little less time because I guess I'm kind of used to, I'm getting used to my new reality, I guess and what my body can and can't do. Sometimes it's super frustrating, you just want to do it all or not suffer consequences. You want to just do things and then not pay for it. That's probably when I get the most frustrated, is when I have pushed myself and then get that little reminder that that wasn't a good idea, and that's when I'm really grrrrr, I just want to feel normal. I think it has just been time and getting used to, we all get used to life and whatever form it presents itself. Just gradual. (Melissa: Interview 10)

Significantly, despite experiencing fluctuations and setbacks in their functional abilities, participants actively sought ways to adapt, with the goal of continuing to participate in their valued activities. This was demonstrated by Tammy, who tried to keep her focus on her daily goal of doing as much as she wanted to, adapting her approach to activities when necessary and accepting the changes that needed to be made. In order to achieve continued participation in valued tasks, Tammy declared, "I'm trying to do something, I'm trying to get better, and I need to do certain things to do that, and I just keep working at that, making my decisions based upon that, and working towards that" (Tammy: Interview 6). Throughout

Tammy's nine interviews, she intentionally focused on what she could do, not what she had lost. She celebrated the new skills she learned as well as the small accomplishments. When no longer able to conduct tasks as easily as before, Tammy persevered, seeking to be as independent as possible as she adapted to participation challenges. Her determination and confidence to keep active led to an increase in functional capacity over the year that she was interviewed. Tammy triumphantly said, "when people say, 'oh let me do that for you,' I say 'no, I can do it myself.' So what if this is the way I peel my orange? I can peel my own orange" (Tammy: Interview 9). Tammy adapted by creatively changing how she completed tasks and by working hard.

Other participants described their strategies to adapt activities despite encountering difficulties arising from declining physical abilities. In her first interview, Jessica described the importance of journaling or writing things down to help process the shifts she had experienced over the passing months.

> Well, it's shocking, and it hits your core and you feel destabilised, like you feel really rocked, your world has been rocked. … When you feel like you're losing your sense of self, … I record things and write things down, and that's helped me just stay on track. … You feel like you're being proactive, and you're trying to take care of your spiritual self, your mental self, your physical self, and your dignity along the way, and then people around you. So, I think those different aspects, if you can try to focus on the things that are important to you and the people around you, that's where you kind of start. (Jessica: Interview 1)

In the face of impaired function, participants had to adapt how they engaged in everyday activities to foster a sense of normalcy, often adapting and remodifying activities over and over. Lisa wanted to work for as long as possible, despite living with the ongoing challenges of advanced cancer. To do so, she had to shift from full-time to part-time work, with flexible hours. This change allowed her to continue working, which gave her a sense of meaning. She described how, over time, doing certain activities grew increasingly difficult, yet these tasks were very important to maintain as normal a life as possible. "It's difficult. You just do. You just have to. You just do what you have to do, and that's it. [Having as normal a life as possible is] very important" (Lisa: Interview 1). Similarly, Melissa discussed that feeling normal for her entailed doing what she wanted to do:

> Normal would be an absence of pain and the ability to do what I want when I want to do. That would be normal, what I would say would be normal, even though that's not normal for lots of people. Now, I guess if I had, like ideally it would be structure in the day to do a couple things in the morning, have a little lie down in the afternoon, maybe do one more thing, and then go to bed early and stay in bed longer in the morning too. I could live with that, if doing that wouldn't be too painful the next day, then that kind of would feel like my new normal, I guess. (Melissa: Interview 10)

#### 7.1.3.2 I Adapt How I Do Things

> *Melissa: Just getting out for a short walk versus doing a big hike. It's still I'm getting out, I can be in nature a little bit, but it's not huge. [My husband] takes me for drives. I like driving, but if I can be the passenger and still see things just as we drive around, I enjoy that. It's not full-on getting out there. Around here, there are so many scenic drives, like we're kind of lucky. Yeah, I'm not hiking, I'm not in the backcountry, but I'm still seeing beautiful scenery and spending time with him because he never liked hiking, so it works. We call it going for a walk in the car. (Interview 10)*

Participants' desire to engage in meaningful activities became heightened in the face of progressive functional deterioration. They adapted *how* they did tasks so they could continue to do what they wanted to do and feel as though they were living well in the midst of disease progression. Peter summed this up in his third interview. Aware that how he played with his children changed significantly now that he used a wheelchair, he announced, "you just find a way, and you do what you've got to do, you just adapt and overcome" (Peter: Interview 3). The ability to modify how they engaged in an activity was crucial to participants' successful adaptation to their reduced capacities. This meant being flexible, substituting one activity for another or changing one component of the activity, modifying how the activity was conducted, or changing the degree of involvement in an activity from a more active to a less active level of participation or role. Participants recognised that adaptation occurred by doing, and they needed to continually adapt to keep actively engaged in life, even though they were dying. They also acknowledged the necessity to accept help from others when needed.

Adaptation was influenced by participants' *ability to go with the flow*. Participants described how living with advanced cancer made it hard to make concrete plans. There were many last-minute appointments to coordinate or unexpected symptoms to manage (Peter: Interview 3; Lisa: Interview 1). Lisa discussed the importance of being flexible and adaptable: "I suppose you have to be. I don't know what you do if you're not [flexible]" (Lisa: Interview 1). The rapidity and unpredictability of changes participants experienced meant that they had to adapt to different or fluctuating experiences on most days. Tammy shared, "every day is a different day … I just take it as it comes. I'm learning to live in the moment. Lots of big changes but learning to live in the moment" (Tammy: Interview 2). However, flexibility also took its toll and was hard work to sustain with competing demands of family responsibilities, appointments, and social expectations. Conversely, inflexibility was required at times in order to avoid physical pain or minimise fatigue brought on by overextending themselves. This was evidenced by maintaining firm boundaries about the time of day they would go for a walk or choosing to meet a friend when energy levels were higher. Participants had to incorporate various strategies appropriate to their own fluctuating context in order to engage in those activities important and meaningful to them. Without sufficient flexibility and clear boundaries, adaptation did not occur.

*Substituting one activity for an alternate one* was another important aspect of adaption described by participants. Tammy chose this adaptation strategy when she experienced a spinal cord compression that limited her hand function. She could no longer swim due to a flaccid arm, so she substituted walking instead of her usual swim (Tammy: Interview 1). When Amanda was no longer able to take her dog for frequent walks, she found other activities that she could do with her dog. Amanda recounted that this adaptation was "okay; we find other ways to do things together, cuddle up on the couch and watch a movie. [My dog] likes to watch dog movies" (Amanda: Interview 1). David described the satisfaction he felt from attending his faith community meetings in person. However, he transitioned to watching faith events on his television as he became increasingly fatigued and weaker with cancer progression. This option became more important to him as his health declined (David: Interview 4). David also used the strategy of substituting one activity for another when he went shopping. Once he was no longer able to leave the house easily or to ambulate independently, David changed from going to the stores to shop, to doing online browsing:

> I would like to be able to go out even more, even to walk through Walmart or whatever. … I like shopping and I like going through Canadian Tire, just seeing the

> different things that, the new plumbing stuff or building stuff. … [Now] I do go on YouTube and look at the new gadgets and stuff like that, stuff that Amazon has … which is I guess the next best thing to do. (David: Interview 2)

When not practical to swap one task for another, another adaptation strategy was to *change a component of the task*. Jessica enjoyed washing dishes by hand in the sink; however, when she was having a bad day, Jessica would use the dishwasher instead, a simple but effective adaptation (Jessica: Interview 1). David substituted components of a self-care task in his morning routine when he could not walk up the stairs to his bathroom. "I prefer the [razor] blades, but the electric [shaver] worked out better for my case now … You get used to it. It doesn't give you quite the clean feeling, but it's a lot better than nothing at all" (David: Interview 4). Switching a component of the task helped David remain independent with shaving, and he described how this made him feel more like himself.

Tammy described another example of adaption by changing a component of an activity. She could no longer drive due to the loss of her hand function, so she brainstormed other ways to access her community. She spoke about asking friends to pick her up from home to go for coffee or to the movies (Tammy: Interview 1). Tammy also discussed her plan to slowly walk into town from her home and then take a taxi home to conserve her energy (Tammy: Interview 5). She also planned to go to the grocery store with her family, so their help would save her energy for shopping (Tammy: Interview 6). Switching components of the task (how she managed her trip to town) gave Tammy multiple options to enable continuing an activity she found meaningful.

A fourth way in which participants described adapting activities to maintain involvement was *modifying how a task was conducted*. For example, seeking to maintain her independence when her cancer progressed, Tammy re-examined how she conducted her self-care tasks. She wore loose clothing in order to independently dress herself while managing with minimal hand function (Tammy: Interview 1). Lisa also began to use other strategies, adapting how she got to and from work in order to save her energy levels for her workday. This meant that she stopped cycling to work and started taking a taxi instead or accepted a lift home with a workmate. These strategies enabled Lisa to focus her energy expenditure on tasks at work (Lisa: Interview 1).

A fifth way of adapting was shifting from *more active to less active participation* in activities or taking a lesser role in an activity. For example, David previously enjoyed tinkering with projects around the house. When his cancer progressed, he had increasing difficulty doing so, and therefore he adapted by watching others in the community build their projects. He described the most important part of his day as

> coming up here [to the main floor of the house] and just watching if there is any building or anything going on … I just like to see stuff going on … Yesterday they put in [forms] for the sidewalk, so they'll probably be pouring that within the next day or two. (David: Interview 1)

Watching the progress was a seemingly simple activity but very meaningful to David. It connected him to activities that he enjoyed but could no longer do. Modifying his mode of participation helped David adapt to his loss of strength and independence. Speaking of the shift from doing handyman tasks to watching others do these activities, David said, "just being able to do that gives you a little more confidence … so watching other people build [is important]" (David: Interview 1).

Three months after this first interview, David had become increasingly fatigued and could no longer spend much time on the main floor of the house watching the neighbours build through the window. His main living space became limited to the basement suite, but he maintained his involvement and sense of still being a handyman in the neighbourhood by getting daily updates from his wife on how the building was progressing next door or by just listening to the building noises outside. David felt that he was still able to contribute through this form of communication:

> I ask [my wife] if they had put strings across because that's the best way to line everything up … because I have done stuff like this before, I like to, you know, if they're doing it the same way, great, but I don't know. So, if I can suggest an easier or better way of doing it, at least I'd be able to help in that way. (David: Interview 4)

Adaptation occurred through the *doing* of valued activities. When active participation was no longer possible due to declining function, participants could still enjoy valued activities by adapting *how* they were involved.

#### 7.1.3.3 I Adapt How I Think

> *Peter: My outlook on life has changed a little bit. Like I say, those small things matter, don't [just] matter, but they matter the most. Your outlook on life changes, and I appreciate things a lot more, especially family and friends. (Interview 1)*

It was evident from participant interviews that constant change and loss due to disease progression over weeks and months took more than a physical toll on participants. Participants not only needed to adapt how they engaged in activities, but it was often necessary to also adjust how they thought about everyday life. Adaptability involved developing a flexible mindset with a focus on opportunities rather than limitations. At times, this included knowing what was achievable and what was not. Tammy described how her thinking changed. She began recognising the importance of being proactive. As her thinking shifted over the course of her illness, Tammy noted that she thought more about persevering, trying to do what was enjoyable, and accepting both the good and challenging parts of life (Tammy: Interview 9). Tammy actively sought to pursue these lines of thinking despite the increasing difficulties she experienced as her cancer progressed. She explained, “you have your challenges, but you just be happy” (Tammy: Interview 8). As noted in the previous chapter, Tammy was very intentional in how she spent her time in order to actively pursue independence and continued relationships with those important to her.

The importance of an adaptable mindset while facing loss and change was observed in other interviews. In the midst of functional decline and bodily deterioration, Peter described how he wanted to continuously “make the most of it and look on the positive side of things” (Peter: Interview 1). He sought to do so not only for himself but also to benefit his wife and children. By shifting his primary focus off of loss, physical decline, and approaching death and on to what he was still able to manage, Peter was able to appreciate and enjoy what he could do while focusing his energy on his relationship with his wife and children, satisfied with adapting how he played with them (Peter: Interview 2). Tammy focused on what she could do instead of what she could not. “I love the water, but I’m not swimming right now because I’ve lost the use of my upper body. But I walk” (Tammy: Interview 1). This focus on the opportunities available was important so that she could continue engaging in valued activities.

Some participants identified *how* they developed the skills of flexibility of thought and an adaptable mindset. Peter attributed his flexible thinking and adaptability to working in the criminal justice system, where he was constantly doing risk assessments and adapting his behaviour towards those he worked with. He also believed that these skills at work were originally developed through playing soccer, where it was important to learn to read the game and be able to change positions quickly. He considered his flexible thinking as a natural part of who he was:

> Well, if you can't adapt, what are you going to do? You might as well just give up. The ability to adapt and think on the go is something which I've always done. … It is something that I have always done; it just comes natural to me. (Peter: Interview 1)

Another participant, Chris, also attributed his adaptability to skills sharpened at his place of work. However, he also recognised that it was difficult to completely accept ongoing change and loss due to functional decline. He said, "change has always been something that I have been able to get through. … I coach people on the aspects of change … [but] I don't think you ever really accept anything. Just look at a hockey fan" (Chris: Interview 1).

At times, participants thought they were not able to fully accept the changes they experienced. At other times, there was a sense of acceptance whilst thinking about the reality of bodily deterioration, functional decline, and cancer progression. This was a balancing act. How flexible thinking was lived out was unique to the individual.

As Melissa reflected on what the future might hold, she emphasised the importance of being open-minded and having an adaptable mindset. She needed to

> re-jig my parameters of what's possible. I think it would be a mind thing where you would have to come to terms with it and accept it and figure out you could be okay with that. Like with anything that life throws at you, you just have to get your head around it and deal with it. (Melissa: Interview 8)

Similarly, Tammy had to shift her perspective in order to adapt to her current functional levels. Maintaining a tidy house was not always possible due to her fatigue levels and limited upper extremity function. As a result, Tammy had to rethink her priorities and accept that her home would not be as clean as she would have kept it previously. Flexible thinking allowed her to adapt to her changing involvement in a valued activity (Tammy: Interview 1).

Jessica sought to maintain the sense of her old self while acknowledging the functional changes she experienced as her cancer progressed. This was difficult for her due to the impact of increasing fatigue, pain, and worsening bowel function. Describing herself as a high functioning individual who could multitask well, she commented on previously coordinating her son's medical and schooling needs, helping her husband around their rural property, while also working at a local business. However, how she thought of herself was now changing. Jessica had to modify not only what activities she engaged in but also how she thought about and approached these activities. Jessica shared this struggle:

> You had this life before and these responsibilities that still exist, but you need to kind of rebuild your feelings and your perception and your goals on who you are and what you want to do. So that´s hard because you're in this limbo, so that's very difficult for people, I think, who still had a very active life and were still working, and then you´re trying to get the strength up to just re-participate. (Jessica: Interview 1)

Coming to terms with a new normal was an important consideration for all participants, particularly because what constituted 'normal' in their own eyes continued to change over time.

### *7.1.4 Theme Summary*

Increasing dependency and unremitting change affected participants' ability to engage in valued activities; life shifted and was reshaped during their interview series. Participants described the frustration and uncertainty felt, and the difficulty experienced when they lost any independence or had to contend with unexpected events and circumstances due to declining health. The experience of increasing dependence was challenging, as it often fluctuated yet remained continuous throughout the duration of their interviews. Participants grieved the losses they had already experienced and anticipated potential losses they had not yet experienced. Meanings attached to occupations were connected to participants' sense of self, competence, dignity, hope, and normalcy.

Adjusting to the challenges of relentless change and loss was essential for continued occupational engagement as their disease progressed. Significantly, the ability to adapt grew through active engagement in meaningful occupations. As their capabilities declined, participants modified how they conducted activities, substituted one activity for another, changed a component of the task, or modified how it was done. Adaptive strategies extended beyond how a task was done. Participants had to change how they thought about activities in the face of ongoing loss of independence due to cancer progression. These shifts in how participants processed and reframed changes in their functional abilities were crucial to their well-being, particularly as the months elapsed and death approached.

## 7.2 Conclusion

In this longitudinal study, a recurrent focus of participants' narratives was the active, ongoing process of adapting to unremitting change, uncertainty, increasing dependency, and loss. Adapting to change was an essential aspect of continuing meaningful occupational engagement for these working-aged adults despite functional decline. Although the activities participants valued were unique to the individual, the desire to intentionally pursue everyday activities through adaptation—despite a trajectory of deteriorating health—was common to all. The following chapter will discuss the findings in relation to current research and theory, identifying ramifications of the findings, and highlighting future steps in research.

# CHAPTER 8: DISCUSSION

> *Peter: I know that I've lost some of my independence and that's fine, it's going to happen, and there is not much you can do about that. But that being said, I've also been able to regain some of my independence, which has been FANTASTIC, whether it be getting a glass down or rolling out to the porch lift and going outside, you know, out to driveway and watching the kids paint with chalk or draw with chalk or do whatever they want to do, and be part of their lives and take it all in again, it has been great. … You don't know how much time you've got left on this earth, so being able to enjoy it makes a huge difference, as opposed to being stuck in one place and never being able to move. (Interview 3)*

The ability to participate in meaningful activities is vital for people in their final months and weeks of life. Valued activities help them feel like they are still living and foster their roles and relationships as important members of their family or community. They provide purpose and meaning in the midst of decline and loss.

Employing a longitudinal, hermeneutic phenomenological approach, underpinned by MOHO as the theoretical framework (Colaizzi, 1978; Saldaña, 2003; Taylor, 2017; van Manen, 1990), this study examined the lived experience of occupational engagement for working-aged adults living with advanced cancer. It set out to accomplish this in the context of the Rocky Mountains' Bow Valley Corridor, a large rural catchment area in Alberta, Canada. The Model of Human Occupation (MOHO) and illness experience provided the theoretical and conceptual foundations for this study (Chapters 2 and 3). They highlighted the impact of illness on a person's sense of meaning and normalcy, the experience of loss, and the centrality of occupation for quality of life and well-being. A series of vignettes (Chapter 5) captured the longitudinal nature of participant experiences of daily life as their cancer progressed, noting how these experiences changed over time. Study findings in the sixth and seventh chapters revealed the intentional nature of occupational engagement while dealing with continual loss, pointing to occupation's dynamic, contingent relationship with environment. Chapters 5 to 7 used participants' voices to describe occupational engagement, such as "doing an activity" or "task." The current chapter resumes the occupation-based language used in the theory, literature review, and methodology chapters, as the concept of occupation is central to the study's findings.

