

Living with Hope in the Midst of Change:
The Meaning of Leisure within the Context of Dementia

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Research exploring identity in the dementia context reveals that some aspects of personal and social identity persist in dementia while others evolve as persons living with dementia find ways to live with the changes in their lives. Leisure can be a space for developing and expressing identity and a space to resist stereotypical images and social expectations. Leisure may also play an important role in providing meaningful activity and engagement in life. Nonetheless, the meaning and experience of leisure in the context of dementia have received very little attention in the literature. Guided by the personhood movement, this phenomenological study aims to understand the subjective experience of dementia and the meaning and experience of leisure in the lives of persons living with early stage dementia. It explores leisure's role in identity maintenance and/or development and leisure as a space for slowing down the process of dementia and resisting stigma associated with dementia and identity loss that could occur in dementia.

Four persons living with early stage memory loss were recruited through local agencies to participate in this study. Each participant engaged in four conversational interviews following McCracken's (1988) long interview format. Interviews were recorded and transcribed verbatim. Data were also collected through participant observation. The participants and I engaged in at least one of their favourite leisure activities together. Detailed field notes were recorded following each participant observation session. Using the method of photovoice, participants were given disposable cameras and asked to take photos of objects, places, and subjects that were meaningful for their leisure. These photos were discussed in Interview 2. Data were analysed in a manner consistent with phenomenology.

Findings revealed that the participants experienced their journeys of memory loss within a paradox of challenge and hope. Participants juxtaposed the negative aspects of living with memory loss with the positive aspects of their lives. Essences of the experience include *struggling with change*, in which participants experience a wide variety of challenges as a result of being diagnosed with memory loss, including *muddled thinking*, *fluctuating abilities*, *draining energy*, *frightening awareness*, and *disquieting emotions*. However, participants counter these changes with the variety of ways in which they *tackle life with dementia*, including *reconciling life as it is*, *battling through the changes by being proactive*, *living through relationships*, *being optimistic*, and *prolonging engagement in meaningful activity*. Participants also experience *threatening assaults on identities*. Identity is threatened in terms of *disappearing roles*, *losing independence*, *struggling with demeaning images and expectations*, and *losing confidence*. However, participants juxtapose these threatening assaults by *upholding identities*. They do this by *emphasizing abilities through leisure*, *changing perspectives*, and *engaging in life through leisure*.

This study deepens our current understandings of the subjective experience of dementia and leisure's role within that experience. It helps us to understand the experience of leisure within the context of memory loss in terms of four lifeworld existentials: lived time, lived space, lived body, and lived other. The findings also contribute to our understandings of how persons living with dementia use leisure to resist a master status of dementia. Participants in this study used leisure as a space for resisting both the stigma of memory loss and the progression of memory loss. They overcome challenges in their leisure to demonstrate to themselves and others that they have many remaining abilities and are able to maintain valued aspects of their identities.

The findings suggest that service providers, family members, and persons living with dementia should carefully consider the meaning of leisure and find ways to facilitate involvement in leisure that is meaningful for persons living with memory loss. In terms of future research, leisure in the context of relationships, including the importance of advocacy work for persons with dementia, should be examined. Although this study provides insight into the possibilities of alternative methods for understanding the experience of memory loss, further exploration is needed in this area.

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Dedication

For my mother,
Sheila Genoe
1945 - 2006

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Chapter 1: Introduction

The journey towards this study commenced four years ago when I began to work on my doctorate. I spent the previous year as a recreation programmer in a long-term care facility, planning and implementing recreation programs designed to engage persons living with dementia in a wide range of physical, mental, and social activities. My time at the nursing home re-ignited my passion for working with persons living with dementia. When I arrived at the University of Waterloo, I knew I wanted to explore leisure in the context of dementia, but had not yet decided upon a specific topic. My advisor's suggestion that the meaning of leisure in early stage dementia was an area that had not been extensively explored intrigued me, and since then, I have developed my understanding about research with persons living with early stage dementia throughout my course work, my comprehensive exams, and countless funding applications. Both the literature I have read on the subjective experience of early stage dementia and the realization that there is a need for increased understanding of leisure in the context of dementia have played a significant role in developing this project. However, my inspiration comes mainly from my work as part of the research team on the Eating Together study, which explores the meaning of mealtimes for persons living with early stage dementia and their families. My role as a research assistant involved interviewing persons living with dementia and their partners in care regarding mealtimes. As I got to know the participants in the study and as they learned about my interest in leisure, they mentioned the importance of leisure in their own lives. They discussed, although briefly and informally, their commitment to advocacy and their use of leisure to keep their minds active. Their enthusiasm for their leisure made me wonder, what *does* leisure mean to persons living with dementia? Is it just a way to pass the time? Or does leisure become even more significant after diagnosis of an

illness causing dementia? How so? Their comments led me to believe that leisure may play a very important role in the lives of those diagnosed with dementia. However, leisure may also be one more loss in a long list of changes that persons living with dementia experience. The participants of the Eating Together study have taught me the importance of living life to the fullest, of appreciating what I have, and of simplifying my life. Their positive attitudes and the hard work they put into their lives in order to live with dementia lead me to wonder about leisure's role in living life to the fullest with dementia.

My own leisure has also inspired this study. As a student of leisure, I have learned about the benefits of leisure. In the past, I valued it highly for other people, but the truth is, until recently, I have paid little attention to my own interests outside of school. I always felt too busy with school to take the time to develop more than just casual interests. However, recent changes in my life have made me look at my own leisure in a new light, and I have come to value it as part of my life and my personal identity more than ever. My leisure interests separate me from my peers and they make my life multidimensional. They give me respite from the constant nagging in my brain about my research, deadlines, and other responsibilities. What will happen to me if I can no longer focus my camera or if I cannot recall which way the saddle goes on the horse? Alternatively, how would I be able to use my abilities to continue to be myself?

This study is aimed at answering these kinds of questions and drawing upon the perspectives of persons living with early stage dementia to expand our understanding of what living with dementia means. I am interested in what leisure means and how it is experienced by those with dementia. This study is designed to not only hear the perspectives of persons living with dementia but also to *see* their lives the way they see them. I then hope to use this

information to alter perceptions about dementia among those living with the disease, their family members, formal service providers, and the general public. In this way, I hope to be able to produce a “portrait” of dementia that reflects the reality and complexity of the experience as described and seen by those living with it.

Understanding Dementia

From the biomedical perspective, dementia refers to a group of progressive syndromes that affect many cerebral functions. What might originally appear to be simple memory loss advances to affect all mental faculties (Jacques & Jackson, 2000). Dementia includes Alzheimer’s disease, Vascular dementia, Lewy body dementia, Frontotemporal dementia, and Creutzfeldt-Jakob disease (Alzheimer Society of Canada, 2009a). It is progressive and cannot be reversed, although medications can improve or maintain functioning in some people diagnosed with memory loss for a while (Alzheimer Society of Canada, 2009b). The biomedical model suggests that dementia progresses in stages, including, early, mid, and late stages, that bring about many changes. However, each person living with dementia is unique and the duration and symptoms of each stage can vary (Alzheimer Society of Canada, 2009b).

The incidence of dementia is expected to increase as the population ages. The Alzheimer Society of Canada (2009c) estimated that about 500 000 Canadians have dementia. It is projected that within the next five years, 250 000 Canadians could develop an illness causing dementia. Within the next 25 years, it is predicted that more than one million Canadians will receive a diagnosis of dementia. As probable dementia is diagnosed earlier and more people are expected to get an illness causing dementia, the need to understand the experience of dementia has never been greater.

Dementia is associated with a great deal of loss, including the loss of cognitive functions such as memory and ability to think, judge, understand, and perceive to such an extent that daily living is affected (Dempsey & Baago, 1998). Orientation, language, behaviour, personality, and physical well-being can all be impacted by dementia. There may be a loss of self worth, self respect, sense of competency, and relationships (Gillies & Johnston, 2004). These losses can threaten one's identity as opportunities for meaningful social roles or statuses perish (Cheston & Bender, 1999a; Oppenheimer, 2006). Threats to identity can restrict opportunities in life as the individual faces an uncertain future (Cheston & Bender, 1999a; Harris & Sterin, 1999). Indeed, persons with dementia acknowledge social and personal role loss, including practical tasks, such as paying the bills or cooking, and family and community roles that they had played in the past (Langdon, Eagle, & Warner, 2007). Identity loss can become cyclical in dementia – as fewer roles are available, one is at greater risk for neurological degeneration, which then decreases capacity to sustain roles that remain (Cheston & Bender, 1999a).

In addition to threatened identities, when an individual is diagnosed with dementia the label he or she receives is associated with a great deal of stigma (Benbow & Reynolds, 2000; Depla, de Graaf, van Weeghel, & Heeren, 2005; Werner, 2005, 2006). Dementia discourse tends to focus on its debilitating and demeaning features (Jolley & Benbow, 2000). The medical world relays messages about dementia that focus on losses and deficits. Older adults receive these messages and then conform to these expectations (Harding & Palfrey, 1997). Further, older adults living with dementia may experience a double or triple jeopardy (Benbow & Reynolds, 2000), as stigma arises through dementia's association with mental decline and loss of independence, and through its association with aging (Harman & Clare, 2006). Even

the word dementia, which means deprived of mind, implies that a person with dementia is less than human: “because demented really means mindless or without a mind. And without a mind, one is not really fully human...in fact, not human at all” (Sterin, 2002, p. 7). Indeed, persons living with dementia are reluctant to use the word dementia, preferring terms such as “forgetfulness” (Langdon et al., 2007). Persons living with dementia are concerned that negative stereotypes “...would threaten their unique individual identity” (Langdon et al., 2007, p. 995). The impact of negative stereotypes becomes compounded when they are internalized. This may lead to lowering of mood and increased belief that one is useless, which, in turn, can lead to decreased functioning (Cheston & Bender, 1999a).

The personhood movement

With incidence of dementia on the rise, threats to identity and the experience of stigma become increasingly relevant. The framing of dementia can have an impact on those living with the disease, their care partners, and the ways in which services are provided. Dementia has principally been considered from a biomedical perspective. The biomedical model focuses on the pathology of dementia and its effect on behaviour, cognitive symptoms, and psychotic symptoms (Bond, 1992; Downs, Clare, & MacKenzie, 2006). From this perspective, dementia is considered to be an abnormal pathological condition leading to cognitive impairment (Cheston & Bender, 1999a; Lyman, 1989), caused by progressive deterioration of the brain regions that control intellectual functioning (Lyman, 1989). The biomedical approach is used frequently as scientists try to find a cause for dementia and an effective treatment or cure (Downs et al., 2006; Phinney, 1998). However, since there is no effective long term treatment or cure (Adams, 1998; Clare, Baddeley, Moniz-Cook, & Woods, 2003; Steeman, de Casterle, Godderis, & Grypdonck, 2006), considering dementia only in terms of causes and treatments

may not be beneficial for those currently living with the disease. Reframing the way we look at dementia is essential for understanding the experience of memory loss and for providing services that better meet the needs of those living with illnesses causing dementia. Indeed, researchers are beginning to address the experience of dementia and the perspectives of persons living with dementia are increasingly being sought (Harris & Sterin, 1999; Keady, Nolan, & Gilliard, 1995; Phinney, 1998; Phinney & Chesla, 2003).

The personhood approach (Kitwood, 1997a) was developed as a counterdiscourse to the biomedical approach and has resulted in a change in the way we think about dementia. It has led to research that focuses on the perspectives of persons living with dementia, rather than only relying on proxy voices. Morton (1999) notes that Kitwood's reconceptualization of dementia was motivated by the desire to improve the lives of humans living with dementia.

Kitwood's aim was to:

...present a paradigm in which the person comes first. It accommodates a richer range of evidence than the biomedical model and resolves some of its most serious anomalies; also it provides a rationale for an approach to care that looks to more human than to medical solutions. (Kitwood, 1997a, p. 2)

Kitwood (1997a) defines personhood as "a standing or status bestowed upon one human being by others in the context of the relationship and social being. It implies recognition, respect and trust" (p. 8). Personhood recognizes the individual's values and assumes that something can be done to improve one's quality of life (Li & Orleans, 2002). Traditionally, personhood was linked to autonomy, but Kitwood argues that it should be linked to feelings, emotions, and the ability to live in relationships. Recognition of the essential unity of all human beings regardless of differences in mental capabilities is vital to personhood. Personhood can be maintained for individuals with dementia by enabling choice, using remaining abilities, through expression of feelings, and by living in the context of relationships

(Kitwood, 1997a). While some say that personhood is diminished in dementia, others believe that an individual's uniqueness and personality can be maintained (Goldsmith, 1999). Aspects of self persist.

Kitwood draws upon Buber's (1937) "I-Thou" perspective in the personhood approach to dementia (Kitwood, 1997a; Morton, 1999). Buber contrasts "I-It" relationships with "I-Thou" relationships. I-It relationships are characterized by coolness, detachment, and instrumentality (Kitwood, 1997a; 1997b). I-Thou relationships imply going out towards the other, self-discovery, and spontaneity. I-It relationships are banal and trivial, but I-Thou relationships rise above that, to include not only anxiety and suffering, but also fulfillment and joy (Kitwood, 1997a). Kitwood's approach to dementia calls for a move away from relating to persons living with dementia in the I-It mode to relating to them in the I-Thou mode, where the person is met with openness, tenderness, presence, and awareness. It is Kitwood's (1997b) belief that I-Thou relationships replenish personhood, which involves lowering our defenses and allowing our true feelings to show.

Kitwood's work has received criticism for its focus on long-term care (Cheston & Bender, 1999b; Morton, 1999), its lack of attention to agency in the lives of persons living with dementia (O'Connor & Bartlett, 2006), and its framing of persons living with dementia as recipients of care who are not actively involved in how that care plays out (Reid, Ryan, & Enderby, 2001). This approach fails to "...capture the interdependencies and reciprocities that underpin caring relationships" (Nolan, Ryan, Enderby, & Reid, 2002, p. 203), which are key to continuity and self. Although relationships are important for personhood, the focus remains on the individual with dementia, neglecting the needs of all those in the broader relationships surrounding the person (Nolan, Keady, & Aveyard, 2001). However, personhood provides

researchers and formal service providers with a way to consider and respect the whole person instead of focusing on pathology and behaviours associated with dementia. Steeman et al. (2006) identified 43 qualitative studies exploring the subjective experience of dementia. Their review summarizes core findings in this body of research, including the losses that threaten security and autonomy, difficulty in understanding their circumstances or hiding them from others, and how persons living with dementia cope with it and adjust to the changes in themselves and their lives. This body of work moves beyond addressing biomedical factors associated with dementia and considers dementia in a holistic way, including both positive and negative aspects. The personhood approach has expanded our understanding of the perspectives and experiences of persons living with dementia (Ferguson & Keady, 2001; Harris, 2002). Accordingly, the personhood movement guides this study as I aim to understand the meaning of leisure in the dementia context and its role in sustaining or re-creating personhood and identity in dementia.

Leisure and the Subjective Experience of Dementia

While inroads have been made regarding the subjective experience of dementia, researchers have yet to extensively explore the meaning of leisure for persons living with dementia, although some work has explored meaningful activity (Phinney, Chaudhury, & O'Connor, 2007) and daily occupations (Ohman & Nygard, 2005). Researchers have typically focused on the impact and experience of therapeutic recreation programs in long-term care for people living in the later stages of the disease process (e.g., Buettner & Kolanowski, 2003; Fitzsimmons & Buettner, 2002; Kolanowski, Buettner, Costa, & Litaker, 2001; Kolanowski, Litaker, & Buettner, 2005; Sullivan, Pedlar, & Miller, 2002), but have paid little attention to the exploration of leisure for people living in the community with early stage dementia.

Nevertheless, there is evidence that leisure participation may be relevant to the experience of dementia. Harris and Durkin (2002) suggest that replacing relinquished roles with new roles helps people to cope with dementia. At the same time, maintaining a connection with past meaningful activities allows persons living with dementia to use skills that they had prior to the diagnosis (Harris & Durkin, 2002), perhaps allowing them to retain some of their previous identity and abilities. Furthermore, Harris and Durkin found that altruistic activities emphasize the continued ability to be productive and give back to the community. Given the changes and losses experienced in dementia, leisure may play a particularly important role in identity and continued engagement in life. In addition to the benefits and opportunities that leisure may represent, some research indicates that participation in meaningful activity, including leisure, is valued by persons living with early stage dementia (Phinney et al., 2007). For some participants in Phinney et al.'s study, engaging in valued activities was "the central driving force in their lives" (p. 387). Lifelong leisure activities were retained and some started new leisure pursuits. While Phinney et al.'s work sheds some light on the meaning of leisure for persons living with dementia, our understanding remains limited. Examining the role that leisure plays in sustaining and developing identity, as well as leisure as a space for persons living with dementia to resist negative stereotypes and identity loss provides insight into leisure's role in the lives of persons living with dementia.

Purpose

In this phenomenological study, I worked with persons with early stage dementia to co-construct an understanding of the meaning of leisure for persons living with dementia, paying particular attention to the notions of leisure as a space for creating or sustaining identity and as a space for resisting the stigma of dementia and loss of identity. Thus, the purpose of this

study is to explore the meaning and experience of leisure and its role in maintaining identity in the lives of persons in early stages of dementia living in the community. This study is guided by the following research questions:

1. How do persons in the early stages of dementia think about themselves?
2. How do persons in the early stages of dementia interpret their situations? How do persons living with dementia experience it?
3. How do persons with dementia describe leisure? What meanings do they attach to leisure in general? How do persons with dementia experience leisure?
4. What role does leisure play in the lives of persons with dementia and in the maintenance or enhancement of identity more specifically?
5. What role does leisure play in reproducing or resisting society's expectations regarding people living with dementia?
6. What issues or challenges do people living with dementia experience in trying to maintain valued leisure activities? How do they address those issues or challenges?

In chapter 2, I present an overview of the dementia literature and identify the gaps that exist in our understanding. More specifically, I continue my discussion of the recent research that explores the subjective experience of dementia. Next, I present conceptual definitions of identity and discuss how dementia research has shown that identity is both sustained and recreated in dementia. I explore what we currently know about leisure in the context of dementia, including what we know about therapeutic recreation and dementia, the effects of leisure on cognition, and leisure's role in identity in the dementia context. Finally, I discuss the notion of leisure as a space for resistance for persons living with dementia.

In chapter 3, I describe the epistemological assumptions that guide this study, followed by a description of the research process that was used to gain an understanding of the meaning and experience of leisure in the dementia context. This involved three data collection

techniques – the long interview, participant observation, and photovoice. All data were analyzed in a manner consistent with phenomenology as they were collected. The findings of this study are presented in chapter 4. I outline how participants experience leisure within the context of memory loss. Finally, chapter 5 summarizes the study and locates it within the current research regarding dementia and leisure. I close by addressing how this study contributes to our body of knowledge and expands understanding of leisure within the context of memory loss.

Chapter 2: Literature review

The Subjective Experience of Dementia

In the past, the belief that persons living with dementia lack awareness of their own experience led to the neglect of exploring dementia from the perspectives of those living with it (Snyder, 2001). However, a growing body of literature stemming from the personhood movement is beginning to capture this side of dementia (Downs, 1997; Harris, 2002). Such research can result in context-rich accounts of the experience of dementia (Bassett & Graham, 2007). People living with early stage dementia often welcome the opportunity to share their experiences and express their needs (Cottrell & Schulz, 1993), and a great deal can be learned when we include their voices. In the early stages of dementia, people are able to express themselves, their wishes, and their concerns about the disease (Beattie, Daker-White, Gilliard, & Means, 2004; Keady & Gilliard, 1999; Ohman, Josephsson, & Nygard, 2008; Phinney, 1998; Phinney & Chesla, 2003). People living with mild or moderate dementia can describe their experiences and the quality of their lives as they change and as they face an uncertain future (Parse, 1996). Even in the later stages of the disease, people are able to express their needs and their appreciation of care (Barnett, 2000). Phinney and Chesla (2003) argue that expression of the lived experience of dementia may result in a more complete account of symptoms than the biomedical model alone. Lyman (1998) stresses the importance of listening to the voices of people with dementia for respecting and maintaining their personhood:

If we listen to the voices of people living with dementia, we find that life continues with a sense of direction, if not a clear destination. As clinical practitioners and researchers, when we hear the voices of people with dementing illness, we are challenged to find ways to recognize their personhood as they become less able to articulate their own perspective, and support their struggle to create meaning while living with Alzheimer's disease. (p. 56)

To date, research exploring the subjective experience of dementia has focused primarily on the experience of being diagnosed, the experience of living with the symptoms of dementia, how people cope with dementia, the nature of relationships with others, thinking about the future, and the overall experience of living with dementia.

When symptoms of dementia first appear, people experiencing them face uncertainty about what is happening to them. Some persons living with dementia notice the beginning of dementia when life transitions such as retirement lead them to believe that things are no longer right. After receiving a diagnosis, persons living with dementia struggle with whether or not to disclose it to others (Beard, 2004). They want those around them to respond honestly about their memory difficulties. They wonder what others are thinking when they are not given direct feedback about memory problems (Langdon et al., 2007). Some feel that telling others about the diagnosis has many benefits. It can be empowering, it can foster compassion, it allows one to ask for help, it justifies or explains behaviour, and it can foster a safe environment (Beard, 2004; Snyder, 2001). Disclosing the diagnosis can be a powerful strategy for coping with dementia (Harris & Durkin, 2002), yet disclosure can also lead to stigmatization (Snyder, 2001). There may be a greater willingness to be open about one's diagnosis with one's family than with one's wider social circle because of the misconceptions people hold about dementia (Langdon et al., 2007).

In addition to diagnosis and disclosure, the symptoms of dementia have an impact on how persons living with the disease experience it. In the early stages of dementia, people are aware of their deteriorating memory, yet still want to be treated as they were prior to the diagnosis (Beattie et al., 2004). People experience dementia as a simple memory problem that they consider to be a normal part of the aging process and they seek to minimize or deny the

pathology of the condition (Gillies, 2000). Later on, people living with early to moderate stages of dementia feel uncertain of themselves and their behaviour since awareness of their symptoms fluctuates (Phinney, 1998).

Symptoms affect one's body as well. Phinney and Chesla (2003) found that people living with dementia feel their bodies slowing down and feel lost. Rhythms slow down and the world around them can seem overwhelming (Mitchell, Jonas-Simpson, & Dupuis, 2006). Crowds and noise can be overwhelming (MAREP, 2007a). Truscott (2003) notes how her own body has slowed since living with memory loss: "Today my pace is slow and measured. I move with the snails. I rest as much now as I used to race before" (p.12). People living with dementia begin to disengage from activity and become less involved in the world. They experience slowing down in day-to-day activities and the ability to use equipment, such as buttoning a shirt or driving a car. They also experience slowing of conversation as they have to take more time to think about the right words. Participants reduce levels of involvement as they disengage from everyday habits. They feel scared when they cannot remember things and feel that they need to be reflective, but are unable to do so (Phinney & Chesla, 2003). Doing simple tasks can be tiring, and when fatigue sets in, thinking and speech slow down even further (Truscott, 2003).

Persons living with dementia also experience apraxia (i.e., inability to coordinate a desired action with the appropriate motor response), problems with reading and writing, and changes in driving ability due to changes in perception and memory (Gillies, 2000). Difficulty finding words can also be frustrating (MAREP, 2007a). Memory loss can affect daily function and self-esteem (Snyder, 2001). Mitchell et al. (2006) note that persons living with dementia experience *bewildering absences*, such as forgetting important events or familiar information.

They may forget how to take a familiar route home. When an unreliable memory is obvious to others, persons living with dementia may experience humiliation (Gillies, 2000). Bewildering absences can be surprising and embarrassing, but also frightening (Mitchell et al., 2006). All of these changes can impact not only enjoyment of one's activities, but also one's self-esteem and self concept, which are further eroded by communication difficulties, functional losses, and shifts in independence and autonomy (Gillies, 2000; Snyder, 2001). Discomfort about one's failing memory is compounded if persons living with dementia feel as if they are disappointing loved ones (Gillies, 2000).

In addition to the experience of the symptoms, research exploring the subjective experience of dementia has focused on how people cope with dementia. Persons who are diagnosed with dementia find ways to cope with it despite the change and uncertainty that accompanies dementia (Clare, 2002; Harman & Clare, 2006; Harris & Durkin, 2002; MAREP, 2006; 2007a; 2007b; 2008). Hoping that memory problems will get better or that the diagnosis is wrong is effective for some people living with dementia, while others prefer not to worry about their memory problems, feeling that there is nothing to be done about them (Clare, 2002). However, Keady and Gilliard (1999) suggest that persons living with dementia undergo an active process of learning to cope with dementia. They cope with the early stages of dementia by first trying to explain to themselves the reasons for the symptoms. This is a self-protective act aimed at maintaining integrity and sense of self. It allows the person living with dementia time to adjust to the changes. Next, they draw on coping behaviours to accept the changes that are occurring. Together with their care partner, the person living with dementia uses adaptive coping mechanisms to live out the condition. Sharing the burden with the care partner is a cathartic experience that allows the person living with dementia to explore options

and resources available and helps those with dementia to develop a sense of mastery over their situation (Keady & Gilliard, 1999).

Maintaining normalcy as much as possible is meaningful for persons living with dementia and helps them to cope with the changes (Beattie et al., 2004; Menne, Kennedy, & Morhardt, 2002; Phinney, 1998). For example, people attending a day program want to engage in activities that are age appropriate and that they enjoyed prior to experiencing dementia such as going out for lunch or attending museums (Beattie et al., 2004). Similarly, Phinney (1998) found that people living with Alzheimer's disease are concerned about how they can continue to live as they had before being diagnosed in order to diminish the impact of the changes they are experiencing. They do so by monitoring their failing memory and by keeping an active mind to stay on top of the disease. They continue to stay engaged in the world in order to feel as though life is normal and meaningful. Downplaying the disease and interpreting the experience in the context of growing older helps some persons with dementia to feel "normal" (Clare, 2002; Gillies, 2000; Phinney, 1998). Maintaining normalcy is also apparent in doing household chores. Phinney et al. (2007) found that participants are eager to complete household chores that play an important role in everyday life. Chores continue to be valued even when assistance is needed from family members (Genoe et al., in press; Phinney et al., 2007). Participants do not want to relinquish these tasks, but instead "emphasized how much it mattered to them to be able to continue in these kinds of activities, even if it meant they had to use different strategies than before" (Phinney et al., 2007, p. 387).

In addition to maintaining normalcy, coming to terms with and accepting the diagnosis and oneself and having a positive attitude can help one to cope with dementia (Harris & Durkin, 2002). Harris and Durkin's research participants were creative in finding techniques

and using technology to learn about and deal with dementia. For example, anticipating adaptation helps persons living with dementia to become familiar with the challenges they will face in the future and integrate new behaviour into their lifestyles before it is needed. For some, accepting the diagnosis leads to the adoption of a “fighting spirit”, or active engagement in fighting the impact of their difficulties (Clare, 2002). Remaining active in one’s life and doing everything one can is one way that persons living with dementia may fight back against the disease (MAREP, 2006; Phinney et al., 2007). Experiencing the full emotional impact of the diagnosis helps to develop the “fighting spirit”. However, some may feel uncertain about whether they should fight the disease or passively accept it (Harman & Clare, 2006). Often persons living with dementia go back and forth between seeking understanding and avoiding understanding of the disease (Harman & Clare, 2006). They may avoid situations that challenge their failing memories (Gillies, 2000) or they may avoid discussing their problems (Van Dijkhuizen, Clare, & Pearce, 2006). Alternatively, they may minimize memory loss to convey a sense that it is not problematic (Van Dijkhuizen et al., 2006).

Persons living with early stage dementia want to give back to their communities and want to continue to feel useful (Clare, 2002; Menne et al., 2002; Stansell, 2002). Doing so has been found to be important for coping with dementia (Clare, 2002). Steeman, Godderis, Grypdonck, de Bal, and de Casterlè (2007) suggest that doing or having done things that are of value for others is linked with feelings of being valued, which is of central importance to persons living with dementia. Focusing on the good things in their lives, such as valuing a relationship or appreciating a good day, can be a valuable coping mechanism. Clare (2002) found that participants believe that dementia provides a means for developing and learning

about themselves. In this way they come to terms with dementia, accepting their limitations and losses and balancing despair with feelings of hope (Clare, 2002).

Along with acceptance and a fighting spirit, persons living with dementia adopt many practical ways to cope with memory loss (MAREP, 2007a; 2007b; 2008). Following a routine enables persons with dementia to maintain a sense of normalcy (MAREP, 2008; Clare, 2002). Relying on a partner or caregiver to remind them of important dates and appointments and to serve as proxy memories is common among people living with early stage dementia, although some are concerned about becoming too dependent on their partner (Clare, 2002; Gillies, 2000; Preston, Marshall, & Bucks, 2007; Van Dijkhuizen et al., 2006). Persons living with dementia seek reassurance, guidance, and clarification (Gillies, 2000; Van Dijkhuizen et al., 2006). External memory aids, such as diaries, calendars, lists, and notes are used as reminders (Clare, 2002; Gillies, 2000; MAREP; 2008; Phinney, 2007; Preston et al., 2007). Familiarity with the environment is important for coping with dementia, since well-rehearsed skills and routines can help persons with dementia overcome difficulties (Van Dijkhuizen et al., 2006). These strategies seem to have a positive effect on independence even though they can, and do, fail. Still, they are valued because they maintain or improve self-confidence (Clare, 2002). Persons living with dementia also cope by removing pressure from themselves by being aware of their limits, focusing on strengths, protecting themselves from certain situations, and taking time away from stressful situations (Preston et al., 2007).

Humour can also be an important means of coping with dementia. Snyder (2001) found that people living with dementia emphasize the importance of humour in everyday life. Having a sense of humour and ability to laugh at one's symptoms can transform what seems

tragic into the comedic. Snyder found that people living with dementia had hope for themselves, providing an "...affirming testimony to the human spirit" (p. 19).

Researchers exploring the subjective experience of dementia have also focused on relationships. Barnett (2000) found that friendship is important to people living with dementia. They want to communicate with people who are familiar to them, and doing so leads to meaningful and valuable relationships. When family and friends are understanding, persons living with dementia experience relief in being understood (Mitchell et al., 2006). Parse (1996) found that relationships with family and friends are appreciated among people living with dementia who wish to spend more time with family members, but accept being apart from them. Friends and family are relied upon for maintaining a sense of belonging (Cassolato et al., 2009; Keller et al., in press; Van Dijkhuizen et al., 2006). Families living with dementia often find mealtimes particularly meaningful as a space for connecting with each other by catching up, making plans and decisions, and reminiscing. Eating together strengthens family bonds (Keller et al., in press). Participants attending day programs find enjoyment in the company of new friends (Reid et al., 2001). Interactions with other persons living with dementia can be particularly meaningful as they provide feelings of reassurance as stories are shared (Phinney et al., 2007). Beattie et al. (2004) found that younger adults living with mild dementia who attended day programs appreciate both the friends they make and engagement in meaningful activities. Day away participants enjoy each other's company and feel a sense of interdependence among all members of the group (Reid et al., 2004). A warm, welcoming day program can facilitate social interaction (Barnett, 2000).