This eighth and final chapter situates the study findings within the context of existing research. Following a brief overview of the study's significance and main themes constructed from participants' stories (Section 8.1 and 8.2), this chapter explores and analyses the interplay between the findings and van Manen's (1990) hermeneutic phenomenological understanding of the lived world.

A five-part exploration of the study's findings in relation to existing literature and MOHO theory follows (Sections 8.4 to 8.8). It begins with a discussion of the illness experience of loss and proceeds to examine the significance of participants' intentionality in pursuing occupational engagement within the context of cancer progression. The third and fourth parts explore the role of the environment in facilitating or hindering occupational engagement and the consequences of occupational disengagement. Finally, an investigation into the centrality of occupational adaptation for the cohort of working-aged adults living with advanced cancer completes this examination of the study's findings. Chapter 8 concludes with a consideration of clinical implications of this study (Section 8.9), followed by a discussion on limitations and possibilities for future research (Section 8.10).

## 8.1 Addressing the Knowledge Gap

Few studies in palliative care settings have explored the lived experience of occupational engagement for working-aged adults living with advanced cancer. Examination of the illness experience of this cohort is timely given the rapid growth in the numbers of people living longer with cancer and the subsequent implications for their care needs (Brenner et al., 2020; Canadian Cancer Society's Advisory Committee, 2019; Dolgoy, Driga, et al., 2021). Furthermore, the increasing number of individuals choosing medical assistance in dying due to an inability to engage in meaningful occupations (84.9% to 90%) reminds us of the urgency to better understand this phenomenon (Health Canada, 2021; Oregon Health Authority, 2021; Washington State Department of Health, 2018). However, there is a paucity of occupational therapy and palliative care research focused on working-aged adults living with advanced cancer who live in their own homes. Little is known about how and why these individuals participate in valued occupations and how participation changes as cancer progresses. In addition, research has often overlooked the impact of the environment on occupational engagement, despite its significance as a facilitator or barrier to participation. Finally, although occupational adaptation has been explored in a general theoretical context, existing occupational theoretical frameworks do not sufficiently address differences in occupational adaptation for people living with life-limiting conditions (de las Heras de Pablo, Fan, et al., 2017; Grajo et al., 2018; Schkade & Schultz, 1992; Schultz & Schkade, 1992; Walder & Molineux, 2017a; Walder et al., 2021).

This study deepens our understanding of the pursuit of everyday life while dying for adults under 65 with advanced cancer, and it addresses the gaps identified above. The subjective meaning of the phenomenon under investigation—the lived experience of occupational engagement for working-aged adults living with advanced cancer—was explored by examining participants' experiences of everyday life as they changed over time (Finlay, 2011; Liamputtong, 2013; van Manen, 1990). The three main themes reflect the essence of participants' shared experiences: (a) *The intentional pursuit of engagement in everyday activities*, (b) *Everyday life is contingent on my environment*, and (c) *The challenge of unrelenting change and loss*. The importance of ongoing engagement in meaningful occupations for people living with advanced cancer was a common thread running through these themes, as engagement assists in maintaining an individual's sense of self and personal causation (sense of capacity and self-efficacy).

## 8.2 The Lived Experience of Occupational Engagement

This research examined the illness experience of participants living with advanced cancer, focusing on their lived experience of occupational engagement and how it changed over time. The study's significant, original contribution to knowledge is threefold, each building on the other. Findings confirm the following:

- Working-aged adults living with advanced cancer seek to *intentionally* continue engaging in occupations *related to their volition* (their values, interests, self-efficacy, and sense of capacity). A person's values and interests are drivers for what occupations they choose to engage in as they seek to maintain their sense of self-efficacy and capacity; occupations are often related to their valued roles or relationships. Continued intentional engagement in occupations whilst living with advanced cancer can facilitate a sense of normalcy (Section 8.5).
- The *physical and occupational environment* can significantly affect the (a) ability to make participation choices, and (b) a sense of normalcy. Addressing environmental barriers can affect occupational engagement if barriers are eliminated, as bodily decline does not always necessitate a decline in function (Section 8.6).
- Existing MOHO theory on occupational adaptation has limited applicability to

working-aged adults living with advanced cancer. Current theory proposes that adaptation requires a plateauing of occupational identity and competence (de las Heras de Pablo, Fan, et al., 2017), which is unattainable for those who experience progressive deterioration. Findings from this study reveal a process of occupational adaptation in which *volition* plays a pivotal role as motivator for change. For people living with advanced cancer, there is a close link between *occupational adaptation* and the person's *occupational identity* and *volition* (values, interests, personal causation) rather than their occupational competence. This study's conceptualisation of occupational adaptation builds on the existing MOHO theory (Section 8.8).

This study's original findings point to the dynamic relationship between purposeful striving for independence, increasing dependence and loss, adaptation, and the environment. Understanding the lived experience of occupational engagement, how it affects identity, and how it changes over time is essential to supporting ongoing participation in valued and meaningful occupations for working-aged adults at the end of life.

## 8.3 The Lived World of Occupational Engagement for Working-Aged Adults With Advanced Cancer

Constructed themes foregrounded participants' voices and were mapped against van Manen's (1990) hermeneutic phenomenological understanding of the lived world. Each of the central components of van Manen's (1990) lived world (temporality, relationality, spatiality, and corporeality) was evident in the lived world of participants in this study.

The common experience of occupational engagement within the context of advanced cancer is one bound by time (*temporality*). Having been diagnosed with a life-limiting condition, participants in the current study felt the constrained nature of time remaining. As Heidegger (1962) states, "the less time it has to lose, the more 'precious' does that time become" (p. 418). The notion of altered time was also expressed by other individuals living with cancer (Khatri et al., 2012), who recognised their limited time and being-towards-death (Heidegger, 1962). Time was a precious commodity and little things became increasingly important (Jacques & Hasselkus, 2004; la Cour & Hansen, 2012), so participants were intentional in their occupational choices. Subjective differences in experiences of lived time were reported between caregivers and participants; when rushed in self-care tasks, experienced time as a barrier, thus impacting their sense of self.

Consistent with other literature, participants in this current study, aware of the limited time remaining, wanted to leave a legacy for family that would create a lasting memory in the future (Coyle, 2006; Jacques & Hasselkus, 2004). Several participants, however, reflected on the uncertainty of the future and how their family would cope after they died. These findings support van Manen's (1990) contention that the dimensions of time involve more than just the present. *Temporality* was a crucial component of the occupational environment for people living with advanced cancer, affecting the experience of their day.

A second aspect of the lived world, according to van Manen (1990), is that of *relationality*. The importance of valued relationships at the end of life was a recurrent theme in this study and consistent with existing research (e.g., Bates et al., 2018; García-Rueda et al., 2016; Park et al., 2017). Participants were intentional about spending time doing meaningful activities with those they loved. Importantly, occupation was the context in which participants fostered and maintained valued relationships. Lisa prioritised her job and relationships with workmates as they were central to her identity, despite changes in her occupational status. The meaning ascribed to relationships shifted due to the impact of cancer, symptoms, and increasing dependency. Some relied more on their spouse or caregivers, and others were concerned about being a burden. The notion of relationship changes between partners and family is reflected in other palliative care, occupational therapy, and illness literature (Carel, 2016; Doumit et al., 2007; Kleinman, 2020; la Cour, Nordell, et al., 2009; McCaffrey et al., 2016; Park et al., 2017; Peoples, Nissen, et al., 2017). This study's finding about the sustaining nature of relationship with pets supports an emerging but very small body of research (MacDonald & Barrett, 2016). The importance of meaningful roles and relationships was a key component in choosing to engage in specific occupations, regardless of whether that role was of worker, spouse, parent, or pet owner.

*Spatiality* is a third construct of van Manen's (1990) lived world. He described lived space as more than the physical world, one that includes how people experience a space, often subconsciously. Although the aesthetic nature of their environment was appreciated (la Cour & Hansen, 2012), it was the *experience of lived space* that shaped everyday life and resulted in a sense of calm, feeling grounded, or feeling rushed and anxious. This study's finding of the connection between a sense of well-being and the restorative atmosphere within a space is consistent with a study on environmental aspects of a cancer and palliative rehabilitation programs (Malcolm et al., 2016; Roessler et al., 2021). Participants experienced joy and peace when in the mountains, satisfaction when their home was tidy, or frustration when confined to one space in the home. When not addressed, physical barriers in the home environment shrunk their world and took away the ability to choose, resulting in occupational disengagement—a similar finding to research on occupational engagement in the hospital environment (Eriksson et al., 2016). Seasonal changes also affected the ability to choose. Similar to findings from Ripat et al.'s (2015) study on challenges to wheelchair use in Canadian winters, participants living with advanced cancer also struggled to traverse the icy snow-covered sidewalks in winter. The space participants inhabited was a significant contributor to their experience of occupational engagement and sense of well-being, lending support to van Manen's (1990) statement, "we become the space we are in" (p. 102).

A fourth aspect of the lived world pertains to corporeality, the lived body. Physical decline in advanced cancer was more than something that happened to participants' bodies; it affected their whole self. In illness, the body was brought to the fore (Frank, 2002; Kleinman, 2020; la Cour & Hansen, 2012; Morgan et al., 2017). Participants grieved when cancer progression resulted in functional decline and their bodies no longer worked as they previously did. The burden of symptoms impacted involvement in daily life (Gill et al., 2012; Morgan et al., 2017), and in turn, occupational disengagement then affected their well-being and sense of self. This highlights the need to not only attend to their unfamiliar, deteriorating body (Morgan et al., 2017; Park Lala & Kinsella, 2011), but also the need to modify *how* occupational engagement occurs within the constraints of their changed bodies (la Cour & Hansen, 2012). Bodily deterioration meant that, at times, participants could not engage in valued activities, yet at other times, participants delayed treatment or pushed through symptoms in order to keep doing what they wanted to do. The primary goal for participants was not to simply improve or maintain their strength or another biomechanical domain; rather, they sought improvement *in order to participate* in valued activities as best as possible, consistent with Morgan et al.'s (2017) study on embodiment, functional decline, and adaptation at end of life. The experience of the lived body in advanced cancer was often linked to their experience of occupational engagement.

Having briefly outlined how van Manen's (1990) lifeworld existentials interact with this study's contextually grounded findings and existing literature, the following section discusses the lived experience of illness. The experience of loss is fundamental to the illness experience for those living with advanced cancer, amid increasing dependence and a deteriorating body.

## 8.4 The Illness Experience of Loss

The illness experience affects a person's sense of meaning and way of being-in-the-world at a time when life feels disrupted due to a life-limiting condition (Carel, 2016; Kleinman, 2020). A hermeneutic phenomenological approach was chosen for this study in order to elicit the meaning participants ascribed to their illness experience amid loss (Carel, 2016; van Manen, 1990). Individuals living with advanced cancer experience continuous change, uncertainty, and inescapable bodily deterioration, as well as fluctuating symptoms such as nausea, pain, or fatigue (Health Canada, 2018; Henson et al., 2020; Mercadante et al., 2000; Morgan et al., 2017). Consequently, participating in valued occupations became increasingly difficult, and the person's sense of self was shaken (Aoun et al., 2016; Charmaz, 1995; Maersk et al., 2018; Raanaas et al., 2019). The impact of the illness experience on the ability to engage in occupations was significant.

Adults of all ages living with advanced cancer experience multiple, complex losses. Illness-related losses include the loss of wholeness, certainty, control, freedom to act, and the familiar world (Carel, 2016; Toombs, 1987). This study's working-aged participants were particularly vulnerable to the *loss of wholeness* in bodily integrity as their cancer progressed, often associated with a loss of strength, energy, or functional skills. Chris and Peter struggled to accept their significant and premature loss of strength as they still viewed themselves as young, strong, physically active men (Chris: Interview 1; Peter: Interview 1). The devastating impact of a deteriorating body on occupational identity in this cohort was consistent with the early conceptual work of Christiansen (1999), who considered occupation as the primary means of expressing identity. However, limited physical abilities or presence of symptoms do not always equate to a reduction in quality of life (Carel, 2016; Toombs, 2004), nor do symptoms necessarily result in reduced participation (Sampedro Pilegaard et al., 2020).

Participants also experienced a *loss of certainty* when life seemed fragile or when grieving future anticipated losses, a common experience whilst living with a life-limiting illness (Etkind et al., 2017; McKechnie et al., 2007; Shilling et al., 2017). The longitudinal design of this study highlighted the fluctuating emotional and physical experiences of participants during the span of interviews up to 14 months. No day was the same: some were ‘good’ and other days more challenging. No participant had expected an early death, and they expressed this vulnerability of being-towards-death through anger, frustration, general distress, and sadness, consistent with other end-of-life research (Farcus, 2012; Jacques & Hasselkus, 2004; la Cour & Hansen, 2012).

The third loss explored by Carel (2016) and Toombs (1987) as part of the illness experience was the *loss of control*, a loss keenly felt in this cohort due to the loss of valued roles, responsibilities, and independence at work, in the community, and at home (Cotterell, 2008). Loss of control was more profound when related to increasing dependence, the manner of assistance provided, or the lack of privacy. Participants also experienced the *loss of the freedom to act* when their lived space became smaller. They could not leave their house due to environmental barriers; this concept is similar to the shrinking world described by Deckert et al. (2018). Barriers prevented participants from engaging in some of their valued occupations and relationships within their communities. Similar to Frank’s (2002) commentary on the loss of his future plans, this younger cohort acutely felt the loss of freedom to make future plans. They grieved the loss of future independence and future moments with their children. The freedom to choose was no longer taken for granted. The *loss of the familiar world* was closely linked to the other losses. Consistent with existing palliative care research, this study found that routine habits were increasingly challenging, work was no longer the same, and relationships shifted (Maersk et al., 2021; Nissim et al., 2012). As a younger cohort, they grieved the loss of the familiar world as they shifted from independence to increasing dependence with the prospect of an early and untimely death. Previous assumptions about what life would be like were shattered, so they deliberately sought ways to participate in meaningful activities to maintain a sense of normalcy in their new, shortened future. There was no period of stability nor time to adjust, unlike many other chronic illnesses (Carel, 2016)

In addition to the losses described above, participants spoke of significant non-cancer losses that occurred throughout their interviews, such as deaths of their children, siblings, friends, and pets; damage from floods; and losing significant places due to fire. These losses affected their emotional landscape and further disrupted life, adding to their experience of grief. These non-illness related experiences of loss were consistent with losses noted by Coyle (2006) in her study on living with advanced cancer whilst facing death. Participants “express[ed] a feeling of loss of control, of power, of identity, of place in the world, and of a future" (p. 273). Importantly, the experience of loss and the experience of occupational engagement can coexist over time (Vehling et al., 2018).

## 8.5 The Intentional Pursuit of Occupational Engagement

The desire to engage in activities is unique to the individual and based upon their volition: their values, interests, and sense of self-efficacy and capacity (Lee & Kielhofner, 2017b). This section explores the purposeful nature of occupational engagement demonstrated by this working-aged adult cohort, and examines the driving force of volition as motivation, particularly when making the decision to participate or not in activities. The intentionality of *choosing* and *participating* in occupations related to their volition is a significant contribution of this study to existing knowledge, as this has not been explored in MOHO research and theory for people living with advanced cancer.

### *8.5.1 Intentional Occupational Engagement*

Participants *intentionally* sought to engage in *valued* occupations *throughout* the advanced stages of their cancer with its resultant *declining abilities and loss*. This intentionality, defined as a facet of a meaningful life by Hammell (2004), was a recurrent theme throughout this longitudinal study and present in all 33 interviews. Significantly, in the face of ongoing losses that accompanied progressive disease, continued occupational engagement helped maintain both a sense of *normalcy* and the person's *sense of self*.

The desire for a sense of *normalcy* was evident through participant conversations about prioritising everyday occupations that were part of normal routines. The strong connection between a sense of normalcy and engaging in routine activities is a common finding in existing palliative care and occupational therapy research. Studies have demonstrated that equipping people living with advanced cancer to continue doing things important to them facilitates a sense of normalcy (Arantzamendi et al., 2020; Black, 2011; Carter et al., 2004; Dewhurst et al., 2020; García-Rueda et al., 2016; Haug et al., 2015; Knox et al., 2017; Lundquist et al., 2019; McCaffrey et al., 2016; Park et al., 2017; Peoples, Brandt, et al., 2017; Raanaas et al., 2019; Svidén et al., 2010; Vig & Pearlman, 2003). Building on a study by Peoples, Brandt, et al. (2017) which highlighted strategies participants used to manage their occupations, this current longitudinal study provided new insight into existing knowledge through a deeper understanding of *how* and *why* occupational engagement facilitates a sense of self and normalcy. Thus, living a "normal" life in advanced cancer meant living out their values and interests (volition) in occupations consistent with their previously inhabited roles and their relationships with loved ones, thus reinforcing their occupational identity.

The current study also identified that participants' desire for normalcy was related to the hope of maintaining their pre-cancer *sense of self*, both amid and despite fluctuations in progressive disease. This study built on Christiansen's (1999) premise that "occupation [is] the principal means through which people develop and express their personal identities" (p. 547). Findings are also consistent Raanaas et al.'s (2019) study which concluded that identity can be maintained through occupation during life transitions. It affirmed the importance of engaging in occupations to maintain a sense of normalcy and a sense of self across the final months of life, including when nearing death. Participants sought to intentionally engage in occupations that supported their values and interests by which they defined themselves, thus bolstering their sense of capacity and self-efficacy (i.e., MOHO's concept of personal causation). This study found that these three aspects of volition (values, interests, and personal causation) are the driving factors behind *why* people living with advanced cancer choose to engage in certain occupations and not others (Lee & Kielhofner, 2017b). Thus, to maintain their sense of self, participants chose to engage in occupations in line with their volition, despite the shifts they experienced in their abilities, routines, or daily habits.