While appreciation and desire for family and social relationships seems to be part of the experience of dementia, these relationships can change (Harman & Clare, 2006; Keller et al., in

press; Phinney et al., 2007). For example, some persons living with early stage dementia feel that their interactions with others change because of differences in the way people understand dementia. As such, participants feel that the diagnosis of dementia alters the way other people interact with them (Harman & Clare, 2006; MAREP, 2007b). Changes in communication emphasize the stigma that they feel as a result of their diagnosis. They sense that family, friends, and service providers no longer speak directly to them, but speak behind their backs (Harman & Clare, 2006). In addition to changes in interactions, some people living with the disease withdraw from relationships due to over-stimulation they experience in social settings (Snyder, 2001). Conversations can become more difficult if persons living with dementia and/or their care partners feel frustrated as a result of changing communication (Keller et al., in press). Graneheim and Jansson (2006) describe the experience of dementia among persons living in residential care. Their findings suggest that persons with dementia who engage in “disturbing” behaviour do so because they feel as though they have been “set aside” by staff and family members. A breakdown in interaction with others including care providers and other residents occurs, but there are occasional episodes of togetherness, in which participants feel as though they were making a contribution to relationships with others, including care providers and other residents.

In addition to relationships, researchers have explored how persons living with dementia think about the future. People living with dementia are often aware that changes will occur, yet feel uncertain about what that change will be and how to evaluate change (Harman & Clare, 2006). They seem to have varying views on thinking about the future. Some emphasize that they do not want to focus on the future because of its uncertainty, but prefer to take one day at a time (Keady & Gilliard, 1999). In contrast, Snyder’s (2001) findings show how

people express concern about their futures and the progression of the disease and how lack of discussion about the future can be distressing. Awareness of an uncertain future leads to an appreciation for the present and trying to accomplish what one can while one can (Parse, 1996). People living with dementia recognize that they face limitations, yet they see that they also have opportunities and thus have some hope for the future (Parse, 1996). Some report positive changes as a result of dementia, such as meeting new people, developing greater sensitivity, developing new interests, being more open, and no longer worrying about less significant things (Preston et al., 2007).

Research on the subjective experience of dementia provides insight into what it is like to live with dementia. This research can go beyond the experience of symptoms, coping strategies, and the changing nature of relationships to focus on the tensions and balancing acts that persons living with dementia experience in their daily lives. For example, Pearce, Clare, and Pistrang (2002) found that men living with early onset dementia manage their sense of self by balancing the wish to maintain a prior sense of self with reappraisal and reconstruction of a sense of self. Delving deeper into the positive spin that persons living with dementia place on their experiences, Steeman et al. (2007) found that persons living with dementia work to balance the tension between abilities that are lost and those that are retained. Being valued is central to their experience, and Steeman et al. argue that feeling valued is more important than loss of cognition or identity: “They struggle to remain someone of value, often in the face of many threats posed by dementia itself and by how others interact with the person with dementia” (p. 127). Steeman et al.’s narrative analysis reveals that participants are constantly balancing being valued and becoming worthless. They place a positive spin on their lives, minimizing losses and emphasizing remaining competencies and past and present

accomplishments. They express contentment with their lives and feeling loved and valued by family and friends. However, they also report feeling devalued by family members, lonely, uncertain, shameful, useless, as if one is losing one's mind, disregarded, and a burden. Thus an important part of the experience of dementia is balancing the positive aspects of life with the negative aspects in order to feel as though they are still valued persons.

Bassett and Graham (2007) also explored the general experience of living with dementia. Their findings indicate that persons living with dementia experience problems in awareness, attention, and anticipation in everyday activities. As a result of loss of awareness of past experiences, and loss of attention to both oneself and objects around them, persons living with dementia are unable to complete everyday tasks. A decline in anticipating the future is also part of the experience of dementia. Loss of ability to imagine undertaking daily activities in the future marks the loss of anticipation: "Being unable to relive past memories in the present allows no future to anticipate" (Bassett & Graham, 2007, p. 548). These changes can lead to negative labeling such as being lazy or a quitter. They also lead to a sense of no longer recognizing oneself. This research highlights the complexity of the experience of dementia.

Research exploring the subjective experience of dementia indicates the importance of listening to the voices of people with dementia to understand how they cope with the disease and adapt to change. It allows people living with dementia to express their needs, their continued abilities, and strategies they use to live with dementia. Furthermore, this body of research points to the abilities and strengths of persons living with dementia, which can be used to develop more positive understandings of dementia (Preston et al., 2007). As more researchers are seeking to understand the subjective experience of dementia, persons with dementia are being increasingly recognized "...as actively engaged in shaping the nature of

[their] experience of AD and responding in ways that have implications for [their] sense of identity” (Clare, 2002, p. 147). These insights are critical to helping others with dementia to live meaningful lives. Research that seeks to understand the subjective experience of dementia provides insight into the experience of memory loss from the perspectives of those who live with it. It is my hope that this study will continue to add to our limited understanding of how dementia is experienced by those living with it.

Identity and Dementia

In addition to the subjective experience of dementia, researchers who have been influenced by the personhood movement have considered identity in the context of dementia. Identity refers to attributes, actions, and appraisals of self (Charmaz, 1987). It includes both personal and social aspects, and it is shaped by the way one sees oneself as a member of a group and by the way one sees oneself in opposition to the group. “Personal identity is a product of internal consistencies and inconsistencies with one’s past, differences and similarities one has with others, and plans and goals for the future” (Kleiber, 1999, p. 95). Sabat (1998) defines personal identity as

...the self that is experienced as the continuity of one’s point of view in the world, the self that is the location, in psychological space, of beliefs, attitudes, hopes, fears, the location of one’s sense of personal agency or intention, and of responsibility for one’s actions. (p. 42)

Social identity results from identification with others or belonging to a group (Kleiber, 1999). It refers to sense of self that develops over time as the individual participates in social life and identifies with others. It involves identifying with a group of people (Hewitt, 1991). Identity is imperative because it organizes and energizes conduct (Hewitt, 1991). “To have identity...is to gain energy and direction in one’s conduct by adopting the perspective and

purposes of the situation and of one's role in it as one's own" (Hewitt, 1991, p. 127). Each person works to create and maintain identity, however, persons living with dementia may face greater challenges in doing so (Beard, 2004).

Since maintaining identity is particularly challenging when one's health is threatened, identity loss is considered to be a central part of chronic illness (Charmaz, 1995; Gillies & Johnston, 2004). An individual can be left with "a master status and overriding stigmatizing identity" (Charmaz, 1995, p. 660) when diagnosed. When valued attributes, physical functions, social roles, and personal pursuits are lost as a result of illness, identity dilemmas result (Charmaz, 1994). One's body feels alien when body function diminishes as a result of chronic illness. Some struggle against illness, hoping to regain past identities, while others struggle with illness in order to keep their bodies functioning and maintain normalcy in their lives as much as possible (Charmaz, 1995). One may be forced to give up cherished identities when responsibilities accompanying a particular role can no longer be fulfilled. For example, Harris and Sterin (1999) found that personal identities were affected by the losses that persons living with dementia experienced, especially when these losses could not be replaced. This led to feelings of frustration, embarrassment, anger, despondency, fear, disempowerment, and uselessness. However, some people living with chronic illness are able to sacrifice some identities in order to retain others (Charmaz, 1995). This awareness of changing identity due to role loss is acknowledged by persons living with dementia: "Many participants were aware of their changing social status in the world and their increased difficulty carrying out the roles that had previously given them a sense of self worth and social standing" (Langdon et al., 2007 p. 996).

Some may argue that identity is weakened or lost with the progression of dementia. For example, Addis and Tippett (2004) consider the role of autobiographical memory in identity, suggesting that with memory loss, identity becomes vague and of lower quality compared to those who do not have dementia. Autobiographical memory is believed to facilitate the combination of past and present selves and contribute to the continuity of identity. Thus, if autobiographical memory is lost, then one's sense of identity will be affected. Addis and Tippett measured identity and autobiographical memory and concluded that persons living with dementia have more changes in identity compared to those without dementia, suggesting that identity becomes weaker in dementia. When asked to provide 20 statements to answer the question "Who am I?" persons with dementia provided answers that were more vague and more negative than the control group, demonstrating changes in the quality of their identities. Personal incident memory and autobiographical fluency for early adulthood are also related to weaker identity. When identity is considered to be maintained by joining past state with present state and involving psychological continuity and connectedness, persons with dementia may lose their status as persons if they lack psychological continuity. The person is not considered to be the same person as they were before having dementia. If thoughts at one time are disconnected from thoughts at another time, the person is considered to be two persons (Hughes, 2001). Conceptualizing identity in terms of continuity and memory is limiting for persons living with dementia. However, research influenced by a personhood perspective emphasizes that identity may remain until the most advanced stages of dementia.

Sabat and Harrè's (1992) social constructionist approach to identity in dementia provides insight into how identity might be retained. Their research has shown that identity continues to exist when it is considered in terms of personal and social identity. Sabat (2002) describes

three aspects of self. The first of these, Self 1, refers to personal identity, which is expressed through personal pronouns such as “I” and “me” (Sabat, 1998, 2001, 2002; Sabat & Harrè, 1992). Sabat (2001, 2002) argues that each person has a continuous single point of view that forms his or her narrative. Persons living with dementia demonstrate an intact sense of personal identity through the use of first person pronouns (Sabat, 1998; Sabat & Harrè, 1992). Self 2 refers to physical and mental characteristics and beliefs about such characteristics (e.g., height, sense of humour, pride). Self 3 refers to our social personae, which are constructed in many different situations. Each persona requires a specific pattern of behaviour and another person to respond to that behaviour. For example, if one has the social persona of a teacher, one acts as a teacher would act, and others respond in a way that confirms that persona. While Self 1 and Self 2 can be maintained, Self 3 is often threatened and can be lost among people living with dementia due to lack of cooperation from others since they cannot live out their personae if they are not recognized as having a certain role (Sabat, 1998, 2002).

Through a number of interviews with two people in early and later stages of dementia, Sabat and Harrè (1992) found that self exists regardless of severe problems resulting from the disease, as evidenced by indicating self through the use of “I” or by gesturing to oneself once language is lost (see also Sabat, 1998, 2001, 2002). Personal identity remains intact even in the latest stages of dementia when deterioration is quite severe. One’s personae can be manifested in the later stages of dementia with the cooperation of others (Sabat & Harrè, 1992). One of Sabat’s (1998) participants constructed social identity by avoiding situations that labeled her only as a person with dementia, and with cooperation she was able to construct social identities that she valued. Drawing upon Sabat and Harrè’s approach, Shenk, Davis, Peacock, and Moore (2002) found that with help from others, a woman living with dementia

was able to retain aspects of her identity that were related to her work, family, and religious life. Thus, a constructionist approach to identity in dementia indicates that both personal and social identities continue as dementia progresses. Snyder (2006) also draws upon the constructionist perspective and demonstrates how one woman living with dementia maintained Self 3 by continuing her lifelong role as a health care advocate when she joined a support group for persons living with dementia. She was able to continue her identity as an advocate for others with the affirmation of the other support group members.

While Sabat demonstrates that identity is sustained in dementia, Charmaz's (1987, 1994) work exploring identity and chronic illness can provide insight into changing identity in dementia. Charmaz's (1994) research reveals that identity can change when valued attributes, social roles, and personal pursuits are lost due to illness. A sense of self must be reconstructed when role identities disappear (Cohen-Mansfield, Golander, & Arnheim, 2000). Charmaz (1987) found that adults living with chronic illness construct their identities in relation to their hopes and desires, juxtaposed with expectations and definitions of specific circumstances. People living with dementia may have similar experiences in striving to find and maintain their preferred identity while facing stereotypes and stigma associated with dementia. As people living with early stage dementia deal with many losses, they try to maintain their sense of identity while adjusting to change (Clare, 2002; Genoe et al., in press; Harman & Clare, 2006; Pearce et al., 2002; Steeman et al., 2007).

While Beard (2004) argues that discourse focused only on loss threatens identity, there are many ways that persons living with dementia can assert continuity with the past in order to protect their identities (Beard, 2004; Cheston & Bender, 1999a). Persons living with dementia cope with threats to identity by keeping up appearances or trying to position oneself as

“normal” (Cheston & Bender, 1999a; Pearce et al., 2002). This requires monitoring actions to present the appearance of being as they were before the diagnosis (Cheston & Bender, 1999a). Persons living with dementia develop systems to minimize things that might expose them as having dementia (Beard, 2004). They control the conversation to avoid discussion about things that are difficult to talk about. They seek validation by asking if they are on the right track in conversation. Other ways of coping include maintaining a daily routine, making lists and keeping a calendar, support from family members and support groups, and maintaining a sense of humour and faith (Beard, 2004; Harris & Sterin, 1999). These strategies are adopted to resist being assigned the status of “demented”.

Pearce et al. (2002) found that men with early stage dementia protect their prior sense of self by perceiving memory problems as having minimal impact upon their daily lives and focusing on their remaining strengths. They also try to live as “normally” as possible by accepting and managing limitations. Furthermore, they change their expectations as they reappraise their abilities, relationships and roles. Some persons living with dementia find unique ways to maintain their identity. For example, one man who had been an active volunteer before diagnosis became a spokesperson for the Alzheimer’s Association after being diagnosed with dementia (Harris & Sterin, 1999). Others volunteer as partners in development of resources and services designed specifically for persons living with dementia (see Dupuis, Gillies, Mantle, Loiselle, & Sadler, 2008; MAREP, 2006, 2007a, 2007b, 2008).

Since persons living with dementia experience failure and frustration in maintaining their abilities, they construct new roles and downgrade expectations about self (Pearce et al., 2007). Pearce et al. argue that this reflects Charmaz’s (1987) work as some men with dementia choose less preferred identities over time, while others are able to reconstruct a preferred identity.

Despite threats to identity in dementia, Harris and Sterin (1999) identified core values of self identity in the context of dementia. These include meaningful productivity (i.e., the need to be productive was a central part of identity), primary autonomy (i.e., independence was valued over everything else and considered synonymous with survival), and comfort and security. In their comparison of persons living with cancer and persons living with dementia, Gillies and Johnston (2004) found that both groups reclaimed identity through references to past accomplishments that contrast reminders of decline. Acknowledgement that there are people who are worse off than themselves helps them to retain dignity and sense of purpose as they try to help those who are less fortunate.

Research exploring identity in the context of dementia is hopeful, demonstrating that instead of losing one's identity, some aspects of identity remain, while others change and develop as threats are experienced and new ways of coping emerge. Research also indicates that having meaningful roles remain important to identity in dementia and that persons living with dementia want to continue to make a contribution to society (Genoe et al., in press; Langdon et al., 2007). However, the role of leisure in sustaining and recreating identity in the dementia context remains to be explored. With an understanding of the ways in which identity is conceptualized in relation to chronic illness and dementia, I will now discuss our limited knowledge regarding leisure and dementia.

Leisure and Dementia

Little is known about the role of leisure in the lives of people living with early stage dementia. However, research that has sought the subjective experience of dementia can provide insight into the role of leisure. Phinney (1998) found that people living with early stage dementia seek activities that keep their minds active to guard against further impairment.

Staying engaged in the world by going out for lunch with friends or traveling contributes to feelings of a meaningful, “normal” life. Being included or invited to participate in discussions and activities is valued by persons living with dementia (Graneheim & Jansson, 2006). Ohman and Nygard (2005) found that people living with early stage dementia prefer to maintain their previous patterns of daily life, prefer activities in familiar locations, and want to add to the social context to feel as though they are contributing to society. Staying active distracts from social isolation (Van Dijkhuizen et al., 2006). Participation in daily occupations (including leisure) emphasizes autonomy, independence, and continued abilities (Ohman & Nygard, 2005). Furthermore, “through *doing*, people with mild to moderate dementia find their lives to be meaningful” (Phinney et al., 2007, p. 390, original emphasis).

Activity is meaningful if it provides the opportunity for people to live up to the concerns and commitments that matter most in their lives (Phinney, 2006). Many persons living with dementia derive meaning from activities that once would have been experienced as ordinary (Snyder, 2001). Participation in community programs for persons with early stage memory loss seems to be a significant way of participating in meaningful activity and establishing social support (Snyder, 2001). As well, it has been reported that when partners in care and persons living with dementia engage in shared leisure activities, both experience high levels of happiness, although the person living with dementia experiences greater happiness when engaging in daily tasks with his or her partner in care (Voelkl, 1998).

Phinney et al. (2007) examined the meaning of activity for persons living with dementia. First, persons living with dementia engage in activities because they are enjoyable and pleasurable. They provide a way of feeling like one is still alive. Some choose activities that are not particularly demanding. For example, one woman chose activities that “did not require

her to think or talk, but she could do them alone and not feel embarrassed if things went wrong” (Phinney et al., 2007, p. 388). Second, feelings of connection and belonging that derive from activity made them meaningful; people feel like they are still part of the world around them. Keller et al. (in press) similarly found that preparing meals together led to feelings of connection and belonging, even when the person living with dementia made only a small contribution. Third, activity allows participants to retain personal autonomy, although support from family members may be required for persons with dementia to maintain involvement in meaningful activity in an effort to counter the losses faced when experiencing dementia (Phinney, 2006). As persons living with dementia and their care partners balance control as abilities change, independence can be experienced (Genoe et al., in press). Family members do this by reducing the demand of the activity so that the person can complete it successfully. They may do so by using reminders and instructions to guide the person living with dementia through activities that are meaningful to them, and by accompanying the person with dementia as they engage in activities (Genoe et al., in press; Phinney, 2006). With support, persons living with dementia can continue to engage in meaningful activities, including leisure.

Therapeutic recreation and dementia

Although little is known about leisure in the context of dementia, a great deal of the research regarding recreation in the dementia context focuses on therapeutic recreation programs implemented in long-term care facilities and day away settings. Therapeutic recreation researchers tend to focus on the impact of planned recreation activities on “problem” behaviours. When residents in long-term care participate in prescribed activities that meet their interests and skill level, they demonstrate increased positive affect, ability for self-care,

and level of engagement on a task (Buettner et al., 2006). They also demonstrate decreases in passivity, agitation, negative behaviours such as yelling or banging, aggression, and the need for medication (Buettner & Kolanowski, 2003; Fitzsimons & Buettner, 2002; Kolanowski et al., 2001; Kolanowski et al., 2005). For example, Buettner, Fitzsimmons, and Serdar (2006) measured the physiological impact of prescribed therapeutic recreation interventions intended to reduce agitation and passivity among people living with dementia in long-term care. They found that calming activities reduce heart rate among agitated persons and alerting activities increase blood volume for residents who are passive. Similarly, Buettner and Fitzsimmons (2002) found that when persons living with dementia and depression in long-term care participated in an intensive wheelchair biking program, followed by lower intensity maintenance of the program, residents experienced increased levels of activity and interaction with other residents, staff, and guests. Individualized social activity has also been shown to reduce daytime sleep and improve day/night sleep ratios among residents with dementia in long-term care who have difficulty sleeping (Richardson, Beck, O'Sullivan, & Shue, 2005).

In addition to changing passivity or agitation, positive correlations have been found between well-being and time spent in therapeutic or leisure activities (Chung, 2004). Participating in therapeutic recreation programs and general recreation programs in long-term care leads to feelings of enjoyment, feeling good about being able to be a contributing member of a group, and the opportunity for socialization as well as the opportunity for involvement in meaningful activity, which in turn leads to transformation of character (e.g., a normally quiet resident became more social when participating in an activity that was particularly meaningful) (Sullivan et al., 2002). Furthermore, Schreiner, Yamamoto, and Shiotani (2005) found that persons living with dementia in long-term care express happiness seven times more during

planned recreation programs than they do during other times of the day. They are also more likely to have their eyes open during recreation interventions, indicating that therapeutic recreation has a significant role in stimulating positive affect and thus improving quality of life for persons with dementia in long-term care.

Therapeutic recreation extends beyond long-term care and into day programs designed for persons living with dementia. Brooker and Duce (2000) found that among persons with early to moderate dementia attending day hospitals, participation in reminiscence therapy leads to higher levels of well-being than participating in other group activities (such as crafts, exercise, or games). Both reminiscence therapy and group activities result in higher levels of well-being compared to unstructured time with no involvement from staff, indicating that structured, organized activities have a positive impact on persons living with dementia. Adam, Van der Linden, Juillerat, and Salmon (2000) used a case study approach to show that participation in an individualized leisure program in a day program setting could restore engagement in a meaningful activity. Engagement in the activity increased gradually until the individual was able to do it on her own with no assistance. The case study participant experienced a decrease in apathy and depression, took more initiative in her daily life, and increased participation in conversation. She was more cheerful, less tired, and less lonely, indicating that the intervention improved her quality of life (Adam et al., 2000). Unfortunately, as a case study this cannot be generalized to other participants in day away programs, but indicates that day programs can have a positive impact on persons living with dementia by supporting independence and meaningful leisure.

In sum, research has shown that therapeutic recreation programs in institutional and day program settings can have a multitude of benefits for persons living with dementia. However,

these researchers often focus on what they consider to be problematic behaviours and the ability of therapeutic recreation to decrease undesirable behaviours among persons living with mid to late stage dementia. The meaning of prescribed programs for those who are engaging in them remains largely unexplored. Further, the focus on the desire to change behaviour fails to recognize the meaning behind such behaviour and stops short of recognizing the person living with dementia for who they are at that point in their life.

The effects of leisure on cognition

While there is indication that participation in planned or prescribed activities has benefits for people living in long-term care facilities and attending day programs, little is known about benefits or negative implications of leisure participation outside of the institutional context (For exceptions see Phinney, 2006; Phinney et al., 2007). However, there is some evidence that leisure may provide a degree of protection against cognitive decline. The cognitive reserve hypothesis argues that there are individual differences in ability to cope with AD pathology (Stern, 2002). This could be a passive process, in which reserve refers to the amount of damage that can be sustained before clinical expression. Alternatively, cognitive reserve could be an active process in which the brain adapts to changes by using brain networks more efficiently (Stern, 2002). It appears that having high education and occupational attainment leads to increases in cognitive reserve, reducing the risk of getting dementia (Stern, 2002). Scarmeas and Stern (2003) theorize that everyday experiences could affect cognition and the practicing of cognitive skills and may lead to stable or improved performance due to the plasticity of older adults' cognitive abilities. They hypothesize that leisure activity, particularly stimulating activity, could modify the brain so that it becomes more efficient or resilient to pathology. An engaged lifestyle may enhance the cognitive reserve that allows one

to cope with Alzheimer's disease for longer periods of time. Empirical research, although in the early stages, is beginning to provide some support for these hypotheses. There is evidence that participation in intellectually challenging activities, social activities, productive activities, and physical activities can buffer against cognitive decline (Fried et al., 2004; Hultsch, Hertzog, Small, & Dixon, 1999; Saczynski et al., 2006, Scarmeas, Levy, Tang, Manly, & Stern, 2001; Wang, Karp, Winblad, & Fratiglioni, 2002), and there is an association between frequency of participation in cognitive activities and cognitive function (Wilson et al., 1999).

Evidence of cognitive reserve appears in the well-known Nun Study, a longitudinal study of an order of nuns that included both clinical assessment and brain autopsy after death (Snowdon, 1997). One participant who performed exceptionally well on clinical assessments was shown to have significant pathology in her brain upon autopsy. Her active lifestyle within the convent, including both physical and social activity, seemed to protect against the appearance of symptoms of dementia (Snowdon, 1997). Cognitive reserve is also evident in Scarmeas et al.'s (2001) research which found that people who are at highest risk of dementia have lower levels of leisure participation than those who are at lower risk of dementia. In fact, other studies have found that participation in leisure activities that have mental, social, or physical components, or a combination of these, leads to lower risk of dementia (Karp et al., 2006). For example, activities such as reading newspapers or magazines, visiting, going out to movies or restaurants, and walking for pleasure are associated with reduced risk of dementia. Karp et al. also found that even small mental, physical, or social components have a cumulative effect.

Unfortunately, research exploring the impact of leisure activity on cognition focuses largely on older populations without dementia. While it is evident that leisure has benefits for

cognition among older adults without dementia, there is a lack of evidence that the same is true for persons living with dementia. There is, however, some indication that persons living with dementia engage in cognitively stimulating activities in order to maintain function or slow decline. Phinney's (1998) work reveals that her research participants living with early to moderate dementia made time for activities that kept their minds active, such as reading or crossword puzzles. They believed that this guarded against further breakdown. The impact of engagement in mental, social, and physical leisure on cognitive reserve may have implications for the meaning of leisure for persons living with dementia as they try to protect themselves against further memory loss.

Leisure and identity

In addition to potential protection against further memory loss, leisure may provide the opportunity to enhance identity among people living with early stage dementia as it affords a space to make decisions that can be personally fulfilling (Kelly, 1996). Leisure researchers believe that leisure plays a significant role in the self development process whereby individuals "...actively seek to understand themselves in relation to the world around them, and to maintain a sense of self-consistency and positive regard" (Haggard & Williams, 1992. p. 1). Leisure can provide a space for learning new roles and developing individual identity (Wearing, 1998). Leisure's inherent freedom provides an arena to experiment with new identities and enhance selfhood. It is an ideal space for identity expression and development because it provides the opportunity to build competence and have control over one's time and resources. Furthermore, leisure may provide a space for identity expression and development since there is no predetermined outcome that limits opportunity for self-development. Leisure provides opportunities for expression and development of identity denied in other roles (Kelly,

1983). This becomes particularly important in the context of dementia as persons with dementia are often “shut out” of other roles before they need to be and leisure becomes one of the few spaces where identity can be expressed, developed, and reaffirmed to others.

Opportunities for contemplation and self-examination that may occur in leisure are important for helping individuals to discover or create alternative selves (Kleiber, 1999).

Kleiber (1999) argues that identity is formed through both individuation and identification. Leisure affords opportunities for individuation by providing alternative ways of thinking and being. It can be used to distinguish oneself from others in the everyday social world. Identification occurs when individuals adopt the language, customs, and codes of conduct of the group, establishing membership to both self and others. Kleiber goes on to hypothesize that:

Leisure can be a source of identification with others...but it contributes the most to identity formation when (1) it affords an opportunity for exploration of and experimentation with emerging interests; (2) the interests that emerge and are refined are truly personal and in keeping with other values; (3) action taken in response to interests creates feedback from the environment, including recognition from others, that reinforces the interests; (4) there is competence achieved in that action that defines and reinforces one's potentialities; (5) there is a degree of commitment to that action and to others who are involved; and (6) comfort with others emerges in the social world that is created around those interests and skills. (Kleiber, 1999, p. 103)

Leisure could provide space for investment in self that may not occur in other parts of life, such as work. It can be an arena for enacting both personal and social identities as individuals present themselves, develop and establish an identity, and then receive feedback on their performance (Kelly, 1983).

The freedom inherent in leisure to try new identities and roles could help persons living with dementia adapt to changes and transitions in their lives and try new things when other valued roles have been lost. While identity and leisure in the context of dementia is yet to be

investigated, research exploring disability and chronic illness reveals that leisure plays a role in maintaining and developing identities when one's life is drastically changed (e.g., Hutchinson, Loy, Kleiber, & Datillo, 2003; Kleiber, Hutchinson, & Williams, 2002; Reynolds & Prior, 2003; Reynolds & Prior, 2006). Unanticipated events can disrupt one's life story such that personal change is bound to happen. Leisure continues to be salient to one's self identity, and reliance on leisure-related identities can serve as a buffer for negative life events (Kleiber, 1999), especially when such events lead to a disruption in other identities, such as valued work and family identities (Reynolds, 2003).

After a negative life event, such as a spinal cord injury, leisure and enjoyment can provide escape from negative emotions, but can also open up a "realm of possibilities" (Kleiber et al., 2002). Whitehead's (2006) exploration of identity reconstruction among persons with chronic fatigue syndrome/myalgic encephalomyelitis revealed that the women developed identities by giving up some activities but replacing them with less strenuous activities. Two of the participants continued salient leisure pursuits after they had to give up full-time schooling. Additionally, leisure identities may provide a sense of continuity through life transitions and traumas (Kelly, 1999; Reynolds, 2003). For example, Hutchinson et al. (2003) found that persons who experienced a spinal cord injury or chronic illness felt that leisure helped them maintain continuity of self and symbolically linked them to their past. "Returning to past activities...or engaging in new activities that provided a sense of connection with valued self-perceptions, were instrumental in preserving a sense of self, in spite of the changes in functional abilities, relationships, and roles" (Hutchinson et al., 2003, p. 150). Kleiber (1999) notes that leisure is often used to get back to "normal" and activities are adopted because they provide a distraction from pain or distress. Furthermore, leisure provides a means

for connecting with others based on shared experiences instead of illnesses (Hutchinson et al., 2003; Reynolds, 1997, 2003; Reynolds & Pryor, 2003). It can also serve as a space for reconnecting with others, even if involvement in a particular leisure activity has to be modified (Kleiber, 1999). Maintaining or resuming involvement in familiar activities can affirm identity and reinforce valued aspects of one's previous life (Kleiber et al., 2002). As well, leisure helps preserve a sense of competence which, in turn, leads to a sense of independence and helps individuals to feel like "themselves" (Hutchinson et al., 2003).

While it appears that leisure has a role to play in maintaining continuity of self after a negative life event, Kleiber et al. (2002) suggest there is rarely consideration of the way that leisure fits with a changed conception of self. A negative life event can lead one to reappraise "...one's self, life, values and goals, [and] it often culminates in greater openness to and appreciation of experience, other people, and leisure as well" (Kleiber et al., 2002, p. 221). The participants in Whitehead's (2006) study spoke of becoming new selves that were more positive than their previous selves. When life is significantly disrupted, leisure can aid in reconstructing self. Indeed, such an event "...may be liberating for the discovery of new alternatives" (Kleiber et al., 2002, p. 230).

While some research has indicated how leisure presents opportunities for continuity of identity after acquiring an illness or disability and opens the door to many possible selves, Reynolds and Prior (2003, 2006) show how identity can be recreated through engagement in textile art-making activities when coping with illness that leads to drastic changes in one's life. Many of Reynolds' (1997, 2003) participants became involved in art after diagnosis, but doing so restored a familiar and satisfactory self-image and an "able" identity. Engaging in art helped distract one from thoughts of illness and provided an avenue for expressing grief. Art

also "...provided a means to fill the occupational void with satisfying creative activity, paving the way for positive re-evaluation of lifestyle, and self image" (Reynolds & Pryor, 2003, p. 789). Engagement in textile art increased control and choice in their lives which had been eroded due to illness and led to thinking positively about the future instead of feeling uncertain about it (Reynolds & Pryor, 2003). It also resulted in the development of an artistic identity that provided a source for a positive self image. Furthermore, art helped restore status after leaving valued careers (Reynolds, 2003). These findings indicate that leisure may be a space for identity development for persons living with dementia who also experience significant life changes.

While researchers have not specifically explored leisure's role in identity among persons living with dementia, the literature demonstrates that leisure may indeed have a role to play. Ohman and Nygard (2005) found that leisure and meaningful activity provide a space to communicate identity characteristics and a private sphere where one can perform the activity at one's own level without outside influence for people living in the community with early stage dementia. Meaningful activity, including leisure, has been shown to be important to persons living with dementia as a means of retaining a sense of personal identity (Phinney et al., 2007). For example, one research participant in Phinney et al.'s study felt that continued involvement in everyday activities helped her to feel like an independent and responsible person. Meaningful activity can provide a sense of continuity, although it is important to recognize that as situations change in the context of dementia, being involved in activity may become more challenging over time and individuals may need more support to continue to enjoy valued activities (Phinney et al., 2007).

Long-term care research has also suggests ways in which leisure can contribute to identity in dementia, although family, residents, and staff have differing perspectives regarding the type of activities that enhance identity. Family and staff feel that family visits and going for walks are most likely to enhance a sense of identity (Cohen-Mansfield et al., 2000). Cohen-Mansfield et al. found that residents consider being engaged in conversation, listening to music, social activities, watching television, recreational games, and going outside to enhance a sense of identity. These activities appear to be more likely to increase a sense of identity because they are meaningful for the participants prior to moving into long-term care (Cohen-Mansfield et al., 2000). In contrast to residents' perceptions, staff in the long-term care facility feel that playing games is most salient to the identity of persons living with dementia (Cohen-Mansfield, Papura-Gill, & Golander, 2006). This may indicate that family members and staff need to alter their perceptions of how identity can be retained for persons with dementia living in long-term care. It tells us that we must take care to enable participation in activities that are meaningful to residents, and that games, such as bingo, commonly offered in long-term care, may not be effective for sustaining identity for everyone.

Although there is some evidence that leisure may have a role to play in identity development after one receives a diagnosis of dementia, leisure can also constrain identity development (Kleiber, 1999). This can occur if leisure choices are not linked to the individual's other interests, talents and commitments, if commitment to an activity limits attention to other possibilities, or if leisure confirms negative aspects of self. Furthermore, unsuccessful participation in leisure activities can undermine self-esteem and in turn limit development of identity (Kleiber, 1999). Leisure may negatively impact identity in dementia if there is a loss of competence in preferred activities which serves to reinforce negative

perceptions that one holds about oneself since being diagnosed with memory loss. Individuals can be made aware of their inability or inferiority through leisure or can experience exclusion due to incompetence (Kelly, 1983). This may be especially pertinent to persons living with dementia, who might lose valued leisure skills that previously formed part of their personal and social identities. The negative reactions of others to their diagnosis of dementia could impact their ability or desire to engage in their previous leisure pursuits where they once developed competence and expressed personal identity. However, leisure could provide a space to continue competencies and to focus on remaining capacities instead of losses.

While leisure may play a role in personal and social identity among persons living with dementia, the literature actually reveals very little about the meaning of leisure for identity. The experience of dementia can be characterized in terms of a balancing act between past and present identities, and meaningful leisure may provide an arena for expression of both continuous and new identities.

Leisure as resistance

In addition to maintaining or developing identity, leisure may serve as a space for persons living with dementia to resist negative stereotypes and stigma. Resistance refers to struggle against power structures that spread through every day life (Foucault, 1982).

“Resistance can be seen as an act or series of actions that enhance freedom of choice and personal control” (Shaw, 2006, p. 534). According to Shaw (2001) “leisure as resistance implies that leisure behaviours, settings and interactions can challenge the way in which power is exercised, making leisure a form of political practice” (p. 186). The role of resistance is to struggle against dominant ideologies or belief systems, such as gender, race, or sexuality (Shaw, 2001).

Resistance can be considered both individual and collective: “The individual may engage in acts of resistance, and these will affect her or his life on an individual level, but at the same time such acts will also affect others in similar situations” (Shaw, 2001, pg. 193). When considered from a structural perspective, resistance is a collective act against power relations. This occurs when an act of resistance has implications for others (Shaw, 2001). Collective resistance can have implications for persons living with dementia if they use leisure as a space to resist negative stereotypes, thus altering those stereotypes for all persons living with dementia, not just the individual who engages in the act of resistance. Coming together as a group for self-advocacy could be an example of collective resistance among persons living with dementia. Postmodernists argue that resistance only occurs at the individual level, since one is only resisting one’s unique situation, thus the individual act cannot have implications for others. Here, the desired outcome is individual empowerment rather than social change (Shaw, 2001). An individual living with dementia may experience empowerment when using leisure to resist negative stereotypes of what a person living with dementia can or cannot do. However, when exploring leisure as resistance, researchers argue that individuals have agency to resist oppression, yet oppression and constraint are shared among groups of individuals, so individual acts of resistance can have implications beyond the individual (Shaw, 2001). Thus any act of resistance among persons living with dementia can lead to both feelings of empowerment and social change.

Resistance can be both intentional and unintentional (Shaw, 2001). Acts of resistance may not always be deliberate attempts to resist existing power structures. Through resistance, individuals may seek to enhance their personal power and/or they may seek to change negative discourse and existing ideologies. Resistance includes deliberate acts of both individual and

collective empowerment, but it can also include situations that unintentionally empower individuals or challenge dominant views (Shaw, 2001).

Resistance can occur when social constraints and images are challenged (Shaw, 2006). Resistance through leisure could include refusal to conform to dominant notions of appropriate leisure activities or could imply using leisure to resist hegemony (Shaw, 2006). Shaw (2006) argues that the political significance of leisure as resistance lies in the process of communication and the impact that resistant acts can have on others and on political beliefs and ideologies, suggesting that leisure can have potential for not only individual empowerment, but for collective change. Leisure is ideal for resistance because freedom is encouraged - leisure discourse emphasizes abilities and interests and right to time and space for enjoyment and freedom, affording people the opportunity to do what they wish, instead of doing what is expected of them (Wearing, 1995).

Leisure has been considered as a space for resistance largely in the context of women's leisure experiences (Shaw, 2006). Wearing (1998) argues that leisure is a space for women to resist domination and to grow beyond what it is that they are told they should be. Research exploring women's leisure as resistance shows that through leisure some women are able to resist dominant views of traditional passive feminine stereotypes (Wearing, 1998). For example, a study exploring the leisure of young women in heterosexual relationships found that some women use leisure time apart from their partners to resist both their partners' expectations and a belief that their leisure should focus on their relationships (Herridge, Shaw, & Mannell, 2003). Parry (2005) found that women experiencing infertility are able to use leisure to resist pronatalist ideologies by engaging in leisure pursuits where they gain a sense of empowerment or demonstrate their social worth beyond motherhood, while avoiding leisure

that promotes pronatalist ideologies. These studies, and others focusing on women's leisure, demonstrate that leisure can be a space for resistance against dominant ideologies. Leisure involves freedom for individual self expression, and through leisure, some women are able to resist dominant views of traditional passive feminine stereotypes (Wearing, 1998).

While explorations of resistance have focused on gender, leisure can be a space for other groups of marginalized individuals to resist dominant ideologies and provide avenues for self development beyond society's expectations. Wearing (1995) argues that leisure can be a space to resist negative discourse on aging. Dionigi's (2002, 2006) research on masters athletes reveals that older athletes both intentionally and unintentionally resist ageist stereotypes of older adults as dependent and frail. Tulle-Winton (1999) questions whether older adults' acts of resistance are acts that resist the onset of old age or the regulation of old age. Dionigi (2002) indicates that older athletes in fact resist in both ways. They resist the belief that older adults should not participate in competitive sport and they also resist "getting old", believing that engagement in competitive sport keeps them young, fit, and healthy. Dionigi (2002) found that there are social, mental, and physical benefits associated with participation. Older athletes experience a sense of empowerment. They gain feelings of satisfaction from participating in sport and meeting the challenges they face in competing. They feel pride in accomplishments while adapting to limitations in older age. This leads to a sense of control in other parts of their lives.

Wearing (1995) argues that leisure can be a space for older adults to develop positive interests and abilities and resist ageism. This is no less true for persons living with dementia. Researchers have not yet explored leisure as a space for resistance among older adults living with dementia. However, there are indications that both negative stereotypes associated with

dementia and the process of dementia itself can be resisted through leisure. This is evident in the example of the health care advocate who continued her role after being diagnosed with dementia by advocating on behalf of persons living with it:

Within the group she shared stories and experiences and recognized remaining strengths and abilities...by not acquiescing to the dominant fictions about people with dementia and by readily speaking to the media, she was a powerful voice against stigma. With the help of others...who validate her social persona and help co-construct this self, she is not diminished in the face of degenerative illness, but strengthened. She is creating her own reality and living "as if" she is a person of worth and influence despite her diagnosis. (Snyder, 2006, p. 266-267)

By maintaining valued roles, and through recognition of those roles, this woman is able not only to resist stigma for herself, but to contribute to collective resistance on behalf of other persons with dementia. Her actions allow her to express what it means to live with dementia and possibly alter assumptions about and images of dementia. On an individual level, she may experience empowerment by using her abilities to demonstrate her worth. Through leisure, she affirms her identity as an advocate while resisting notions that persons living with dementia are unable to fulfill valued roles.

Research indicates that there are other, less obvious ways of using leisure as a space for resistance in the context of dementia. Engagement in daily occupations, including leisure, emphasizes autonomy, independence, and continued abilities among persons living with dementia (Ohman & Nygard, 2005). By affording persons living with dementia choice and control in their lives, leisure may provide an opportunity to resist loss of control, autonomy, and independence that others impose on persons living with dementia. If persons living with dementia have autonomy, choice, and success through leisure, they may build confidence to retain independence in other areas, further resisting expectations of dependency. Research indicates that persons living with dementia pursue leisure activities such as dining with friends

or traveling to keep their minds active and to stay engaged in the world (Cassolato et al., 2009; Phinney, 1998). Doing so could be considered resistance against negative attitudes associated with dementia. Furthermore, persons living with early stage dementia are eager to continue to contribute to society (Langdon et al., 2007; Ohman & Nygard, 2005). Leisure may be a space for resistance if persons living with dementia use their leisure time to contribute to society, showing both themselves and others that they are capable of doing so.

Leisure may provide a safe space for persons living with dementia to resist stereotypical expectations. Furthermore, it may be seen as important in slowing the process of dementia itself. There is some indication that persons living with dementia do resist notions of incompetence and loss of identity by seeking out and engaging in meaningful activity (e.g., Keady et al., 1995; Paterniti, 2000; 2003; Phinney et al., 2007; Widdershoven & Berghmans, 2006), but this has yet to be explored in depth.

It is important to recognize that leisure may *not* be a space for resistance for all persons living with dementia. Leisure skills valued by the individual may erode, and leisure may serve to remind the individual of the losses associated with dementia. Currie (2004) explored exercise as a space for resistance among mothers and found that while participation is a way to resist dominant discourse surrounding motherhood, it also reinforces the belief that women must "...discipline areas of their body deemed defective according to the societal ideal" (Currie, 2004, p. 238). Similarly, leisure may reinforce the losses experienced by persons living with dementia, instead of serving as a space to emphasize abilities and resist stigma associated with dementia. Leisure may reproduce stereotypical notions of dementia, especially when service providers make decisions about what activities are made available for persons living with dementia to engage in. For example, leisure opportunities available in day

programs and long-term care may perpetuate dementia stereotypes by limiting activities based on staff members' views regarding appropriate activities for clients. Whether leisure can be a space for resistance or whether it is a site for reproduction of stereotypical notions of dementia remains unclear.

Summary

While strides have been made in increasing understanding of the subjective experience of dementia and the sustaining or creating of identity within the context of dementia, we have yet to understand what leisure means to persons living with dementia, or whether leisure can be a space for identity and resistance in the context of dementia. Research on the subjective experience of dementia has demonstrated that persons living with dementia are willing research participants who have much to say about their experiences. They have found ways to cope with dementia and often want to continue to make a meaningful contribution to society while maintaining normalcy in their lives. They work to sustain and recreate both personal and social identity, and are able to do so with hard work and help from others to acknowledge their roles and accomplishments.

Although our understanding of the meaning of leisure in the dementia context is limited, therapeutic recreation has been shown to be beneficial for persons in later stages of dementia, and leisure appears to have benefits in terms of preventing or delaying the onset of dementia. Leisure has been identified as a space for creating and sustaining identity, and as a space for resisting identities ascribed to individuals by society. Leisure and meaningful activity is valued among persons living with dementia. However, little is known about the meaning and experience of freely chosen leisure for people living with dementia and whether or not leisure plays a role in maintaining or renegotiating identity. The research questions that guide this

study as stated in Chapter 1 are aimed at expanding our limited understanding of leisure in the context of early stage dementia.

Chapter 3: Methods

Introduction

Since my aim for this study is to contribute to our understanding of the subjective experience of dementia, I have adopted a qualitative research approach. A qualitative approach to dementia research involves a commitment to view things from the perspectives of the participants. This commitment is essential for maintaining personhood throughout the research process (Bond & Corner, 2001). Both Kitwood's (1997a) personhood approach to dementia and phenomenology's philosophical underpinnings provide the framework for my research. Kitwood's approach to dementia focuses on the person and his/her experience instead of the neuropathology associated with dementia. Personhood's holistic approach to dementia highlights the abilities and strengths of the individual, emphasizing ability to engage in relationships with others. It considers persons living with dementia to be persons in their own right who have life experiences (Adams, 1996), and it emphasizes the importance of understanding those experiences.

Phenomenology is both a research paradigm and research approach that explores "...the meaning, structure, and essence of the lived experience..." (Patton, 2002, p.482) of a particular phenomenon for an individual or group. Although phenomenology is perceived and approached in a number of ways depending on the epistemological stance of the researcher, I draw upon an interpretivist phenomenological approach for this study. Such an approach allows for understanding the meaning and essence of leisure for persons living with dementia, moving away from a positivist/post-positivist approach to research often utilized in exploring therapeutic recreation and dementia. I will begin with a brief discussion of phenomenology's

philosophical underpinnings that will guide my research, followed by a discussion of phenomenology as a research approach. I will then describe data collection and analysis.

Epistemological Assumptions

Phenomenology

Phenomenology is interested in the world as we find it (van Manen, 1997).

Phenomenology focuses on how humans make sense of experience and transform it into consciousness, both individually and as shared meaning. It captures how a phenomenon is experienced (Patton, 2002) and explores the way that things present themselves to us (Sokolowski, 2000).

Phenomenologists describe the subjective world (Fjelland & Gjengedal, 1994) while opposing empirical science, arguing that knowledge is subjective, and that no “ultimate” reality exists (Cerbone, 2006; Hammond, Howarth, & Keat, 1991; Schwandt, 2001; Spinelli, 1989). Instead, objects exist through the meaning that an individual gives them (Spinelli, 1989). Literally, phenomenology means the study of phenomena (Cerbone, 2006). It involves the description of things as they are experienced (Hammond et al., 1991). We experience things not only through perception (seeing, hearing, touching), but also through believing, remembering, wishing, deciding and imagining, feeling, judging, and bodily actions (Cerbone, 2006; Hammond et al., 1991). The philosophy of phenomenology requires that we concentrate on the *character* and *structure* of experience, rather than the cause. It asks what we might learn from an experience and what sort of insights we might gather from it (Cerbone, 2006).

Existential phenomenology

While phenomenology’s roots are attributed to Edmund Husserl, whose transcendental phenomenology cleared the path for further delineations of phenomenology (Cerbone, 2006;

Mackey, 2005; Moustakas, 1994; Sokolowski, 2000; Spinelli, 1989), this project will follow existential phenomenology (Heidegger, 1962). Existential phenomenology seeks to understand the events of human existence (Valle et al., 1989). It is interested in everyday existence (Cerbone, 2006). Existential phenomenologists believe that a person does not exist apart from the world, and the world does not exist apart from persons (Valle et al., 1989). Thus, individuals and the world co-constitute each other (Leonard, 1994; Valle et al., 1989). The meaning of one's existence emerges through the world. It is an individual's existence that gives his or her world its meaning (Valle et al., 1989). Heidegger (1962) conceptualized Being as being-in-the world. Being-in-the-world represents the idea that the object and subject are inseparable (Mackey 2005). The fundamental structure of being-in-the-world is Dasein (Heidegger, 1962). Heidegger (1962) wrote:

In the interpretation of *Dasein*, this structure is something “a priori”; it is not pieced together, but is primordially and constantly a whole. It affords us, however, various ways of looking at the items which are constitutive for it. The whole of this structure always comes first; but if we keep this constantly in view, these items, as phenomena, will be made to stand out. And thus we shall have objects for analysis... (p. 65)

Being-in-the-world refers to subjective experience, or the way humans exist, act, or are involved in the world (van Manen, 1997). *Dasein* reinforces the status quo when individuals are immersed in the natural attitude and lack any sense of individuality (Cerbone, 2006).

Existential phenomenology defines two modes of being – inauthentic and authentic. When they are inauthentic, individuals are lost in their everyday routines. They do what is expected or repeat what others say. They fail to own themselves (Cerbone, 2006). Inauthentic beings conform to prevailing attitudes and morality and respond to life in a passive stance (Spinelli, 1989). However, in an authentic existence, individuals speak for themselves and give voice to individual experience (Cerbone, 2006; Spinelli, 1989). They maintain

independence of thought and action and feel in charge of their lives. Authentic individuals acknowledge their role in determining actions, thoughts, and beliefs, and experience integration, acceptance, openness, and aliveness to the potentialities of being-in-the-world (Spinelli, 1989). In order to transition from inauthenticity to authenticity, something disrupts everyday routines (Cerbone, 2001; Spinelli, 1989). This leads to feelings of anxiety (referred to as *angst* in existential phenomenology) (Cerbone, 2001; Spinelli, 1989). Angst can prevent individuals from living in an authentic mode (Spinelli, 1989). An authentic being recognizes that it only has one death, and subsequently only has one life to live. Acknowledging that death is inevitable, *Dasein* can be authentic, and authentic persons take up the task of projecting themselves onto their many possibilities in life (Cerbone, 2006).

Phenomenology remains relevant today, despite having appeared to peak many years ago, with its monumental works limited to the early to mid 19th century (Cerbone, 2006). Phenomenology's rejection of naturalism as the only form of legitimate inquiry provides an alternative way to view the world (Cerbone, 2006). Cerbone describes the reason for practicing phenomenology:

...to facilitate a return to experience, to reawaken in us a sense of its importance by demonstrating the founding role of experience in our conception of the world, however sophisticated that conception has come to be through the advancement of natural sciences. In striving to reawaken us to our own experience, to the phenomena through which our conception of the world is constituted, phenomenology seeks to awaken us to ourselves, to make us alive to our own existence as subjects who bear a kind of ultimate responsibility for that conception. Phenomenology awakens us to the philosophical and existential primacy of experience, of intentionality, of subjectivity: of everything that comes with the assertion of the words "I am". (Cerbone, 2006, p. 173-174)

Thus, the philosophical underpinnings of phenomenology have implications for human science research that seeks to understand subjective experience.

Understanding lived experience

Phenomenology aims to understand *lived experience*, or the immediate, pre-reflective consciousness of life (van Manen, 1997). It endeavours to develop a deeper understanding of the meaning of everyday experience (van Manen, 1997). Lived experience is explicated through reflection on its meaning, and gains significance as meaning is given to it. The structure of a lived experience should be revealed in such a way that the nature and significance of the experience can be grasped (van Manen, 1997).

Phenomenologists believe that lived experience occurs in the *lifeworld* (or *Lebenswelt*), or the natural attitude of everyday life (van Manen, 1997). The lifeworld is co-constructed and co-created in dialogue between the individual and the world. It is pre-reflective and independent of knowledge derived from reflective thought (Valle, King, & Halling, 1989). Phenomenology is concerned with understanding the *essences* of an experience, or structures that are essential for an experience to be what it is (Cerbone, 2006; van Manen, 1997). Schwandt (2001) describes phenomenology as “...careful description of ordinary conscious experience of everyday life (the life-world) – a description of ‘things’ (the essential structures of consciousness) as one experiences them” (p. 191).

Although each person experiences a different lifeworld, and likely experiences multiple lifeworlds even within one day, each lifeworld has fundamental thematic structures, referred to as lifeworld existentials (van Manen, 1997). The four lifeworld existentials that can be used to understand the lifeworld include *lived space* (spaciality), *lived body* (corporeality), *lived time* (temporality), and *lived human relation* or *lived other* (relationality).

Lived space refers to space as we feel it, not as it is objectively measured. For example, “the home reserves a very special space experience which has some thing to do with the

fundamental sense of our being...Home is where we can *be* what *we are*" (van Manen, 1997, p. 102, original emphasis). Lived space refers us to the world or landscape in which human beings move and find themselves at home. Understanding the lived space in which an activity takes place lends itself to understanding the meaning of that particular experience (van Manen, 1997). de Witt, Ploeg, and Black (2009a) focused on lived space in their study of women living alone with dementia. Participants reported feeling comfortable at home and wanting to remain in their own space. They contrast being at home with the possibility of having to move into long-term care and work on maintaining their ability to remain in their own homes. Going outside of the home to run errands or attend social events could be uncomfortable for the women because of their memory loss, and the way others treat them within the community.

Lived body refers to the fact that we are always "bodily in the world" (van Manen, 1997, p. 103). Individuals both reveal and conceal aspects of self with their physical presence, although not necessarily deliberately. For example, "under the critical gaze the body may turn awkward, the emotions appear clumsy, while under the admiring gaze, the body surpasses its usual grace and its normal abilities" (van Manen, 1997, p. 104). Through their physical presence and expressions, persons living with dementia may reveal some of the essences of their leisure experiences. Research regarding lived body has demonstrated that memory loss is experienced as a breakdown in bodily flow (Phinney & Chesla, 2003). Kontos (2004) explored lived body among persons living with dementia in long-term care. She argues that embodied selfhood is revealed in the way the residents are aware of their surroundings, and how they engage with the world. Residents know where their bodies are and have a pre-reflective sense of their environment, enabling them to move around it and use space without thinking about it. Embodied selfhood is also apparent in social interaction, both through contextual discourse and

through natural expression of their bodies. Lived body continues to be a source of agency even when other forms of communication have become very difficult.

Lived time refers to subjective time (van Manen, 1997). It speeds up when individuals enjoy themselves and slows down when one is bored or anxious. Persons living with dementia often experience time as slowing down (Mitchell et al., 2006). It can also refer to our temporal way of being in the world – we look to the future or reflect on the past. For example, de Witt, Ploeg, and Black (2009b) found that participants experienced temporality as “holding back time” (p. 13) to remain in their homes as long as possible. They were aware that future time would lead to moving into long-term care and possibly forgetting family and friends, so they tried to maintain their current experience of time in their homes as long as possible. Lived time is useful for exploring personal life history and one’s views on the future. Understanding how persons living with dementia experience their present time when engaged in leisure and past and future time in relation to leisure in the dementia context may reveal some structures of their lived experience.

Lived human relation or *lived other* refers to the relations we maintain with others in the space we share with them (van Manen, 1997). We meet people in a corporeal way based on their physical presence. We then develop a conversational relation that transcends self. “In a larger existential sense human beings have searched in this experience of the other, the communal, the social for a sense of purpose in life...” (van Manen, 1997, p. 105). How persons living with dementia experience relationality in their daily life may provide some insight into their experience of leisure in the context of dementia.

While these four lifeworld existentials are differential, they are not separate from one another: “they form an intricate unity which we call the lifeworld” (van Manen, 1997, p. 105).

However, van Manen (1997) argues that we can study these existentials in their differentiated aspects while recognizing that one always brings forth the others. The four lifeworld existentials will guide data collection and analysis.

Phenomenology and dementia

Phenomenology's underlying philosophy, especially as rooted in interpretivist or existential traditions, translates into a qualitative research approach directed at identifying and describing subjective experience (Schwandt, 2001). The goal is to gain a deeper understanding of the nature of everyday experience as it tries to gain insightful descriptions of how people experience the world (van Manen, 1997). Phenomenological research seeks to understand the essence of the phenomenon of interest. It is a systematic attempt to uncover and describe the structures of lived experience and it tries to describe and interpret the meaning of such experience with depth and richness (van Manen, 1997). This is done through first-person reports of lived experience (Moustakas, 1994). The goal of phenomenological research is to:

...transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own experience. (van Manen, 1997, p. 36)

Phenomenology seeks to learn how the lifeworld contributes to the commonalties in and differences between the subjective experiences of the study participants (Lopez & Willis, 2004). It calls for researchers to go beyond what is given in order to uncover hidden phenomena and discover meaning that is not immediately apparent to our intuiting, analyzing, and describing and from this create an “animating evocative” description of the human action, behaviour, intention, and experience as individuals meet in the lifeworld (Cohen & Omery, 1994).

A phenomenological approach provides insight into dementia as it is experienced by those living with it as well as the essence of leisure for persons living with dementia. Phenomenology is appropriate for exploring dementia as it directs focus away from neuropathology of dementia towards the subjective experience of living with the disease (Bond & Corner, 2001; Lyman, 1998). By seeking to uncover the meaning that dementia has for people living with it, and how they experience it, phenomenology challenges the biomedical model and argues that problems associated with dementia are not only physiological, but also socio-environmental (Bond & Corner, 2001). A phenomenological approach to dementia research ensures that our understanding is grounded in the lived experience of those with dementia (Lyman, 1998). Phenomenology is consistent with a personhood approach to dementia which looks to the individual's experience instead of focusing on the neuropathology of dementia. As it provides "...a voice for the lived experience of individuals, as well as alternative cultural interpretations, this perspective supports people as they struggle to maintain their own personhood" (Lyman, 1998, p. 52).

Research Design

In order to understand the meaning of leisure from the perspectives of persons living with dementia, data were collected in three ways. First, data were collected through qualitative interviews. Participants of this study participated in long interviews, which were guided by conversational interview guides. Second, participant observation enhanced understanding of the lived experience. Third, photovoice was used so that participants could express the meaning of leisure through photos. I analyzed the data following van Manen's (1997) steps for interpretive phenomenological analysis.

Participant recruitment

I set out to recruit three or four persons living with early stage dementia living in the community to participate in this study in order to understand the role and meaning of leisure in their lives. Participants were accessed through early stage support groups and a dementia research program in Southwestern Ontario. I contacted agencies by telephone (see Appendix A), and arranged for in-person meetings with agency staff at that time to further explain my research and to ask them for assistance recruiting participants (see Appendix B). Agency staff were given a Fact Sheet describing the study (see Appendix C). A letter introducing myself and the study (see Appendix D) and a Fact Sheet for potential participants (see Appendix E) were provided to potential participants by agency staff members. Four persons living with memory loss indicated to agency staff that they would be interested in participating in this study. I later telephoned all four potential participants to determine if they wished to participate in the study (see Appendix F), who all agreed that they would like to be involved. An initial interview was set up at that time. Subsequent meeting times were arranged during the first interview. In order to participate, persons living with dementia were required to be able to provide informed consent (see Appendix G), and be able to use a camera somewhat independently (i.e., with minimal assistance in person, with written instruction, or completely independently). They were requested to be willing to participate in all aspects of data collection, including interviews, participant observation, and photovoice. Participants received a gift certificate as a token of my appreciation for participating in this study. They were sent a thank you letter upon completion of the data collection (see Appendix H), and a feedback letter with a summary of the findings upon completion of the study (see Appendix I).

Participants

Two men and two women with early stage dementia who were living in the community agreed to participate in this project. The age of the participants ranges from 59 to 81 and time since diagnosis ranges from one year to four years. Three participants live with their spouses, while one participant lives alone. A brief biography and description for each participant is presented below. Participants have been given pseudonyms to protect confidentiality.

Jack

Jack is a 70 year old man who was diagnosed with Alzheimer's disease two years ago. Jack lives with his wife in a bungalow in a seniors' community. Over the course of the data collection, Jack moved from one seniors' community to another. Both communities are very similar, each having a variety of leisure opportunities available, including swimming, golfing, exercise, and social activities. Jack and his wife have three children and a few grandchildren. They moved from their previous community, where they had lived for most of their lives, to be closer to their daughter.

Both Jack and his wife love physical activity and much of their leisure focuses on being fit and healthy. Jack plays golf as frequently as possible, often going to the golf course on his own, and joining a foursome of people he has never met. Jack enjoys both the physical and social aspects of golf. Jack and his wife also like to dance, but they have switched from ballroom dancing to social dancing since Jack can no longer remember the steps and he has a difficult time leading. Jack also plays crokinole and darts. He used to sail competitively but had to give it up when he was diagnosed with dementia due to safety concerns. Jack has a very competitive nature and was very demanding of his crew on the sailboat. He has now turned that competitive nature inwards, and competes with himself to stay mentally and physically fit.

In addition to all of these activities, Jack attends a day away program for persons living with dementia twice per week.

Jack considers himself to be an extremely lucky person who has led an interesting life. His parents moved from the USA to Canada when he was a child, but he was not granted immigrant status so he was drafted into the American army when he was 25. He looks at even this as a positive time in his life. Upon returning to Canada, Jack worked as a draftsman in the oil and gas industry. Jack loved his work and the companies that he worked for. His job was dangerous and a mistake could result in injury or death, but Jack was confident in his abilities and he was very trusted within the industry to be safe. Although he was retired, he was still doing contract work when he was diagnosed with dementia. He had to give up the contract work to avoid putting lives at risk. Jack also gave up driving as soon as he was diagnosed and was happy to do so because of the risk factors.

Living in the seniors' community provides Jack with freedom since he can walk around the complex by himself safely and he is able to walk to a nearby golf course for a round of golf, which he does a couple of times a week in the summer. He is a very confident person who believes he always makes the right decisions: "...because I always felt that whatever I did I did it because it was the right thing to do at the time. And I'm feeling that life what I'm doing now is the right thing to be doing because I'm doing the right thing" (Jack, Interview 1). Some of this confidence is beginning to wane, but Jack does not feel badly about it.

Jack is very open about his diagnosis of dementia with others. He loves to talk about his experiences so that other people better understand what it is like to live with dementia. He and his wife have been featured in their local newspaper three times to talk about living with dementia, and it is important to Jack to continue to make a difference in the world. He intends

to donate his brain to research upon his death so that he can continue to make a difference. Jack also likes to be prepared for the future, and wants to have control over when he moves into long-term care. Jack thinks it is important to understand as much as he can about the progression of dementia so he can be prepared for the future:

But we are active and the most important thing is to find out as much as you can as soon as you can when you find out you have dementia. Because that gives you the opportunity to for at least for your caregiver and everybody else that you are with to know that it isn't something that isn't going to happen tomorrow. (Jack, Interview 1)

Jack was the only participant to talk about his experience of diagnosis in a positive way. While he was somewhat surprised by the diagnosis, he decided to trust his doctor and his family, and immediately accepted the diagnosis. Jack's geriatrician takes the time to explain things to him and his wife, and Jack feels satisfied with the care he receives.

Jack maintains his positive attitude and expresses a great deal of satisfaction with his life. He enjoys being physically active and he keeps very busy, despite having to give up his contract work, which he does occasionally miss. Jack talks about leisure as giving him something to do everyday and something to look forward to when he wakes up in the morning. He has always been an active person, and although some of his activities have changed, he remains very engaged in life. Right now, the most important thing in Jack's life is his family. "Uh...I think...probably, my life is, my life is probably central to my life, my family is very important to me" (Jack, Interview 1). Jack describes himself as having the life of Riley:

And um...I'm very fortunate. I don't know if you ever knew that, my wife tells me I have the life of Riley. Because Riley used to have everything, you know like in the old days, it was always the life of Riley and that's what I'm doing now. I'm just enjoying it. Doing well, really. (Jack, Interview 1)

Alice

Alice is a 59 year old woman who lives by herself in a seniors' walk up apartment building in a rural town. Alice was officially diagnosed four years prior to the first interview. Alice began experiencing vascular dementia about eight years ago. She has since been told that she may have a mixture of both vascular dementia and Alzheimer's disease. In addition to dementia, Alice has Type II Diabetes.