The ability to successfully participate in valued occupations was significant for this cohort. Compensatory strategies or environmental modifications created the opportunity and facilitated participation in those activities that had become difficult. Seemingly minor successes were celebrated because they reinforced their sense of self-efficacy. Although existing research identifies the increasing significance of the "little things" in life when living with advanced cancer (Arantzamendi et al., 2020; García-Rueda et al., 2016; Jacques & Hasselkus, 2004; Morgan et al., 2017), there is limited focus on the role of compensation or environmental modifications in regaining the ability to do these little things (la Cour & Hansen, 2012; Peoples, Brandt, et al., 2017). These small gains are often viewed as significant by people living with advanced cancer. This was illustrated by one participant, Tammy, whose functional trajectory appeared stable throughout the majority of interviews; objectively, her functional status on the AKPS did not change. However, she achieved deeply meaningful gains in little things due to compensatory strategies and environmental modifications. These small functional improvements may go unnoticed by health professionals whose primary focus is often on symptom control or an individual's independence in self-care or mobility tasks as a whole (e.g., bathing, dressing, walking) rather than smaller components (e.g., doing up a zipper, shaving). Furthermore, many assessment and screening tools used to capture outcomes at a research or health service level, such as the AKPS scale or the Palliative Performance Scale, lack the sensitivity to detect these small but significant changes (Abernethy et al., 2005; Anderson et al., 1996). However, for these participants, small gains can contribute to a sense of normalcy, self-efficacy, and sense of self despite disease progression. Successes reinforce the motivation to intentionally seek participation in valued occupations as much as possible, at all stages of functional decline.

### *8.5.2 The Motivation Behind Occupational Engagement*

Since the lived experience of occupational engagement in advanced cancer is unique to the individual, the value of participation is contingent on what matters to that specific person: their volition. In MOHO, the construct of volition describes the motivation behind why people chose to engage in particular occupations (Lee & Kielhofner, 2017b). People may be drawn to an activity due to their level of *interest* or because it relates to something that they *value*. However, not all occupations are enjoyed, reflect the person's values, or are given meaning by the individual. Some occupations affirm, while others rebut the individual's sense of capacity or how effective they feel in their abilities *(personal causation)*. According to MOHO, these aspects of volition are apparent in the volitional process[12] (the steps involved when an individual participates in an occupation): the anticipation of the occupation, choosing the occupation, engaging in it, and then reflecting on how it went (Lee & Kielhofner, 2017b). However, no research has explored the longitudinal impact of volition on the experience of occupational engagement involving people living with advanced cancer until now. Participants were purposeful about which occupations they pursued and those they were willing to let go as function declined; these choices were unique to them. The first two steps of the volitional process—*anticipation* and *choosing an occupation to engage in*—were important components of occupational engagement for participants in this study. These steps shaped their experience of that

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[12] Please refer to Figure 2.1 for MOHO's conceptualisation of the volitional cycle.

occupation, and consistent with MOHO theory on the volitional cycle (Lee & Kielhofner, 2017b).

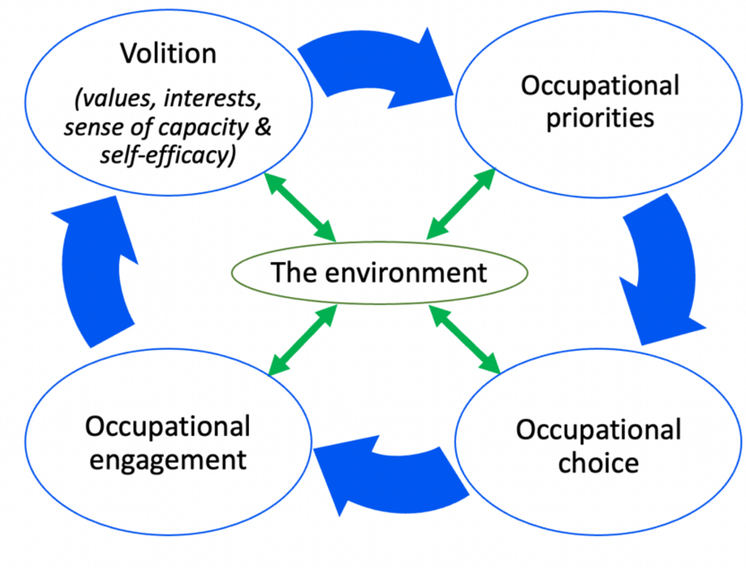
A study by Pritchard et al. (2014) explored volition and participation in occupations for older adults in the community, highlighting the positive association between what activities an older adult wanted to participate in and their volition. The authors recommended that rehabilitation programs for this cohort should focus on occupations that reinforced their volitional priorities in order to maximise a person's sense of well-being. Thus, it is insufficient to simply look at a list of which occupations a person engages in when seeking to understand their lived experience of occupational engagement (Lee & Kielhofner, 2017b). Participants in this study spoke about the activities they intentionally pursued and the motivation behind choices. From their interviews, it became apparent that it was essential to understand the first half of the volitional process (anticipation and choice) in order to gain a more comprehensive picture of the occupational world of the person living with advanced cancer.

The significance placed on the drive to engage in valued occupations was evidenced by participants pushing through cancer or treatment-related symptoms in order to continue doing the activities they wanted to do. Consistent with research by Morgan et al. (2017) and Vig and Pearlman (2003), continuing to participate in occupations despite symptoms in order to do what was important was a common thread in interviews, as this ability to engage in meaningful occupations was central to how participants viewed their quality of life.

Ultimately, a person's volition is central to their lived experience of occupational engagement, as their values and interests shape their occupational choices and affect how occupations are prioritised. *The experience of occupational engagement therefore reinforces, reshapes, or challenges an individual's volition.* Occupational engagement or disengagement affects their sense of self-efficacy and feelings of control while living with an ever-changing body. Thus, the motivation behind occupational engagement in advanced cancer is central to the lived experience of occupational engagement. A revised cycle, developed from participant experiences while living with advanced cancer, is represented in Figure 8.1.

**Figure 8.1**

*The Volitional Cycle: Advanced Cancer*



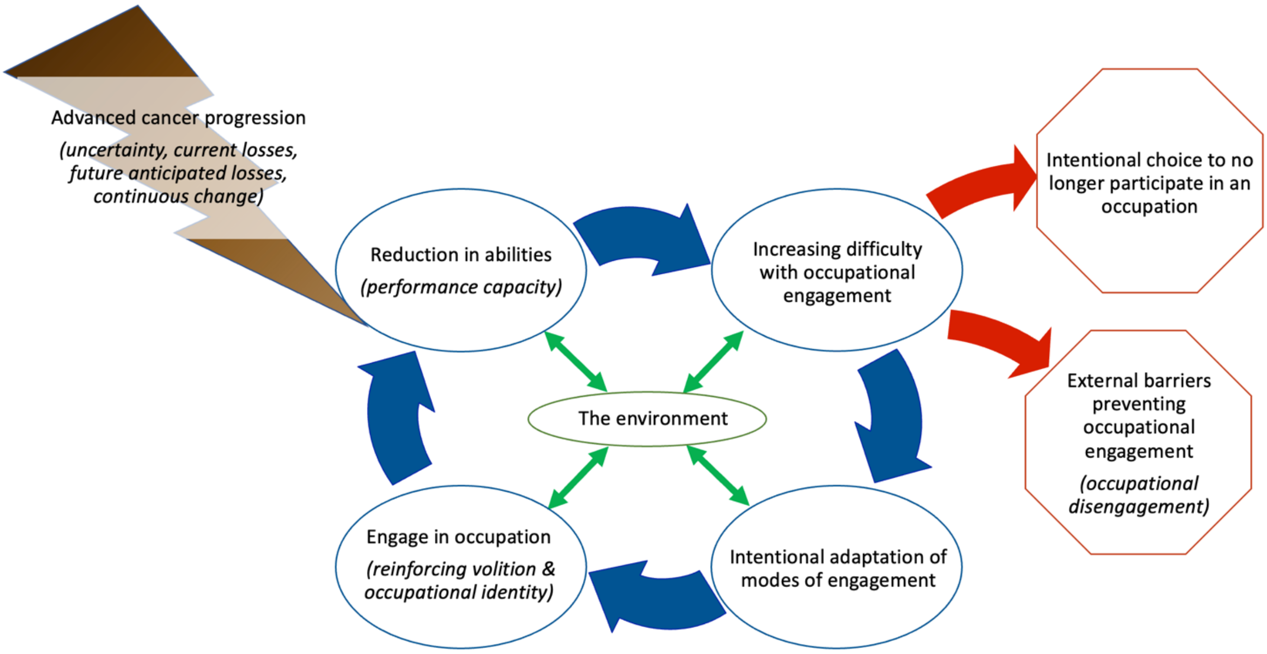
Living with advanced cancer results in an eventual decline in abilities over time, and consequently, the difficulty of participating in specific occupations also increases (Hammill, Bye, et al., 2019; Jacques & Hasselkus, 2004; la Cour & Hansen, 2012; la Cour, Johannessen, et al., 2009; la Cour, Nordell, et al., 2009; Lyons et al., 2002; Morgan et al., 2017; Park Lala & Kinsella, 2011; Svidén et al., 2010; Vrkljan & Miller-Polgar, 2001). The longitudinal design of this study enabled observation of participants' occupational choices over the year of interviews, and three occupational paths were identified in the context of advanced cancer, bodily deterioration, and functional decline:

- the intentional choice to no longer participate in the occupation,
- the intentional choice to continue engaging in the occupation (i.e., adapting the mode of engagement as required), or
- external barriers preventing occupational engagement.

Figure 8.2 provides a visual representation of the three occupational paths, one of which is adaptation, in the context of advanced cancer with increasing dependency, occupational choices, adaptation, and the environment. Each will be discussed in turn.

**Figure 8.2**

*The Process of Occupational Adaptation: Advanced Cancer*



First, the intentional choice to cease an occupation. Participants in this study chose to give up some activities that were no longer important to them, often due to a lack of interest in or a decrease in value placed on the occupation, usually in the face of increasing dependency or decreasing energy levels. For example, Melissa decided to stop playing golf, as the steps involved became increasingly difficult as her cancer progressed (Interview 2). The decision to stop engaging in an occupation was a personal one, contingent on the person's volition.

A second occupational path is that of being prevented from occupational engagement (i.e., occupational disengagement). This topic is rarely discussed in advanced cancer literature yet can have significant ramifications for individuals with declining health. External barriers may exist that preclude the ability to participate in occupations. This may include the presence of stairs if someone uses a wheelchair for mobility, or insufficient time allotted by home care staff, thus preventing the opportunity for the person to participate in specific tasks in their morning care routine. This will be discussed further in Section 8.6.

In the third occupational path, participants intentionally decided to continue participating, either in a modified form of the activity or in an alternate occupation that provided meaning and value, often related to their occupational identity or what they were interested in (occupational adaptation). Fostering important relationships was a common motivator for participants choosing this path; it is consistent with existing research involving younger adults living with advanced cancer that highlighted the desire to do things with and for their families (Bates et al., 2018; Dewhurst et al., 2020; Knox et al., 2017; Lundquist et al., 2019; Lundquist & Berry, 2019; Park et al., 2017; Svidén et al., 2010). Understanding the volitional process in advanced cancer is an important consideration when addressing experiences of occupational engagement as illness progresses.

### *8.5.3 Occupational Intentionality Pertaining to Valued Roles*

This section furthers MOHO theory by its elucidation of the ways in which working-aged adults living with advanced cancer sought to maintain engagement in occupations related to their valued roles; this occurred while contending with multiple losses and a deteriorating body (Morgan et al., 2017). Existing research speaks to *how* people continue to engage in occupations (Peoples, Brandt, et al., 2017). This section explores the *why*.

The Model of Human Occupation's conceptualisation of roles describes the impact of roles and habits on daily routines (Lee & Kielhofner, 2017a). However, findings from this study highlighted the primacy of roles, not as a part of habituation, but as a component of values (volition), thus expanding MOHO's conceptualisation of volition to incorporate *the value of roles* as a significant driving factor for occupational engagement for working-aged adults living with advanced cancer.

In MOHO, a person's volition shapes how they view themselves, and their values impact what occupations they wish to engage in. This is consistent with findings in the current study (Lee & Kielhofner, 2017b). Striving to maintain *valued* roles such as parent, spouse, worker, or a pet owner was often the impetus to engage in particular activities for the working-aged study participants. The ways in which occupational engagement (related to roles) was expressed differed among participants, depending on what they valued and the roles they played prior to becoming unwell due to cancer. Understanding the volitional focus of the individual in their choice of activities was important, as this was not always related to functional independence. Consistent with MOHO and other research, the ability to engage in activities connected to valued roles was important to participants' well-being and identity; therefore, *continuing to do* the activities related to roles remained a priority for all (Bates et al., 2018; Dewhurst et al., 2020; Doumit et al., 2007; Lee & Kielhofner, 2017a, 2017b; Maersk, 2021; Park et al., 2017). The impact of disability on roles is discussed in MOHO, including barriers to continued involvement in valued roles and the consequences of ceasing certain roles. However, the nuances of *how* a person maintains their role when living with the progressive, life-limiting condition of advanced cancer has not been explored in MOHO.

Two primary roles prioritised by the working-aged participants in this study were their roles within their family and friend units, and their role as worker. Consistent with research on parents of young children (Lundquist, 2017; Park et al., 2017), participants in the current study intentionally sought to engage in occupations that would involve those they loved. Parents of young (toddler to school-aged) children deliberately chose to eat meals together (Melissa), play together (Peter), go for walks (Jessica), help with homework (Melissa and Peter), or just spend time together (Jessica, Melissa, and Peter). Roles within the family with older children shifted (compared to parents of younger children), as there was a greater focus on adult relationships. Tammy had older children and continued in her parenting role by being a confidant, mentor, and problem solver for her children and their friends, particularly after her daughter's death. This difference in how parental roles were lived out by participants with older versus younger children is under-represented in existing research in advanced cancer. In addition, occupations reflecting parental supportive roles, such as helping their children transition out of high school or supporting their children's friends who may be struggling, were unique findings of this study. Participants in this study wanted to care for others and do things for those they loved; they did not want to merely receive supportive care amid progressive illness. Reciprocity in relationships was valued by all participants.

Lundquist et al.'s (2019) hermeneutic phenomenological study on the experiences of women in their 30s living with advanced cancer highlighted participants' main priority of maintaining a caregiving role for their children. This involved "continuing to assume care for their children and trying to normalise their lives while also preparing them for the future" (p. 333). The current study affirms Knox et al. (2017) and Lundquist et al.'s (2019) findings that working-aged adults living with advanced cancer want to continue in their significant roles and responsibilities such as parenting, as it provides a sense of normalcy in the midst of uncertainty.

Parental roles were important in this study, however, not all participants were parents. Participants also valued other caring roles, especially for spouses or pets. Chris described his most important role as husband: supporting his wife, teaching her skills to manage the household after his death, and spending time with her. His role in his family unit became increasingly important as he approached death. Amanda's most valued role was of dog owner, and her daily routines were filled with occupations shared with her pet. Similar to other meaningful roles of parent or worker, the role of dog owner gave Lisa a sense of meaning and purpose. Although the impact of cancer on the lives of working-aged adults is explored in research (Knox et al., 2017; Lundquist et al., 2019; Park et al., 2017), the significance of roles in occupational choice, prioritisation, and engagement is not explored. Other non-spousal, parental, or friend roles (e.g., pet owner) are also infrequently addressed in advanced cancer research (MacDonald & Barrett, 2016). The unique familial roles of the working-aged adult population are important to consider when working with people living with life-limiting conditions. Given that the occupations people wish to engage in are often relate to their valued roles, a better understanding of their familial roles is required to best facilitate continued occupational engagement for working-aged adults with families. These roles may differ significantly from roles of older adults who are retired and whose children may have their own families and a life elsewhere.

Another meaningful role unique to this population group was the worker role, particularly since work is a central occupation for many working-aged adults and also a role infrequently discussed in advanced cancer research. The majority of literature on work and cancer pertains to work-related interventions for cancer survivors or the impact of cancer (its symptoms and treatment) on returning to work (Dolgoy, Brose, et al., 2021; Thijs et al., 2012). Limited research has examined the meaning behind the worker role, as there is often an assumption that people want to cease working when living with a terminal illness. However, one participant in this study wanted to continue working as long as possible (Lisa: Interview 1), another had to obtain assistance for specific tasks to make working still achievable (Jessica: Interview 2), and a third remained on sick leave so that he could still state that he was employed in his line of work (Peter: Interview 1). For many, the ability to continue working in a meaningful job helped to maintain their sense of who they were, as well as their role in and impact on their world. Yet the desire to work was unique to the individual, as not all participants valued their role as worker. Some participants were thankful to no longer be working (Chris: Interview 1; Melissa: Interview 1 and 2) or now had other priorities more meaningful to them.

Thus, as cancer progressed, a shift in occupational priorities occurred: certain roles became gradually more important, while others became steadily less so, depending on where the participant found meaning. A study by Lundquist (2017) on fathers living with advanced cancer also found that a role shift occurred for fathers from paid employment to domestic or parenting roles. An emerging body of research describes the role changes for those under 65; however, longitudinal research on this area is limited (Hanna et al., 2019; Lundquist et al., 2019; Lundquist & Berry, 2019; Park et al., 2017).

This study highlighted the significance of continuing engagement in occupations related to valued roles as cancer progressed. Although the importance of meaningful roles has recently been studied in relation to cancer survivors or the adolescent and young adult population (Lundquist et al., 2020; Lundquist & Berry, 2019; Wallis et al., 2021), a paucity of research exists within the advanced cancer cohort. Engaging in occupations related to their roles fostered a sense of self and well-being for participants in this study. It reinforced their identity, such as a mother, worker, or pet owner. Participants' valued roles were a recurrent theme running throughout the study, as occupation was not only the means through which they expressed their identity, it was the *means through which* roles were inhabited. For example, it was not simply the act of cooking or eating which was valued, but more importantly, the motivation behind it: the relationships that the occupation fostered by eating a home-cooked meal together. Each participant desired to be with the people they loved. They intentionally participated in occupations that would enable continued social engagement consistent with their unique attributes and roles. These findings highlight the importance of having an individualised approach to care, taking the time to understand the motivation behind occupational engagement.