Alice has two sons, a niece, and a handful of friends who provide support for her to remain in her home. Just over a year ago, Alice adopted a deaf cat from the SPCA, and the two of them provide support and companionship for each other. Alice recently became a grandmother.

Alice has lived with adversity throughout her life, dealing with divorce and being a single mother. She draws on these experiences and how she came through them to remind herself that she is a stronger person: "So... like the past has been good to me, even though the marriage fell apart. And...umm, and that was very difficult, but...we're all given things to make us stronger..." (Alice, Interview 1). Alice is tenacious in her fight with dementia even though there are many setbacks and losses as she travels the journey: "...I'm not as willing to give up. Um as maybe someone else would" (Alice, Interview 1).

At the time of her diagnosis, Alice was a nurse in long-term care, often administering the Mini Mental State Exam to assess her patients. She was asked to leave her job, and due to financial constraints, she was forced to give up her house to move into the apartment. As a nurse, Alice advocated on behalf of and nurtured her patients. Alice has become actively involved in advocating on behalf of persons living with dementia, although she finds it is

getting difficult to talk to a large group of people and has changed her way of advocating to an individual level.

Unlike Jack, Alice had a difficult experience with diagnosis. Doctors took a long time to give her a diagnosis despite the challenges that she was facing at work and in her daily life:

Yes, umm. In 2000 I had two strokes in May of 2000 and December of 2000 and then umm the memory loss...it was more the sequencing umm that didn't come through even with rehab and that, there was still a problem...On the fourth try back to work I managed to work a while, but then umm, sneaky Pete as I call it, just kept on making things difficult and I was unsafe. So it wasn't until, I think it was November '03 that I was diagnosed with Alzheimer's. And then, June of '04, then I went to see a Geriatrician and it was changed to Vascular Dementia. But as he said it could still be the combination of both..." (Alice, Interview 1)

Alice has many bad days as she lives with the progression of dementia. However, her positive attitude and her efforts to face any challenges that come her way has helped her to maintain her independence in her own home, which she highly values.

Alice engages in a wide variety of leisure activities, and has indeed started several new activities since being diagnosed. She began feeding the birds after she moved into her apartment and finds a great deal of pleasure from watching the birds on her balcony. She also learned how to use a computer, which she uses for her advocacy work and plays games to exercise her brain. Alice works on jigsaw puzzles to exercise her brain as well. She recently took up reading and has set the goal to read every Danielle Steele novel. Alice struggles with the concept of leisure since being diagnosed, since what once would have been considered leisure activities she now considers to be work, as they are a means of slowing progression and keeping her mind active. She still enjoys these activities despite their utility beyond merely relaxing or having fun, so the lines between leisure and work are blurrier for Alice than they are for the other participants.

Charles

Charles is a 77 year old who was diagnosed with Alzheimer's disease about four years ago. Charles and his wife belong to the Mennonite church. They live together in an apartment that is part of a Mennonite seniors' community, including retirement apartments and long-term care. Charles and his wife are actively involved in the retirement community. They both belong to the choir and they also lead prayer groups. They have friends whom they enjoy spending time with, often playing cards, watching movies, and going to music concerts together.

Charles also has Parkinson's disease and macular degeneration, and the combination of multiple illnesses has an impact on Charles' life more so than the dementia on its own: "I am very much aware of how each of my ailments relate to the others.... It's a combination of the total that limits me or allows me to do what I was doing before" (Charles, Interview 3).

Charles was born in Pennsylvania. His father was a farmer, but Charles was not interested in farming. Through Mennonite ritual, Charles was ordained a minister, although he was uncomfortable in the role. He moved to Canada to attend a bible institute in order to feel better qualified for the ministry. He continued to feel uncomfortable and eventually he asked to be unordained. He and his wife bought a meat and cheese shop and raised their family in Canada. Later he sold insurance.

After his wife became seriously ill, and subsequently recovered, Charles decided to retire so they could enjoy their life together. After retirement, Charles and his wife became the superintendents of an apartment building. They did so until Charles was diagnosed with Parkinson's: "...and then I was diagnosed with the Parkinson's, and I couldn't get the screwdriver into the right spots anymore and couldn't chase after the lawn mower so I

resigned” (Charles, Interview 1). He was later diagnosed with Alzheimer’s disease, and after that, he and his wife decided to give up their apartment and move into their current, smaller apartment.

Parenting was an important role for Charles, who has five children and 14 grandchildren. His family, friends, and faith continue to be important to him: “It makes me very happy to know that our kids all are Christians with a very personal commitment to Christ and the church. We are not wealthy but we are wealthy in terms of family and what they mean to us and decisions that they made” (Charles, Interview 1). His role as a husband is also important to him, and he values his relationship with his wife very much: “...people know that we have a very beautiful marriage. And I’m sort of proud of that. They’ve affirmed us many times, our friends” (Charles, Interview 1). He goes on to say “...there are so many persons who do not enjoy the...marriage relationship as much as what we do and I feel really good about what we have. I always say if it’s good make it better. Whether it’s marriage or whatever...” (Charles, Interview 1).

In addition to choir and spending time with friends, Charles and his wife walk together every evening in their building. They also use walking poles for walking outside, which help Charles to balance. Charles loves to read and spends much of his time enjoying fiction. Charles has found creative ways to manage the losses that he has experienced. He sees himself as an individual who copes well with change, and wishes to demonstrate to others that he is still able to do so.

Rita

Rita is 82 years old and was diagnosed with Alzheimer's disease about a year before her interviews took place. Rita also has Diabetes. Rita lives in a seniors' condominium building with her husband. She worked for her husband's insurance company "doing the books" for years before her daughter took over her position and she retired. Rita was the first female deacon in her church, a fact of which she is quite proud, and she continues to attend church, although she has ceased participating in other church related activities such as the choir and the women's group.

Rita is a cheerful, bubbly woman who loves to tell jokes and describes herself as having a sense of humour. She is a grandmother of 12 grandchildren, but she has one granddaughter with whom she is particularly close. She spends much of her time with this six year old granddaughter: "...The last one born she uh, phones me everyday...And she calls me every night and says 'have a good night' (laughs) you know'" (Rita, Interview 1). She is close to her family and sees them fairly frequently: "So we have a wonderful family. Our kids are just great, and grandchildren and great grandchildren. They're all great" (Rita, Interview 1).

Receiving a diagnosis of Alzheimer's disease was a surprise for Rita, and an unpleasant and frustrating experience. She told me in our first interview: "I was diagnosed about, like, about a year ago now. And it came as quite a shock." (Rita, Interview 1). She had difficulty with the assessments and found them to be juvenile. Sometimes, Rita questions her diagnosis, and asks her doctor if he might be wrong about it, since she feels the same as she ever did. She feels that she has not changed, yet she does speak of some changes in her skills and abilities. Rita believes that having an optimistic attitude will help her fight dementia and prevent her from getting depressed. She believes that having memory loss is just another part of life: "It's

not like both of my legs have been cut off... Alzheimer's is just part of life" (Rita, participant observation field notes, games).

Rita experiences altered expectations from her family and friends. She feels that they assume that she is no longer capable to look after herself in some respects. For example, they constantly remind her to take her insulin, something that she has never forgotten. She wants to be treated as though she is no different. She becomes uncertain of other people's intentions towards her, fearful that they are being nice to her or asking her how she is because she has dementia.

Rita describes herself as not being all that active because of her age: "I'm not a...very active person now because I'm 82 years old" (Rita, Interview 1). In terms of leisure she watches TV, writes poetry, and socializes with friends and family. Rita has dropped some activities in the past couple of years, but not necessarily due to dementia. In some cases she has lost interest, and in others, she feels that at her age it is no longer appropriate to participate.

Rita loves to go to the mall and shop, but since losing her license, she does not get there as often as she would like. She is reluctant to ask for or accept help from others and dislikes the loss of independence that she has experienced. She wants to be able to go to the mall by herself instead of going with somebody else, so she sometimes chooses to stay home. Rita writes poetry and is currently writing a book of poetry for her grandchildren so that they will remember her as she was. Rita also loves to socialize and plays cards with her neighbour once a week.

Interviews

The first method of collecting data for this study involved in-depth interviews with persons living with dementia. Interviews are a collaborative effort that lead to "...a contextually bound and mutually created story" (Fontana & Frey, 2005, p. 696). Interviews allow entry into another person's perspective, beginning with the assumption that others' views are meaningful, knowable, and able to be made explicit (Patton, 2002). Although persons living with dementia may at first be reluctant to talk about their experiences due to fear of not knowing the answers, when researchers listen to their voices, participants are pleased that their comments are taken seriously and that their views are considered (Proctor, 2001). Although communicating with people with dementia may pose challenges not found in other interviews, research has shown that the subjective experience of dementia can be understood. People with dementia can participate actively in interviews up to one hour in length, and follow-up interviews and observations can enrich findings (Phinney, 1998).

There are a number of advantages to gathering data through in-depth interviews (Kleinman, Stenross, & McMahon, 1994). Through interviews, researchers can learn how their participants maintain, transform, or challenge an identity. They also afford interviewers the opportunity to draw upon participants' self-reflexivity, and learn how people use experiences, relationships, and identities to construct self. Interviews may provide access to emotions and identities that might not be displayed through participant observation (Kleinman et al., 1994). Kleinman et al. argue that interviews highlight meanings and feelings. They provide a means for persons living with dementia to describe their experiences. In this study, interviews revealed experiences, meanings, and feelings associated with leisure in the dementia context.

The long interview, which provides the opportunity to see into the lifeworld of the participants, guided the interview process. Long interviews consist of a *series* of interviews in which the researcher aims to understand the mental world of the individual (McCracken, 1988). These interviews provide insight into the content and pattern of daily experience, while at the same time considering the social and cultural context. They allow the participant to tell his or her story in his or her own way, yet provide guidance through interview prompts. Such prompts can help the individual to articulate what he or she takes for granted.

The long interviews began by building rapport to put the participants at ease through casual conversation and collection of biographical data. This was followed by questions and prompting around the lived experience being explored, referred to as “grand tour” questions. Grand tour questions are general and non-directive. They are aimed at encouraging participants to talk. Grand tour questions included floating prompts, in which I repeated key terms and watched for key words mentioned by the participants. They also included planned prompts used to discuss aspects of the experience of dementia that are not coming immediately to mind (e.g., How have you adjusted to changes? How does that make you feel?). Planned prompts included category prompts which account for formal characteristics of the topic being discussed (e.g., Do you have any techniques for managing challenges in leisure?). Planned prompts can also include asking the participant about exceptional incidents (e.g., can you tell me about an incident where you were unable to address challenges in your leisure?). A conversational guide (see Appendix J) including both biographical questions and grand tour questions was used to ensure that the interviews thoroughly explored the participants’ experiences, yet did not restrict freedom and variability within the interviews (McCracken, 1988).

The long interview allows for intimate understanding of the participant, while recognizing cultural assumptions and practices. It is distinct from other interview formats as it is a focused, highly intensive interview process that centers attention on cultural categories and shared meanings rather than individual affective states (McCracken, 1988). Consistent with the long interview approach, rapport was built in the first interview. This interview focused on information gathering and open ended questions that sought to understand the participants' experiences, particularly of dementia (see Appendix J). At this interview, the participants were provided with disposable cameras for the photovoice aspect of the project. The second interview focused on the photos taken by participants using photovoice (see Appendix K). The third interview explored how leisure helps the participants cope with change in their lives (see Appendix L). A fourth interview gave the participants the opportunity to reflect on the emerging themes and decide if themes actually reflected their experiences. Interviews were recorded and transcribed verbatim. They ranged from 50 minutes to 105 minutes in length.

Participant Observation

McCracken (1988) argues that the long interview itself is not enough for thorough data collection, and Phinney (1998) suggests that interviews with persons living with dementia can be enriched with observation. Patton (2002) states that: "Observations provide a check on what is reported in interviews; interviews, on the other hand, permit the observer to go beyond external behaviour to explore feelings and thoughts" (p. 306). As such, participant observation served as the second means of data collection for this study. Participant observation is "...a methodology that assumes immersion in a setting (along with observation, reflection and interpretation) [and] is the best way to develop knowledge of others' ways of thinking or acting" (Schwandt, 2007 p. 219). Typically the researcher takes part in the daily activities,

rituals, interactions, and events in order to learn about their life routines (DeWalt & DeWalt, 2002). Atkinson, Coffey, and Delamont (2003) argue that what we observe and what we construct through interviews can together incorporate social actions of different kinds and yield different forms of data. Observation can aid in greater understanding the complexities of a particular phenomenon than interviews alone (Patton, 2002). Participant observation added greater richness and a different perspective to data collected through the long interview to construct a broader understanding of the participants' leisure experiences. Kirby, Greaves, and Reid (2006) note that participant observation involves focused observation of "people's behaviours 'in the field', and it includes providing evidence of those behaviours and of the meanings people attach to them" (p. 147). The researcher observes social life in its "natural habitat" (Kirby et al., 2006, p. 147). Furthermore, Patton (1990) argues that participant observation allows researchers to experience what they are trying to understand, something that cannot be done through interviews alone. He states that:

The purpose of observation data is to *describe* the setting that was observed, the activities that took place in that setting, the people who participated in those activities, and the meanings of what was observed from the perspective of those observed. (Patton, 1990, p. 202)

Participant observation leads to the development of an insider's view of what is happening – the researcher feels what it is like to participate in the activity (Patton, 1990). It can add to data collected via interviews because interviews elicit information about what people say they do, rather than what they actually do (Atkinson et al., 2003). Atkinson et al. (2003) argue that participant observation is significant because it affords researchers with an opportunity to engage with others through practical and symbolic interactions and acquire an understanding of them. Atkinson et al. go on to state that:

Without the capacity and the willingness to commit ourselves to social worlds, and to “participate” in them – albeit to a limited and temporary degree – then we shall never bring to bear those intellectual, symbolic, and emotional competencies to a disciplined understanding of the social world about us. (Atkinson et al., 2003, p. 115)

Phinney (1998) collected both interview and observational data to understand the experience of living with dementia and found that drawing upon both of these data collection methods resulted in rich, detailed data. Observations confirmed interview data and provided a way to understand both daily life and how people interacted with the environment and with each other. Phinney et al. (2007) suggest that participant observation provides a window into everyday habits, which can be difficult to describe in the interview setting because they are taken for granted or forgotten. Similarly, in this study, through participant observation, I engaged with each of my research participants on one or more leisure activities chosen by them. In doing so, I was able to experience with them what it was like to participate in their valued activities and understand those experiences in an alternative way that may not have been reachable through verbal discussion alone.

Patton (2002) notes that the participant observer participates in the activity while observing and talking with other participants about what is happening. He also recognizes that the extent of participation depends on the nature of the activity. I participated as fully as possible in the participants’ chosen leisure activities. I adopted the role of part participant/part observer (Patton, 2002). Observation was guided by sensitizing concepts that served to remind me before and during the leisure activity of what to observe (see Appendix M). While participant observation involves being open to whatever one can learn, sensitizing concepts provide a means of organizing the complexity of the experience (Patton, 2002).

Since field notes are the primary method of capturing participant observation data (DeWalt & DeWalt, 2002), immediately following observation, I reconstructed what occurred through detailed field notes, including my observations regarding the environment, the activity itself, any discussion that occurred, about the specific activity, or otherwise, and other aspects based upon my sensitizing framework. I used three different types of field notes, including descriptive field notes, methodological field notes, and analytic notes. (DeWalt & DeWalt, 2002). Patton (2002) indicates that observational data must have depth, describing what occurred. My detailed field notes focused on specific descriptions of what had occurred. They included description of the physical context, the people involved, their behaviour, and verbal and nonverbal communication, including verbatim quotes, to the extent that I was able to remember them (DeWalt & DeWalt, 2002). My methodological notes contained information on new ways to do things as I learned about and gained experience doing participant observation as well as the method of observing and the outcome or limitations of my choices (DeWalt & DeWalt, 2002). As well, my own feelings, reflections, and experiences with the process of participant observation and the ways in which my presence may have influenced the activity were recorded and included in the data analysis process (DeWalt & DeWalt, 2002; Patton, 2002). My analytic notes included my interpretations of the data. All field notes included my insights and interpretations of what was happening and what it meant (DeWalt & DeWalt, 2002; Patton, 2002).

As with any method, there are limitations of participant observation (DeWalt & DeWalt, 2002). Since it is an experiential approach, it is effective for understanding phenomena that are observable, but some events and activities may not be observable. Second, observation may neglect to consider processes that occur outside of the observed situation that may have an

impact on the activity or event. Participant observation cannot be used to understand distribution of characteristics or the importance of particular ideas and traits, yet it can be useful in identifying patterns of thought and behaviour (DeWalt & DeWalt, 2002). Personal limitations that I faced included difficulty remembering the details over the course of participant observation and the small number of sessions that the participants and I engaged in together. Spending more time with participants in their leisure would have provided me with a better understanding of how they experience their favourite activities. Using participant observation in combination with interviews and with photovoice helped to counter these limitations.

Photovoice

To gain further understanding of the meaning of leisure, the method of photovoice was used (Wang, 1999; Wang & Burris, 1997). Photovoice is a participatory action research method in which participants are provided with cameras and given the opportunity to use photography to express, reflect, and communicate their everyday lives (Wang, 1999). Photovoice enables researchers to see the world from the view of research participants. It “can affirm the ingenuity and perspective of society’s most vulnerable populations” (Wang & Burris, 1997, p. 372). Photovoice may be particularly useful for exploring the subjective experience of dementia because it “... expands the forms of representation and the diversity of voices that help define, and improve our social, political, and health realities” (Wang, Cash, & Powers, 2000, p. 911).

Photovoice enables individuals to act as recorders of their lives and as catalysts for change (Wang & Burris, 1997). Furthermore, participants can use the power of the visual image to communicate their life experiences (Wang et al., 2000). Through photovoice,

researchers are afforded the opportunity to see the world from the view of others, and research participants have the chance to describe what their photos mean and reflect (Wang & Burris, 1997). Photos can enrich interviews with their capacity to generate multiple meanings and to trigger discussion (Clark-Ibáñez, 2004). Hagedorn (1994) summarizes the advantages of using photography in research:

Photographs invite open expression while maintaining concrete and explicit reference points. The images captured in photography invite people to take the lead in inquiry, facilitating their discussion of an experience. Photographic interviews elicit a unique return of insights that might otherwise be impossible to obtain with other techniques. Photographs sharpen memory and give the interview an immediate character of realistic construction and function. (p. 47)

Photovoice has a great deal of potential for increasing insight into the experience of leisure within the context of dementia as it provides entry into the research participants' point of view (Radley & Taylor, 2003). Many benefits of the photovoice method have been documented. The use of photos in research has been shown to provide reflective opportunities for participants (Loeffler, 2004; Samuels, 2004). Photovoice can provide persons living with dementia with an alternative way to consider their everyday lives and the role of leisure within daily life by using a visual memory aid to reflect upon their experiences and situations. Photos can also help build rapport between researchers and participants (Loeffler, 2004) by providing participants with something to focus on, thus easing anxiety (Clark-Ibáñez, 2004; Harper, 2002) and encouraging communication (Hagedorn, 1994; Loeffler, 2004). Photos can capture greater levels of detail about the emotional meaning of experience than words-only data collection (Loeffler, 2004). The use of photographs can be a means for expressing emotions (Radley & Taylor, 2003) and unidentified needs (Levin et al., 2007). Photovoice may lead to increased understanding of one's own life experiences.

Photovoice researchers have been able to demonstrate some of the motivations and advantages of using this method for research participants. Baker and Wang (2006) found that photovoice participants with chronic pain became involved in the research to help others better cope with pain, and to learn more about the physical and emotional experience of pain. When used with persons experiencing aphasia after a stroke, photovoice led to a new means of self-expression. Photos were shown to family and friends to express concerns and hopes about the present and future (Levin et al., 2007). Through photovoice, participants and researchers could identify previously undefined needs and participants experienced empowerment as they gave voice to their concerns and needs. They experienced feelings of control in their lives that were lost in the medical model of treatment (Levin et al., 2007). Photovoice could provide similar opportunities for persons living with dementia to help others cope with the daily experience of dementia, and understand the role of leisure in maintaining identity and resisting stigma associated with dementia. Further, Levin's et al. (2007) research exploring aphasia provides an example of how photovoice can benefit everyone. Photos taken by their participants are posted on a website, showing how persons living with aphasia can lead full lives (Levin et al., 2007). Photovoice has been shown to be empowering for research participants as they have control in deciding what to depict about their lives (Levin et al., 2007; Stewart & Floyd, 2004). This technique can increase feelings of competence as strengths and capabilities are discovered (Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005). Persons living with dementia may experience feelings of empowerment when using visual aids to tell their stories, especially if their abilities to communicate verbally have altered. The use of cameras to reveal experience may uncover hidden strengths and abilities and ensure that persons living with dementia are recognized as the experts of their own experience. In addition to personal benefits, Carlson,

Engebretson, and Chamberlain (2006) argue that photovoice challenges assumptions embedded in cultural norms, leading to change. Adopting a critical reflection approach to photovoice in the context of leisure and dementia focuses on both positive and negative issues within the lives of persons living with dementia. Such an approach may portray the experience of dementia in a more holistic way in a public arena, moving away from the predominantly negative discourse surrounding dementia and promoting positive identities for those living with the disease.

Although photovoice is typically a participatory action research method in which participants meet in groups to discuss the resulting photographs and outline the strengths and weaknesses of their communities, Baker and Wang (2006) modified the method to work with individuals instead of groups. This study similarly involved one-on-one discussions between the researcher and the photographer instead of requesting that participants attend multiple meetings to learn how to use their cameras or participate in public forums. In my study, I gave participants disposable cameras upon the conclusion of the first interview and asked them to take photos of meaningful objects and experiences relating to their leisure. Since other research using photovoice with older adults has pointed out the challenges of using disposable cameras (e.g., small print, manual dexterity required) (Kelly, Wakewich, Simmons, & Leipert, 2007), participants were given the option to use their own cameras if they preferred, however, all four participants chose to use the disposable cameras provided to them. Participants received both written and verbal instructions regarding the operation of the camera. While I had hoped that participants would take photos independently, three of them asked family members to take the photos so that they could be included in the photo engaging in leisure. As well, two participants asked me to take photos of them before I collected the cameras to be

developed. While this could have influenced what the participants chose to photograph, Radley and Taylor (2003) found that assisting with photography increased knowledge about the context in which the photos were taken and increased awareness of the decision making process participants underwent when deciding what to photograph. The persons with memory loss decided which photos they wanted and set up the shots.

Once participants finished taking photos, the cameras were picked up and two sets of photos were developed. One set was returned to the participants and I kept one set to use in discussion with the participant and as part of the collected data. Additionally, photos were transferred onto two compact disks. One was given to the participant and the other was kept as data. The second interview involved discussion around the photos taken by the participants to contextualize issues around leisure, including what was seen in the picture, what was really happening in the photo, and how the photo related to everyday life (Wang & Burris, 1997). Since using photos alone contradicts the essence of photovoice, the participants were asked to discuss (give voice) to their individual experience – they were asked to narrate the meaning of the photos (Wang & Burris, 1997). In order to understand the meaning behind the photos, discussion focused on the leisure activities represented in the photos. The lifeworld existentials were used to guide a series of questions around each photo to reveal how the activity is experienced in terms of spatiality, temporality, corporeality, and relationality (see Appendix K).

The use of photovoice added a unique element to this study, providing further insight into the subjective experiences of the participants. This distinctive way of communicating led to greater understanding of the meaning of leisure in the context of dementia. Visual images provided persons living with dementia with a starting point for discussing the meaning of

leisure and whether or not leisure has a role in sustaining identity and resisting negative discourse surrounding dementia.

Data collection process

Jack, Alice, Charles, and Rita participated in four interviews and one or two participant observation sessions. In this section, I provide details on data collection with each participant, outlining the general time line of data collection, length of time in each meeting, and a brief overview of the locations of the data collection meetings.

Data collection with Jack took place over five months. His interviews ranged in length from one hour to one hour and forty minutes. Our first interview was arranged at Jack's daughter's house, with his wife and daughter present, in early spring, in the early afternoon. At this first meeting, Jack and his family and I got to know each other and I began to understand Jack's experiences with dementia. At this meeting, Jack was given a disposable camera and asked to take photos of objects, spaces, and subjects that are meaningful for his leisure. Jack's wife said she would develop the photos for me so we could discuss them at our second meeting. One month later, Jack was again visiting his daughter when our second interview took place. By this time, Jack and his wife were looking for a new place to live to be closer to their daughter and son-in-law. This interview involved the 24 photos that Jack and his wife had taken and developed. Jack and I went through the photos together while Jack's wife listened and occasionally clarified Jack's comments. This interview took place in the evening, and I noticed Jack seemed more tired and had a more difficult time focusing on the questions, yet his enthusiasm for talking about his leisure was very strong. The third interview took place in a local coffee shop in late spring where Jack, his wife, and I discussed what leisure means for Jack. At this time, Jack and his wife were preparing to move to the area. Our participant

observation meeting occurred at Jack and his wife's new home in a local seniors' community. This meeting occurred approximately two months later, on a warm sunny midsummer day. Jack taught me how to putt on the putting green in his retirement community. We spent three hours together putting and socializing both before and after the activity. Due to Jack's move and busy lifestyle, we were only able to schedule one participant observation meeting. Our follow up meeting to discuss my findings occurred four months later at the new home of Jack and his wife. At this meeting, Jack concurred that the findings reflected his experiences with memory loss.

Interviews with Alice took place in her apartment over the course of three months. Her interviews ranged from 50 minutes to 105 minutes. The first interview took place in early spring where we talked about her history and her experience with dementia. During this interview, I gave Alice a camera and asked her to take photos of things that were meaningful for her leisure. I returned to see Alice about three weeks later, where upon I picked up the camera, and Alice and I participated in one of her favourite leisure activities for two hours. Alice taught me some of the computer games that she plays to keep her mind active. Three weeks later, I returned again for our second interview to discuss the 20 photos that Alice took. Alice and I sat at her kitchen table and went through the photos she took and discussed them in detail. We scheduled for a third interview at that time. I returned for our third follow up interview, where Alice and I chatted more about the meanings of leisure for her and some of my preliminary findings. We planned for a final meeting to do some crafts together. On our fifth meeting, Alice and I did a variety of activities. We did crafts, including crocheting and rug hooking, for about one hour. After this, Alice taught me how to play Yahtzee and we played for two hours. Time of day varied for Alice's data collection, ranging from mid-

morning to early afternoon. A fourth, follow up interview was conducted with Alice approximately six months later where I presented the findings of the study to Alice, and she provided feedback. Alice felt that my themes reflected her experiences.

Interviews with Charles took place in his apartment. His wife was busy doing volunteer work for the retirement home during our interviews. Data collection with Charles spanned two months. Our first interview took place in spring, where Charles and I talked about his experiences with dementia and he told me about his life story. At this interview, I gave Charles a camera and asked Charles and his wife to take photos of people, places, objects and activities that were important to Charles. As a result of Charles' Parkinson's disease and visual impairment, his wife took the camera and consent forms, and she took 11 photos. At our second meeting, approximately two weeks later, Charles and his wife taught me how to play their favourite games – golf using Skip-bo cards, and a dice game called Phase 10. We played games for one hour. At the end of the session, I took the camera and developed the photos. Our second interview discussing Charles' photographs occurred about two weeks later, and this was followed by our third interview explored meanings of leisure for Charles in greater depth one month later. One week after our third interview, Charles and I went for a walk with the walking poles along a local river for our second leisure activity. I borrowed Charles' wife's walking poles, and Charles showed me a frequent walk they do not far from their home. We walked for about 35 minutes, but spent an hour together in total. All meetings with Charles took place in the late afternoon. Our final follow up interview occurred about six and a half months following our pole walking meeting. Charles and I discussed the findings and he agreed that the diagram and themes well represented his story.

Interviews with Rita took place in her condominium while her husband was out for coffee with his friends. The interviews took place over two months and ranged in length from about 45 minutes to 70 minutes. Our first interview took place in spring, where Rita and I got to know each other and chatted about her experiences. During this interview, I gave Rita a camera and asked her to take photos of her leisure for the study. I returned ten days later for our second meeting, where Rita and I went for a walk around the block in her neighbourhood and then we chatted over a cold drink and cookies. At this time I took a couple of photos of her and her leisure, and I picked up the camera to be developed for our next meeting. Rita and I spent one hour and five minutes together during this meeting. Eleven days after that, Rita and I discussed the 11 photos that she had had taken of herself. Our third interview followed this, where we talked more about the meaning of leisure for Rita. For our final participant observation session, approximately one month after the third interview, Rita taught me how to play Skip-bo. We played for about an hour, and followed this with cold drinks and cookies and a half hour chat about her grandchildren. After our last meeting, Rita and her husband moved from her condominium to a retirement residence in a nearby town. Our final follow up meeting to discuss my findings took place in her new apartment. At that time, I learned that Rita's husband had spent much of the summer in the hospital with poor health, and was only beginning to recover. Like the other three participants, Rita felt that the findings did indeed reflect her experiences with dementia. Interviews with Rita were always scheduled for mid-morning.

The final interviews were designed not only to ask participants to reflect on the findings of the study, but also to fill out any themes that were not adequately developed in the bulk of data collection. In many cases, I asked participants to comment on themes that only emerged

for one or two of the participants. In some cases, participants provided further insight and examples into those particular themes, and in other cases, they felt that the particular theme did not represent their experiences. For example, Alice identified feelings of inertia as part of her experience, and further probing in follow-up interviews revealed that Jack and Charles had similar experiences. Rita however, did not feel that she ever experienced inertia.