The lived experience of occupational engagement in this study occurred within the context of their life stage as working-aged adults. This included parenting young children, pursuing careers, and negotiating an active lifestyle, as well as the ability to multitask and juggle work, home, children, partners, friends, and their leisure time. Working-aged adults living with advanced cancer may be working, recently placed on sick leave, recently resigned, or involved in full-time parenting. Their roles may shift as their cancer progresses. Many participants in this study had to prepare their children or spouse for the future after they died. These social roles and contexts are different for younger adults when compared to older adults (Knox et al., 2017; Lundquist et al., 2019; Park et al., 2017). The value and meaning ascribed to occupations and roles is unique to the individual (Black et al., 2019; la Cour, Nordell, et al., 2009; Morris & Cox, 2017) and may increase or decrease with age-related changes. Due to these life-stage differences for working-aged adults, it is imperative that the motivation behind occupational engagement for this cohort is understood, as well as the context in which this engagement occurs.

The current study developed a more nuanced understanding of the significance of volition as it pertained to valued roles, highlighting the relationship between valued roles, occupational identity, and occupational engagement. Theme 1, *The intentional pursuit of engagement in everyday activities,* highlights that doing things with and for others (e.g., their children) is an important part of maintaining identity (e.g., valued role as a parent).

## 8.6 The Environment Makes or Breaks It

Physical and occupational environments significantly impacted the lived experience of occupational engagement for all participants in this study. In particular, the environmental context[13] shaped their *ability* to engage in meaningful occupations. Although this has been explored in hospital settings (Eriksson et al., 2016), there is limited research on the role of the environment in facilitating or preventing occupational engagement for working-aged adults living in their own home. The emphasis on the person's lived world is central to this hermeneutic phenomenological study, as the situatedness of being-in-the-world shapes experience of the phenomenon under investigation: occupational engagement for working-aged adults living with advanced cancer (Heidegger, 1962; van Manen, 1990). A person's situatedness in this study also included their physical and occupational environments. As the theoretical model underpinning this study, MOHO's conceptualisation of the environment includes its role as part of a dynamic triad alongside the person and occupation; therefore, adjustments to one of the three areas impacts all three (Fisher et al., 2017). This study furthers MOHO's conceptualisation of the environment by exploring not just its role, but its centrality in the experience of occupational engagement and occupational adaptation for this advanced cancer cohort. This is visually represented by the environment's central position in Figures 8.1 and 8.2. Ongoing occupational engagement

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[13] The physical environment in this study included the presence or absence of stairs, medical equipment such as wheelchairs or commodes, assistive technology, and seasonal variations including hot weather, icy sidewalks, and forest fires. The occupational environment included the impact of the lived space on the individual, and whether there was sufficient time and support.

was achieved by an appropriate match between participants' environment, their desired activity, and their functional status. For some participants, however, the environment became a barrier or significant concern due to the mismatch between their abilities, the task chosen, and their physical space.

Despite the impact and important role of the environment, many advanced cancer studies view it as a non-modifiable entity, include only the home (not the community or yard), or overlook it entirely (Madsen et al., 2019; Rasmussen & Edvardsson, 2007; Rigby et al., 2010). Importantly, people living with advanced cancer often assume that their inability to participate in an occupation is due to their deteriorating body, rather than a constraint in the environment (Carter et al., 2004). Ensuring an environmental match to abilities allowed participants to adapt and continue to engage in valued occupations. The next sections discuss the role of the environment in occupational choice, the significance of seasonal factors, and the occupational environment.

### *8.6.1 Choice is Removed When Environmental Barriers Exist*

The ability and freedom to choose which occupations to participate in can be taken away if environmental barriers are present. When left unaddressed, the environment can impact relationships, daily routines, occupations, and a person's sense of self-efficacy. Participants in this study struggled with the inaccessibility of the world outside their homes or their inability to leave a room in their house.

While person-related factors (e.g., functional decline) are significant contributors to challenges in occupational engagement, modifying the mismatch between the person and environment provides additional options for the person to participate. Barriers in the environment can result in a person's world shrinking and take away a person's ability to decide what their final months or weeks will look like, thus decreasing quality of life (Deckert et al., 2018; Eriksson et al., 2016). However, when environmental factors are properly addressed, a deteriorating body does not always necessitate a corresponding decline in functional abilities. Modifying environmental factors can positively affect functional outcomes and facilitate occupational engagement and well-being across the course of the illness.

Although the environment was an element of the current study's design (interviews conducted in participant's homes), the level of significance that the environment played in the experiences of everyday life for adults living with advanced cancer was unexpected.

Furthermore, in contrast to other studies on the home environment that note the irrelevancy or undesirability of medical equipment (Appelin et al., 2005; Maersk et al., 2018), participants in the current study acknowledged the positive aspects of medical devices. Medical equipment such as a wheelchair, commode, or stair lift, afforded the opportunity to access desired areas of the home, to move independently around the house and community, or to conserve energy for other tasks. Participants demonstrated the positive impact that an environment—intentionally matched to meet their needs and abilities—had on their sense of personal causation and identity.

In comparison, existing palliative care research on the environment often focuses on the overmedicalisation of the home (medical devices associated with increasing decline), fostering social relationships in the home, or the feelings that the home environment evokes: a shrinking world, a sense of normalcy, or feeling ‘at home’ (Collier et al., 2015; Maersk et al., 2018; Rasmussen & Edvardsson, 2007). The current study furthered existing scholarship on the role that the environment plays for the person living with advanced cancer through a focus on its centrality and impact on everyday life. In addition, the environment affects a person’s volitional expression or is an expression of their volition (e.g., Peter’s man cave). This also fits within the framework of the existential of spatiality found within van Manen’s (1990) lived world. Understanding the significance of the context and its effect on the lived experience of occupational engagement is crucial to inform comprehensive care at end of life.

### *8.6.2 The Impact of Seasons on Occupational Engagement*

Another key finding of this study is the impact that seasonal differences in the environment had on engagement in activities. Participants lived in the Bow Valley Corridor of the Rocky Mountains of Canada and there were significant seasonal variations over the course of the study. This included forest fires in summer, winter snowstorms and icy roads, and the dangers of bears coming out of hibernation and protecting their newborn cubs in the spring. The chinook winds also contributed to the seasonal variation, where warm, dry winds coming over the mountains could change the weather by 20° Celsius (36° Fahrenheit) from one day to the next during winter months. Theme 2, *Everyday life is contingent on my environment*, describes how weather and other factors related to the seasons impacted participants’ ability to make choices, often removing the choice to take part in valued activities altogether, or occasionally, limiting their ability to leave their house. The impact of the inability to leave the house was particularly significant for these working-aged adults, as the demographic profile of those who live in these mountainous communities are active individuals who enjoy the outdoors. Participants highly valued being physically active, spending time outside in the natural environment with their friends and family. Thus, when the ability to be in that environment was removed, it had a marked effect on what occupations they could engage in, and more importantly, their occupational identity as active, outdoorsy individuals (e.g., Chris losing his ability to ski, Melissa no longer hiking).

Although studies exist on wheelchair use in winter (Ripat et al., 2015), there is a paucity of research about the impact of seasonal variability on everyday life for working-aged adults living with advanced cancer; no studies were identified at time of study completion. The unspoken assumption in much of the research in palliative care settings is that people living with advanced cancer will not be leaving their house, apart from going to medical appointments. Therefore, other factors are rarely explored, such as the impact on energy levels of clearing a walkway in winter by shovelling deep snow between the front door and the car, or in order to reach the main sidewalk, or the impact that breathing in smoke due to forest fires has on the individual’s ability to be outdoors. Study findings indicate that the weather and season-related aspects of the physical environment must be considered in the exploration of occupational engagement for people living with advanced cancer, as this enables or eliminates the choice to participate in certain valued occupations.

### *8.6.3 Occupational Environment*

Awareness of the occupational context is crucial to facilitate occupational engagement and is a precursor to and a requirement for occupational choice. MOHO defines the *occupational environment* as the occupational context in which participation occurs (Fisher et al., 2017). The occupational environment includes the time allotted to participate in an occupation, the flexibility to adapt the task, whether supports are available, or what occupational opportunities are given. It also pertains to how a person is set-up or positioned to conduct an occupation.

Time is a component of the occupational environment and is broader than simply how time is used. It considers factors such as the creation of routines or the perception that time is short and also includes the experience of lived time (Khatri et al., 2012; la Cour, Nordell, et al., 2009; van Manen, 1990). Time-related occupational factors described by van Manen (1990) included how, when, or even if a person was able to participate in what they wanted to do. Was the individual given sufficient time to adequately complete the task? What time of day was optimal for the activity to be done? Was there flexibility within the person's day or week to shift the time of the activity if required, or was it paced throughout the day to conserve energy? These temporal aspects of van Manen's (1990) lived world were evident in participant narratives, and impeded or facilitated engagement in an occupation. The experience of lived time was significant for this working-aged cohort, as their lives were often busy and involved multiple tasks throughout the day, due to their life stage (e.g., work, children, household maintenance, leisure pursuits).

Ensuring availability of sufficient supports was another aspect of the occupational environment that was transformative for this cohort, enabling participation in activities that previously could not have been done. Support was not simply receiving assistance, but what it facilitated: assistance with self-care in the mornings can conserve a person's energy to participate in other valued occupations during the day. The occupational environment is often closely linked with the individual's volition. When the environment is set-up appropriate to the person's abilities, they are able to live out their values, do things that interest them, feel that they can control what they do, and affect change in their lived world, despite declining function.

Melissa's narratives exemplified the effect that the occupational environment had on her sense of self and capacity. Previously an avid traveller, she had to choose travelling companions wisely once her function began to decline due to cancer progression. She described the tension she felt, not wanting her walls and world to shrink yet aware of her physical limitations and the uncertainty of barriers in her occupational and physical environment when she travelled (Melissa: Interview 10). Maintaining occupational balance was important (Black et al., 2019).

This study contributes to existing occupational theory and palliative care research by identifying the significant role that the occupational environment plays on the ability to participate in activities for adults living with advanced cancer. Thus far, no studies address the role of the occupational environment in experiences of occupational engagement for people living with advanced cancer. A mismatch between performance capacity and the environment can restrict an individual's ability to engage in valued occupations; their occupational choices are limited or can be taken away as a result. Similar to Eriksson et al.'s (2016) research, participants in this study described feeling physically and emotionally stuck at times. However, this study highlights that this sense of ‘being stuck’ is often due to unaddressed limitations in their occupational environment. On the other hand, the environment can also be transformative, allowing people to participate in activities that had been abandoned because the environmental set-up was inappropriate. It is impossible to separate a person’s ability to engage in an occupation from their physical and occupational environments; they are not distinct, independent entities but exist in a dynamic relationship. This complex, nuanced relationship between the environment, the person’s abilities, and the occupations they choose to engage in must be addressed in clinical practice in order to optimise function and ensure provision of comprehensive care.

## 8.7 Occupational Disengagement with Advanced Cancer

Adults living with advanced cancer experience bodily deterioration that inevitably results in a reduced ability to participate in some of their meaningful occupations (Eriksson et al., 2016; Hammill, Stewart, et al., 2019; Morgan et al., 2017; Peoples, Brandt, et al., 2017). Occupational disengagement occurs when factors external to the individual prevent occupational engagement. These factors include environmental barriers or lack of support to prepare or participate in an occupation and can have detrimental consequences on the person experiencing occupational disengagement. This is described in Chapter 5 (Vignettes), the Chapter 7 (Findings Theme 2) and in existing literature (Durocher et al., 2014; Hammill et al., 2014; Keesing & Rosenwax, 2011; Morgan et al., 2017; Park Lala & Kinsella, 2011; Rasmussen et al., 2010). In this study, functional deterioration prevented participants from engaging in valued occupations, thus altering the meaning they ascribed to their everyday activities. Their occupational identity and sense of capacity were adversely affected through the subsequent loss of valued roles or important relationships. Life was more physically challenging than it had been previously. However, it is important to note that their experience of loss was not about the loss of independence in and of itself. *Rather, the meaning that these adults attached to their increasing dependence was connected to the occupational disengagement that resulted*. Pre-diagnosis, they had considered themselves to be competent, capable individuals, consistent with their life stage. In order to provide optimal care to this population group, it is crucial to listen to the meaning behind increasing dependence and occupational disengagement.

The detrimental impact of occupational disengagement on the well-being of adults living with advanced cancer must not be underestimated. What is ultimately at stake reaches further than simply bodily deterioration; it affects their relationships, occupational identity, and sense of meaning. Occupational therapy and occupational science literature have explored some of the implications of occupational disengagement, including losing a sense of normalcy, feeling a loss of control, and the inability to do those things that define a person's sense of self (Durocher et al., 2014; Polatajko, Molke, et al., 2013; Whiteford, 2000). This is due to the interrelationship between a person's volition and their ability (or inability) to participate in valued occupations. Interestingly, the inability to engage in meaningful activities is often described as an aspect of suffering outside of occupational therapy, despite minimal exploration into what this entails or why valued activities are so important to quality of life (Beng et al., 2014; Boston et al., 2011; Health Canada, 2021; Nilmanat et al., 2010; Pasman et al., 2009; Sacks, 2013). As discussed earlier, people living with advanced cancer may express who they are, what they value, and the relationships they cherish through the occupations they choose to engage in. When a person is unable to do what they want to do (participate in valued activities), their occupational identity is under threat. Occupational disengagement has greater significance and impact on the illness experience when it relates to a person's volition because a threat to volition has the potential to disrupt one's sense of capacity and self-efficacy (i.e., personal causation).

As noted earlier, the significance of occupational disengagement and its link with volition is evident in the medical assistance in dying clinical audit data. Across Canada, 84.9% of people who ended their life through medical assistance in dying chose to do so because of the "intolerable suffering" that the "loss of ability to engage in meaningful life activities" causes—in other words, occupational disengagement (Health Canada, 2021, p. 6). This is consistent with clinical audit data from Oregon in the United States of America, where people have been able to end their life with physician prescribed life-ending medications since 1998, and in Washington, where this practice has been legal since 2009 (Oregon Health Authority, 2021; Washington State Department of Health, 2018). Importantly, of those in Oregon who chose to end their life, more than *double* rated occupational disengagement as a reason for doing so rather than simple physical deterioration. In over 20 years of data collection[14], only 43% of people chose to end their life because of loss of physical abilities, while 89.9% chose to end their life because of

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[14] More than one option could be chosen for end-of-life concerns, so the numbers do not add up to 100%.

reduced ability to participate in enjoyable activities and a further 90.6% because of a loss of autonomy (Oregon Health Authority, 2021). The clinical audit data from Canada and the United States of America supports this study's finding that the loss of the ability to engage in meaningful occupations resulting from the disease process is a primary concern at end of life for many people, more so than symptoms. Participants in this study wanted to have their symptoms managed and physical decline addressed, for the purpose of being able to engage in the activities they wanted to do (Morgan et al., 2017).

The link between occupational engagement, volition, identity, and adaptation for people living with advanced cancer is explored only briefly in occupational frameworks. In addition, MOHO as a theoretical framework has rarely been used in advanced cancer research: only one study has used MOHO as a framework to investigate the experiences of people living with advanced cancer (Morgan et al., 2017) and one opinion piece on the role of MOHO in palliative care settings (Costa & Othero, 2012). No studies were found that explicitly investigate the relationship between volition and occupational engagement, nor the significance of volition in occupational adaptation for this cohort, discussed in the next section.

Ongoing engagement in meaningful activities, even in a modified form, made participants feel like they were still living while at the end of their life and facilitated a sense of self-efficacy for all participants. As bodily function deteriorated and cancer progressed, participants began to lose the ability to independently engage in some of their occupations of choice; however, their desire to engage in meaningful occupations remained strong. In order to avoid or delay occupational disengagement, participants needed to adapt. Occupational adaptation can facilitate continued occupational engagement; this will be explored further in the following section.

## 8.8 Adaptation Driven by Volition, Through Occupational Engagement

Occupational adaption played a crucial role in the lives of study participants by re-establishing meaningful occupations that had been lost through progressive functional decline and increasing dependence. Participation in valued occupations reinforced a sense of identity and their desire for continuity with how they previously viewed themselves: that they were still the same person that they had always been before their cancer. From the perspective of the participant facing increasing dependence and loss of abilities, the significance of occupational adaptation was substantial.

Numerous occupational scientists and occupational therapists have theorised and researched the concept of occupational adaptation; however, the majority of these studies pertain to non-life limiting conditions (Bontje et al., 2004; Cotton, 2012; George-Paschal & Grajo, 2019; Klinger, 2005; Walder & Molineux, 2017a). MOHO describes occupational adaptation generically, primarily focusing on the experience of life transitions or non-progressive conditions that often stabilise (de las Heras de Pablo, Fan, et al., 2017). Occupational adaptation is defined in MOHO as "the development of a positive occupational identity, coupled with the experience of occupational competence over time within the context of one's environment" (p. 116). Adaptation can be the process or the outcome. Building on the existing MOHO understanding of occupational adaptation, this thesis posits that adaptation for the advanced cancer cohort is linked to their volition and occupational identity rather than their identity and occupational competence as per MOHO. In order to explore this further, a recap of related terms is provided.

Volition, occupational competence, occupational identity, and occupational adaptation are four vital and interrelated concepts[15] (Lee & Kielhofner, 2017b). *Volition* is comprised of the values, interests, and personal causation of the individual. The *values* a person has determine what is important to them. *Interests* relate to what a person enjoys or is interested in. *Personal causation* is the person's *sense of capacity* (their interpretation of their physical, cognitive, or psychosocial abilities) and their *sense of self-efficacy* (how effective a person feels in using their abilities to achieve the outcomes they have set). For the person living with advanced cancer, personal causation asks the questions: Do I feel I am able to effectively do this? Do I have a sense of control in this scenario? Do I have the required physical and cognitive abilities? This differs from occupational competence, which asks the question: Can I competently participate in a meaningful occupation while living with a deteriorating body? What happens if my symptoms flare up? The concepts of personal causation and occupational competence are similar yet different: one involves the self-perceived sense of capacity (personal causation) whilst the other is the actualisation of participation (occupational competence).

*Occupational competence* is defined in MOHO as "the degree to which one sustains a successful pattern of occupational participation that reflects one's occupational identity"

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[15] These concepts are discussed further in Chapter Two (Theoretical Concepts).

(de las Heras de Pablo, Fan, et al., 2017, p. 117). According to MOHO, *occupational identity* is closely related to the person-related factors of volition, habituation, and the lived body. Occupational identity is shaped by how a person views themselves in the present and their hopes for the future. Volition and the volitional process are central to this concept, as a person's occupational identity is shaped and driven by their volition.

MOHO describes occupational adaptation generically, primarily focusing on individuals who experience a life event or who may have acquired a disability or illness which reaches a general level of stability, or who are in a time of transition. At some point in their journey, there will be a stabilisation or plateauing of abilities and the individual can develop "a positive occupational identity" and experience "occupational competence" as described in MOHO (de las Heras de Pablo, Fan, et al., 2017, p. 116). In contrast, the experience of people living with advanced cancer is one of unremitting loss and change. They are not moving towards a time of stability which contributes to the development of a stable identity, as described in MOHO. For people living with advanced cancer, maintaining a stable level of participation is not sustainable due to their often rapidly declining function and increasing dependency over time.

On initial examination of this study's findings, it appeared that participants wanted to maintain their level of *competence* when doing activities. However, deeper examination of the data highlighted that it was not simply the competent participation in an activity which was central. Rather, participants wanted to maintain their *occupational identity* through their *volition*. They sought to maintain their ability to engage in occupations related to their *values* and *interests* through adapting the task and reimagining what was possible. Significantly, *their personal causation was* central: their internal evaluation of and beliefs about their sense of capacity and abilities, and feelings of control in achieving their aims. This distinction between occupational competency and personal causation (self-efficacy and sense of capacity) is crucial when we consider the experiences of occupational engagement for people living with advanced cancer. Their observed competency can differ from their self-efficacy and sense of capacity. Although still important, occupational competence was not the primary concern for working-aged adults living with advanced cancer in this study. They were aware of their cancer or treatment-related limitations and knew that their physical capacity would continue to decline, suddenly at times and, at other times, more gradually. Occupational competence is elusive in advanced cancer and unattainable as the end-of-life approaches; the majority of individuals may lose it entirely in the last weeks and days of life. However, it is the contention of this thesis that personal causation may still be preserved in the last months to weeks of life.

Engagement in meaningful occupations reinforced the *occupational identity* of these working-aged adults. However, maintaining their occupational identity became increasingly difficult as the cancer progressed and occupational engagement became more difficult. As these adults continued to seek a sense of normalcy, they sought to adapt in order to continue participating in everyday life activities. Normalcy was desired even when unattainable at times, a finding consistent with existing literature (Black, 2011; García-Rueda et al., 2016; Knox et al., 2017; Lundquist et al., 2019; Park et al., 2017). Therefore, the desire for continuity with how they previously viewed themselves (i.e., occupational identity) was a significant driver for participants to adapt.

The contention of this thesis that a *stable* sense of competency and normalcy are untenable constructs for people living with advanced cancer furthers existing literature in occupational therapy and advanced cancer. Study findings demonstrate that in a palliative care cohort, *occupational adaptation needs to be redefined* from its current conceptualisation in MOHO. The existing MOHO definition does not work with the advanced cancer population when occupational competence is not attainable. This thesis argues that a revised definition of occupational adaptation in MOHO should include considerations for people living with life-limiting conditions, wherein levels of competence continue to decline as bodily deterioration and disease progression inevitably occurs.

More specifically, this study furthers MOHO's conceptualisation of occupational adaptation by positing that the process of occupational adaptation for people living with advanced cancer is as follows (see Figure 8.2):

- Advanced cancer progression results in a reduction in abilities (performance capacity) alongside experiences of uncertainty, current losses, future anticipated losses, and continuous functional change.
- As a result, there is increasing difficulty engaging in occupations.
- There are three responses to reduction in functional abilities (see Section 8.5.2):
    - Inability to participate in the occupation due to external barriers preventing occupational engagement (i.e., occupational disengagement),
    - Intentional choice to not participate in an occupation (often due to the

    occupation not being in line with their volition), or
    - Intentional adaptation of the occupation (e.g., shift from active to passive involvement, modify or substitute one component, or substitute multiple parts of the occupation).
- If they choose to adapt, occupational engagement can then occur; they participate in the activity of choice (albeit modified), thereby reinforcing the person's volition and occupational identity.
- The environment can act as a barrier or a facilitator of occupational engagement, as it affects the occupational adaptation process.

This study affirmed that people experiencing functional decline due to advanced cancer may not experience a *stable participation level* in valued occupations as the individuals in this study experienced fluctuation and change throughout the trajectory of their disease. Functional ability changed regularly, predominantly in a downwards trajectory. Thus, with minimal plateauing of function, there was no stable sense of normal to return to. Their environment required ongoing monitoring and modifications as their abilities shifted and their bodies deteriorated. With the growing number of people living longer with advanced cancer, occupational frameworks should incorporate discussions around adaptation to deterioration within the context of unremitting change and fluctuations in abilities. The interconnectivity between volition and occupational adaptation in advanced cancer may also be relevant to those living with degenerative neurological disorders or other progressive, life-limiting conditions (Cahill et al., 2010; Foley et al., 2014a, 2014b; Månsson Lexell et al., 2010). The current study advocates for a shift from existing occupational adaptation conceptualisation in MOHO to include the significant role that volition plays as a motivator for occupational adaptation. Occupational competency, as defined by MOHO, is not a primary determining factor for occupational adaptation in this cohort; rather it is the preservation of personal causation and support of the volitional cycle.

### *8.8.1 The Process of Adaptation for People Living With Advanced Cancer*

The active, intentional desire for continued occupational engagement while living with advanced cancer was demonstrated in how participants adapted to functional decline. Study findings were consistent with a study by la Cour, Nordell, et al. (2009) which recognised that adaptive strategies are often woven into everyday life. The current longitudinal study highlighted the dynamic nature of adaptation, where frequent shifts and recalibrations were required as participants' cancer progressed and bodily function deteriorated. Active adaptation provided a space where participants could process their losses. They compensated for their changes in function and continued engaging in meaningful occupations. The desire to adapt was strong as participants sought to maintain their occupational identity, their sense of capacity and self-efficacy (i.e., personal causation), their valued roles, and their meaningful relationships.

The process of adaptation was important for participants, involving modifications to what they did and how they thought. Occupational adaptation occurred across the dynamic volitional process of anticipation, choosing an occupation, experiencing it, and evaluating the engagement (Lee & Kielhofner, 2017b). Melissa exemplified this in her decision-making over the course of her ten interviews, intentionally selecting which activities she engaged in. First, Melissa spoke about her *anticipation* of an activity. She looked forward to going for a walk at the lake or spending time with family at Christmas. Second, Melissa *chose* to go on a walk with friends, as she valued her relationships and walking along the water was an interest of hers. However, her *experience* of the walk was different to what she expected. The walk was much longer than she anticipated, and she did not feel capable to continue. Finally, Melissa felt disappointed with herself on *reflection*. Her sense of self-efficacy did not match her experience. She interpreted this experience as one where she felt she was misled; she had trusted her friends' explanation that the walk would not be long yet felt they had betrayed her trust by taking her for a much longer walk than proposed. This perceived betrayal of trust was difficult for Melissa to reconcile. The process of adaptation occurred across the volitional cycle, and included aspects noted in Table 8.1.

**Table 8.1**

*Examples of the Volitional Cycle in Advanced Cancer*

| Stage of Volitional Cycle | Adaptation |
|---|---|
| Anticipating | Prioritising important occupations that align with their volition (values, interests, sense of self-efficacy, and self-perceived capacity to engage in the occupation) |
| | Self-awareness of fatigue, pain, or other symptom levels at different times of day |

| Stage of Volitional Cycle | Adaptation |
|---|---|
| | Modifying the physical environment to current needs; anticipate future needs |
| | Ensuring a good fit between the occupational environment, occupation, and person |
| Choosing | Intentionally making the choice to engage in an activity |
| | Replacing one activity for another; an alternate yet still a meaningful occupation |
| | Planning how occupational engagement will occur, depending on how they feel at that time:<br>• Changing how an occupation is engaged in<br>• Substituting one component of the activity for another in preparation<br>• Adapting the degree of involvement in an occupation (e.g., shifting from a more to less active role, pacing) |
| Engaging | Pushing through symptoms or delaying treatment to continue doing important activities |
| | Level of enjoyment during the activity, presence of valued relationships |
| | Modifying how an activity is done part-way through, depending on symptoms and supports |
| | Substituting one component of the activity for another whilst engaging |
| Interpreting | Reframing perspectives (e.g., Is this occupation congruent with valued roles?) |
| | Reflecting on their sense of capacity and self-efficacy within the context of disease progression |
| | Shifting expectations and sense of limited time remaining (e.g., will this activity continue to be a priority?) |

### *8.8.2 Desire to Engage Amid Physical Deterioration*

Adapting to occupational and bodily changes involves maintaining a balance between living and dying, hope and reality. This is affirmed in existing research which highlights the desire to continue living while dying (Morgan et al., 2017; Park Lala & Kinsella, 2011), along with the balance between a focus on engagement in life and a focus on losses experienced or anticipated (Vehling et al., 2018). García-Rueda et al. (2016) conducted a meta-synthesis of literature examining everyday experiences of people living with advanced cancer. They described the internal processes of adapting to changes that people experienced and noted that “when the person accepts reality, they are … maintaining their personal identity.” However, what does acceptance of reality mean for these individuals? Peter knew he was dying, but in his final interview shortly before he died, he spoke of wanting to get a wheelchair-accessible vehicle for travel. This was not a denial of approaching death, but a focus on hope for the future. This supports Heidegger’s notion of being-toward-life but also being-toward-death (Heidegger, 1962). These states of being are not mutually exclusive. Tammy hoped that her rehabilitation efforts, essential oils, crystals, and positive psychology would result in healing from her cancer. Although she made some functional gains despite physical decline over the course of several months, her cancer continued to spread. As Saunders (2000) stated, “people should be helped not only to die peacefully, but to live until they die” (p. 8). Similarly, these working-aged adults living with advanced cancer chose to live intentionally while they were dying. Living meant participating in everyday activities that facilitated a sense of self and hope, as this was the context in which they could spend time with those they loved and also maintain their valued roles. Living intentionally was an expression of their volitional self, demonstrating what they valued, their interests, their sense of capacity, and their self-efficacy. Doing so made them feel that they were living, not dying (Morgan et al., 2017).

### *8.8.3 Outcome of Adaptation: Maintaining Occupational Identity and Sense of Normalcy*

The desire to adapt and continue participating in meaningful activities is strong for people living with advanced cancer (Ashworth, 2014; la Cour, Johannessen, et al., 2009; Maersk et al., 2021; Morgan et al., 2017; Peoples, Brandt, et al., 2017; Svidén et al., 2010; Vrkljan & Miller-Polgar, 2001). This study’s findings support this emerging body of occupational therapy research; the working-aged participants in the current study sought to deliberately pursue occupations related to how they defined themselves. As these occupations became increasingly difficult or impossible to do, participants adapted their valued activities with the aim of reinforcing their sense of capacity and agency, as well as to establish a sense of normalcy. These adults wanted to feel that they were capable. The desire to engage in valued occupations was strong, as noted in Theme 1, *The intentional pursuit of engagement in everyday activities*. Similarly, the desire to adapt when experiencing difficulty participating in certain occupations was a recurrent theme as described in Subtheme 3 of Theme 1, *Adapting to change is an active, ongoing process*. The following section will describe the importance and manner of adaptation required to maintain valued roles, which is unique to the working-aged adult population in this study.

### *8.8.4 Outcome of Adaptation: Maintaining Valued Roles*

Adaptation was also crucial for sustained involvement in valued roles in advanced cancer, including the roles of worker, parent, spouse, and friend. These roles were influenced by their volition. Volition was a primary motivating factor for why participants prioritised and chose certain occupations to engage in, as per Figure 8.1. Modifications required to maintain the worker role amid functional decline were often reflected in multiple arenas. To maintain a sense of capacity and agency, adaptations might include changes in transportation to and from work, working hours, or reprioritisation of what tasks needed to be completed. These adaptations were vital to continue in a worker role, and assisted in maintaining a sense of self, sense of normalcy, and feelings of competence in the midst of uncertainties while living with advanced cancer.

Participants also described the adaptations they made so that they could continue in the role of parent. As established earlier, although they purposefully strove for independence (Theme 1, Subtheme 1), the desire to do tasks independently was not the primary goal of adaptation for the majority of participants. Rather, participation was the context which allowed them to maintain their roles and relationships, mutually caring for those they loved and valued. Often it was the routine activities that participants modified, knowing that these were important to do with their family. Adaptations might include shifting from more physically active occupations to less physically demanding ones or from walking independently to using a wheelchair to conserve energy. The significance of retaining the parental role is consistent with existing studies on the lived experience of losses experienced and attempts to maintain responsibilities when parenting while dying (Lundquist et al., 2019; Lundquist, 2017; Park et al., 2017).

The role of friend remained a high priority despite requiring adaptation of how they socialised with friends as their cancer progressed. Other studies confirm the desire for reciprocal friendship at the end of life (Black, 2011; Romotzky et al., 2019). Maintaining friendships often meant adjusting the time of day they got together or reframing how to best engage in life together, instead of ruminating on occupations that were no longer doable. Melissa described her “focus on what I can do … I am still a good friend because I text or I chat with them, I can still participate in some things, or I can still buy presents, I can still be involved in different ways” (Interview 10). The nature of the friendship role continued to shift as function declined. Like Melissa, Tammy was thankful that a shift to less physically involved activities enabled her to continue socialising with her friends, despite declining health. “I can listen, and I care … because I don’t need to use this hand. I can do things without it” (Interview 7). Doing things with others was important to all participants, and active adaptation enabled them to maintain their key relationships.

## 8.9 Clinical Implications

An interdependent relationship exists between research, theory, and clinical practice, whereby each informs and shapes the other. This study extends existing theoretical knowledge on occupational engagement and occupational adaptation within the context of advanced cancer and MOHO (de las Heras de Pablo, Fan, et al., 2017). Clinically, it translates to asking questions such as: What does everyday life look like for the individual? What brings meaning within the experience of daily routines and occupations? How is the ability to engage in valued occupations maintained in the face of progressive decline? Assistance and support given to this population should seek to optimise their ability to participate in occupations meaningful to them through an awareness of their volition, and thus, enhance their quality of life.

An understanding of both the lived experience of occupational engagement for people living with advanced cancer and the theoretical framework of MOHO can inform and enrich clinical practice, guiding health care providers to deliver targeted, individualised care beyond acute symptom management. The findings of this study challenge occupational therapists to focus not merely on symptoms or occupational categories of self-care, productivity, or leisure, but to identify how cancer affects the individual’s everyday life. There is an imperative for clinicians to listen to the person’s illness experience in order to understand what is important to them. Interventions can then be prioritised to enable the individual to engage in those meaningful occupations that relate to their volition.

MOHO, with its focus on occupation, identification of the motivation behind the doing, and the dynamic systems approach is a theoretical framework that can inform clinical practice. MOHO asks: What motivates a person (volition), how do they organise and structure their life (habituation), and what is their subjective and objective abilities (performance capacity)? How have their valued occupations, roles, and relationships been affected by advanced cancer and increasing dependency? What role does the space they are in (e.g., home, community, work environments) play in their well-being or inability to participate? This study extends MOHO into clinical practice through recognising the centrality of volition in facilitating adaptation and thus continued engagement.

This nuanced understanding of the person within their lived world provides the occupational therapist with insight into the individual's everyday life as they contend with increasing dependency, unremitting change, and loss. If the individual is unable to participate in a valued occupation due to symptoms limiting their ability, then symptom management should be the focus; however, addressing symptoms should be done with the goal of resuming or adapting to everyday activities (Morgan et al., 2017). Illness related losses may also be significant and include the loss of the sense of wholeness, control, certainty, and freedom, and the impact loss has on daily life (Carel, 2016; Toombs, 1987). Different types of loss may be addressed by interventions that focus on meaningful occupation rather than clinician or health service goals (Boa et al., 2019; Miranda et al., 2018). The clinician should move beyond a simple awareness of factors affecting the patient's everyday life or the presence of symptoms. Once the person's motivation for doing is known, the occupational therapist and the individual can develop priorities to be addressed. For example, in this study, participants valued relationships and wanted to continue doing activities that related to their meaningful roles of parent, spouse, worker, friend, or pet owner. Areas of reduced performance capacity must be recognised, environmental barriers highlighted for intervention, and occupational disengagement addressed.

Interventions should be tailored to provide opportunities for the individual to engage in their valued occupations. This may involve modifying a part of the occupation to alter how participation occurs, substituting one aspect for another, or replacing one activity for a similar one. The mode of engagement may differ, such as having a less active role in an occupation than before, but the individual is still able to participate in the occupation, albeit in an adapted form. While this is not dissimilar to existing occupational therapy interventions with people who have palliative care needs, this thesis posits that a focus on preserving volitional expression can support a person to maintain their occupational identity through engaging in occupations that support volitional expression. Thus, the use of terms such as *level of independence* or *occupational competence* may not be as applicable to this group, as their level of competence is not stable and independence level is in the eye of the individual (e.g., the person may be 'dependent' on others for yard work tasks, yet 'independent' sitting on the sofa watching others do the yard work).

Importantly, the cycle of occupational adaptation occurs within the context of advanced cancer, resultant losses, functional decline, and also within their specific environment. The clinician should identify the environments that individuals frequent and address any barriers to occupational engagement as needed. Physical environmental factors such as stairs, the distance required to walk between two locations, or toilet height should be noted, as well as seasonal factors (e.g., summer heat, winter snow, and bears in the spring), and aspects of the occupational environment such as time, supports, and space available. Addressing environmental factors can thus provide the freedom of *choice* to participate in valued occupations with the people or pets that they love.

Due to the nature of advanced cancer and functional decline, ongoing monitoring is required to ensure that the occupational adaptation process continues as needed. When further reduction of abilities occurs, reflected in increasing difficulty with occupational engagement, reassessment of what currently needs to be adapted enables continued participation in the individual's valued occupation. Participants in the study highlighted the significance of the "little things," such as being able to hold a pen, play with their young children, or sleep in the same bed as their spouse. This thesis argues that enabling occupational engagement in these little things can support volitional expression and help to maintain valued roles even as disease progresses. Although it may seem minor to a health care provider, supporting a person's volition may be essential to enhancing an individual's quality of life.

## 8.10 Limitations and Further Research

The limitations of this study are both methodological and demographic in nature. Due to its phenomenological approach, this research provides insight into the essence of a phenomenon (the lived experience of occupational engagement) within its lifeworld, an experience often unique to the specific cohort (working-aged adults living with advanced cancer) within their context. This limits the generalisability of the findings. This study took place within the Bow Valley Corridor of the Canadian Rocky Mountains, and as a result, participants reflected the type of people and occupations undertaken by those living in these communities. Many individuals living in these smaller, rural, and mountainous communities enjoy the outdoors and being in the mountains. Therefore, their occupations were often local, such as going for walks in their communities. Furthermore, there was minimal demographic diversity of participants. All eight participants were Caucasian, six were married, six had pets, and five were women. The sample size was small (8).