Data Analysis

Consistent with phenomenology, data (including interview transcripts from all 16 interviews, field notes from observations, photos and their respective narratives, and my journal of thoughts, observations, and impressions) were analyzed using van Manen's (1997) phenomenological reflection, which aims to grasp the essential meaning of the phenomenon being explored. Since meaning is multilayered and multidimensional, reflecting on lived experience involves reflectively analyzing the structural or thematic aspects of that experience (van Manen, 1997). Thematic analysis, which is a process of invention, discovery, or disclosure, was used to interpret the meaning of the lived experiences of my participants. A theme captures the phenomenon one is trying to explain. Thematic analysis produces a description of an aspect of the lived experience being explored. Grasping and formulating thematic understanding is the act of seeing meaning. Phenomenological themes are essences that compose an experience. The researcher tries to uncover something meaningful in the data (van Manen, 1997). Themes uncovered through phenomenological reflection are not just objects, rather "...they are more like knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes" (van Manen, 1997, p. 90). While van Manen outlines three approaches to uncovering the thematic aspects of a phenomenon through phenomenological reflection, including the holistic approach, the

selective reading approach, and the detailed approach, I adopted the detailed, line by line approach to analyze the data. The steps I followed for data analysis included:

1. Reading and re-reading individual transcripts and field notes several times (Halldórsdóttir & Hamrin, 1997; van Manen, 1997) to get a sense of the lived experience as a whole.
2. Each sentence or sentence cluster was carefully read while considering what it revealed about the phenomenon being described. Key statements that had bearing on leisure in the dementia context were underlined (Halldórsdóttir & Hamrin, 1997).
3. Themes identified were noted in the margins of the transcripts and field notes (Halldórsdóttir & Hamrin, 1997). As themes began to emerge, those that recurred as possible commonalities were noted and appropriate phrases or statements were lifted to describe the meaning of the themes (van Manen, 1997).
4. Themes in each interview and participant observation session were compared for commonalities and differences, and overall themes that best described the essences of the participants' lived experiences were identified (van Manen, 1997).
5. Themes in transcripts or field notes that were not accounted for in the original themes were considered in terms of whether they should be included and why (Halldórsdóttir & Hamrin, 1997). Themes that upon further reflection were deemed not essential to the experience of leisure within the context of memory loss were removed from the findings.
6. Descriptions of the themes and how they were interrelated continued until themes and their relationships accurately captured the experiences of the participants (Parsons, 1997).
7. The essence of the phenomena was discussed and verified with all of the participants to see if they agreed with my interpretations (Halldórsdóttir & Hamrin, 1997; van Manen, 1997). Such discussion attempted to understand if the themes truly reflected the experience as it was described and reflected to me, asking "is this what the experience is really like?" Participants were shown the diagram that represents the findings. I described the diagram in detail, asked participants to reflect on my interpretations as presented in the diagram and to indicate if they felt that it reflected their experiences. All participants agreed that the diagram was an accurate portrayal of their experiences.

As I analyzed the data, I reflected upon the four lifeworld existentials discussed above.

van Manen (1997) suggests that doing so will allow the researcher to "...perceive an immediate immense richness of meaning" (p. 105). This reflection led to a rich account of the

lived experience of leisure in the dementia context in terms of spatiality, corporeality, temporality, and relationality. Throughout this process of phenomenological reflection, the essence and meaning of leisure for persons living with dementia were explicated.

Crystallization

Many researchers perceive validity and reliability as irrelevant for judging qualitative research (Denzin & Lincoln, 2005). de Witt and Ploeg (2006) suggest that expressions of rigour such as credibility and confirmability, common in qualitative research, are philosophically different from interpretive phenomenology. As such, I drew upon Richardson's (1997) notion of crystallization. Crystallization provides a means of ensuring quality qualitative research. It is Richardson's (1997) response to the process of triangulation, whereby the researcher uses different methods to validate findings. Triangulation assumes that there is a fixed point that can be triangulated (Richardson & St. Pierre, 2005). Richardson and St. Pierre caution against the "rigid, fixed, two-dimensional object" (p. 963) of the triangle. Instead, Richardson (1997) argues that there are many ways to approach the world. The image of a crystal provides a metaphor for research that is multidimensional. The crystal:

...combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities and angles of approach. Crystals grow, change, and are altered, but they are not amorphous. Crystals are prisms that reflect externalities and refract within themselves, creating different colors, patterns, and arrays casting off in different directions. What we see depends on our angle of repose... (Richardson & St. Pierre, 2005, p. 963)

Crystallization moves away from the notion of validity, in which there is one single truth (Richardson, 1997). It provides us with a "...deepened, complex, and thoroughly partial understanding of the topic" (Richardson & St. Pierre, 2005, p. 963).

As part of this multidimensional project, I adopted a reflexive approach to my research to ensure crystallization. Reflexivity refers to "...the process of critical self-reflection on one's biases, theoretical predispositions, preferences and so forth" (Schwandt, 2007, p. 260). Bochner (2000) calls for reflexivity in which researchers demonstrate ethical self-consciousness in the way they show concern for those who are part of the story being told and recognizing the evolutionary process an individual experiences in telling their story. Schwandt (2007) notes that reflexivity shows that the researcher is part of the setting, context, and social phenomenon she wishes to understand. It is a means for critically inspecting the research process, and for examining personal and theoretical commitments in order to see how they impact the collection and interpretation of data.

Dupuis (1999) calls for greater use of reflexive methodology within leisure research, arguing that:

For leisure researchers, a deeper and more comprehensive understanding of what leisure means to different people and how leisure is experienced in different contexts can only be enriched by a fuller use of the self in leisure research, not by the omission of the self. (Dupuis, 1999, p. 48)

She holds that leisure researchers must use both "...their research self and their human self throughout the research process" (p. 48).

Reflexivity is considered to be an important aspect of participant observation, since the researcher can have an impact upon the actions of those being observed (DeWalt & DeWalt, 2002; Patton, 2002). As the researcher, I considered my own impact on what I was able to observe, hear, and understand when observing (Patton, 2002). DeWalt and DeWalt argue that field notes taken following participant observation are better when the researcher has considered the impact of personal characteristics and theoretical approaches on the observations.

Reflexivity moves away from the tendency to separate the researcher from the research, avoiding bracketing of the researcher's world (Fine, Weiss, Weseen, & Wong, 2000). Reflexivity allows researchers to "come clean at the hyphen" between self and other, questioning who we are as researchers as we co-produce narratives with research participants (Fine et al., 2000; Fine & Weiss, 1996). Working the hyphen requires that researchers do not "silence" their own voices while giving voice to their participants (Fine, 1994). Instead of writing about those who have been Othered, Fine (1994) calls for qualitative researchers to work the hyphen by engaging with those who have been exploited. Doing so reveals a great deal about one's self and about the structures of othering. With the intention to come clean at the hyphen, as a researcher I am responsible for interrogating who I am as I co-produce narratives together with research participants. Fine et al. argue:

It is now acknowledged that critical ethnographers have a responsibility to talk about our identities, why we interrogate what we do, what we choose not to report, how we frame our data, on whom we shed our scholarly gaze, who is protected and not protected as we do our work. (Fine et al., 2000, p. 123)

In order to "come clean at the hyphen" a reflexive journal was kept throughout the process to address the struggles and experiences of the research process and my own role as the researcher. This data added my own perspective to the research process, shedding yet another beam of light throughout the study.

In addition to reflexivity, crystallization is characterized by multiplicity – multiple voices, multiple perspectives, and multiple layers of meaning (Denzin & Lincoln, 2005; Guba & Lincoln, 2005). Denzin and Lincoln describe how different points of view are used in qualitative research to bring a "...psychological and emotional unity – a pattern - to interpretive experience" (Denzin & Lincoln, 2005, p. 5). They go on to state that: "In texts based on the metaphors of montage, quilt making, and jazz improvisation, many different

things are going on at the same time - different voices, different perspectives, points of views, angles of vision” (p. 5). In crystallization, the writer tells the story from different points of view. By incorporating the voices and the perspectives of myself and the participants gathered in various ways (i.e., interviews, photos, participant observation, reflexivity), I attempted to construct a collage of what it means to live with dementia and the meaning of leisure within the experience of dementia. Multiple meanings emerged as the participants and I worked together to stitch together an understanding of what it means to live with dementia and leisure’s role within the experience of memory loss.

Crystallization moves away from “criteriology” that attempts to specify criteria for assessing the quality of qualitative research based on postpositivist notions of what makes research “good” (Schwandt, 1996; Seale, 2002). Schwandt (1996) argues that moving away from criteriology requires a departure from “...autonomous, indisputable criteria for distinguishing legitimate from not so legitimate social scientific knowledge” (p. 70). In keeping with Schwandt’s call for a move away from criteriology, Bochner (2000) outlines six ways to identify good research, especially when using alternative research approaches. Qualitative research must include plentiful, concrete detail, including both trivialities of everyday life and feelings that go along with them. Structurally complex narratives that reflect the process of memory work also help to distinguish good qualitative research. Third, the author must “...dig at his or her actions and underneath them, displaying the self on the page, taking a measure of life’s limitations, of the cultural scripts that resist transformation, of contradictory feelings of ambivalence and layers of subjectivity, squeezing comedy out of life’s tragedies” (Bochner, 2000, p. 270), which I attempted to do through use of my reflective journal. Fourth, narratives should demonstrate one’s journey as one’s life is transformed by

crisis. Fifth, the author should show concern for those who are part of the story being told and recognizing the evolutionary process an individual experiences in telling their story. Finally, Bochner calls for a moving story that elicits a response that is both emotional and intellectual. I hope that by adopting Bochner's arguments, this research yielded more than just an understanding of lived experience, to include a "...narrative...as a source of empowerment and a form of resistance to encounter the domination of canonical discourses" (Bochner, 2000, p. 271).

In addition to Bochner's ways to judge the quality of qualitative research, de Witt and Ploeg (2006) propose five expressions of rigour for interpretive phenomenology. These include balanced integration, openness, concreteness, resonance, and actualization. Balanced integration refers to "articulation of the general philosophical theme and its fit with the researcher and the research topic...in-depth intertwining of philosophical concepts within the study methods and findings...and a balance between the voice of participants and the philosophical explanation" (de Witt & Ploeg, 2006, p. 224). I attempted to balance the philosophy of interpretive phenomenology with the findings of this project by considering the findings in terms of the lifeworld existentials. Openness refers to "the need for a systematic, explicit process of accounting for the multiple decisions made throughout the phenomenological study..." (p. 225). My reflexive journal provided a space for me to be open about the research process and decisions made. Concreteness can be recognized by examples that "...situate the reader concretely in the context of the phenomenon..." (p. 225). I have provided rich, vivid examples through the findings that aim to place the reader directly in the context of the lived experience of leisure within the context of dementia. Resonance refers to the effect of the findings on the reader. Resonance is judged by asking if reading the findings

was a moving experience. I have also aimed to present the findings in a way that resonates with readers. It is my hope that my readers moved by the voices of the participants, and see memory loss in new ways. Finally actualization addresses the notion that findings will continue to be interpreted by readers in the future (de Witt & Ploeg, 2006). I anticipate that readers will continue to think about and reflect on the lived experience revealed in this study.

By using a variety of methods, the data collected reflect the lived experience of dementia and leisure in many different ways, from different perspectives. Interviews shone one beam of light on leisure's meaning for persons living with dementia, while photos gathered and discussed through photovoice gave yet another perspective. Participant observation provided the opportunity to understand the experience as it is being lived, adding to the understanding gained through reflection. Finally, by keeping a reflexive journal throughout the research process I included my own perspectives and carefully considered their influence upon the research. Drawing upon Bochner's six points for judging qualitative research enabled me to co-create with the participants a complex (although partial) understanding of the meaning of leisure for persons living with dementia.

Ethical Considerations

The interests of vulnerable populations require special attention when conducting research, yet the assumption that they are unable to participate denies them the opportunity to benefit from and make a meaningful contribution to research (Slaughter, Cole, Jennings, & Reimer, 2007). For research to be ethical, researchers must ensure that consent is informed, that participation is voluntary and can end at any time, that confidentiality is maintained, and that benefits of the study outweigh the risks (Gilhooley, 2002).

Issues of informed consent can be particularly challenging for dementia research. For example, Van Dijkhuizen et al. (2006) found that although all participants consented initially and in an ongoing manner, sometimes the participants seemed uncertain about the identity of the researcher. Participants were worried that the researcher intended to move the individual from her home. Revisiting the purpose of the research and addressing anxieties was therefore necessary throughout the project. Taking the time to reassure participants and build rapport may address these problems (Van Dijkhuizen et al., 2006). While some researchers seek informed consent from family members, Hubbard, Downs, and Tester (2003) suggest that contacting relatives can erode autonomy and contribute to infantilization. Dewing (2002) argues that relying on proxy consent is not consistent with a personhood approach to research. Since this study focuses on early stage dementia, obtaining informed consent directly from the participants was possible, and ensured a person-centred approach to research. Furthermore, Dewing argues that dementia research informed by a personhood perspective must include the principle of social justice. The researcher must use his or her research as an opportunity to contribute to equal opportunity for persons living with dementia, and can do so by “talking directly to the person about the research and possible consent in a way that enables the person to be involved and exercise choice” (Dewing, 2002, p. 164). Thus, consent was attained only from the person living with dementia and it was reaffirmed on an ongoing basis. Throughout the process, I continuously reiterated the purpose of the research and monitored participants’ willingness to continue their involvement in this study.

Research participants must not feel pressured into taking part in research (Gilhooley, 2002). As the researcher, I made it easy for potential participants to refuse to participate by allowing them plenty of time to think about whether or not they would like to participate

(Gilhooley, 2002). Upon commencement of data collection and throughout the process, participants were informed that they could withdraw from the study at any time without consequence (Alzheimer Society of Canada, 2007). Confidentiality and privacy were respected (Gilhooley, 2002) unless participants provided consent to have their images revealed in the photos they included. Participants were informed that they could refuse to answer questions they were not comfortable with. Anonymity was protected for participants (Kayser-Jones & Koenig, 1994) by using pseudonyms and removing any information that could potentially identify participants. However, participants' images appear in the photos that they included in this study, and informed consent was given by participants to have their images used for the purpose of this study and shared in presentations and written reports resulting from this project.

Considering the interests of persons living with dementia who participate in research requires "open dialogue and honest communication regarding the person's wishes, potential conflicts of interest...and the balancing of risks and benefits" (National Advisory Council on Aging, 2004, p. 19). Potential harm to participants must be balanced with the benefits of participation (Kayser-Jones & Koenig, 1994). There may have been minimal risk to participants in this study as they were asked to reflect on their leisure, which could have led to discussion of sensitive or personal issues. There were also benefits for the participants, such as the opportunity to share their story with others, the opportunity to advance our understanding of the experience of dementia, and the opportunity to have their voice heard. Indirect benefits also included "a diversion from routine, the opportunity to meet people and to feel useful and helpful..." (Keyserlingk, Glass, Kogan, & Gauthier, 1995, p. 327). These benefits could contribute to well-being, morale, and sense of purpose (Keyserlingk et al., 1995).

In addition to ethical issues relating to research with vulnerable populations, photovoice presents a unique set of ethical challenges for researchers. Photovoice is a method that respects autonomy, promotes social justice, upholds good, and avoids harm (Wang & Redwood-Jones, 2001), thus it is consistent with a personhood approach to ethics that respects participants' self-determination, uniqueness and autonomy. However, attention must be paid to issues of consent, intrusion, and ownership of photos (Wang & Redwood-Jones, 2001). Informed consent is pertinent in photovoice, and in addition to informed consent to participate in the study, consent must be obtained from subjects of photos. In this study, participants were given copies of an information letter explaining the study to individuals or guardians of persons they wished to photograph (see Appendix N). They were also given consent forms and told that these must be signed in order to photograph other people (see Appendix O). I obtained consent from participants to use their photos in the project and subsequent publications (see Appendix G). Participants own the negatives of photos that they took, and must give permission, and be given credit, in publications. In addition to getting consent from human subjects, photovoice participants should avoid intrusion on individuals, groups, neighbourhoods, and communities. As well, the participants and I were careful not to place subjects of photographs in false light. The rights of the subject may be compromised if the interpretation of the events conflicts with his or her thoughts or feelings. Finally, since the goal of photovoice is to bring about change, I am ensuring that photos used will not reinforce the status quo and add to the stigma and negative stereotypes associated with dementia but present an alternative, more holistic perspective of dementia.

Research ethics surrounding persons living with dementia are complex. Ensuring the safety and assent of participants may be difficult if communication is difficult. The onus is

placed on the researcher to ensure that participants understand all aspects of the project, do not feel coerced to participate, and are aware that they can withdraw at anytime. The use of photovoice adds to this complexity and participants must be made aware of the responsibilities they have to protect human subjects in photos and of their ownership over their photographs and how that will be respected. This project received ethics approval from the University of Waterloo's Office of Research Ethics.

Chapter 4: Living with Hope in the Midst of Change

Introduction: The Paradox of Challenge and Hope

The participants with whom I had the privilege of working throughout this study experience their journeys of dementia within a complex *paradox of challenge and hope*. This paradox is revealed through the juxtaposition of both negative and positive aspects of living life with dementia. Jack, Alice, Charles, and Rita are confronted with several hurdles in their daily lives as dementia progresses. They are challenged by the changes they experience as a result of dementia, such as forgetting and losing skills. They also face the loss of valued roles and the negative assumptions of others regarding their abilities. Despite these adverse conditions, the participants experience a great deal of hope, exemplified by their optimistic outlooks on their lives, their positive attitudes, and their continued active engagement in life. The participants struggle with balancing remaining strengths with changes in skills and abilities. Their fear of further memory loss sits alongside their dreams of possibilities for both today and the future. The challenges that the participants face in their journeys of dementia affect their leisure, and yet at the same time, they use leisure to counteract transitions and continue their fight against dementia.

Challenge and hope are experienced by all participants, but some experience more challenges at this point in their journey than others. For example, Rita, who was diagnosed a year prior to the interviews, has experienced very few challenges so far and continues to have a great deal of hope. Charles, however, has experienced greater change in his journey and recognizes that he faces a multitude of challenges. Despite the increased challenge, he too, carries a great sense of hope about his life.

The paradox of challenge and hope is revealed in the way the participants speak of both challenge and hope at the same time. Alice confirms that the journey is indeed paradoxical: “Yeah, it is. Because like for me personally because I still want to appreciate what I can still do, but there’s this sense of grief over the losses as well. So it is, it’s a real paradox” (Alice, Interview 3). Jack reveals the paradox when he tells me how he experiences some change, but not a great deal of change. He tries to focus on his remaining abilities even though he is starting to experience increased challenges as he travels through the journey. I ask him about his experiences with memory loss, and he tells me:

Sometimes it’s...quite a thing (laughs). I can’t remember sometimes but it’s not, so far I’ve been um, very lucky and have had lots of help and I haven’t had any real changes from the time that I was diagnosed until now. Now I’m starting to get into, maybe not quite the second part of it and I get lazy sometimes because I sleep a lot and I don’t seem to have the same get up and go that I once had. But we’re still trying... (Jack, Interview 1)

All of the participants juxtapose both the challenges in their lives with the hope that they have for their present and future while remaining actively engaged in the world around them.

The paradox of challenge and hope plays out within the tensions between the essences of the dementia journey. There are four major essences of the paradox, including struggling with change; tackling life with dementia; threatening assaults on identity; and upholding identities. *Struggling with change* refers to the various changes that the participants experience as a result of both dementia pathology and as a result of being labeled as a person with dementia. These can be quite negative, leading to feelings of sadness, frustration, and embarrassment. However, the participants *tackle life with dementia* often by adopting an optimistic outlook and remaining hopeful despite both current and anticipated losses.

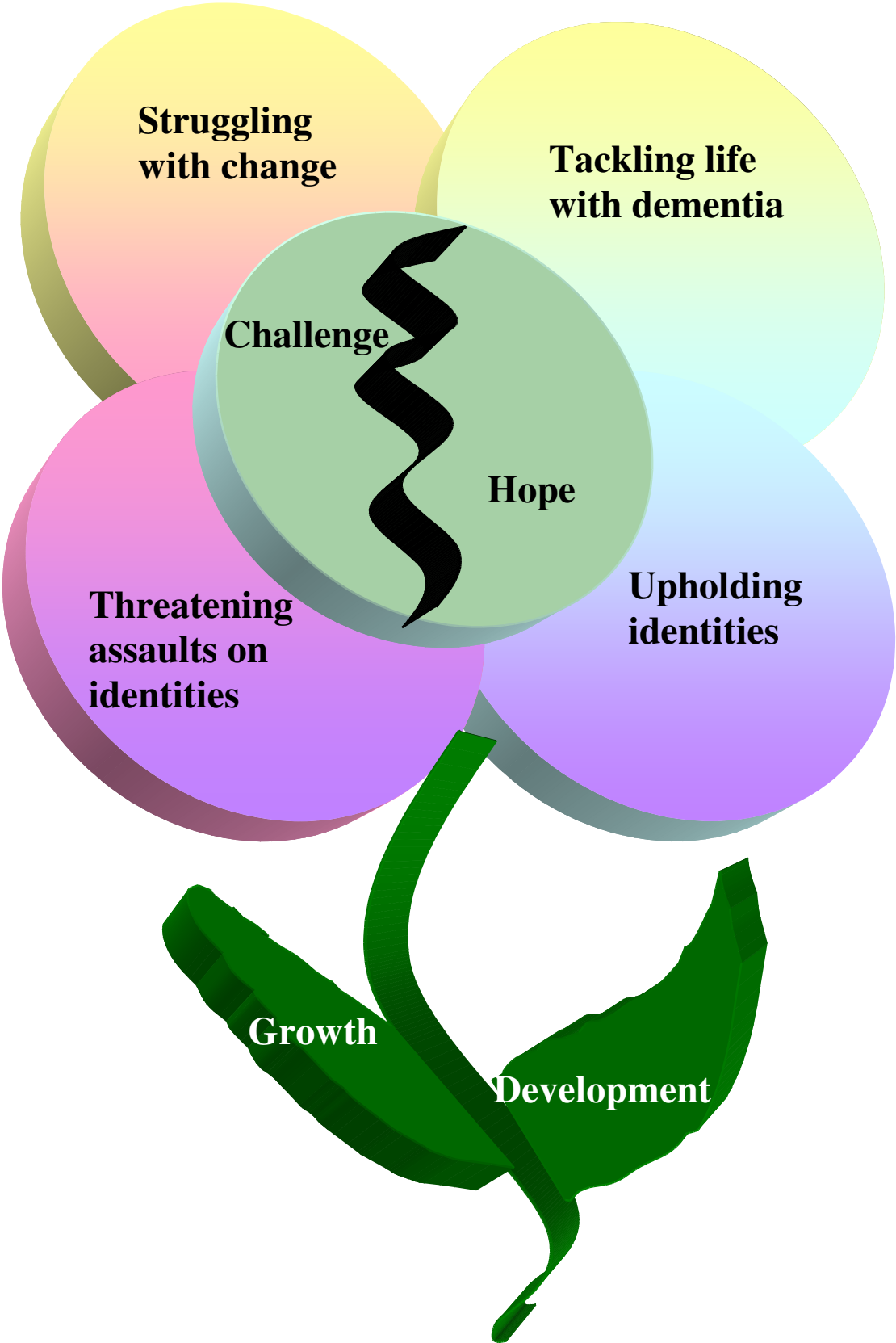
The experience of the paradox of challenge and hope also lies in the tension between *threatening assaults on identity* and *upholding identities*. The identities of the participants are

threatened not only by the challenges they face, but also by negative perspectives that society holds regarding dementia. Instead of acquiescing to these identity threats, the participants rise to the challenge of being themselves regardless of the uncertainties they face.

The findings of this study are summarized in Figure 1. The centre of the diagram represents how challenge and hope are paradoxical, sitting alongside one another through the experience of dementia. The four outer circles represent each essence of the paradox. They overlap to represent that no essence stands alone, rather they are influenced by and influence each of the other essences. The stem and leaves indicate that growth and development continue when living with memory loss. Alice, Jack, Charles, and Rita feel that the diagram represents their experiences with memory loss quite accurately while accommodating individual differences in the experience. When participants were shown similar diagrams both with and without the stem and leaves, they preferred the diagram that included the stem and leaves because they felt it reflected their experiences by highlighting that memory loss continues to be a time of growth and development.

This chapter will explore the paradox of challenge and hope and how it plays out in the lives of the participants within the context of leisure. First, I explore and describe the experience of encountering change, followed by the experience of tackling life with dementia. Next, I explore how the participants experience threats to their identity. Following this, I explore how the participants respond to threats to identity and continue to be themselves (See Appendix P for a chart describing themes and subthemes).

Figure 1: Living in the paradox of challenge and hope



Struggling with Change

The participants of this study encounter many changes that affect all facets of their lives, including leisure. Struggling with change refers to the obstacles or alterations that participants have experienced since being diagnosed with dementia. Many of these changes are the result of changes in cognition that occur in dementia. The changes that are encountered along the journey include *muddled thinking, fluctuating abilities, draining energy, frightening awareness, and disquieting emotions.*

Muddled thinking

Each participant experiences muddled thinking, or alterations in thought processes that make thinking and cognition more challenging. Muddled thinking occurs in all spheres of life for the participants, including leisure. The participants sometimes have difficulty remembering, judging, concentrating, and accessing thoughts. Charles told me: “Thinking clearly is probably the biggest challenge” (Charles, Interview 1). Participants experience muddled thinking while reflecting on the interview questions. Charles tells me during his third interview: “I’m having difficulty today, Rebecca. Um...understanding the question and thinking through how it relates to me” (Charles, Interview 3). Charles’ comment highlights how muddled thinking can occur for participants and can affect what was once a simple, everyday occurrence, such as communication. The essences of muddled thinking are *disconcerting forgetfulness, distracting concentration, losing access to thoughts, baffling environment, and troublesome learning.*

Disconcerting forgetfulness

Disconcerting forgetfulness is experienced frequently by all four participants. It refers to the difficulty of remembering recent, current, and future events more so than usual.

Disconcerting forgetfulness has minimal effect on long-term memory at this point in the participants' journeys of memory loss. It can be both predictable and unpredictable. For example, Rita always has difficulty remembering names, but all participants find some days they remember things they had forgotten the previous day. Charles tells me about forgetfulness early in our conversations: "I'm just saying that over and over again, I forget the important things of life, the important things of life. Some aren't important. That's just the way it is" (Charles, Interview 1). For example, participants might forget to take their medications, or they might forget what they had planned for the day. Charles talks about the frustration of forgetting: "It's certainly inconvenient for me, because I can't remember what's happening for the...tomorrow, or much less today even" (Charles, Interview 3).

Disconcerting forgetfulness can have an impact on leisure when rules for games or leisure routines are forgotten. Jack talks about forgetting ballroom dance steps despite having practiced them for many years. He included a photo of himself and his wife dancing together (see Photo 1), and in describing the photo, he tells me how dancing had become more challenging:

...some of it is losing the ability to remember what we should, like you learn a step for, for months and months and months and then all of a sudden I can't, can't remember to, remember what I'm supposed to be doing. (Jack, Interview 2)



Photo 1: Jack dancing with his wife

Charles, who loves to read, has difficulty remembering plot lines and characters: “...there’s a number of, of, of persons in the plot and to remember what happened before sometimes I forget very easily. Very quickly” (Charles, Interview 3).

Disconcerting forgetfulness is experienced to different degrees as it can vary across hours, days, and situations. Since participants in this study are at various points since diagnosis, some experience more forgetting than others. For example, Charles speaks extensively of forgetting in terms of taking medication, rules for games, and plotlines, while Rita only has trouble remembering names at this point.

Distracting concentration

Distracting concentration is the second essence of muddled thinking. Participants often find their attention span is shorter than it once was. They may lose focus on a conversation or during a television show. They may not be able to follow a sequence of events in a story or recall a character in a later scene. Charles summarizes how his ability to concentrate has changed: “I can’t concentrate um...I don’t have the cognitive skills that used to be there” (Charles, Interview 1). He has difficulty following the story when reading or watching a movie:

But um the other night we watched a movie that [my wife] had picked up from the thrift shop. Crimes of the Heart I believe it was, or something like that. And um, I watched it a couple times before but I could not get the sense of it. When it was all over I said [to my wife]... “I’m clueless as to what was it all about. Can you tell me the story?” (Charles, Interview 1)

Charles talks about some of the challenges of following along and concentrating on something. He likes to watch movies and included a photo of himself in front of the television (see photo 2). When describing the photo, he explains how challenging watching a movie can be:

I am having more and more trouble um following the plot with the Alzheimer’s. I can’t see as well and um, I miss some details in sight. I don’t hear as well, and so I, especially with accents, whether it’s a Southern accent or an English, British accent, I have trouble following. (Charles, Interview 2)

Participants are easily distracted and find it difficult to concentrate on one project or activity. Alice finds it challenging to follow her morning routine which involves making breakfast for herself and feeding her cat: “Because I’m, and some days I don’t know what I’ve done previously, like cognitively I can’t follow things through in a sequence. So to backtrack and pick up where I was, I have no idea where I was” (Alice, Interview 3). She tells me how she gets distracted when doing multiple tasks and may not be able to follow through on any of them: “So I have to actually, once I get started at a project I’ll work on it but then I’m easily

distracted and I'll have maybe two or three things going on and not complete one thing" (Alice, Interview 2).



Photo 2: Charles watches television, but has difficulty following the plot

Losing access to thoughts

In addition to distracting concentration, losing access to thoughts is common among the participants. This is apparent not only as they relay their lived experiences of dementia, but also in the interviews themselves. Participants are occasionally unable to follow a line of thinking. They may find it difficult to retrieve their thoughts. Jack explains how he was always quick to respond in any situation in the past, but now he needs more time: "I knew what I was going to do, and I knew I was doing it the right way and everything and now once in a while I say 'well you'll just have to wait until I think of what I was going to do' (chuckles)" (Jack, Interview 3). Charles has similar experiences in accessing his thoughts: "But there are times when I feel that my mind just goes to mush. I just can't *think*. I *know* I know the answer but it's not there, it's gone, I can't express it" (Charles, Interview 3).

Losing access to thoughts can lead to difficulty relaying ideas to another person. The participants may not be able to find the words they need to express an idea or desire. As well, household tasks can be particularly overwhelming, especially if participants are unable to access thoughts regarding how to begin or complete a task. Alice tells me how housework can be overwhelming: “Because of right now, I’m overwhelmed with the condition my apartment is in. Because, it’s so uncomfortable, and yet, I don’t know where to start to make it better” (Alice, Interview 1). Similar to forgetting, losing access to thoughts varies across participants, days, and even hours. Rita talks about being uncertain of what’s going on in her head at any particular time:

...it’s sometimes really hard, and I wonder what goes on in your head really, because you sort of think some days you’re not very clear, you know as clear as you should be and other days you remember names all the time. But, so you sort of wonder what’s going on in your thinking, you know because it was never like that before. (Rita, Interview 3)

Baffling environment

Sometimes participants experience bafflement in their environments. Senses of time and space are altered. Time vanishes and space becomes bewildering. Participants can feel lost in both new and familiar environments.

Time disappears for participants when they lose track of it. They are occasionally unable to figure out the current time or an important time in the future. Alice feels like time itself disappears. It is becoming unimportant and often goes by unnoticed.

When I’m alone, um, it’s like a sort of, the clock slows down, or I slow down, because I don’t seem, I’m going into the phase now where time is irrelevant. Um, I look at the clock and it maybe 12:00. 12:00, so what, what am I doing. (Alice, Interview 2)

This has an impact on her daily life as being on time for appointments is becoming more challenging for Alice:

Um...and also it's getting more difficult now to be up and ready for um, the county service to go for my doctors' appointments, because it's taking longer and longer to get going in the morning, doing personal care and getting out that door. So but when people are here, or when I'm doing something, time is irrelevant. I can honestly say that. So as long as I'm done my project in time to watch hockey I'm fine (laughs). (Alice, Interview 2)

Time is challenging to keep track of in other ways as well. Charles talks about the difficulty he has setting his timer to remind him to take his medications:

This little pill box that, I can set the time and it beeps. Um, I sometimes have a lot of difficulty saying well let's see. Now it's um, say 2:15 and I want to take my pills at 3:45, of knowing how, how many hours it is I have to, is it an hour, an hour and a half, two hours. I have trouble...somehow, I can't understand why it is as much of a problem as it is, but I have a problem knowing how to set it. I know I want to take my medications at 4:00 for instance, but now at 2:43, how much time do I set it for. I wish it was more like you can set it at 4, you can set it at 4:30 or whatever, but you have to figure that out. (Charles, Interview 3)

Jack tells me a story about an international trip with his wife and the feeling of being lost in time and space while going on tours.