A limitation in longitudinal studies occurs when a participant does not complete multiple interviews (Steinhauser et al., 2006). Two participants had only one interview due to death and gatekeeping, as discussed in Chapter 4 (Methodology). This is a common limitation in longitudinal palliative care designs, such as Lundquist et al.'s (2019) study, where unexpected deterioration and rapid symptom, physical, and emotional changes are the norm.

Given the interdependent relationship between research, theory, and clinical practice and the empirical foundation of MOHO theory, this thesis forms the foundation for further research regarding occupational engagement and occupational adaptation at the end of life. More specifically, four areas of future research warrant further investigation. Recommended future research includes longitudinal research on occupational engagement involving a larger cohort of people living with advanced cancer or living in different communities (e.g., urban or outside of Canada). A second topic for further exploration is the experience of occupational adaptation for people living with other progressive degenerative conditions, using this study's conceptualisation of volition and occupational identity. Third, examination into how occupational therapists assess and address occupational adaptation and volition in their hospital, hospice, and community settings could inform future care. A fourth area of future research is development of an assessment tool to capture strengths and needs regarding occupational engagement, volition, and occupational adaptation for working-aged adults living with advanced cancer, including incorporation of the valued roles of this younger cohort.

## 8.11 Conclusion

This study explored the lived experience of occupational engagement for working-aged adults living with advanced cancer. It sought to understand the person's way of being in the world by prioritising participants' voices through a hermeneutic phenomenological approach. A longitudinal design provided rich, in-depth accounts of how participants experienced and adjusted to disease progression and how (or if) they continued engaging in their daily activities as function shifted and changed over the disease trajectory.

Although I set out to look at the value participants placed on occupational engagement, this study led me to a deeper, more nuanced understanding of what gave life meaning for working-aged adults living with advanced cancer. It was not simply having loved ones near, nor living a symptom-free life. It was the ability to engage in meaningful occupations with their loved ones. Their volition shaped what they did, which in turn reinforced their volition, sense of self, and occupational identity. These adults wanted to participate in occupations that reinforced their mutual relationships and important roles as a parent, friend, spouse, and pet owner. They sought a sense of normalcy through continuing to participate in activities they valued and gave them joy. They also wanted to feel a sense of control and self-efficacy, adapting how they did tasks in order to keep doing things that made them feel like they were still themselves. Adaptation did not result from their achieved competency level, as advanced disease processes meant that competency levels would continue to decline with their deteriorating function. Rather, adaptation was modifying the manner of occupational engagement in order to participate in an occupation—even if in modified form—that reinforced their volition. Ultimately, their volition (values, interests, personal causation) shaped their choices at end of life.

The significant impact of the environment was another unexpected finding. It played an important role as gatekeeper, facilitator, or barrier to whether a person could engage in their valued occupations and remains under-investigated. This study demonstrated the value of the home and community environment, as well as occupational environmental factors (such as time, supports, and space) in shaping a sense of well-being and quality of life for the person living with advanced cancer. Seasonal variations were a significant aspect of the environment, impacting participants' ability to engage in their meaningful occupations.

This study's significant original contributions to knowledge for working-aged adults living with advanced cancer are threefold: (a) participants *intentionally* sought to engage in occupations related to their *volition* across the trajectory of advanced cancer, (b) the *physical and occupational environment* can significantly affect a person's experience of everyday life due to its impact on *occupational choice*, and (c) *occupational adaptation* occurs in order to maintain one's *occupational identity* and *volition* (not competence). Significantly, occupational identity and volition are motivating drivers for adaptation to declining abilities of those living with advanced cancer. This is in contrast to the relationship between occupational adaptation, identity, and competency, as described in the current MOHO definition of occupational adaptation (de las Heras de Pablo, Fan, et al., 2017). Thus, this study findings build on current conceptualisations of occupational adaptation, which have been informed predominantly by research with individuals unlikely to deteriorate quickly (such as people living with advanced cancer). This study highlighted the importance of not only addressing the person's functional abilities but also the motivation behind their desire for occupational engagement. What this looks like shifted as priorities changed, dependency increased, and cancer progressed; adaptation was an ongoing process.

The complex downward trajectory of living with advanced cancer often results in an inability to engage in meaningful occupations as function declines, due to factors such as loss of ability, confidence, and symptom burden (Canadian Association of Occupational Therapists, 2002; Hammell, 2014; Keesing & Rosenwax, 2011; Lindqvist et al., 2006; Morgan et al., 2017; Park Lala & Kinsella, 2011). This increasing difficulty in occupational participation at the end of life impacts a person's well-being, identity, and quality of life (Eriksson et al., 2016; Maersk et al., 2017; Rasmussen et al., 2010; Vrkljan & Miller-Polgar, 2001). However, when a person is not afforded the opportunity to participate in their valued occupations, occupational disengagement results. The detrimental effects of occupational disengagement on the lives of people living with advanced disease are seen in the primary reason why people choose medical assistance in dying in Canada and the United States of America: the loss of the ability to engage in meaningful occupations (Health Canada, 2021; Oregon Health Authority, 2021; Pasman et al., 2009; Washington State Department of Health, 2018). This lends support to the primacy of volition and meaning in the process of occupational adaptation at the end of life.

Looking forward, this study has significant implications for health care in the future. A greater understanding of occupational engagement is crucial to our understanding of the lived experience of clients who are at the end of life. The number of Canadians who have cancer is predicted to increase by 79% in the next 10-15 years (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2017). This, combined with extended prognoses due to advances in medical care, means that the number of people impacted worldwide by advanced cancer will continue to grow. Further research on the impact of occupational engagement is warranted to ensure the future needs of this expanding population of chronic advanced cancer are met.

Study findings extend current theory regarding occupational engagement, occupational adaptation, and occupational identity. The existing conceptualisation assumes a plateauing of identity and competence after a health or life event and does not address the unremitting and unexpected changes that occur for people who have palliative care needs. Rather, a person’s volition significantly impacts the lived experience of occupational engagement and the process of occupational adaptation. This study sought to increase understanding of the lived experience of occupational engagement for working-aged adults with advanced cancer. Greater insight into occupational engagement in advanced cancer will inform theoretical frameworks that underpin clinical practice and person-centred care into the future.

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# APPENDIX A: ETHICS AND OPERATIONAL APPROVALS

Ethics boards and operational approvals were obtained from the following sources:

1. Social and Behavioural Research Ethics Committee (SBREC) at Flinders University (approved 22 February 2018).
2. Transfer form from SBREC to the ResearchNow Ethics & Biosafety – the new ethics approval system at Flinders University (approved 21 September 2020)
3. ResearchNow Ethics & Biosafety final report for closure of ethics (12 January 2021)
4. Health Research Ethics Board of Alberta: Cancer Committee approval (original approval dated 17 December 2017)
5. Health Research Ethics Board of Alberta: Cancer Committee modification approval (modification was requested by SBREC, approved 12 March 2018).
6. Health Research Ethics Board of Alberta: Cancer Committee renewal approval (10 December 2018).
7. Alberta Health Services Operational Approval.

HE **Human Research Ethics**
7858 SBREC Final approval notice (22 February 2018)
To: Julie Brose, Deidre Morgan, Eileen Willis

Inbox - Flinders February 21, 2018 at 4:36 PM

Dear Julie,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. This means that you now have approval to commence your research. Your ethics final approval notice can be found below.

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# FINAL APPROVAL NOTICE

Project No.: **7858**

Project Title: A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults with advanced cancer

Principal Researcher: Mrs Julie Brose

Email: [redacted]

Approval Date: 22 February 2018

Ethics Approval Expiry Date: **31 January 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

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## RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

### 1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

*This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.*

## 2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **22 February** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **22 February 2019** or on completion of the project, whichever is the earliest.

## 3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

## 4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Rae

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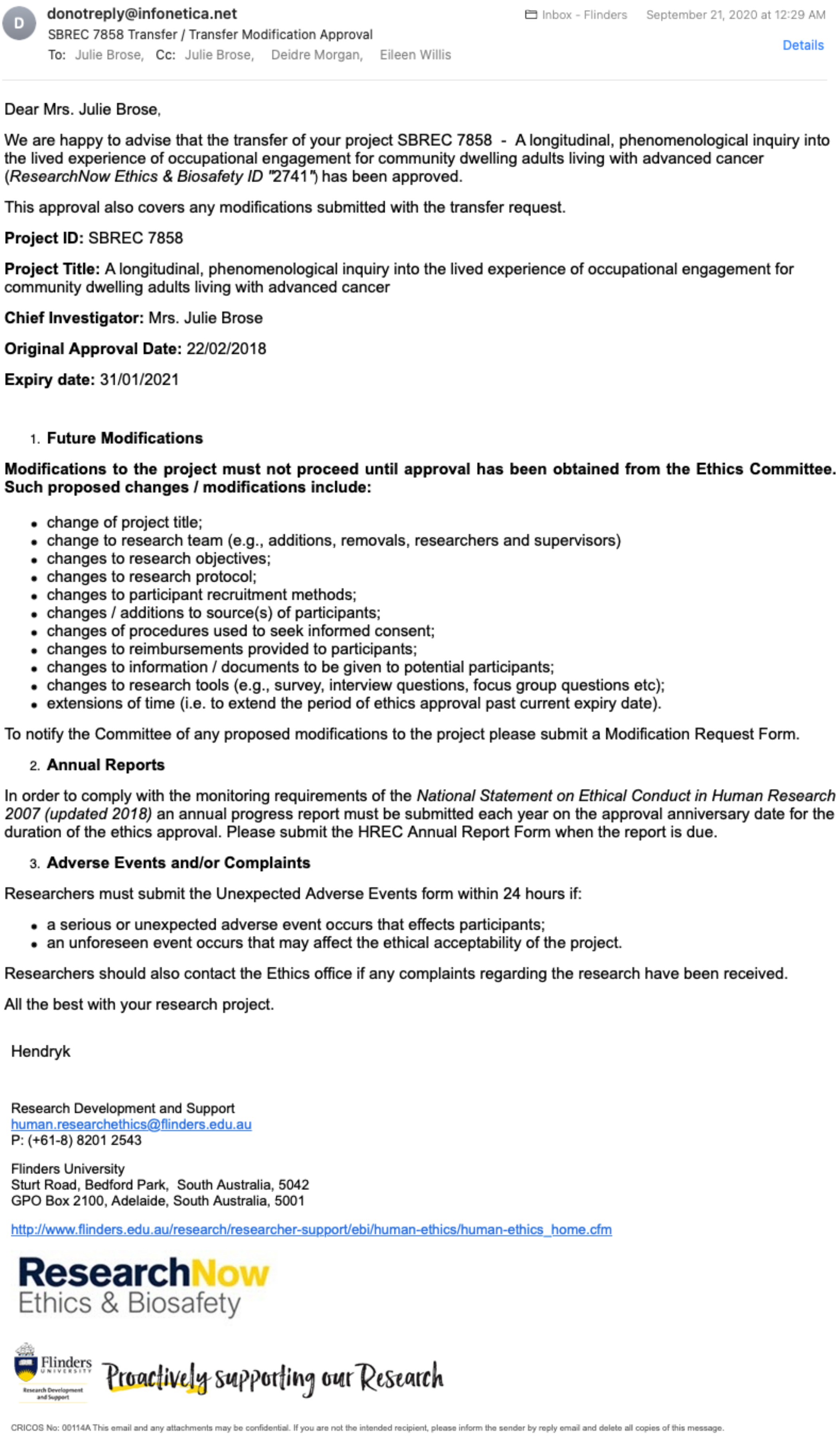
**Ms Andrea Mather** (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

| | |
|---|---|
| Ms Andrea Mather I Monday - Friday | T: +61 8201-3116 I E: human.researchethics@flinders.edu.au |
| Ms Rae Tyler I Monday, Wednesday and Friday mornings | T: +61 8201-7938 I E: human.researchethics@flinders.edu.au |
| A/Prof David Hunter I SBREC Chairperson | T: +61 7221-8477 I E: david.hunter@flinders.edu.au |
| Dr Deb Agnew I SBREC Deputy Chairperson | T: +61 8201-3456 E: deb.agnew@flinders.edu.au |
| Dr Peter Wigley I Manager, Research Ethics and Integrity | T: +61 8201-5466 I E: peter.wigley@flinders.edu.au |
| SBREC Website | Social and Behavioural Research Ethics Committee (SBREC) |

Research Development and Support IUnion Building Basement
Flinders University
Sturt Road, Bedford Park I South Australia I 5042
GPO Box 2100 I Adelaide SA 5001



D **donotreply@infonetica.net**
SBREC 7858 Transfer / Transfer Modification Approval
To: Julie Brose, Cc: Julie Brose, Deidre Morgan, Eileen Willis

Inbox - Flinders September 21, 2020 at 12:29 AM
Details

Dear Mrs. Julie Brose,

We are happy to advise that the transfer of your project SBREC 7858 - A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults living with advanced cancer (*ResearchNow Ethics & Biosafety ID "*2741*"*) has been approved.

This approval also covers any modifications submitted with the transfer request.

**Project ID:** SBREC 7858

**Project Title:** A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults living with advanced cancer

**Chief Investigator:** Mrs. Julie Brose

**Original Approval Date:** 22/02/2018

**Expiry date:** 31/01/2021

1. **Future Modifications**

**Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:**

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form.

2. **Annual Reports**

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submitted each year on the approval anniversary date for the duration of the ethics approval. Please submit the HREC Annual Report Form when the report is due.

3. **Adverse Events and/or Complaints**

Researchers must submit the Unexpected Adverse Events form within 24 hours if:

- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Researchers should also contact the Ethics office if any complaints regarding the research have been received.

All the best with your research project.

Hendryk

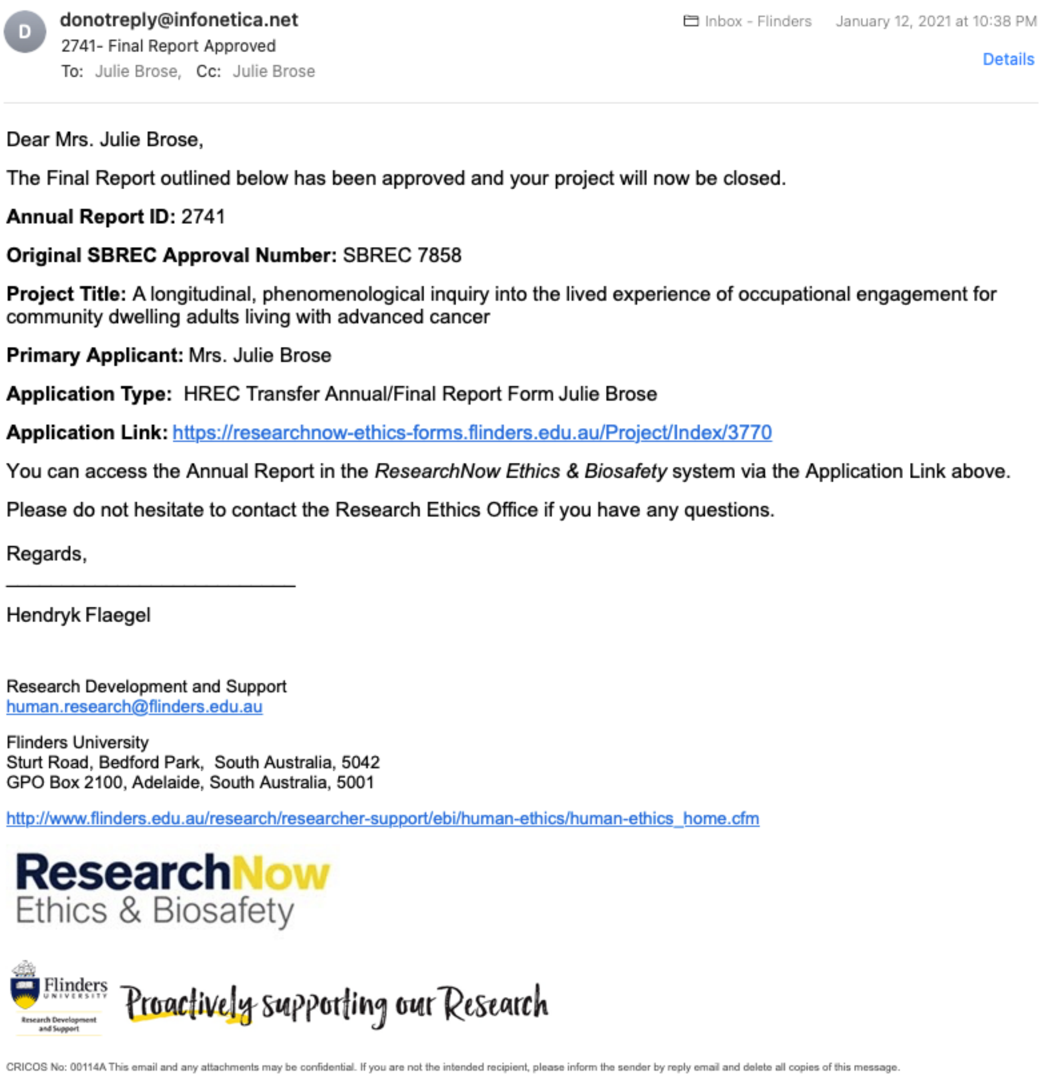
Research Development and Support
human.researchethics@flinders.edu.au
P: (+61-8) 8201 2543

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

**ResearchNow**
Ethics & Biosafety

Flinders University Research Development and Support
Proactively supporting our Research



D

**donotreply@infonetica.net**

2741- Final Report Approved

To: Julie Brose, Cc: Julie Brose

January 12, 2021 at 10:38 PM

Dear Mrs. Julie Brose,

The Final Report outlined below has been approved and your project will now be closed.

**Annual Report ID:** 2741

**Original SBREC Approval Number:** SBREC 7858

**Project Title:** A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults living with advanced cancer

**Primary Applicant:** Mrs. Julie Brose

**Application Type:** HREC Transfer Annual/Final Report Form Julie Brose

**Application Link:** https://researchnow-ethics-forms.flinders.edu.au/Project/Index/3770

You can access the Annual Report in the *ResearchNow Ethics & Biosafety* system via the Application Link above.