Back on the bus, yes, like we went on bus trips and it was a matter that I wanted to be back on the bus, and not wanting to miss it....And [my wife] would say "Well we've got another 25 minutes" and I said "No, no". And the other thing is keeping time is a lot of difference once it happens because once it happens because all of a sudden you look at the clock and you know it's twenty minutes after and you're thinking well somebody else well it's twenty minutes after and somebody else say it's ten minutes to, you get a little confused with is ten minutes to or twenty minutes after and that sort of stuff. (Jack, Interview 1)

In addition to vanishing time, space can be confusing and bewildering. Participants may get lost in their neighbourhoods or feel disoriented in their own homes. Bewildering space was apparent during participant observation. Jack demonstrates this in his neighbourhood when we were walking back to his bungalow after putting:

We followed a path around the bocce ball court and over a small stream. It came out along a different street. We walked along the street for about a hundred feet, when Jack realized he did not know how to get home from there. (Jack, participant observation field notes, putting)

Alice often finds herself disoriented in her own apartment when she wakes up in the morning: “Because I’ll get up in the morning, and I’m very lost in the morning...But I really, even I’m disorientated in my own apartment” (Alice, Interview 2).

Unfamiliar spaces can also be baffling. Jack spoke about his fear of getting lost when he was on vacation with his wife:

No I was afraid I mean there’s such crowds there and I kept a red hat on all the time just so that so [my wife] could find me because going up the hills and everything and we walked there a lot too and it was a matter that going up these hills sometimes there was thousands of people going up and down and it was during the festival and it was – if I got turned around and all these other people were around me and I was a little worried I have to say that yes. (Jack, Interview 1)

The experience of time and space changes as a result of memory loss, and participants find keeping track of their environments to be more challenging than ever before.

Troublesome learning

As part of muddled thinking, some participants find it is difficult to learn new things. Charles can no longer play new games because he cannot learn the rules: “I can’t learn new games. It just doesn’t register” (Charles, Interview 2). He reiterates this in Interview 3: “Learning new table games, um, is extremely difficult if not impossible for me” (Charles, Interview 3). Jack talks about being unable to learn how to do Sudoku puzzles, when all his life he had excelled at math. He is also no longer able to learn new dance steps: “And if we take a new lesson, you know before I was diagnosed, I would do it right the day, and the next day I couldn’t remember what the step was” (Jack, Interview 1).

Charles and Rita both talk about having difficulty learning how to use new equipment. Rita finds it difficult to use the new television, and during our participant observation session, she tries to turn it on to show me:

She told me she had a hard time working with the television and when [her husband] turned in on later, it would often be frozen and he couldn't use it. She pressed a few buttons on the remote control. The widescreen television in the corner flashed on and said "Press any key for cable." She read the words aloud and pressed a button on the remote control. The screen went blank and then the words came across the screen "Press any key for television". Rita pressed another button on the remote control. The television went staticky. She said, "Why don't we go to the other television, it's easier to use." (Rita, participant observation field notes, walking)

Charles tells me how he has not been able to learn how to use the DVD player: "But then I have difficulty setting it, I have to have my son to help me or with the stereo system to go from TV to VCR or, I can't even think of the um...CDs? The one that shows the...DVDs" (Charles, Interview 3).

Despite the troublesome nature of learning with memory loss, participants are still able to grow and develop. They learn new ways to live with memory loss and constantly adapt to their ever-changing circumstances, which I will discuss later in this chapter.

Fluctuating abilities

In addition to muddled thinking, fluctuating abilities play a role in the experience of struggling with change. The participants find their abilities altered and often cannot perform skills that were once very easy for them. For example, the participants experience difficulty with adding and subtracting, or have trouble figuring out the proper change when paying for something. Although Rita took care of the finances for her family's business, she has difficulty managing money now:

I was the, the uh one that took care of all the finances in the business, and when I think of it now, um, I couldn't possibly go back there. My daughter's got my job and, and she said to me, "Would you like to work here again?" And I said "Nope" (laughs). No I have no desire for that, and I said "I'd really mess things up." But I think, um that, that's one hardship is, is the money end of it. (Rita, Interview 1)

Jack also worked with numbers in his career, and now finds it difficult to do simple math in his head:

Math was my thing. Because I did all quotes and everything for business and then in 2006 I all of a sudden I couldn't add, subtract. And now I can't subtract. You know I get confused like and I'm very careful. (Jack, Interview 1)

Leisure can become more difficult because of fluctuating abilities. Jack summarizes some of the challenges he faces in leisure:

Most in a lot of stuff now, when you're saying encountering changes, yeah there's the brain and the eye has got a big difference in what I can do and what I can see safely, like I said with the darts, I wouldn't throw darts now because I don't know where it's going to end up. It's the same and I was out and I went out and because I was asked to go bowling, like five pin, and I couldn't, I couldn't get the eye and the alley lined up right. It's, it's there are a lot of encountering change yes, there are some of the stuff that you lose, the other thing is playing golf, you're okay because if you're hitting anything other than out in the open somewhere it doesn't matter, but sometimes you can't find the ball again, that parts there but that is a big change I think in the mind, mind set of the um, like, even to, even to read something is changed...So there are big changes. There are a lot of changes. (Jack, Interview 4)

Alice similarly finds changes in her abilities to engage in leisure. She loves to play computer games, but finds she is not as quick to identify patterns and complete the levels of games as she used to be.

Alice had difficulty with *Jewel Quest*. She told me she often cannot see the patterns. She also told me she has stayed up until three in the morning trying to get past the first level. The game involves moving jewels, or other pictures (skulls, coins) one space over in order to make a row of three. Seeing the patterns can be difficult. As she gets tired, she has a harder time seeing the patterns. Alice played two games of jewel quest, but was not able to get off of level one. I also played two and found it difficult to see the patterns to make rows of three objects. (Alice, participant observation field notes, computer games)

The participants describe having good days and bad days as their abilities fluctuate. They have days where they can do all the things they used to do, and then they have days

where nothing seems to go quite right. Their abilities can fluctuate throughout the day, from moment to moment, from day to day, and over longer periods of time:

Like I'll either be a higher or lower, because of the motivation if I'm having a good day then my memory loss is not as noticeable. I'll be able to hide it better, subconsciously. Where if I'm having a negative day, than some of the little tweaks of the disease process will come out in the, um...I don't want to say disability, but more of the problems, more of the issues. (Alice, Interview 3)

Rita has similar experiences with her abilities fluctuating in unexpected ways: "I guess it's kind of a hit and miss thing. You know. There's some things you can do easily, and, and others just, are a blank to you, not worthwhile trying" (Rita, Interview 1). Some abilities may be lost for a while and then return later on:

Umm, and believe it or not, thing, some things that I couldn't used to do, I'm doing much better now, like things... are reversing in some aspects. Like, for years I had trouble getting the proper nutrition in the meals. Now...this year I've been able to make say roast beef from scratch, chili from scratch, macaroni and cheese from scratch, my meal preparation doesn't seem to have the problem that it was. (Alice, Interview 1)

Abilities can fluctuate so much that participants may question whether they really have dementia on their good days:

There, there, there's some days when....you know you're not as sharp as you were, you know, and then there's other days when you just feel like you're old self. So. It's a, it's a ...very funny disease, because you, you think that one time you're really, must be going down hill, then you're thinking the next time, that there's nothing wrong with me, it was my imagination, you know. (Rita, Interview 1)

Rita aptly highlights the paradox of challenge and hope here by describing how good days are intertwined with bad days, and fluctuating abilities make her uncertain of what to expect and uncertain of her diagnosis. Alice notes that these fluctuations lead to a constant monitoring of her abilities, since they can change day by day, and hour by hour: "So, there again, it's the challenges and the constant, constant intervening, I guess is a good word. Constantly...

reassessing, hour by hour, 24/7” (Alice, Interview 1). Fluctuating abilities leave participants feeling uncertain about what to expect of themselves from day to day. Each day brings different challenges.

Draining energy

In addition to fluctuating abilities, participants experience a decline in physical and mental energy. Their capacity for acting or being active is reduced. Jack tells me about a reduction in energy levels: “...and I get lazy sometimes because I sleep a lot and I don’t seem to have the same get up and go that I once had” (Jack, Interview 1). Participants tire easily and require more rest. When I asked Charles to tell me about his daily life he told me:

Sleeping. I can get a good night’s sleep, like eight hours or so, and um, afternoon, we both lie down [my wife] for about 15 minutes and I for one to three and a half hours. A couple nights ago, a couple days ago, three and a half hours during the day, and I was still able to sleep at night. (Charles, Interview 1)

Draining energy can be further broken down into *diminished physical strength and capacity*, *fleeing motivation and interest*, and *feelings of inertia*.

Diminished strength and capacity

Diminished physical strength and capacity is common among participants as they no longer have the same vigor to engage in physical and mental activities they used to. They tire easily and cannot participate for long periods of time. While Alice and I played computer games, she tells me about the fatigue she experiences:

She had been for a walk earlier in the day, and mentioned that she would not be able to do anything in the afternoon because of her busy morning. She talked about fatigue and how it affects her – she can’t hear or see, or speak as well when she gets fatigued. All she can do is have a nap. (Alice, participant observation field notes, computer games)

Charles tells me how he tires more easily and is unable to engage in physical activity for long periods of time:

The distance of walking, we used to walk quite a bit, and ah, take rather long walks in the park, trails and so forth. And at the best I can walk from here to [street name] and back which is about a kilometer each way. That's at best. At times I'm so tired I can hardly make it in. (Charles, Interview 1)

Loss of physical strength and capacity is not always solely due to dementia. Charles, who has Parkinson's disease and vision problems, cannot hold a book in his hands to read, nor can he read without magnifiers. There are many physical activities he can no longer enjoy because of Parkinson's disease: "Bicycling...playing basketball, anything like that is completely out. Or even just catching a ball back and forth. But again it's more from the Parkinson's than the Alzheimer's, but it is, it's related" (Charles Interview 3). Charles appeared to tire quickly as we engaged in pole walking together:

We walked 18 minutes in and 18 minutes out [along the path]. Charles suggested that we turn around at a particular point and we did so. On the way back he appeared to be a bit more tired as his pace slowed and he dragged his feet. (Charles, participant observation field notes, pole walking)

Hand eye coordination is also altered. Rita finds she cannot read as much as she used to. She had a photo taken of herself reading and tells me that she spends less time reading now than before experiencing memory loss (see photo 3): "Now my eyes are fine, I can read. But I find my eyes get tired, and so I read for a bit, then I'll put it away and...yeah" (Rita Interview 2).

Draining of physical strength and capacity limits time spent in leisure. Charles' wife took a photo of him sleeping in his easy chair since Charles takes frequent naps and will fall asleep while reading: "I go to sleep many times when I am reading...Now [my wife] just took that to represent that I enjoy sleeping (laughs)" (Charles, Interview 2, see Photo 4).



Photo 3: Rita enjoys reading but tires quickly



Photo 4: Charles falls asleep in his chair

Fleeing motivation and interest

In addition to diminished strength and capacity, fleeing motivation and interest in daily activities contributes to the sense that energy has been reduced or altered. Some of the participants find they now lack the motivation or interest to do the activities they once enjoyed and they associate this with the disease process. Alice talks about how being tired can affect her motivation – it prevents her from doing meaningful activity, leisure or otherwise:

I guess that's the best way to put it because...because it holds me back so therefore, yeah, that's the only, and that's a real problem, that's a real um, I can't say it's a problem, but it's a concern. Is the no-go days. (Alice, Interview 3)

Alice talks about losing interest in some of her leisure activities of time. She tells me how she has not been able to write poetry recently because she has lost the interest in it:

The only thing I've really slowed down...is getting back at my poems. I haven't written one in a while, I haven't had that sense of – I've got one that I've started and I just don't know what to do with it...And um, I just haven't got the wording where I want it. So... it's a work in progress. (Alice, Interview 3)

Similarly, Rita talks about having lost interest in attending the women's group at church:

There are some things that uh, that I was going to, that um, I don't go to now. Like there was a group at the church that meet every Wednesday morning and, and we'd knit, or do something, you know, like that. And ah, I don't know whether I lost interest in it, or whether I just felt uncomfortable there, you know. (Rita, Interview 1)

Often fleeing motivation and interest refers to daily activities or chores around the house.

Both Alice and Rita find they are no longer motivated to cook or clean. Rita always loved to cook but has lost interest in it:

But I just given up cooking and I found that a lot of people get to that stage in their life, where they, they don't like to cook anymore. And I used to love it, I used to love to cook and have people over, but I don't do that anymore, you know. (Rita, Interview 1)

Dementia has resulted in loss of interest and motivation in certain daily activities which contributes to a sense of reduced energy levels.

Feelings of inertia

Draining energy is also characterized by feelings of inertia, or feeling as though one is unable to do anything at all. Alice talks about experiencing “no-go” days:

Mmhm. I know I go through periods of no-go days. Where mentally and physically I just cannot convince myself to go out to an activity or attend an event, or just go out of the apartment, so in that way I have dropped some of my leisure on certain days. (Alice, Interview 3)

In our first interview, Alice informs me that our interview will impact her for the rest of the day and she will be too tired to engage in any further activities after I leave. Her brain shuts down if she has too much activity:

And even when I do a project now, by the time we do our interview, I'll be totally...cognitively just, the computer will turn off, as I call it. So, umm...the length of concentration and the length of being able to be tuned in...is declining. (Alice, Interview 1)

Both Jack and Charles sympathize with this, as they too, experience days where they feel as though they cannot do much of anything: “Now, in my case it's, I have a day every once in a while when I hate to get up out of bed because I don't know what I want to do...” (Jack, Interview 4). This sense of inertia can impact participation in daily activities because giving into it is easier than trying to fight it:

Because it's so easy to sit and stare. See and that's the other thing, it's easy for me to stay in the fog, or in the zone as I call it. And sit on the couch and do nothing just stare. I could do that every waking moment. Very easily. (Alice Interview 1)

Draining energy as dementia progresses has an impact on all aspects of daily life, including leisure. This can be discouraging for the participants, who want to maintain active

engagement in their lives, and, as Charles says: "...it's just I don't want to sleep my life away" (Charles, Interview 1).

Frightening awareness

The fourth essence of encountering change is frightening awareness. Participants are aware of the changes they are facing and will continue to face in the future. All of these changes can be alarming. They fear how they will act in the future as their dementia progresses: "Now when, it starts to get a little deeper in the back of the brain, I might get nasty, and I might lose the thoughts..." (Jack, Interview 1). They are afraid that may wander and be unable to communicate:

Like I say once I came to a place I can't read and I can't think, um, that'll be a different situation completely. I have friends in the Alzheimer's wing just walking around and around and around and around. Can't carry on a conversation. And naturally I know that in reality this may happen. (Charles, Interview 3)

The participants also fear being a burden for their families, having to move into long-term care and not being able to remember their loved ones. Rita talks about the possibility of moving into long-term care:

You always dread the time, that's another thought. That you get in your mind, that someday, somebody is going to say "we can't handle her anymore, so she's going to have to go into a nursing home", so. And um, I don't want that to happen either. (Rita, Interview 1)

Rita talks about a friend who was in late stage of dementia. She indicates her fear of becoming like her friend, who did not recognize her husband near the end:

We had a friend that died just recently, oh maybe three or four weeks ago. And uh, she was an Alzheimer for years and years and years and you knew she was going down. You could see it every time you saw her...She was just, and really going down fast. And she got to the point I went to go visit her and she'd ask who I was and I'd tell her my name and, and she'd said -"I don't know you", you know. And uh, and she wouldn't talk to you and that. And I think, the, I

think about her, I think “Boy, I hope I don’t get like that.” Because it was so sad to watch her like that, because she always a very fussy lady, and always dressed nice, and she was a very nice lady, and uh, then she got so with her husband he moved into the same condo, or place as she was at. And uh, he’d sit beside her and she’d say “you’d better get out of here because my husband’s coming in.” and I think, you know, it’s such a hurtful thing, when you think of what can happen ahead. (Rita, Interview 1)

Participants acknowledge that there is no cure and decline is inevitable: “I don’t know, I guess there’s a, the only thing that would really make me sad, or make me feel down, is the fact that I know it’s going to get worse. And I know that there’s no cure” (Rita, Interview 1).

Alice experiences fear on a day to day basis. As her journey progresses she is beginning to be afraid of daily activities, such as scalding herself in the shower:

The other thing, oh, on daily activities, the other thing is the fear of the shower. That’s a new one. It’s been gradually coming on, and umm, I’ll go days without showering. ‘Cause I’ll have that fear, ah...apprehension, fear, it’s sort of half way between. Um... so I have to figure out where I am... in my day to know how to push to do that shower, and once I’m in it, I love it. But it’s getting, there again, getting started. And I think the reason that has developed is a couple times I’ve almost scalded myself. (Alice, Interview 1)

Frightening awareness occurs not only in terms of being aware of and apprehensive about the progression of memory loss, but also in terms of day to day activities that may be risky.

Disquieting emotions

As a result of both current changes and frightening awareness of future changes, participants experience disquieting emotions. These feelings highlight the losses that have occurred and demonstrate the discomfort that the participants experience as part of life with memory loss. The uncertainty of daily life with dementia as a result of muddled thinking, fluctuating abilities, and draining energy lends itself to a range of emotional experiences, including frustration, embarrassment, sadness, and guilt. Alice talks about the variety of emotions she experiences, even in a short period of time, which can be overwhelming: “Um the

mood swings are incredible, and because I've had past depressions, it's so easy to slip into a depression again. I have to be cognitive of that. And there's many days I feel lost and want to give up" (Alice Interview 1).

Participants often experience frustration as a result of the changes in their abilities. The loss of valued skills and difficulty with cognition leave them feeling irritated with themselves: "So yeah, there are many, many, many, *many* days that I get frustrated, I get down, I cry..." (Alice, Interview 3). Participants feel frustrated over the lack of control over their memory and the changes that are occurring:

And um, I wish that we had, as a person with Alzheimer's I wish we had more control over um, our thoughts, you know and what you're thinking because it's strange to all of a sudden not remember a friend's name you know and ah, and you think this is crazy, especially trying to remember it. (Rita, Interview 3)

Jack talks about his frustration with himself when he could no longer read music to play the violin:

And I get confused. Easily with that, so. That's one of the reasons that I really quit taking again, taking lessons for it, because I was doing pretty good, for a while, but. There's got to be the, I could read the, read the notes and...fluspatated [frustrated] with myself. (Jack, Interview 2)

Participants feel irritated with themselves when having to deal with changes in their thought processes. Occasionally, participants feel a sense of uncertainty about whether or not they are correct, and they may hesitate before responding. Feeling uncertainty can lead to frustration. Jack in particular felt uncertain of his actions and words as a result of the changes. While getting ready to putt, Jack tells me that he is not as confident in himself: "So I'm slipping a bit. I used to know I was always right and now I question myself" (Jack, participant observation field notes, putting). He now takes time to think through a response and questions whether or not he had the correct response.

In addition to frustration, living with memory loss can lead to feelings of embarrassment. Participants feel ashamed when they cannot remember names or activities. Charles is slightly embarrassed when he cannot remember the rules to games that he plays with his friends, although he tries not to let it bother him:

I can play the ones that I played before, and even those I forget what the next move is and I um, have to be reminded. So it's embarrassing. My friends all know about it anyway, so I don't let it bother too much. (Charles, Interview 3)

Social situations can also lead to embarrassment because of difficulty accessing thoughts.

Charles talks about feeling embarrassed: "Challenges are...yeah, sometimes, um...I'm embarrassed because I don't know what to talk about. I can't remember things that are happening to talk about, and so, one because I don't read the paper I feel ignorant" (Charles, Interview 2). Rita tells me about eating lunch at a restaurant with her daughter and granddaughters and comments that she would be embarrassed if she had difficulty paying after eating out: "But the kids are usually really good about that, you know, they're okay. I probably would be embarrassed if I was with a stranger or somebody else, you know" (Rita, Interview 2).

Feelings of embarrassment can lead to reluctance to participate in leisure activities.

Participants are intensely aware of their difficulties in recalling people's names or the rules of games. Rita talks about her difficulty remembering names and its impact on her:

Um...I don't know, I think um, I have a hesitation if I, if I feel that I can't carry on a conversation with somebody because of forgetting names and that. And um but that's the only thing I worry about is maybe being in a group and feeling kind of stupid because I can't remember their names or something, you know. (Rita, Interview 3)

Embarrassment regarding the changes reminds participants that they are not the same as they used to be and that things may continue to get worse.

Participants feel sadness as a result of the changes they have experienced. Charles notes that having a combination of illnesses he must cope with makes him sad: “Well probably the most, the big thing that makes me sad is coping with the variety of illnesses, the Parkinson’s, the Alzheimer’s, the eyes, um...” (Charles, Interview 1). Participants regret losing valued skills and abilities. Rita feels that dealing with money should still be simple and she is disappointed in the loss of skill: “The money is the one thing that, it doesn’t scare me, but it ah, it ah disappoints me. Because it was a simple thing really. And it still is, when you think about it you know” (Rita, Interview 1). Jack explains to me what it is like to write a thank you note. A once simple task is now challenging, which is upsetting for Jack:

...like when I go to write some ah, thank you cards to some people who have done something for me I have to write it in a piece of paper, write it twice. Get out the usually get out the umm, um, ah um, dictionary to see if I’m spelling it right. I know the word I want, but I can’t really write it all the time. So I write it out three or four times, and then I put it in the card, and the card sometimes I’m writing along and I’m dropping letters so I have to do two cards. And that little thing makes me feel really upset because I used to be able to just scribble it off and put my name on it and get it done. I can’t do that anymore. (Jack, Interview 1)

Sadness provides a way of recognizing a new challenge that they may not be able to overcome. Alice talks about having difficulty at the bank and the feelings of sadness that resulted as she tried to get change for laundry:

So, what it ended up to be, I had said, a roll of loonies, a roll of toonies instead of quarters, so with her help and acceptance ...umm, I was able to complete it, but however, I felt very sad. That I made a mistake. It was another signal that...what I was saying, wasn’t what I was thinking. (Alice, Interview 1)

However, the participants try to avoid sadness for long periods of time, fearing falling into a depression that they may not be able to escape: “...I don’t want to ever get, I’ve had a fear when I’ve seen people who get down, and get depressed, I’ve had a few that I don’t ever

want to get like that..." (Rita, Interview 3). Charles similarly states: "I don't ever want to get into depression. A deep depression" (Charles, Interview 1).

Fluctuating skills and abilities occasionally leads to feelings of guilt. Participants feel badly that they need more assistance and that their care partners have to take on more responsibility and adopt new roles. Rita no longer likes to cook so sometimes her husband makes supper:

And he, he likes to cook. He's not very good at it (laughs), but he does like to cook. And he'll make cookies, and stuff like that every now and again. But, umm. Then, that gives me a guilt complex, you know. I'm thinking, you know (laughs) course he tells everybody, you know. "You should have seen the supper I made tonight" (laughs) and, uh, yeah, so. (Rita, Interview 1)

Alice also experiences guilt, although less frequently now than she did at the beginning of her journey. At that time she felt guilty for having to ask for help from others, especially since asking for help undermines her independence:

I would say at the start of the disease process more so than now. Um I rejected help, I felt less of a person and very guilty about asking for help. Um, I still do in some ways but it's not as much. But there's still that part of it yeah, you still want to be that independent um quote unquote normal person. So there are times when it does have a bearing. (Alice, Interview 4)

Disquieting emotions are felt in response to the changes that participants struggle with as a result of memory loss. These emotions highlight the complex nature of living with memory loss.

While the changes experienced present challenges to the participants in their daily lives and in their leisure, they juxtapose them by finding ways to manage them and live fully. Alice describes how she is able to live with a sense of hope despite the increasing challenges she faces and the uncertainty of what lies ahead:

Like each, each few months it seems to be steadily losing a little bit. And that is, is very sad. That I'm aware that I'm losing it in certain areas. I can still do

certain things, but it's becoming more and more difficult. So that's...that's frustrating and sad. But...what keeps me going...are all the other things in my life. And I look at that when I have the sadness of not being able to complete a project, or to do something, I now turn that sadness into reaching out for assistance. Or lowering my expectations of what I can accomplish. So in that way...I can decrease the sadness...into a more positive emotion rather than a negative... (Alice, Interview 1)

Tackling Life with Dementia

Despite the changes encountered while living with dementia, the participants find creative ways to tackle life with dementia by working through challenges and adapting their lives to continue to participate in valued activities. In doing so, they juxtapose challenges encountered with a sense of hope. The experience of tackling life with dementia is composed of *reconciling life as it is, battling through by being proactive, living through relationships, being optimistic, and prolonging engagement in meaningful activity.*

Reconciling life as it is

The first essence of tackling life with dementia involves reconciling oneself to the diagnosis and subsequent changes. Participants do so by acknowledging their diagnosis and the impact of memory loss and subsequently incorporating the changes they encounter on their dementia journeys into their daily lives. The participants talk about the importance of accepting their diagnosis in order to tackle life with dementia. They recognize that they cannot change the fact that they have dementia, so they accept it for what it is. When I ask Charles what is most important in his life now he responds: "To accept life as it is" (Charles Interview 1). Jack accepted his diagnosis immediately, adopting a new perspective on life: "I took a different view of what my life was right then" (Jack Interview 3). Rita similarly tries to keep things in perspective. She tells me when we play games together: "It's not like both of my

legs have been cut off’...She said that ‘Alzheimer’s is just part of life.’” (Rita, participant observation field notes, games). Instead of worrying all the time about having dementia, Rita accepts it and goes on with her life:

...you can’t expect you’re going to walk away with nothing in life. So you’re going to have some up and downs. And if this is one of the crosses you’ve got to bear that’s okay, you know, that’s how it is. So. I don’t like it, but I don’t have to be concerned about it all the time, you know. (Rita, Interview 1)

Participants believe that they cannot change their diagnosis, but they can make the best of what has happened. Rita compares herself to another participant in her support group who has a more difficult time accepting dementia:

...when I was over [at the support group] and there was three of us over there. And this one lady kept crying because her husband didn’t understand her, you know. And my reaction was “what are you crying for?” You know. Like you can’t change life. It’s here, and let’s make the best of it, you know. (Rita Interview 1)

Charles shows how the changes can be reconciled when he indicates that he has come to accept his loss of energy, despite the fact that he does not want to sleep his life away. He acknowledges that his life is different now and accepts that definitions of normalcy have changed as a result of memory loss:

...it’s normal for me to take a long nap. Once a day, sometimes twice a day, and um, feel good about it. Feel I need it. Yeah. If by normal, if what you mean by normal we’re talking about patterns in our life, um, I certainly see normalcy as being different now than what it was before. (Charles, Interview 4)

Once change has been reconciled and the inevitability of further decline is acknowledged, some of the participants begin to prepare for their future. They wish to have control over their lives as their memory loss progresses, and preparation for what may come helps them to accept the future changes with a sense of hope. The participants think about where they might end up and make plans for how to live when changes occur:

But I'm not to a point where I'm at finding, I'm really not finding any shocks. Like I'm saying, I haven't in my life yet thought in the morning "I don't want to wake up, I don't want to get up, I don't want to do this." I'm not there yet. But I think I will be there and when I am there I'm going to have to admit it and make sure that someone else knows that I'm changing within my own body and, and but so far I haven't been doing that. (Jack Interview 1)

Charles thinks about quitting choir. He does not want to inconvenience the choir in any way and wants to know when it is time to quit. He thinks about when that time might come and prepares for that change by recognizing that he may need to be told by others when they feel it is no longer appropriate for him to participate in choir:

When change is necessary, I want to know. I want people to tell me when it's time to drop out of choir. But I'd rather drop out of choir and there's no way I want to be like somebody I knew in choir that ...was a...made it difficult for them to work around them. Talking out loud when the director's trying to direct us and things like that. But, but neither do I want to get to the place where, oh people saying, hoping that I would drop out. When I get to the place where I feel that people would feel more comfortable if I dropped out then I would do it on my own. (Charles, Interview 3)

In addition to preparing for the future, reconciling life as it is plays out in terms of moving on instead of dwelling on the changes. They live their lives the way they want to despite the changes. They try not to let the changes bother them or worry about the consequences of mistakes. For example, Rita avoids dwelling on the changes that she has experienced but instead aims to continue to live her life despite them: "No, I don't, I don't a lot, think a lot about my feelings. And uh. Maybe I just think, you know well this is a good day, or it's not, you know" (Rita, Interview 1). Rita illustrates how she tries not to sweat the small stuff. She has difficulty counting money, but she does not worry about getting back the right change: "And you know...lose a few dollars, that's too bad. You know. Doesn't mean anything really" (Rita, Interview 1).

Reconciling the changes that occur is not always easy. Since abilities are frequently changing, acceptance is an ongoing process. Alice talks about how she should be easier on herself and more accepting of her abilities:

And I gotta learn not to be embarrassed but the, say for example now the state of the apartment. This isn't the way I wouldn't, would normally want it to be. But because of the way I've been and having dog sat I'm... I've had to let things go. And because winter is the most difficult and...I don't aschieve [achieve] as much in the winter as I do in the spring, and summer and fall. (Alice, Interview 1)

Reconciling life as it is in terms of their diagnosis helps the participants to work through the changes and live life with a sense of hope. It is with this reconciliation they are able to be proactive in managing dementia.

Battling through by being proactive

Although the participants face a great deal of challenge as a result of dementia and respond emotionally to these changes, they battle through by being proactive in their responses. They acknowledge that dementia is a progressive disease without a cure at the present time, yet they all fight dementia instead of letting it get the better of them:

And I know that there's no cure. That's why, I guess I'm fighting to stay on top, you know. And, and uh, not let it get me down, because I think...and maybe I'm wrong, but ah, I think that that keeps you going better than if you were sitting in a corner and feeling sorry for yourself. You know. And that doesn't get you anywhere at all, so. (Rita, Interview 1)

Participants are proactive in their efforts to live with dementia in a variety of ways, including *stalling decline with activity*, *cuing memory*, *maintaining a sense of humour*, *avoiding stress and worry*, and *being open (or not)*.

Stalling decline with activity

Participants take proactive steps to slow further changes in cognition. Stalling decline includes participating in activities that are believed to prevent or slow the progression of

dementia. By engaging in such activities, the participants feel that they are prolonging their remaining abilities:

And I'm doing everything that I know to do, like playing electronic games and reading I feel is very good for me mentally. And walking and um...and exercise is very important for my Parkinson's. So I'm doing all I know to do in terms of being able to keep going. (Charles, Interview 1)

The belief that decline can be slowed gives participants a sense of hope for the future that counteracts the challenges they face. For example, they respond to frightening awareness of the future by actively trying to prevent that future, even though they recognize its inevitability, highlighting the paradox of challenge and hope. Stalling decline becomes cyclical – as participants engage in leisure pursuits in order to slow the changes, they feel they increase the length of time they will have the ability to engage in that particular activity. Charles included a photo of himself playing electronic games that exercise his mind (see Photo 5). When describing the photo, Charles tells me about the role of such activities in this cycle of stalling decline:

Because I think that...I feel that the decline is slower. If you keep your mind active, you don't lose...same way with the electronic games. Hand held. It's ah, keeping my mind active and so I might be able to, to play longer in fact I do it as much as I do, I might be able to continue to do it longer. Then I expect what could happen with Alzheimer's. (Charles, Interview 2)



Photo 5: Charles playing electronic games



Photo 6: Rita feels good when she succeeds at a crossword puzzle

Furthermore, having ability in leisure activities that are believed to stall decline leads to positive feelings about oneself. For example, Rita enjoys crossword puzzles and included a photo of herself working on one, noting her success: “Um, yeah, and I enjoy cras, crosswords.