Please do not hesitate to contact the Research Ethics Office if you have any questions.

Regards,

Hendryk Flaegel

Research Development and Support
human.research@flinders.edu.au

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

ResearchNow
Ethics & Biosafety

Flinders University Research Development and Support

Proactively supporting our Research

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

# Certification of Ethics Approval

This is to acknowledge that the following research has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC) I am granting approval for your site's participation in the research.

| | |
|---|---|
| Ethics ID: | HREBA.CC-17-0556 |
| Principal Investigator: | Julie Brose |
| Co-Investigator(s): | Deidre Morgan<br>Heather Shantz<br>Eileen Willis |
| Student Co-Investigator(s): | There are no items to display |
| Study Title: | A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults with advanced cancer |
| Sponsor: | |

**Effective:** December 17, 2017 **Expires:** December 16, 2018

Study reviewed and approved by delegated review on 17 December 2017

The following documents have been approved:

- Information sheet_Brose, 2, December 11, 2017
- Introduction letter_Brose, 1, November 28, 2017
- Consent Form_Flinders_Brose, 1, November 28, 2017
- Consent Form_HREBA_Brose, 2, December 11, 2017
- Interview Guide_Brose, 1, November 28, 2017
- Study proposal_Brose, 1, November 28, 2017
- Peer review_Interim milestone at 6 month FTE mark of PhD, 1, November 23, 2017

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health

Canada's *Food and Drug Regulations* (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Deliberations of the HREBA-CC included elements described in Section 50 of the HIA. The Committee found the research to be in accordance with requirements of the Act.
The Committee determined that consent will be obtained from participants for the disclosure of personal identifiable health information to be used in the research.

As a requirement of the HIA, if your study uses health information a copy of this certification will be sent to the Office of the Information and Privacy Commissioner (OIPC).

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

This approval is subject to the following conditions:

1. It is being granted only for the research described in this application.
2. Any modification to the approved research must be submitted to the Committee for approval prior to implementation.
3. Reportable events (SAE's, new safety information, protocol deviations, audit findings, privacy breaches, and participant complaints) are to be submitted in accordance with the Committee's reporting requirements.
4. A request to renew this ethics certification must be submitted and reviewed by the Committee in advance of the expiry date indicated above. Failure to submit a request will result in the file entering into an expired state, whereby all research must cease.
5. A closure request must be submitted to the Committee when the research is complete or has been terminated.

This approval does not guarantee that you will be able to access health records for research purposes. Other institutional or organizational requirements may be in place that you will be required to meet prior to initiating your research. These include approvals for the allocation of resources in support of your study. Inquiries regarding these additional approvals should be directed to the appropriate institutional or organizational body.

Please accept the Committee's best wishes for success in your research.

| **Approved on behalf of CC by,** | **Date:** |
|---|---|
| Jackson Wu , HREBA-CC | December 18, 2017 |

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

# Modification of Ethics Approval

This is to acknowledge that the modification to the research indicated below has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC), I am pleased to advise that approval has been granted.

| | |
|---|---|
| Ethics ID: | HREBA.CC-17-0556_MOD1 |
| Principal Investigator: | Julie Brose |
| Co-Investigator(s): | Deidre Morgan<br>Heather Shantz<br>Eileen Willis |
| Student Co-Investigator(s): | There are no items to display |
| Study Title: | A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults with advanced cancer |
| Sponsor: | |

**Effective:** 12/17/2017 **Expires:** 12/16/2018

Reviewed and approved by delegated review on 12 March 2018.

The following documents have been approved:

- Information sheet_Brose FINAL (no track changes), 4, February 28, 2018
- Consent to Contact_AHS_Brose_Footer, 2, March 5, 2018
- Consent Form_HREBA_Brose FINAL (no track changes), 4, February 28, 2018

The following information was received and has been acknowledged:

- AHS Approval, 1, February 28, 2018
- Ethics Approval_Flinders University, 1, February 29, 2018

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's *Food and Drug Regulations* (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

Please note that the approval of this modification does not change the effective or expiry dates of this study as indicated above.

Please accept the Committee's best wishes for success in your research.

**Approved on behalf of CC by,** **Date:**

Jackson Wu , HREBA-CC Wednesday, March 14, 2018

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

HREBA Health Research Ethics Board of Alberta Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

# Certification of Ethics Approval - Renewal

This is to acknowledge that the renewal to the research indicated below has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC), I am pleased to advise that approval has been granted.

| | |
|---|---|
| Ethics ID: | HREBA.CC-17-0556_REN1 |
| Principal Investigator: | Julie Brose |
| Co-Investigator(s): | Deidre Morgan<br>Heather Shantz<br>Eileen Willis |
| Student Co-Investigator(s): | There are no items to display |
| Study Title: | A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults with advanced cancer |
| Sponsor: | |

**Effective:** Monday, December 10, 2018 **Expires:** Monday, December 9, 2019

The Annual Progress Report was reviewed by delegated review on 10 December 2018.

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's *Food and Drug Regulations* (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

This renewal is subject to the following conditions:

1. Approval is granted only for the research described in this application.
2. Any modification to the approved research must be submitted to the Committee for approval prior to implementation.
3. Reportable events (SAE's, new safety information, protocol deviations, audit findings, privacy breaches, and participant complaints) are to be submitted in accordance with the Committee's reporting requirements.
4. A request to renew this ethics certification must be submitted and reviewed by the Committee in advance of the expiry date indicated above.
5. A closure request must be submitted to the Committee when the research is complete or has been terminated.

**Approved on behalf of CC by,** **Date:**

Jackson Wu , HREBA-CC Tuesday, December 11, 2018

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

# Provincial Research Administration
# Study Summary &
# Administrative Approval For Research to Proceed

16-Jan-18

| | | | |
|---|---|---|---|
| **Study Information** | | | |
| **Title:**<br>A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults with advanced cancer | | **Expected End Date:** | December 31, 2020 |
| | | **Expected No. of Subjects:** | 8 |
| | | **Study Type** | Observational |
| | | **Intervention Type (if applicable):** | Choose an item. |
| **Research Ethics Board** | | | |
| **REB #:** | HREBA.CC-17-0556 | **REB Approval Date:** | 18 December 2017 |
| **REB2 # (if submitted to multiple boards):** | Waiting for approval from Flinders University | **REB2 Approval Date:** | Click here to enter a date. |
| **Research Finance** | | | |
| **Funding Source** | None | **Sponsor/Funder Name(s)** | Unfunded |
| **Financial Account Administered by:** | Choose an item.<br>If Other (specify): | **Account Reference Number(s):** | |
| | | **Account Set-up Status:** | Choose an item. |
| **Research Contracting** | | | |
| **Contract or Legal Requirements Negotiated/Administered By:** | Choose an item.<br>If Other (specify): | **CTA/Legal Requirements Completion Date:** | Not required |

| | | | | |
|---|---|---|---|---|
| **Purchased Services Agreement Executed** | | | | |
| **Lab** | **DI** | **Pharmacy** | **HIM** | **Other (specify)**: |
| Choose an item. | Choose an item. | Choose an item. | Choose an item. | Choose an item. |

| | | | |
|---|---|---|---|
| **Principal Investigator:** | | **Primary Contact:** | |
| **Supervisor for Trainee/ Project** ☐ | | **Student/Trainee Level:** | Choose an item. |
| **Name:** | Julie Brose | **Name:** | Julie Brose |
| **Faculty:** | N/A | **Title:** | PI |
| **Department:** | N/A | **Research Team/Unit:** | PhD student at Flinders |
| **Division/Section:** | N/A | **Phone:** | |
| **University:** | Flinders University | **Email:** | |
| **Phone:** | [redacted] | | |
| **Email:** | [redacted] | | |

## A. Study Summary

This qualitative study seeks to answer the question: How does the lived experience of occupational engagement for community dwelling adults with advanced cancer change over time? The primary objectives are to: 1. Explore the subjective experience of occupational engagement during disease progression; 2. Explore how these experiences map against current theoretical frameworks; and 3. Track how occupational engagement is experienced over time.

A series of semi structured interviews with participants will be conducted with participants who have a prognosis of approximately 6 months. Interviews will occur fortnightly or until they choose not to withdraw from the study.

## B. Population under Recruitment (lay language):

• Adults (between 18-64 years old) • Diagnosed with advanced cancer • Living at home • Able to participate in interviews • Score 80 or below on the Australia-modified Karnofsky Performance Status (AKPS) scale (indicating some difficulty or more to do everyday tasks)

Recruitment will occur through the home care program in the communities west of Calgary,
The Cochrane Home Care team will identify patients who meet the age and diagnosis criteria. The patients home care provider will introduce them to the study during a regular home care visit with a verbal explanation and an Information Sheet (attached). Patients who are willing to be contacted will review and sign the Consent to Contact form (attached) which will then be provided to the PI. The PI will contact the patient and ask if they are willing to hear more about the study. Patients will consent to a visit by the PI via phone or email. The PI will obtain written consent during the first visit.

## C. Operational Impacts:

Integrated Home Care – Banff, Canmore, Cochrane - PI has contacted Cheryl Grady

**Operational Areas Impacted /Approvers**

| Unit/ Program | Facility | City/Town | Approver Name | Title | Approval Date |
|---|---|---|---|---|---|
| Integrated Home Care | Community Services - Banff, Canmore, Cochrane | Calgary Zone | Barbara Wheler/Amy Good | Executive Director, Seniors, Palliative & Continuing Care—Calgary Zone | January 12, 2018*<br>*Amy Good approved on behalf of Barbara Wheler |

## D. Data/System Impacts:

PARIS
For confirming eligibility re: advanced cancer
Basic demographics – age, gender, name, phone number, address, diagnosis
For researcher purposes only – no identifying information will be included in research report

**HIA/FOIP Research Agreement** Status: Completed
If applicable, enter date fully executed: 1/12/2018
*If HIA/FOIPP Research Agreement is required and in progress at the time Administrative Approval is granted, the fully executed agreement will be required for the release of the data product.*

**Repository(s) Impacted / Signatories**

| Database/System/Repository Name | Assigned Analyst | Repository Owner Name | Title |
|---|---|---|---|
| PARIS | | Jared Temple Oberle | Director, Quality, Accountability & Program Support |
| Home Care Paper Charts | | Barbara Wheler | Executive Director, Seniors, Palliative & Continuing Care—Calgary Zone |

**E. Transfer of AHS Data:**

**Data Transfer Agreement** Status: Not Required

*If the Data Transfer Agreement in progress at the time Administrative Approval is granted, a fully executed agreement will be required prior to the transfer of any data.*

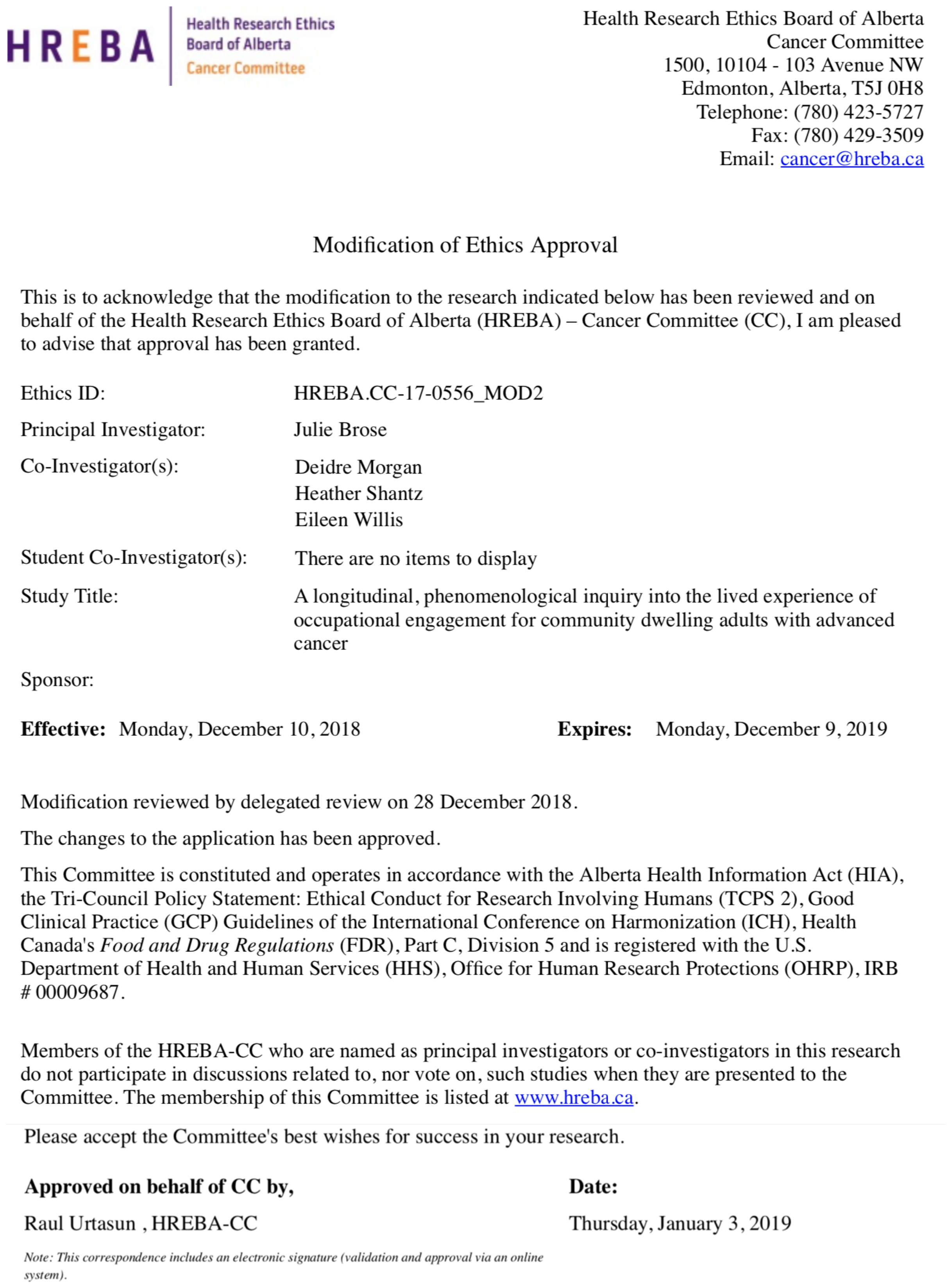
Recipient Organization Data Security Information Received (SOP, Policy, Specifications): ☐

**Parties to Data Transfer**

| Recipient PI Name(s) | Recipient REB Name & Approval # | Recipient Organization | Contact in Recipient Organization Name & Email |
|---|---|---|---|
| | Name: | Name: | Name: |
| | Approval# | Postal Address: | Email: |

**AHS Administrative Approval (All Zones Except Edmonton):**

| Date Issued | Name of Approver | Title | Approved |
|---|---|---|---|
| January 16, 2018 | Helen Shannon | Research Administration Advisor | Alberta Health Services<br>PROVINCIAL RESEARCH ADMINISTRATION<br>ADMINISTRATIVE APPROVAL |



HREBA
Health Research Ethics
Board of Alberta
Cancer Committee

Health Research Ethics Board of Alberta
Cancer Committee
1500, 10104 - 103 Avenue NW
Edmonton, Alberta, T5J 0H8
Telephone: (780) 423-5727
Fax: (780) 429-3509
Email: cancer@hreba.ca

## Modification of Ethics Approval

This is to acknowledge that the modification to the research indicated below has been reviewed and on behalf of the Health Research Ethics Board of Alberta (HREBA) – Cancer Committee (CC), I am pleased to advise that approval has been granted.

| | |
|---|---|
| Ethics ID: | HREBA.CC-17-0556_MOD2 |
| Principal Investigator: | Julie Brose |
| Co-Investigator(s): | Deidre Morgan<br>Heather Shantz<br>Eileen Willis |
| Student Co-Investigator(s): | There are no items to display |
| Study Title: | A longitudinal, phenomenological inquiry into the lived experience of occupational engagement for community dwelling adults with advanced cancer |
| Sponsor: | |

**Effective:** Monday, December 10, 2018 **Expires:** Monday, December 9, 2019

Modification reviewed by delegated review on 28 December 2018.

The changes to the application has been approved.

This Committee is constituted and operates in accordance with the Alberta Health Information Act (HIA), the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2), Good Clinical Practice (GCP) Guidelines of the International Conference on Harmonization (ICH), Health Canada's *Food and Drug Regulations* (FDR), Part C, Division 5 and is registered with the U.S. Department of Health and Human Services (HHS), Office for Human Research Protections (OHRP), IRB # 00009687.

Members of the HREBA-CC who are named as principal investigators or co-investigators in this research do not participate in discussions related to, nor vote on, such studies when they are presented to the Committee. The membership of this Committee is listed at www.hreba.ca.

Please accept the Committee's best wishes for success in your research.

| **Approved on behalf of CC by,** | **Date:** |
|---|---|
| Raul Urtasun , HREBA-CC | Thursday, January 3, 2019 |

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

# APPENDIX B: RECRUITMENT AND CONSENT DOCUMENTATION

**Palliative and Supportive Services,**
**College of Nursing and Health Sciences**
Sturt Road, Bedford Park
GPO Box 2100
Adelaide SA 5001
[redacted]
[redacted]
http://www.flinders.edu.au/people/deidre.morgan
CRICOS Provider No. 00114A

Date: November 5, 2017

## LETTER OF INTRODUCTION

Dear Sir/Madam/Name

This letter is to introduce Mrs Julie Brose, a PhD student in the College of Nursing and Health Sciences, Palliative and Supportive Services at Flinders University. Julie is undertaking a research project that explores how people receiving palliative care adjust to changes in their ability to complete everyday activities.

Her study is entitled "The experience of everyday activities for adults living at home with cancer." People receiving palliative care may experience changes in their ability to participate in everyday activities; however, there is limited research into how people adjust to these changes over time. This study will help us better understand how people manage these changes and what is important to them at this time of their life. Findings from this study will lead to completion of a PhD thesis for Julie.This project is supported by Flinders University, College of Nursing and Health Sciences.