And I'm pretty darn good at it (laughs)" (Rita, Interview 2) (see Photo 6). Stalling decline occurs in two ways, *exercising the brain*, and *keeping fit*.

Exercising the brain involves engagement in leisure activities that challenge one's thinking and thought processes. All participants engage in activities that require problem solving in order to keep their brains active and to slow decline. Participants exercise their minds in a variety of ways, including crossword puzzles, jigsaw puzzles, computer games, hand held electronic games, card and dice games, reading, playing the violin, and playing darts. While discussing his photo of a jigsaw puzzle, Jack tells me why it is important to engage in mentally stimulating activities (see Photo 7): "That's a whole idea is to keep, keep your brain up and, and ...and the only way you can really do your brain work is to get out there and work at it" (Jack, Interview 2). Similarly, Charles plays games not only because they are fun, but also because they require thinking and problem solving: "I asked him if he played Phase 10 (dice game) to practice adding. He said he plays games to stay on top of things and keep his mind working" (Charles, participant observation field notes, playing games). Alice plays Yahtzee to practice her math skills: "Alice stressed how therapeutic playing Yahtzee is: 'I seldom win but I play for therapy.' She told me she feels the skills – picking out sequences and adding up numbers - help her to exercise her mind" (Alice, participant observation field notes, crafts).



Photo 7: Jack working on a jigsaw puzzle

Activities that involve thinking are perceived as being important for maintaining thought process and memory: “So I think it’s important to keep your mind going all the time you know about certain things, because you, you need it when you are out talking to people but even in um, by yourself you need to keep thinking about names” (Rita, Interview 3). Activities that have multiple steps or tasks are believed to be important for brain exercise. Jack talks about the challenges of doing jigsaw puzzles to keep his mind active as we discuss his photo of a jigsaw puzzle:

And this one is working the jigsaw puzzle. And that’s something they can think, think about and ...it’s really, it, I think that’s one of the better things, because first of all, you got a, you got a, turn everything upside down, and then you got a try and find the right colours, and then, and they’re so hard to get them in the exact same spot because they, you try to force one in and then pretty soon you’re way out of whack...(Jack, Interview 2) (see Photo 7)

Leisure activities that exercise one’s mind are useful on a daily basis. Alice plays computer games when she wakes up in the morning, when she feels most confused, in order to wake her brain up and feel less foggy. Alice took a picture of her computer (see photo 8) and

tells me: “But that’s one of the things in the morning that’s key to me, um...getting my mind active because when I first wake up I’m really lost” (Alice, Interview 2).



Photo 8: Alice uses the computer

Stalling decline through activity is linked to fluctuating abilities and subsequent disquieting emotions. As abilities fluctuate, mentally stimulating activities become increasingly challenging, which can sometimes lead to frustration for the participants. Jack talks about doing puzzles to exercise his brain, yet feeling frustrated when the pieces do not fit properly:

...I can sit down and relax and try to get the right pieces in the right jigsaw puzzles and it makes me, relaxes me until I can’t find it and then it upsets me because I you know because they have to be right in the right spot. You know they don’t fit like they should or that and um, I have to, I have to find some better ones than what I had, but I’ve been doing it and I got it done. (Jack, Interview 3)

Despite the occasional feelings of frustration, these activities contribute to a sense of hope as participants try to, and often succeed, in overcoming the challenges the games and puzzles present. However, even when not successful, participants feel that they are doing

something positive – the attempt and thought process used are believed to keep progression at bay regardless of one’s level of success. Alice highlights this paradox when she tells me that despite her loss of ability in playing computer games, she continues to play with the hope of succeeding. I ask Alice to tell me why she still keeps trying even though the computer games become increasingly difficult:

The reason I do that [keep trying a computer game that is becoming more difficult] is it still gives me hope. That one day I might conquer. A different level, a different way. It may trigger a recall of something or it may trigger something more positive. And it’s the sense of the stubbornness not wanting to give up. (Alice, Interview 3)

Although these activities become increasingly difficult, the participants use mentally stimulating leisure to fight the progression of dementia.



Photo 9: Charles pole walking

In addition to exercising the brain, participants value *keeping fit* as a way of maintaining physical and mental capacity. Keeping fit occurs exclusively through physical activity. Most of the participants engage in physical activities to maintain their current abilities, slow further decline, and maintain independence. These activities include walking, pole walking, dancing,

golf, and fitness classes including stretching, balance, and muscle strengthening. Jack talks about the importance of his many physical activities:

This girl that we, that gives us our lessons she says anybody that's over 45 has to start balancing themselves and use themselves because if you don't you lose it. And we believe that and so we still do that. Yeah maintaining my health as much as I can. (Jack, Interview 3)

Charles and his wife go pole walking a few times a week and walk throughout their apartment building to maintain physical abilities. Charles included a photo of himself and his wife walking with the poles (see photo 9), and tells me: "Again, it, it's...one of my basic motives is to...keep my Parkinson's from going too quickly, and exercises would be extremely good for Parkinson's and for Alzheimer's. And that's part of the daily um, activity, to help keep us in shape" (Charles, Interview 2). Rita notes that exercising seems to help her memory: "I feel like I have to be active because it helps my memory" (Rita, participant observation field notes, walking). Jack, who values physical activity very highly, talks about how his exercise programs and physically active leisure choices help to maintain his health and well-being. Jack included photos that emphasize the importance of physical activity (see photos 10 and 11):

...but it's easy to slide into the spot that you're not even walking from the car to the store anymore....We think it's very important, I, I know that...or, at least I think that, ...if, if it wasn't for being active...I probably wouldn't be as well. With the health, that I am. And I think that everybody has, has to try and, try and ...get better and better and better. And, because sometimes, you're not going to be able to get out of bed, or something, and that's what we're trying to do. (Jack, Interview 2)



Photo 10: Jack stays in shape by walking



Photo 11: Jack stretches after his walk

Participants frequently choose mentally stimulating and physically active leisure pursuits in order to slow progression of dementia. They view this to be a proactive way to fight the progression of dementia.

Cuing memory

In addition to stalling decline, participants respond proactively to life with dementia by using a variety of tricks to remind themselves of important things. Memory cues include using calendars, medication dispensers, timers, routine, mnemonic devices, and reminders from family and friends. Charles tries to place his keys and glasses in the same spot each time:

“Yes...I cope by trying to have a special place to put my watch or glasses or anything that I am

going to use early tomorrow morning or later today” (Charles, Interview 3). Rita has difficulty with names and tells me about a trick she has to remember my name when we went for a walk together:

When we left the apartment to begin our walk, she told me she was having a hard time remembering my name, and her husband suggested that since she likes Reba McIntyre, she should just think of her, and then she would remember my name. She told me that she laughed at him and said, “But that’s shorter than her name.” Then she told me that it was working, she just thought of Reba McIntyre and my name came back to her. (Rita, participant observation field notes, walking)

Alice uses a routine to remember to take her medication:

So I sort my pills into the time of day, and I have to now, I used to put that pill casing up in the cupboard, now it has to sit on the counter where I see it because oft times I’m late with my meds now. The odd time I’ll forget them completely, but that’s still, I’m still reaching a 90-95% level of maintaining my medication. (Alice, Interview 1)

Memory cues can come from family members and friends as well, who remind participants of many things, including when to take one’s medications and how to complete an activity or task. Charles relies on his wife to remind him when to take his medication: “[my wife] has to help me with the medications. I would forget them at least half the time. If she weren’t here to help me” (Charles, Interview 1). He also relies on her to prompt him regarding games they have played for a long time. Charles’ wife not only reminds Charles about the rules, but helps him keep track of his score and tells him when it is his turn to play. He explains how to play the game to me, and how his wife helps him:

There are ten different phases that you have to – well with three turns, with each phase you get the highest score that you can get. And you have three choices, chances to do it. Well I always forget “Is this my second choice or is this my third choice?” And [my wife] will say “No it’s your second.” (Charles, Interview 1)

Cuing memory was apparent when I played cards with Charles and his wife. Since the game was challenging for both Charles and I, Charles' wife gently cued both of our memories so we could play:

[Charles' wife] always let Charles and I think it over before offering advice about what we should do next. After giving us a moment she would then offer suggestions about what might be the best move. This was followed by the warning "But it's a gamble, you never know what will happen." (Charles, participant observation field notes, games)

Cuing memory counteracts forgetting and is one way that participants battle through by being proactive in order to tackle life with dementia.

Maintaining a sense of humour

All of the participants maintain a sense of humour and laugh at themselves in order to handle the changes and challenges that they face. Charles says to me: "I can't change Alzheimer's, but I can laugh at my mistakes" (Charles, participant observation field notes, games). Using humour can help participants deal with negative feelings about themselves that may result from the changes that they experience:

And the bad things that happen, if you can make it humorous it helps allay, the umm...I was going to say disrespect, or allay the, the umm, frustration and, the and umm...how would you say it? A down feeling, a degrading feeling of yourself, yeah. So if you can use humor at any time, it's even better. (Alice, Interview 1)

Charles laughs at himself for forgetting. When we were finished playing games, he laughed when he forgot to give me my coat: "On my way out, Charles asked if I had everything, and I said I didn't have my jacket. He laughed and said 'It is a good thing you remembered'" (Charles participant observation field notes, games). He also joked about not being able to remember my name:

He forgot my name once and asked me what it was. [His wife] said, just like your niece. Charles laughed and said he had a lot of nieces. He told me his daughter-in-

law was also named Rebecca, but they call her Becky. He said he called her Mary once, and now she calls him George. (Charles, participant observation field notes, games)

Rita identifies herself as being someone who has a sense of humour, and similarly looks at how funny things can be when living with dementia:

I have a strong feeling that if you keep yourself um, feeling good or being able to laugh once in a while or find the funny side of life, so much better than finding the dark side and worrying about things that may or may not happen. And if they do you just have to accept that when it comes. (Rita, Interview 4)

Having a sense of humour helps one accept the challenges that result from dementia and is a way of making light of a situation that could be embarrassing or uncomfortable. Rita provides an example of how she uses humour to ease the changes that she experiences. By making fun of herself, she redirects attention from her forgetfulness towards her sense of humour, a valued part of her identity:

I'll even joke to somebody, "I remember you", it's a lady and "Your name is Bill is it?" (laughs). And that kind of thing you know gets me through and they tell me what the name is. So um, yeah, it's um, I think I'm so strong with the opinion if you deal with something that is happening to you that is not good and it's something that may be terrible. If you deal with it that way and live in it then you're lost. (Rita Interview 4)

Humour provides a means for the participants to deal with their losses and challenges. Being able to laugh at oneself helps participants to avoid feeling sorry for themselves or dwelling on the losses that they face.

Avoiding stress and worry

In addition to using humour to respond proactively to dementia, from time to time, participants respond to the changes by evading worry and frustration. For example, Rita steers clear of activities that might make her feel frustrated or that challenge her too much:

That's kind of hard to say because, it's just something that I pick up, and I don't even think I'm, it's like working at it, you know, it's just, and if I come across a, a

few...they're beyond me, or I can't really think about what to, how to answer it, then I'll give it up for a while, you know, and... I never like to get frustrated with anything. (Rita, Interview 1)

Participants also live hopefully with memory loss by trying not to worry about what is happening. Worrying can cause stress and Rita believes that this may exacerbate some of the challenges: "But I think when you worry yourself about it, then you're getting farther away from the answer" (Rita, Interview 2). She also avoids worrying about where she may have put things that she cannot find: "I don't get really hung up on things like that. No I don't. Because I think, uh, it will turn up somewhere, you know. Put something down" (Rita, Interview 1). In fact, Rita rarely even thinks about having dementia: "I don't worry about it. I very seldom think about it. Yeah, yeah. And nobody has asked me saying 'How's your Alzheimer's today?' you know (laughing). As long as they don't ask then I forget about it" (Rita, Interview 3). Alice agrees that avoiding worry and frustration can be very beneficial when having a difficult day:

And if there's some particular outing that I'm just not up for, I avoid it. That doesn't happen too often, but there are occasions where avoidance is very handy, and I think that's, I think that's a very optimistic approach to it, because we are not always up to these things. (Alice, Interview 4)

Avoidance helps participants deal with memory loss by focusing their attention towards what they can do instead of what they can no longer do. By evading activities that have become difficult, participants stay away from reminders that they are not the same as they once were: "I don't um, I sort of steer away from anything that's heavy, because I don't need that anymore..." (Rita, Interview 3). Avoiding more challenging activities eases the discomfort of feeling different. Charles provides an example of this when he tells me how he avoids speaking out in bible study to avoid the stress of not being sure if he'll know what to say:

I think for me the avoidance is in terms of speaking, talking publicly. Um, bible study's a good example of that where I used to be one of the first to raise my hand or express myself, and I've backed off completely. Um, sitting in the front row where I can see better and hear better, but the leader knows I don't want to be called on, because I know I'm going to have trouble expressing, or think I am anyway. So I just sit there like a bump on a log. I enjoy it though, but it's my way of coping. (Charles, Interview 4)

Avoidance can be a useful strategy to manage life with dementia. It helps participants focus on what they can do rather than their losses.

Being open (or not)

The final way in which participants respond proactively to memory loss is by being open. Three of the participants are open about their diagnosis with others and one is not. Both disclosure and non-disclosure of diagnosis lend themselves to comfort and safety around others. Those who are open feel better when others are aware of their memory loss, yet Rita, who is not open, feels she may be threatened by being open about her diagnosis. Charles talks freely with others regarding his diagnosis and the changes he experiences in order to explain his challenges to other people. By being open, he accounts for why he might forget someone's name or why he may have difficulty playing a well-known game or remembering a movie plot. Openness allows Charles to avoid uncertainty in others regarding his behaviour or forgetfulness: "And there's no more wondering what's wrong with him. And so I'm much freer and I think the people that I um...meet here and become friends with, most of them know it" (Charles, Interview 1). Being open is comfortable because it explains his forgetfulness. It eases feelings of embarrassment caused by muddled thinking:

I can get away with saying I don't know, I don't understand, I don't remember. Um in many ways, it's not embarrassing as before I knew I had it. Because now people know why. We live together, there's you know there's a lot of people here, and they pretty well, most of them like, know I have it. So it takes away the embarrassment of not being able to remember who the person is. (Charles, Interview 3)

Alice is not only open about her diagnosis, but her shifting moods as well. She tells her family when she is having a bad day so that they can change the way in which they support her:

Yeah, like, so, I think that's what's important is to be willing to let people see the real thing. Don't disguise it. And I don't...If I'm having a bad day, I'm having a bad day, if I'm miserable, I'm miserable. And I warn them "I'm having a bad day, I'm totally miserable, and I'm not sure what language will come out of my mouth" (laughs). So they know. And that's, that's, honesty, that's still being aware of...and there's some days I just have to stay away, because I want to have a fist fight, I get so frustrated. (Alice, Interview 1)

Different from the other participants, Rita avoids being open about her diagnosis with others. She would prefer if others do not know about her memory loss because she does not want to be viewed as a person with Alzheimer's disease. She explains this in her follow-up interview, after she has moved into the assisted living facility:

...today we had a nurse in here that was going to give some help to my husband and my daughter was here and she says "My mother has Alzheimer's you know" and uh, I was kind of shocked because I thought, we don't talk about that you know and um, but I don't think it's a thing that you have to be ashamed of, it's just something that happens to you, but it's um, it's something you'd rather not talk to people about because some people think oh isn't that too bad you know and it isn't a terrible thing to go through as far as this stage is concerned though. (Rita, Interview 4)

While openness is viewed positively by most of the participants as a way of explaining behaviour and garnering support from others, Rita feels better about keeping her diagnosis from others so that it does not change the way they think about her or treat her.

In sum, participants battle through the challenges they face in a wide variety of proactive, practical ways. In doing so, they are able to tackle life with dementia, facing their challenges and working through them or around them, gaining hope from their ability to find creative solutions, deal with their emotions, and take an active approach to fighting memory loss through leisure.

Living through relationships

The third essence of tackling life with dementia is living through relationships. Participants have close knit relationships with their family and friends that provide the participants with the support they need to counteract the challenges they face. All participants note that some of their relationships with their family and friends have strengthened as a result of dementia. Alice tells me about her niece, who has become closer to her and her sons since her diagnosis:

But...and... let's see one that's been really, really, (sighs), my niece and I would say we were close before, but she's my angel now. Umm, she's the one that understands the disease process the most, and she's the one helping teach the boys, the boys are very close with their cousin. (Alice, Interview 1)

Similarly, Rita notices that her children have become closer to her, especially since moving from her condo to the seniors' residence over the course of this study:

Well I think with our daughter, she doesn't live very far from here now and she's over here quite a bit and very good to you know to help us out here and get the place ready and everything and she's very good. I think we are much closer to her than we were when we lived in [city name], so, she's ah, we got closer to her. I think maybe to all our children a little bit because I think they're fathering us and (laughs) they're helping us live you know. (Rita, Interview 4)

Relationships with others are composed of *supporting each other, being together to secure a sense of belonging, trusting in others, and being accepted.*

Supporting each other

The participants describe their relationships with others as supportive. Family and friends provide emotional and practical support that help participants to live with memory loss. Participants, in turn, provide support for their family members and other people living with memory loss. Emotional support involves validation of feelings and experiences, being treated the same as they were before diagnosis, encouraging participation in leisure, and advocating

with the participants. Practical support includes providing transportation, helping with errands, keeping track of appointments, and assistance with paying. Charles' comments summarize the feelings of all participants towards their care partners: "She's a beautiful caregiver. She does not put me down in any way. It's very, very supportive" (Charles, Interview 1).

Having relationships means that participants have someone with whom they can share their journey of dementia. Alice, Charles, and Jack find their relationships with other persons living with dementia particularly supportive because they can compare experiences and encourage each other through the journey. Alice snapped a shot of her friend at a local coffee shop on their way to a support group meeting (see Photo 12). When describing the photo, she tells me what relationships with her peers mean to her in terms of support from others who are having similar experiences with memory loss:

I can't say more, but it's a combination of peers being together, friends being together, with a purpose. And that's the best way to put it. And of course it gives us, it gave us time to talk about what we each found difficult at that period of time, with our journey. As well. Because it's like, have you found this or if you notice that, and then, we find that we notice things similar. So there again it [the photo] reinforces the bond and for me it gives me a purpose to continue because I know I'm not alone. (Alice, Interview 2)



Photo 12: Alice has coffee with a friend

Support from others assists participants in their continued involvement in leisure and other daily activities. Alice's family supports her leisure in part by helping her feed the birds:

Oh the family endorses it. Because they, if I'm low on food they'll take me to get more and they'll bring it, so, um, there again they are endorsing my efforts. And that's important. Because if your family believes in what you are doing, then it only makes it that much better for myself because I know that I, if I'm having a problem I can go to them. I can consult with them. And it's nice to know, quote unquote I have their blessing. Because it was a new endeavor. And they, they're very keen on encouraging new...new projects and...um, trying to keep me active and things like that which is very important. (Alice, Interview 2)

In some cases support can be as simple as encouraging participation in meaningful leisure. Charles included a photo of himself playing cards with some friends (see photo 13).

This photo is meaningful for Charles because of the leisure related support it represents.

Charles gives a specific example of a close friend who supports his leisure and will continue to do so in the future:

One day...the lady in charge of the um, support group...said that really we should have Alzheimer partners. Someone that can learn to know you and your interests now and then as you lose these can remember what the interests were and help bring back memories and so forth. And um, I mentioned this at the table that I was looking for a partner and...a friend of ours said "I'd be happy to be

your partner for you.” And so we eat together a lot, we play games from time to time, we go out to dinner from time to time. Go to bible study every week. Go to hear musicals. (Charles, Interview 2)



Photo 13: Charles plays cards with his friends

Rita receives support from her husband for her leisure in terms of transportation: “[my husband]’s very good about driving me somewhere, and, and picking me up, you know” (Rita, Interview 1). Support also comes from family and friends for Rita when they treat her as though nothing has changed, supporting her sense of self:

And I’m so grateful for the fact that my friends don’t make any big deal about it you know and treat me the same and so does my family. And I think that helps a lot. I think if you’ve got somebody who’s looking at you like “Oh gee, I wonder what she’s gonna pop”, you know something, something’s wrong there (laughs). But I don’t get that impression anywhere, so that, that’s good. (Rita, Interview 3)

Participants also receive formal support from the Alzheimer Society, volunteers, and day away programs, which sustains engagement in many aspects of life, including leisure. Over the course of our interviews, Alice started receiving formal support from a volunteer who could help her with the housework:

So in that way... by making sure weekly the dishes and the meal prep, and the umm... umm...bed is changed, and fresh laundry and that. It's going to help me immensely. Ah, emotionally, physically, every way, because...umm, it's going to make me happier. (Alice, Interview 1)

Jack attends a day away program and finds the staff are very supportive of him and his leisure.

They support his interest in music:

Yeah, and it's good, and they treat me really good at the [day away program] there. I'm still playing with the xylophone and the ... guy that plays the music he was ah, he takes me down after the um, when the busses come in and [my wife] picks me up at 3:30 or 3:15 or something like that so we take the piano over and the xylophone it and sort of jazz it and he plays the um, the piano and I play the, try to keep up with the xylophone and it works out really good for us. And he was good enough to let me do it. So they've been good to me and I try to be good to them I guess. (Jack, Interview 4)

Alice uses the photo that she took of the birds on her balcony as a metaphor for the importance of having family and friends to feel supported on the journey of memory loss (see Photo 14):

And doves are always mates, they always keep the mate for life. And so it kind of supports in a way indirectly memory loss, because your mate supports you. If you don't have a mate then you have your family support and your friends. So that's kind of unique there in that you can see it in the birds they support each other in the memory loss. (Alice, Interview 2)

Feeling supported is reciprocal and some of the participants talk about supporting their care partners:

The fact that um, [my wife] and I are still able to enjoy looking after each other, is two streets, it's not one way. And I feel good about, I think I help my wife a lot more than healthy people do... In the fact that I, that I purposely try very hard to do what I can to help Ruth to be comfortable. (Charles, Interview 4)

Support can be reciprocal for friends as well. Jack talks about himself and his wife providing support for friends who are also living with dementia:

We have friends that we go out with every Sunday morning with them and um, this other chap has Pike's disease...Pick's disease. And he goes on and on and on and on but it's nice to...we do it for them and they do it for us sort of thing and that's still on...Yes for breakfast with him. [My wife] and his wife can sit there and

listen and I can sit there and listen to what he has to say because once he gets on the line he just goes on and on and on (laughs). (Jack, Interview 3)



Photo 14: Alice feeds the birds on her balcony

As part of reciprocating support, participants draw on their own experiences with memory loss to help others who are affected by it. Alice talks about how she helps her friend who has a relative with later stage memory loss. She is aware that her family and friends support her and will continue to do so, and she is aware of how she, in turn, can support them:

[my friend]'s grandmother is showing dementia and while she's well into her 80s but she's got her stepsister's aunt I believe is in the mid stages of dementia and she was asking me pointers on what to get her to do, because she's very anxious and she's sort of um, almost advancing to the end stage where there's no concept of normalcy, there's words don't mean anything, time doesn't mean anything, she's

extremely agitated. So she was a person who didn't have a lot of leisure, so I suggested to her that she had seven or nine children, so I suggested getting um, a doll and some clothing so she could dress that baby and um, because she tends to throw things. And then also folding, she was always great at ironing and folding so things like that, so. Yeah. So really um, I know as my journey progresses, they will only progress with me because they have a very good understanding, but also it felt good to be able to help give tips to them for how to deal with their loved one that is very um...lost in her own way and um, what do you call it, agitated. So um, yeah, I felt helpful, for them as well. (Alice, Interview 2)

Reciprocating support reminds participants that they are still able to make a contribution.

Helping others leads to feeling needed. By living in supportive relationships with friends and family, participants are able to continue to counter the losses they experience in leisure and engage in meaningful activities.

Being together to secure a sense of belonging

Spending time with loved ones is important to all four of the participants and contributes to a secure sense of belonging. Engaging in leisure or other daily tasks with their spouses, other family members, and friends leads to feelings of happiness and connection to others. When I asked Charles what makes him happy, he said: "Being together with [my wife] and doing things together" (Charles, Interview 1). Later in the interview he says: "What makes me happy is having, having her with me and having her as a caregiver" (Charles, Interview 1). Alice took a photo to demonstrate the significance of being together with her family and friends (see photo 15). In this photo, Alice is having dinner at a restaurant with her son and some family friends. She says of the photo: "...like anytime we're together with [my friends], and [my older son], or any of - or [my younger son] and [his wife], we're just one big family when they come..." (Alice, Interview 2). This photo emphasizes the close-knit relationships with family and friends for Alice.



Photo 15: Alice has dinner with friends and family

Similarly, Rita had a photo taken of herself and her granddaughter (see photo 16), with whom she is very close. She experiences a great deal of happiness from the relationship:

Umm, our grandchildren, especially this one that calls us all the time is uh, just the light of our life, you know. And uh, and we've really enjoyed her because we figure she might be the last grandchild we'll have, you know. And uh, uh, well all our grandchildren are very special to us, so. And we've always had, enjoyed them. And uh, that makes me happy. (Rita, Interview 2)

Jack also talks about the importance of being with his family. He tells me how he and his wife moved to be closer to their family members:

...and um, it other than that our, like we're blessed too in the fact that our family feel as a family and we do a lot of things together and they know that sometimes I'm not going to be here and that's why we're moving here too now we've got family. We moved from where we were which was wonderful and ah, this new place will be just as good. Now we'll have it, we'll have [my wife] and I, we'll have [our daughter] here, we'll have two nieces who are moving back into here and they've got two babes, you know two twins, and then the other one is having one (laughs) so, so we're making a family, a family get together more into a family deal...and not everybody's got that so I'm blessed in that. We do a lot of stuff together. (Jack, Interview 3)



Photo 16: Rita spends time with her granddaughter

By spending time with family members and friends, participants feel a sense of belonging in their relationships and find enjoyment and happiness, which in turn play a role in their sense of hope for their present and future. Spending time with significant others is a motivator for continuing on the journey of memory loss with a sense of hope despite the changes that occur.

Trusting in others

Living in relationships also involves trusting in others. Participants have faith that other people will look after their best interests, even complete strangers. Rita trusts that people will give her back the right amount of change so she can continue to shop on her own:

So I've learned to trust people, you know. You know you take, my hair dresser, when I go down to her I just, I give her more than it, than it, it is. She charges me \$22 for shampoo, and ah, so might give her two dollars ah, at more than that. And she always brings me, gives me back the change, and. So then. So you have to trust people more too. (Rita, Interview 1)

Rita reiterated this need to trust strangers regarding money when we went for a walk together in her neighbourhood.

We also talked about her problems with money. She told me she is no longer able to give the correct change and she just has to trust that people will give her the correct change back. She said that was another difficult thing, since she has always been good with money, both saving and spending it, since she “did the books” at her husband’s insurance company. (Rita, participant observation field notes, walking)

Having to trust others reminds Rita that she has indeed lost her skills.

Jack opted to trust his family as soon as he was diagnosed in terms of how he should handle life with dementia. He decided to believe their concerns and comments once diagnosed instead of questioning whether something was actually wrong:

Well I knew, once I found out like about golfing and stuff like that, and when [my daughter] said things and everything, I just decided if that’s what they’re saying, then they know more about it than I do, at that particular time. And ever since then. And they’ve always taken, taken me and looked after me well. (Jack Interview 1)

While trusting others enables Rita and Jack to continue to engage in leisure instead of backing off, Alice is less trusting and not as apt to have faith in other people, particularly strangers. She emphasizes how important it is to trust others, yet how difficult it can be to trust:

Trust is another thing too. Trust is, you have to trust who you’re working with in order to be umm, comfortable and relaxed with them. And have that confidence in the other person. So...umm, those assisting you, I have to have ...their trust, or I have to have trust in them. It’s utmost to me too. It’s something we didn’t talk about. Trust is a very strong issue I think for most of us. (Alice, Interview 1)

Being accepted

The final essence of living through relationships is being accepted by others. The participants are accepted for who they are now. Both their strengths and their limitations are acknowledged by their family and friends. Rita talks about how her husband accepts her,

perhaps more so than she accepts herself in terms of the losses that she has experienced or the loss of interest in some activities: “Yeah, yeah, my husband especially, you know will say ‘You know you can do a lot of things Rita that you did, that you don’t feel like doing now’” (Rita, Interview 3). Rita tells me that her husband accepts her no matter what: “...so he told me he would have married me even if I was like this all the time you know...” (Rita, Interview 3). Alice talks about how it can be challenging for family to accept the changes. She praises her family for working to accept her and facilitating her independence instead of taking over:

They’re very good, and [my niece] and my friends are very good at allowing me to have my dignity. And that’s a difficult role to play for them. Very difficult. It would be very easy to me to say “Well mom we’re going to do this, well mom we’re going to do that” and make the decisions for me. (Alice, Interview 3)

Other people acknowledge the participants’ strengths and abilities, and inform them that they are coping with dementia very well. Charles tells me how others believe he copes well with his illnesses: “Earlier I mentioned something that I feel that I cope well and people give me affirmation that um, I sort of handle it, handle my disease well” (Charles, Interview 2). Similarly, Alice says: “The people that really understand the disease are totally amazed at how I’m coping” (Alice, Interview 1). However, sometimes other people indicate to the participants that they do not appear to have dementia at all. This experience contributes to the paradox of challenge and hope because of the conflicting feelings it can create within the participants. In some ways it is frustrating for the participants, because they know they have memory loss and for the most part do not want people to think otherwise. At the same time, they take this feedback to be positive; it is a sign that they are indeed handling their dementia very well. For example, while Charles mostly experiences acceptance from his friends, sometimes they deny his experience with dementia, which demonstrates the paradox of challenge and hope. This denial that he has dementia, or the suggestion that he is doing so well

they would not know he had it makes him feel good by suggesting that he is able to cope with dementia, yet at the same time, it bothers him to have his experience denied: “I guess it bothers me a little when people say ‘I don’t, I don’t think you have Alzheimer’s.’ And I simply say, ‘Well look, I have two opinions and um, specialists both say I have it’. I know that I have it. I can feel it. Sense it” (Charles, Interview 1).

Being accepted supports the identities of the participants. They internalize the positive comments they receive from others and identify their personal characteristics in terms of being able to handle adversity well. When viewed positively, participants are supported by others to retain their social identities. Recognition of one’s ability to cope with memory loss contributes to positive aspects of identity. This contrasts with the negative impacts that memory loss can have on one’s identity such as lowered self worth. By tackling life with dementia, participants resist the overriding stigma of having memory loss and replace it with a more positive view of oneself.