You are invited to take part in several one-on-one interviews with Julie who will ask you some questions regarding your experience of living with cancer. You will not have to travel for the interviews as Julie will visit you at home. The interviews will take between 20-60 minutes and will occur approximately once a month over a period of a few months. Julie will make a mutually acceptable time to visit you at home where she will answer any questions you have about the study before obtaining your written consent to participate. If you consent to participate she will conduct the interview with you at this time. The interviews will be audio recorded using a digital voice recorder so she can accurately record what is discussed.

inspiring achievement

Be assured that any information provided will be treated in the strictest confidence, however, if family or friends are present in the interview we cannot guarantee total anonymity. The audio-file of the interview will be sent to a professional transcriber who will be asked to sign a confidentiality agreement before receiving this file. It is likely she will hear your name if it is used in the interview but she will not have access to any other identifying information about you. You will be sent a one page summary of the interview to verify that we have recorded your answers accurately. When the results are published, we will not use your real name in order to protect your identity.

Participation in these interviews is entirely voluntary and you may withdraw at any time either during an interview *or* over the course of the study.

Please direct any enquiries you may have concerning this project to Dr Deidre Morgan at the address at the top of this letter, or by telephone on [redacted] or e-mail [redacted]

Thank you for your attention and assistance.

Yours sincerely,

[redacted]

Dr Deidre Morgan
Lecturer, Palliative and Supportive Services,
College of Nursing and Health Sciences,
Flinders University, South Australia.

*This research project has been approved by the Health Research Ethics Board of Alberta – Cancer Committee (HREBA.cc-17-0556) and the Flinders University Social and Behavioural Research Ethics Committee (SBREC). For more information regarding ethical approval of the project only, please contact HREBA-CC at cancer@hreba.ca or 780-423-5727 or SBREC at +61 8 8201 3116 or human.researchethics@flinders.edu.au.*

**Mrs. Julie Brose**
College of Nursing and Health Sciences

Sturt Road
Bedford Park SA 5042

GPO Box 2100
Adelaide SA 5001
[redacted]

CRICOS Provider No. 00114A

# INFORMATION SHEET
for interview

**Title:** The experience of everyday activities for adults living at home with cancer

**Researcher(s)**
Mrs. Julie Brose
College of Nursing and Health Sciences
Flinders University
Tel: [redacted]

**Supervisor(s)**
Dr. Deidre Morgan
College of Nursing and Health Sciences
Flinders University
Tel: [redacted]

**Supervisor(s)**
Prof. Eileen Willis
College of Nursing and Health Sciences
Flinders University
Tel: [redacted]

**Local Contact**
Heather Shantz
Clinical Nurse Specialist
Palliative Care Consult Service, Calgary Zone
Tel: [redacted]

**Description of the study**
This study is part of the project titled "The experience of everyday activities for adults living at home with cancer." This project will investigate the lived experience of

*This research project has been approved by the Health Research Ethics Board of Alberta – Cancer Committee (HREBA.cc-17-0556) and the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7858). For more information regarding ethical approval of the project only, please contact HREBA-CC at cancer@hreba.ca or 780-423-5727 or SBREC at +61 8 8201 3116 or human.researchethics@flinders.edu.au.*

participating in everyday activities for adults living at home with cancer. and will track this experience over time. This project is supported by Flinders University, College of Nursing and Health Sciences.

### Purpose of the study

This project aims to find answer the following questions:

- What is the lived experience of participating in everyday activities when a person has cancer?
- How does this experience change as time passes?

### What will I be asked to do?

You are invited to be part of one-on-one interviews with a researcher who will ask you some questions regarding your experience of living with cancer. Participation is entirely voluntary. The interviews will take about 30-60 minutes. and will occur approximately once a month over a period of a few months. The interviews will be audio recorded using a digital voice recorder to help with reviewing the results.

### What benefit will I gain from being involved in this study?

We cannot guarantee or promise that you will receive any benefits from this research; however, a possible benefit may be that the study provides you with additional opportunities to speak about your care needs and improves your feeling of support.

Information from this study will inform palliative care clinicians how they can better support clients care needs as they realte to participation in everydaty activities.

### Will I be identifiable by being involved in this study?

Any information obtained in connection with this research project that can identify you will remain confidential. You will be identified by a pseudonym and participant number, not your actual name. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

### Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study. However, some participants could experience emotional discomfort talking about their experiences of everyday activities whilst living with cancer. If you experience any emotional discomfort, please contact your case manager or nurse for support or counselling that may be accessed free of charge. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

### How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions, and you are free to withdraw from the interviews at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to

*This research project has been approved by the Health Research Ethics Board of Alberta – Cancer Committee (HREBA.cc-17-0556) and the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7858). For more information regarding ethical approval of the project only, please contact HREBA-CC at cancer@hreba.ca or 780-423-5727 or SBREC at +61 8 8201 3116 or human.researchethics@flinders.edu.au.*

participate please read and sign the form, and you can either email it to [redacted] or mail to [redacted]

### How will I receive feedback?

After each interview, you will be provided with a one page summary sheet of what was discussed in the interview for you to provide feedback about. If you would also like to read the entire transcript of your interview, this will also be provided on request. Following the project completion, outcomes of the project will be given to all participants via email / post / website.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

*This research project has been approved by the Health Research Ethics Board of Alberta – Cancer Committee (HREBA.cc-17-0556) and the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7858). For more information regarding ethical approval of the project only, please contact HREBA-CC at cancer@hreba.ca or 780-423-5727 or SBREC at +61 8 8201 3116 or human.researchethics@flinders.edu.au.*

*This research project has been approved by the Health Research Ethics Board of Alberta – Cancer Committee (HREBA.cc-17-0556) and the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7858). For more information regarding ethical approval of the project only, please contact HREBA-CC at cancer@hreba.ca or 780-423-5727 or SBREC at +61 8 8201 3116 or human.researchethics@flinders.edu.au.*

# CONSENT TO CONTACT FOR RESEARCH PURPOSES

**STUDY TITLE**: The experience of everyday activities for adults living at home with cancer

**ETHICS ID**: HREBA.CC-17-0556

**INVESTIGATOR(S):** Julie Brose, Dr. Deidre Morgan, Prof. Eileen Willis

You are being invited to give consent for Julie Brose (principal site investigator) to contact you regarding your potential participation in a research study.

Are you willing to learn more about the "*The experience of everyday activities for adults living at home with cancer*" study?
**(Circle one)**

**YES** **NO**

If yes, you will be contacted by Julie Brose. Please include your contact information below.

☐**Name:** ______________________________

☐ **Telephone number:** (      ) ______________________________

☐ **Email:** ______________________________

You authorize your health service provider to disclose *your name, your telephone number and email address* that you provided above, to Julie Brose for the purpose of being contacted to learn more about the research study, "*The experience of everyday activities for adults living at home with cancer*".

Please notify us if your contact information changes as Alberta Health Services is not permitted to release contact information to us.

Every effort will be made to safeguard your contact information. Although access to this information will be limited, there is a small chance that this information could be inadvertently disclosed or inappropriately accessed.

This consent is effective immediately.

Your consent to be contacted can be revoked by you at any time.

**Patient Signature:** ______________________________________________

**Date:** _______________

**AHS Staff Member:** _____________________________________________________

## Informed Consent Form for Participation in a Research Study

# The experience of everyday activities for adults living at home with cancer

Researcher: Julie Brose
College of Nursing and Health Sciences
Flinders University, Australia
[redacted]

You are being invited to participate in a research study because you are living with cancer. This consent form provides detailed information about the study to assist you with making an informed decision. Please read this document carefully and ask any questions you may have. All questions should be answered to your satisfaction before you decide whether to participate.

The study staff will tell you about timelines for making your decision. You may find it helpful to discuss the study with family and friends so that you can make the best possible decision within the given timelines.

Taking part in this study is voluntary. You may choose not to take part or, if you choose to participate, you may leave the study at any time without giving a reason. Deciding not to take part or deciding to leave the study will not result in any penalty or any loss of medical or health-related benefits to which you are entitled.

The researcher will discuss this study with you and will answer any questions you may have. If you do consent to participate in this study, you will need to sign and date this consent form. You will receive a copy of the signed form.

## WHAT IS THE BACKGROUND INFORMATION FOR THIS STUDY?

People with cancer may experience changes in their ability to participate in everyday activities over time, however, there is limited research into how people adjust to these changes. This study will help us to better understand how people manage these changes and what is important to them at this time of their life. Findings from this study can be used to help improve the quality of life of people with cancer who are living at home.

The Health Research Ethics Board of Alberta – Cancer Committee (HREBA-CC), which oversees the ethical acceptability of research involving humans, has reviewed and granted ethics approval for this study.

## WHY IS THIS STUDY BEING DONE?

The purpose of this study is to help understand the experience of participation in everyday activities for adults with cancer, and to see how this experience changes over time.

## WHAT ARE OTHER OPTIONS IF I DECIDE NOT TO PARTICIPATE IN THIS STUDY?

You do not have to take part in this study, in order to receive continued medical care.

## HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Eight to ten people will take part in this study.

## WHAT WILL HAPPEN DURING THIS STUDY?

You are invited to take part in one-on-one interviews with a researcher who will ask you a some questions regarding your experience of living with cancer. The interviews will take between 20-60 minutes, and will occur approximately once a month over a period of a few months. The interviews will be audio recorded using a digital voice recorder so we can accurately record your perspectives.

## WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

Participation in this study may or may not be of personal benefit to you. However, based on the results of this study, it is hoped that this will improve the care of future patients of Alberta Health Services.

## WHAT ARE MY RESPONSIBILITIES AS A STUDY PARTICIPANT?

If you choose to participate in this study, you will be expected to:

- Participate in interviews with the researcher at your own home;
- These interviews will take place approximately once a month for up to six months.

## HOW LONG WILL I BE PARTICIPATING IN THIS STUDY?

This study will last for up to approximately six months, however you are able to withdraw from the study at any point.

## WILL THERE BE ANY LONG-TERM FOLLOW-UP INVOLVED WITH THIS STUDY?

If the researcher needs to follow up with you but cannot locate you, either because you have moved and not updated your contact information or if, for some reason, your contact information is no longer accurate, the researcher would like to obtain your new contact information (e.g., address, telephone number) by calling or writing to the persons you've named as your secondary contacts. This is optional, please indicate your decision using the check boxes below.

You give permission to the researcher to contact your secondary contacts if the researcher no longer has accurate contact information for you.

☐ Yes ☐ No Participant's Initials: __________

Name/phone number of secondary contacts: ________________________________

## CAN I CHOOSE TO LEAVE THIS STUDY EARLY?

You can choose to end your participation in this research (called early withdrawal) at any time without having to provide a reason. If you choose to withdraw early from the study, you are encouraged to contact the researcher to inform them.

If you decide to leave the study, you can ask that the information that was collected about you not be used for the study. Let the researcher know if you choose this.

## CAN MY PARTICIPATION IN THIS STUDY END EARLY?

The researcher may stop your participation in the study early, and without your consent, for reasons such as:

- You are not able to participate in interviews;
- A regulatory authority (for example, Health Canada) or the research ethics board withdraws permission for the study to continue.

If you are removed from the study, the researcher will discuss the reasons with you and plans will be made for your continued care outside of the study.

## HOW WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the researcher and study staff will only collect the information they need for this study.

Records identifying you, including information collect from your medical files/records, such as your Electronic Medical Records (EMR), charts, etc., will be kept confidential to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your identifiable medical/clinical study records at the site where these records are held for quality assurance purposes and/or to verify that the information collected for the study is correct and follows proper laws and guidelines:

- Members of the Regulatory/Audit team in Home Care for quality assurance purposes;
- The Health Research Ethics Board of Alberta – Cancer Committee, which oversees the ethical conduct of this study;
- The study team.

Authorized representatives of the above organizations may receive information related to the study from your medical/clinical study records that will be kept confidential in a secure location and may be used in current or future relevant health research. Your name or other information that may identify you will not be provided (i.e., the information will be de-identified). The records received by these organizations will be coded with a number. The key that indicates what number you have been assigned will be kept secure by the researchers directly involved with your study and will not be released.

Any disclosure of your identifiable health information will be done in accordance with federal and provincial laws including the Alberta Health Information Act (HIA). The organizations listed above are required to have organizational policies and procedures to protect the information they see or receive about you, except where disclosure may be required by law. The researcher will ensure that any personal health information collected for this study is kept in a secure and confidential location as also required by law.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during the study will be used in analyses and will be published to the scientific community at meetings or in journals. This information may also be used as part of a submission to regulatory authorities around the world to support the approval of this intervention.

Even though the likelihood that someone may identify you from the study data is very small, it can never be completely eliminated. Every effort will be made to keep your identifiable information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information.

Any study-related information sent outside of Canadian borders may increase the risk of disclosure of information because the laws in those countries dealing with protection of information may not be as strict as in Canada. However, all study data that is transferred outside of Canada will use a pseudonym (i.e. different name) and be coded (this means it will not contain your personal identifying information such as your name, address, medical health number or contact information). Any information will be transferred in compliance with all relevant Canadian privacy laws. By signing this consent form, you are consenting to the disclosure of your coded information to organizations located outside of Canada.

## WILL MY HEALTHCARE PROVIDER(S) BE INFORMED OF MY PARTICIPATION IN THIS STUDY?

Your family doctor/health care provider will not be informed by the study team that you are taking part in the study. You can choose to let your family doctor/health care provider know, if you like. If you are undecided, the researcher can discuss this with you.

## WILL THERE BE ANY COSTS INVOLVED WITH PARTICIPATING IN THIS STUDY?

Participation in this study will not involve any additional costs to you or your private health care insurance.

## WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

You will not be paid for taking part in this study.

Although no funds have been set aside to compensate you in the event of injury or illness related to the study, you do not give up any of your legal rights for compensation by signing this form.

## WHAT ARE MY RIGHTS AS A PARTICIPANT IN THIS STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of these results, please contact the researcher.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the hospital, investigators, sponsor, involved institutions for compensation or their agents, nor does this form relieve these parties from their legal and professional responsibilities.

## IS THERE CONFLICT OF INTEREST RELATED TO THIS STUDY?

There are no conflicts of interest declared by the researcher.

## WHO DO I CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, or if you suffer a research-related injury, you should talk to the researcher or co-investigator. These person(s) are:

| | |
|---|---|
| Julie Brose | [redacted] |
| Name | Telephone |
| Heather Shantz | [redacted] |
| Name | Telephone |
| Dr. Deidre Morgan | [redacted] |
| Name | Telephone |

| | |
|---|---|
| Prof. Eileen Willis | [redacted] |
| Name | Telephone |

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta – Cancer Committee at:

Telephone: 780-423-5727

Toll Free: 1-877-423-5727

SIGNATURES

**Part 1** - to be completed by the potential participant.

| | **Yes** | **No** |
|---|---|---|
| Do you understand that you have been asked to take part in a research study? | ☐ | ☐ |
| Do you understand why this study is being done? | ☐ | ☐ |
| Do you understand the potential benefits of taking part in this study? | ☐ | ☐ |
| Do you understand what you will be asked to do should you decide to take part in this study? | ☐ | ☐ |
| Do you understand that you are free to leave the study at any time, without out having to give reason and without affecting your future health care? | ☐ | ☐ |
| Do you understand who will see your records, including health information that identifies you? | ☐ | ☐ |
| Do you understand that by signing this consent form you are giving us permission to access your health information and specimens if applicable? | ☐ | ☐ |
| Do you understand that by signing this consent form that you do not give up any of your legal rights? | ☐ | ☐ |
| Do you understand that your family doctor/health care provider will/may be informed of your participation in this study? | ☐ | ☐ |
| Have you had enough opportunity to ask questions and discuss this study? | ☐ | ☐ |

By signing this form I agree to participate in this study.

| | | |
|---|---|---|
| Signature of Participant | PRINTED NAME | Date |

**Part 2** - to be completed by the researcher or designee who conducted the informed consent discussion. Only compete this section if the potential participant has **agreed** to participate.

I believe that the person signing this form understands what is involved in the study and has freely decided to participate.

| | | |
|---|---|---|
| Signature of Person Conducting the Consent Discussion | PRINTED NAME | Date |

**<u>Part 3</u>** - to be completed only if the participant is unable to read.

- The informed consent form was accurately explained to, and apparently understood by the participant.
- Informed consent was freely given by the participant.

| | | |
|---|---|---|
| Signature of Impartial Witness/Interpreter | PRINTED NAME | Date |

**You will be given a copy of this signed and dated consent form prior to participating in this study.**

# APPENDIX C: PARTICIPANT INTERVIEW SUMMARY

Tammy: Interview 3

Summary from September 5, 2018

I am able to go for long walks now, which feels so amazing! I am tired, but it is so wonderful. I love being outdoors, love camping, and love walking. Right now, in the fall, being able to be outside is fabulous. A month ago, I wasn't getting out and walking every day, but now I am. Even just the 20-minute walk on the street is fabulous.

Meeting my nutritional needs is so important to me, and having the caregivers assist with this means the world. I want to be as independent as possible, but if I do need assistance, then I get it if it means I can then facilitate something that is important to me.

I can now brush my own hair and shower on my own, which feels wonderful! But my new-found independence has a downside too, as I am now more frustrated when I can't do other things, like opening a lid on a container. I get frustrated if I can't do it and hate it when people remind me of this as well. It is a challenge to get people to do things for you the way you want them. They don't always want to do it too, which is hard. For example, I need my meals cut up, but people won't always help with this. I also am very worried about winter coming because I can't do up zippers or put on my jacket, and it's dangerous to go walking outside, so I'll be stuck inside. I'm not able to clean, so I'm worried I will get sick because things won't be cleaned to my standards. People get tired of having me ask them for help. The bumps in the road add up, even though I try to stay positive.

I struggle with having other people tell me their problems, because I feel like I have enough problems on my own. It's hard though, as I am also scared of being alone. I really enjoy doing things with people, as I am a very relational person. I love going out to watch my kids play sports, as they have their own life and are enjoying being happy outdoors. If I couldn't go outdoors, I would be so disappointed.

I'm not able to do things like fix the bed, so my husband does that. I can put most things in the washing machine and try to hang them on my own, but it is still difficult. I keep trying to do more and more, as I want to be able to do it.

With winter coming, I feel nervous. I guess I will just vacuum and play with my kitty and do puzzles or oils. I would like to get more into yoga as well. I'm trying to get a room set up so I can go and be in there during the winter where it's my space.

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Oct 22, 2021

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| Expected presentation date | Oct 2021 |
| Order reference number | 1 |

| | |
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