The relationships that participants have with family and friends are a key part of the experience of tackling life with dementia, of “living” with an illness causing memory loss. With the support of others, pleasure of the company of others, and by being accepted, participants retain a sense of hope while living with memory loss.

Being optimistic

The fourth essence of tackling life with dementia is being optimistic. Positive attitudes towards current and future life are important for living out the dementia journey within the paradox of challenge and hope. Participants view themselves as people with positive attitudes who try to look on the bright side of life. These attitudes help them to sustain their senses of hope.

Thinking positively about the present and future instills a sense of pride in Charles despite the challenges that he faces. It is also a way of resisting the negative doom and gloom beliefs that society tends to hold about dementia. Charles tells me during our second and third interview: "...I keep coming back to a positive attitude, which I think describes me...quite well" (Charles, Interview 2). He later says "And I was talking many times about the positive mental attitude, I feel that I can rise above despair, or um, depression, I think I've done well, well with that" (Charles, Interview 3). Similarly, Rita considers herself to be a very positive person, and she believes that her optimistic outlook will help her to slow decline: "So I'm thinking that, being positive is really the thing that's going to break it. It's going to make it longer, make you feel better. I think that's an answer to it you know" (Rita, Interview 3). Maintaining an optimistic outlook on life is vital for maintaining the balance within the paradox of loss and hope, rather than just falling into despair about what has been lost. There are four ways that participants maintain optimism about their current situations, including *feeling hope for today and tomorrow, focusing on the positive, comparing self to others, and normalizing experiences.*

Feeling hope for today and tomorrow

All participants have positive feelings, aspirations, and dreams for the present and future. They hope that the dementia progression will continue to be slow. They also hope for new drugs to come on the market that will further protect against dementia pathology. During our pole walking session, Charles speaks about his hope for the future: "He told me he had spent the last week counting his joys and that he felt grateful to be alive at this time where doctors can help and there are medications coming out all the time" (Charles, participant observation field notes, pole walking). This sense of hope juxtaposes the frightening awareness that

participants have for the future. Immediately after telling me about his fear of wandering in a nursing home, unable to talk or think, Charles is hopeful: “But um, it may not. Medications are coming on the market all the time, face that when the time comes” (Charles, Interview 3).

Rita is also hopeful that her memory loss will not progress significantly, but since she is aware that it may well progress, she is hopeful that she will not be too bothered by it:

So I think it’s just letting, it’s getting yourself to the poin - position where you are saying to yourself “There’s not that much change to me” you know so I still carry on like I do, and now that day will come where I probably will not be able to carry on the same way, but maybe by that time I won’t care you know (laughs). (Rita, Interview 3)

Jack’s hope for the future focuses on the degree of control he hopes to have over moving into long-term care:

I don’t think that’ll happen until it will be time for me to go into the long-term deal, I want to be in the long-term deal, facility, before, before I really need it. I’d rather be there ahead of time instead of after until it was too late to be a half decent guy. (Jack, Interview 1)

Hope for today and tomorrow extends to leisure as well. Participants have aspirations for their leisure time. For example Rita talks about going shopping:

But that’s, no I don’t generally stay home, um...unless I want to and I haven’t got any plans made, but generally I can go out quite often in the afternoon like today, we’ll probably go somewhere for a ride. I’ve been trying to get him to take me down to IKEA though. I love that store (laughs)...And um, so he keeps saying, “I’m not sure where it is”, and I say “You get in the driver’s seat and I’ll tell you where to go” (laughs) but we haven’t gone there yet, but we’ll get there. (Rita, Interview 3)

Although the fear of future memory loss is part of the participants’ experiences, their experience is paradoxical in that they also have hopes, aspirations, and dreams for their lives.

In addition to having hope for the future, participants no longer take their time for granted. They live in the moment to counteract current and future challenges. By doing so,

they are able to fulfill dreams and aspirations. Jack stresses the importance of living in the moment in our third interview:

So I'm going to live it to the best I can. And if somebody asks me a question, "What should I be doing to make my life better in, in because of Alzheimer's?" I would say "Enjoy it, do it, do the best you can and, and enjoy every moment of it and don't procrastinate, don't think you should be doing it tomorrow, do it today, and if you, if somebody comes in and says to you I did this wrong, well okay you did it wrong but do it again and do it right." And that's what I would like to tell everybody who gets this thing you know like there's no reason for somebody to lay in their couch for half a day or something like that because they think their knee is sore or something like that. Get up and walk and do all the rest, like the last couple weeks, I went out three, four times, four times in a row and I my elbow's sore so we went out and got one of those sticks and now I'm hitting with this thing up here, got the elastic brace. But I still go out and play. And why waste the time? (Jack, Interview 3)

Leisure plays an important role in living in the moment. Participants wish to live in the moment regardless of their stage in the journey and they are able to do so in their leisure time: "because I was forced to look at what I was doing to um, enjoy the moment, enjoy the day, um, at whatever stage I'm at with the memory loss. So it actually reinforced the importance of leisure time" (Alice, Interview 2). They do this in part by fulfilling long and short term dreams. Instead of putting things off, participants choose to do them while they still can. Charles and his wife like to travel. Charles tells me in his first interview that he is planning several trips during the summer: "I think my traveling days are coming closer to an end, and we're sort of saying let's, let's do it while we can" (Charles, Interview 1).

For Alice in particular, being diagnosed with dementia has given her the time to fulfill her dreams – she was a busy single mother and nurse before being diagnosed and now she has time to do what she wants:

...Working full time and being a single mom, there was leisure things I put on hold, so actually with the announcement of the disease, instead of taking a negative view of it, I took, well okay, what are those things that I always wanted to

do leisurely that I didn't have time necessarily to do before. So um...it actually in a way was a blessing. (Alice, Interview 2)

Alice now has a list of dreams she would like to accomplish while she still can, such as going to her favourite poet's home, going to see a local junior hockey game, and going to see a concert of her favourite singer, which she accomplished over the course of our interviews. Living in the moment and in turn fulfilling dreams and aspirations has become increasingly important for most of the participants as they want to take advantage of the time they have in which they can enjoy life.

Focusing on the positive

All four participants highlight the positive aspects of their lives and their remaining abilities. They count their blessings and reflect upon the ways they consider themselves to be lucky, which is fundamental to maintaining an optimistic outlook. Rita reflects on her life as a whole and does not mind having memory loss since she's had a wonderful life: "...she was glad to have this disease now, she had a good life and enjoyed it, and she was still enjoying it. She told me if she only had five years left than she would enjoy it" (Rita, participant observation field notes, walking). Rita believes that this positive attitude helps her to tackle life with dementia: "I think, I really believe, keeping your, keeping your wit about ya and... looking on the brighter side of life is the only way to go" (Rita, Interview 3).

Instead of dwelling on losses, the participants keep them in perspective. Alice tries to forget the negative things that happen in order to focus on the positive: "...I tend to forget the negatives, so ... you know I'm sure there's been more negatives than that, but I've chosen to...let it go. 'Cause I'm wasting time from enjoying the moment" (Alice, Interview 1). Charles talks about his own positive attitude: "Um...I pride myself I guess in feeling that I have an attitude of gratitude (chuckles). I have so many things to be grateful for" (Charles,

Interview 4). Rita talks about being thankful for what she has instead of dwelling on what has been lost: “But no I think being positive about things and laughing at yourself even feels good. So. I, I just um, I just think that everyday you get up is another day you got, and um, I’m just thankful for that” (Rita Interview 3).

Alice works to focus on the positive aspects of her life despite the losses she has experienced: “And umm...then trying to turn around put a positive side on it. So that is the key, is turning it around and trying to bring it...into the proper focus, a more positive focus” (Alice, Interview 1). In order to do this, she makes it a point everyday to focus on the positive aspects of her life while acknowledging the challenges:

...I think it’s just...making the best of what I’ve got, and each hour and each day. Doing the best I can with what I’ve got. And being as happy as I can, and if it’s a bad day, endorse it, but don’t let it be bad for long. I think the important part is just...I guess what’s important to me is making the best that I can of the journey. (Alice, Interview 1)

Jack’s spin on focusing on the positive is slightly different than the others. He talks about the advantages of having a diagnosis of dementia compared to other illnesses, while recognizing that there are many negative things about living with memory loss:

...I tell everybody the good thing about Alzheimer’s is the fact that it gives you enough time to think of what you should have been doing before your time was over....it isn’t like ah, it isn’t like a stroke where right away you’re dead. And the other thing is it is not contagious, so people...have no fear that I might be going on or passing it on to them. And that’s about the only two good things about it. (Jack, Interview 1)

Participants also talk about the slow progression of dementia up to this point in their lives. They are grateful that the disease is not progressing quickly and they are able to adjust because their changes are gradual and often go unnoticed:

No I really, I really don’t feel, like I know that there’s some changes and um, but the changes like I say its like hearing and stuff like that it’s so slow that you don’t really notice it. At least I don’t think I really notice it. (Jack, Interview 1)

Jack goes on to tell me about how gradual the change is – it is not a sudden change that affects your life immediately, rather you have time to plan and prepare for changes that are to come:

Oh there are different changes. There have been some changes yeah but they're not. It's like losing your ear or like losing your, your, so you can't hear. It's very slow. It's like you know you don't have to go every once in a while and get your glasses changed because you don't notice it. And this is a very slow movement. You know, like it's not, it's not like today I'm smart and tomorrow I'm dumb. That doesn't happen. It just sort of pitches over the wave. (Jack, Interview 1)

The sense that progression is slow gives the participants hope that things may not get worse.

Rita often feels that nothing has changed for her; she feels the same as she always did: “And um, but ah, I don't see any, I don't see any real difference myself in my thinking or anything you know” (Rita, Interview 2). Although Rita talks about some of her challenges throughout our time together, she also tells me she has not experienced any challenges. She suggests on a few occasions that her diagnosis could be wrong. Focusing on the positive aspects of her life allows her to disregard the challenges she faces, indicating that the experience of memory loss is indeed complex and fraught with paradox.

Participants also focus on the positive aspects of their lives by celebrating their remaining capacity. Instead of keeping track of what they can no longer do, they rejoice in their remaining abilities. They do what they can on their own and then seek help in areas where they may need it. Alice talks about celebrating her capacity when she finally completes a task she has been working on for a while:

When it happens, it's like a party time. Like we're going to have a big debutante ball tonight because I got this done. After this number of weeks, I finally accomplished this. Yeah. So, it's celebrating the, umm...accomplishments is ah, is actually a celebration. Because, I don't know if two weeks from now I could do it again, so why not enjoy the moment? (Alice Interview 1)

Although Rita rarely cooks, when she succeeds at the task, she recognizes her accomplishment. Rita tells me a story about making a meal for her husband:

Last night, this is a very big thing for me, last night [my husband] had a meeting out at the, in the atrium out here and so I said, well I'm going to cook us supper, and I haven't cooked anything for a long time, quite a while. And we either go out to eat or we buy something, bring it in, you know. So uh, I made a, a casserole, so when he came in I had it ready, he sat down and he says "Really good, I can't get over it, this is really nice." And ah, I said "Yeah, thought I did a good job", you know. And that was the first time and I felt like I'd really done a big job, you know... it was an accomplishment for the day. (Rita, Interview 2)

While Rita has difficulty with money now, she can still use the computer for writing poetry, which makes her feel good: "I do some poetry on the computer, things like that, er, just for my own fun, you know. And um, but ah, I don't see any, I don't see any real difference myself in my thinking or anything you know" (Rita Interview 2). As a result of having lost her abilities with money, she feels particularly proud of her remaining capacity to write poetry on the computer, which is also a complex activity. Charles celebrates his capacity to continue to contribute to the household chores and pull his own weight. This helps him to feel good about himself and contributes to his self-esteem:

I think I'm much happier when I feel good about myself. That's what I was saying about carrying my own weight, I can vacuum the floor and wash the dishes and, and um, take the garbage out on my own, and let [my wife] have space so she can read or write or whatever she's doing. So I'm positive attitude about being able to support her. (Charles, Interview 1)

Celebrating capacity comes in part from belief in one's self and confidence that one can continue to do things independently: "So that's what I would encourage others. You know, like...believe in yourself and try for yourself. No matter how hard it is, you know. Believe in yourself, right to the very end, believe" (Alice, Interview 1).

In sum, participants have a variety of ways of focusing on the positive aspects of their lives in order to maintain their optimistic outlooks. They keep in mind that there are many

things they can still do, they are thankful for their slow rates of decline, and they celebrate their remaining abilities.

Comparing self to others

In addition to focusing on the positive, participants compare themselves to other people living with memory loss. These comparisons highlight the strengths of the participants and help them to remain optimistic. This gives them a sense of satisfaction in their continued abilities and slower progression of dementia. It reminds them that things could be worse. Jack, for example, compares himself to other people with dementia he knows who deny they have memory loss, which Jack believes has negative impacts on their lives:

So, but there's people that are so long in denial that they miss what they could have been doing while they still have the full part of their life. And that's a shame. They're not there to live with the kids and the rest of it. (Jack, Interview 1)

Comparing self to others reinforces identity as individuals who manage well with memory loss:

I know when I go [to the support group], we have the other, some other ladies there too, and um, the one especially cries a lot and gets upset you know and ah that's one thing I really avoid, I don't ah, I don't get to that point where I'm really upset you know. (Rita, Interview 3)

Interestingly, the participants of this study tend to focus on comparisons that emphasize their own strengths, abilities, and advantages, rather than comparing themselves to those who would make them feel worse about themselves, question their abilities, or lower their self esteem. For example, in our follow-up interview, Alice compares herself to some of her peers, noting how lucky she feels to be doing so well:

And there are other times that, more so lately when I see some of my peers going down a little bit and I'm thinking oh I'm so grateful because I'm still where I am. Um, yes there are changes, but um, I'm still able to cope with them, where I see others really, really struggling and that makes me sad. (Alice, Interview 4)

While in some cases they know people who had experienced the end stages of dementia and fear what the future may bring, the participants avoid looking for similarities between themselves and persons with end stage dementia. They also avoid comparing themselves to persons without memory loss. Doing so may protect against frightening awareness.

Normalizing experiences

In addition to comparing self to others, occasionally participants explain their forgetfulness as being normal, indicating that everyone forgets every now and then and they are really no different from other people. They do this to maintain their optimistic outlooks. Normalizing helps them to feel more positively about themselves and the changes they are experiencing. It decreases feelings of worry about memory loss. Rita explains how she forgets names, but this is normal for other people as well:

Forget names once in a while, but I find a lot of people are like that. Like ah, a lot of people will say, you know, "I can't, I'm getting so I can't remember a name." And I say, "Oh don't worry about, you know. Because you're not the only one that's like that." (Rita, Interview 2)

By normalizing her symptoms, Rita is able to avoid worrying about herself and her problems:

"I see a lot of people who have never been diagnosed with Alzheimer's who are doing the same thing. So I said, it's not a big deal with me" (Rita, Interview 2). Rita takes some comfort normalizing her experiences: "...and I'm, I'm so encouraged when somebody says 'Gee I can't remember the name of that person!' (laughs) oh good for you, you know, that's great." (Rita Interview 1). Jack also normalizes changes in cognition with increased age, although acknowledges that Alzheimer's is a bit different:

Like if your Dad is over uh, 65 say, or whatever it is, uh, uh, you can't expect him to be as bright as he was when he was 45. And, and we're all doing that, and, but at least Alzheimer's gives you the opportunity that you can have some of that and extend it. (Jack, Interview 2)

Rita normalizes not only for her own comfort, but also to make other people feel better about her diagnosis, particularly her grandchildren: “And I said, ‘Don’t feel bad about it. What about people that break their legs and stuff like that?’ You know. And a lot of people do, they get a lot of things wrong with them so” (Rita Interview 1).

While normalizing is essential to being optimistic along the dementia journey, sometimes other people normalize the memory loss of the participants, which undermines their experience of dementia, highlighting the paradox in which the journey occurs. Earlier, I demonstrated that participants experience denial on the part of others regarding the experience of memory loss. Similarly, when normalization is forced upon participants, they experience a dismissal of the journey that they are on. Alice explains what this is like: “Those that don’t understand say ‘well I have memory loss, I forget things too’” (Alice, Interview 1). Alice talks about a specific incident with a former friend who told Alice her forgetfulness is normal. The friend told her:

“Oh yeah, I forget too”. And ah, I said, “But...it’s totally different.” “Well I can’t see where it could be any different than anything else.”...And I said, I took my shoes off, I put them in front of her. I said “Now try walking in those for six weeks, come, come back and let me know what you learned.” And she just turned and walked away. (Alice, Interview 1)

Normalizing experiences is a way to tackle life with memory loss providing that the participants themselves were normalizing the experiences. When others normalized their experiences, they found this disrespectful and hurtful.

In sum, participants remain optimistic, having hope for today and tomorrow, focusing on the positive aspects of their lives, comparing themselves to others and normalizing their experiences in order to live with hope through their journey of dementia.

Prolonging engagement in meaningful activities

The final essence of tackling life with dementia involves prolonging engagement in meaningful activities. Prolonging engagement includes a variety of ways in which the participants and their families enable continued participation in leisure and other activities. When abilities are enabled by oneself and others in one area, other areas are also enabled. Prolonging engagement in meaningful activities plays a role in maintaining identity, particularly for Charles who sees himself as a person who copes well with things, so finding ways to enable his own leisure preserves this particular aspect of his identity. Key essences of prolonging engagement in meaningful activities include *seeking help to improve a situation*, and *altering leisure*.

Seeking help to improve a situation

Participants often ask family and friends and even formal service providers for assistance to make leisure and other tasks easier. Asking for and receiving help from others enables leisure participation to continue. For example, Alice talks about getting help with letter writing, something she enjoys, but would have to give up without assistance: “So, that’s going to open a whole new field of accomplishment for me as well. So, there again, um, leisure time is going to be even ...more...more fun? More pleasant, more...enhanced” (Alice, Interview 1). By actively seeking help letter writing, Alice believes she will accomplish new things and increase her leisure enjoyment. Alice talks about personal growth on the journey and how she is now able to ask for help, something that was once very difficult for her to do: “I am now asking for assistance. And a proud person like me admitting that, yeah, it’s time, is a big acknowledgement on my own self, of my, of knowing myself” (Alice, Interview 1). By learning her limitations and reacting to them, she is able to maintain involvement in leisure:

“Because I’m giving, not giving in, I’m realizing my self, my own self limitations, and acknowledging it, and reacting to it” (Alice, Interview 1).

Charles similarly seeks help to address the challenges he faces. Charles requested a magnifier from his doctor to help him read (see photo 17). The photo Charles included of his magnifier is meaningful not just because it enables his reading, but because it demonstrates that he is a person who is proactive in solving his problems:

I wasn’t happy with my reading problems and um, I had the optometrist give a letter asking for um, interview at the School of Optometry. So I’m glad they did. This is just made reading a pleasure, where without being able to see clearly it was a problem. So I’m going back on the 30th of May to see what we can do about when I don’t have a machine with me... (Charles, Interview 2)

He goes on to tell me why the magnifier is important: “...learning to know my body and telling my doctor about it, um, is typical how I try to bring the change as much as I can” (Charles, Interview 2). Seeking out help emphasizes Charles’ view of himself as someone who works to solve his problems instead of avoiding them:

And the other thing is that if there’s a problem it’s the reverse of that. Um...and this would include as a good illustration is all four of them, the Parkinson’s, the Alzheimer’s, the eye problem. I’ll go, as soon as I realize there’s a problem, I’ll go and get help. For many people, wait and wait and wait and never, never find out what’s wrong. (Charles, Interview 2)

By seeking out help participants both enable themselves and are enabled by others to prolong engagement in meaningful activity. While Alice suggests that seeking help involves feeling comfortable enough to acknowledge the need for assistance from others, Charles suggests that being attuned to one’s body and the changes that are happening helps one to know when to ask for help and who to ask for help. This indicates that although all participants seek help, the way in which they arrive at the awareness of the need for more assistance differs.



Photo 17: Charles uses a magnifier to read small print

Altering leisure

Participants also prolong engagement by altering leisure activities so that they can continue to perform them. They change both the activity and their goals in order to continue to experience success. Participants act within their capacity instead of giving up an activity all together when their abilities change: “Instead of what can’t I do, it’s what can I do. How can I change what I’m doing, adapt it, so that I can go further in this activity?” (Alice, Interview 1). Although the nature of the activity is different, its meaning and value are retained. Alice tells me that assessing her capacity, acting within that capacity, and altering her activities to match her new capacity are important for meaning and fulfillment:

So, now because I’m not able to work ‘til retirement, or to have quote-un-quote a normal retirement, I have to pick out the things that I’d really like to do that are within my capabilities. Because if I do that, then I achieve the maximum of happiness and pleasure. But if I try to pick out something that’s beyond my ability to understand or to enjoy, it will not give me that fulfillment....So why do something like that, if I’m not going to achieve what I really want, when I can do something, maybe a little lesser in scope, but achieve just as much and maybe more. So I think that’s really a key element too, is realizing what you can get the... most for the buck. And the fact of self satisfaction. (Alice, Interview 1)

While Alice notes that acting within her capacity leads to fulfillment, going beyond it can lead to frustration and disappointment. Therefore altering activities to match capacity is vital for enabling abilities. However, Alice also notes that finding this balance can be difficult:

My desires and my, and my, challenges to within where I can...get the most satisfaction and enjoyment out of. And it's not easy. Because I tend to set my, my goals higher than what I can attain. So learning how to bring the two together so we meet ...it's a 24/7. (Alice, Interview 1)

Participants provided specific examples of how they alter their activities in order to enable their abilities within those activities. Jack and his wife used to ballroom dance, but have switched to social dancing so they can continue to enjoy the activity without the pressure of following ballroom dancing etiquette. Jack included a photo of himself dancing with his wife and explained how they have altered their dancing to accommodate his changing abilities: "...it's the fact that I...we'd taken le, lessons forever. And, and, and now it isn't worthwhile because I can't remember what I'm doing anyways, so we just play a very, very relaxed...dance...yeah..." (Jack, Interview 2, see photo 1).

Charles manages a wide variety of limitations to enable leisure participation, including his vision and balance problems associated with Parkinson's. Charles had a photo taken of himself using walking poles for exercise (see Photo 9). The walking poles help him to manage his mobility limitations, maintain balance, and walk for a longer period of time: "And pole walking is easier...than walking in some senses because you're using all four limbs. And um, going up and down a hill it's easier with poles than it is without" (Charles, Interview 2). Using the poles means that Charles does not have to walk with a cane, thus they encourage his continued participation in physical activity.

Participants change the nature of the activity as well. For example, leisure that is normally competitive in nature becomes individual or cooperative. Instead of competing in darts, Jack plays by himself so he will not risk injuring someone else. In this way, he still practices the skills needed for darts and enjoys a valued activity. He included a photo of himself practicing darts (see Photo 18) and says: “And darts, we do, I do that. Do that about, since I’ve had Alzheimer’s ...I don’t, I don’t play in...the league anymore, I just go and practice, practice, practice throwing darts at the dart board...” (Jack Interview 2). Jack enjoys competition, but now competes with himself to improve his score or ability instead of competing against other people. Alice included a photo of herself and a friend playing Yahtzee (see Photo 19). Her description of the meaning of the photo highlights the cooperative nature of a competitive game:

Yeah, um, I may miss sequences, like you know, or miss, miss a combination, and um, or I’d spot it for her, and it was sort of, it wasn’t, we were sharing it. It wasn’t that one was out to get the highest score, it was sort of like camaraderie, so it was, yeah. So there was times I would see them and there was a lot of times I’d miss certain numbers and she’d point them out, so yeah, it was a camaraderie, yeah. (Alice Interview 2)

The communal nature of the once competitive game was also evident when Alice and I played computer games together:

Alice would show me where a row of three could be made if I couldn’t see it. She told me it was different playing with someone else because she could see all kinds of patterns that I wasn’t getting. I told her I thought the same thing while she was playing. She said if she always had someone to play with then she would do quite well, and laughed. (Alice, participant observation field notes, computer games)

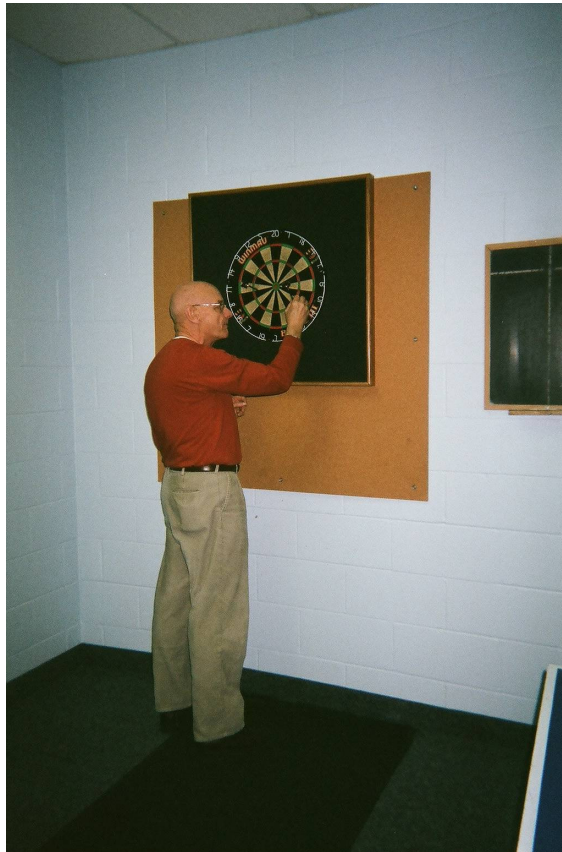


Photo 18: Jack plays darts by himself



Photo 19: Alice plays Yahtzee with a friend

This process of adjusting activities to meet new abilities occurs on an ongoing basis.

Alice tells me that she continually reassesses her abilities and adjusts her activities accordingly.

She will take steps back and build up her skills again:

Even if it means going back four or five steps. Starting over again. And building it up. So it's a 24/7 adaptation and changing, um...process for me. No two days are the same. Um...mentally, physically, emotionally, the whole, spiritually, the whole ball of wax so to speak. It's a 24/7 pro - project - process. Um. Adjustment. (Alice, Interview 3)

Unfortunately, not all activities can be altered to prolong participation and sometimes participants withdraw from activities when challenges can no longer be addressed. This primarily relates to activities that involve group interaction. Charles no longer feels comfortable speaking in a group, so he just listens: "...I'm backing away from people. Where I used to be more aggressive in terms of being outgoing. I am more comfortable sitting back and letting the conversation go" (Charles, Interview 1). Alice no longer speaks in front of large groups as an advocate: "...my speaking ability, umm...(pause)...I'm not able to remember, like what I said to you in the last question, I have no idea what it was. So in that way, speaking's become...too much of a challenge, so I've really withdrawn from it" (Alice, Interview 1). While altering leisure enables activities, it is not always possible to continue to participate in activities that are meaningful for the participants.

In addition to altering their leisure activities, participants alter their expectations of their own performance in those activities in order to enable participation and enjoyment. Doing the best one can is more important than doing as well as one did before being diagnosed with dementia. Accepting that abilities have changed and subsequently altering one's expectations of one's performance based on these is imperative to being able to continue to engage in

activities. Jack talks about how he changes his expectations for physical activity, all the while maintaining a sense of humour and self acceptance:

And I would think it would be more right to make sure you are doing the best you can. Like I tell everybody “I’ll do it the best I can and I know it will be rough enough”, you know. I use that all the time. Because that’s all I can tell people. If somebody comes in and says “Well I can’t walk here” say “Okay, just walk twenty feet or thirty feet or something and come back but don’t try to do it all at once or anything else” and it’s so it’s like, but I’ve always been an athlete, not a good one, but I, I, really all my life, I played ball and I played soccer and hockey and all that stuff, and raced and all that sort of thing. Now I tell everybody I used to run a hundred yards in ten seconds, and now I go out and run for ten seconds (laughs). (Jack, Interview 3)

Accepting their new capacities helps participants to alter their expectations of themselves. Rita steers clear of activities that might be too challenging for her, instead participating in activities in which she knows she can be successful. Rita plays Skip-bo with her friend, which is a simple game, instead of learning how to play bridge, which she thinks she would also enjoy. Rita asked her friend to take a photo of her while they were playing cards (see Photo 20). She explains to me during our second interview:

Uh, no it’s a very easy game we play and she plays bridge a lot, and I keep asking her to show me how to play it and she says it’s very complicated, you know. And I don’t think I’d really want to play it, you know. I like the easy ones. (Rita, Interview 2)



Photo 20: Rita enjoys playing cards with her friend

As well, participants alter activities by setting flexible goals – if they need to adjust their goals to meet their abilities, they can do so easily instead of giving up on the activity all together. Alice talks about crocheting dishcloths for a conference she was helping to plan and attend in the near future when we crocheted together:

As I chined, Alice mentioned that she would like to try to crochet a dishrag for each bag for the [conference]. I asked how many that would be and she told me it would be 200. I said that's a lot of crocheting and she said she just wouldn't tell anybody until she got closer to that number so if they didn't get done, that would be okay. (Alice, participant observation field notes, crafts and games)

By adapting both their expectations of their performance in activities, and changing the activities themselves, participants enable continued participation in meaningful leisure.

Spending time with Jack, Alice, Charles, and Rita revealed for me that they work to tackle life with dementia. They do this in a variety of ways that allow them to continue to have meaning and purpose, and make contributions to their own lives and the lives of others. These techniques provide them with a sense of hope along their journeys and remind them that they

are still capable people who have purpose in their lives. I now turn to exploration of the bottom two circles in Figure 1, in which the paradox of challenge and hope is revealed as the participants juxtapose threats to their identities by upholding identities.

Threatening Assaults on Identities

Earlier in this chapter, I presented findings that explored the changes that participants encounter as a result of the pathology of memory loss. However, participants also experience changes that are related to lowered expectations of others as a result of the diagnosis of dementia. When combined with challenges that result from the pathology of memory loss, participants find their identities are threatened. Alice talks about the lack of acceptance of dementia in society, which contributes to all of the ways in which identity is threatened:

To me it's like having any medical illness. You have to go through your grieving process and then accept it and then make the best of it. It's no different than say if we had cancer, if we had diabetes, if we had any of those illnesses that are accepted. The problem with dementia is we haven't reached the acceptance in society yet, but in the last five years, there's big strides being made. (Alice, Interview 4)

Threats to identity can result in a questioning of oneself and one's remaining abilities, undermining one's sense of self. Valued characteristics and personality traits are altered by threats to identity. Essences of threatening assaults on identity include *disappearing roles*, *losing independence*, *struggling with demeaning images and expectations*, and *losing confidence*.

Disappearing roles

All participants have lost some of their previous roles since being diagnosed with dementia. Two participants, Alice and Jack, were forced to quit their careers that comprised their personal and social identities after diagnosis. Participants were no longer supported to

maintain responsibilities associated with their jobs or to perform those familiar work roles.

Jack lost his contract work after he was diagnosed with Alzheimer's disease. He tells me that he believes he could still do the work, but recognizes the risks:

Yeah. Yeah in my job that I had you could that's right. And that's why I can't go out like, I still think I could go out and do a job in the plant and, and do it right. But then if I did something wrong and, and a valve breaks and a valve breaks, all of a sudden somebody might get hurt and blow up the tower and all that sort of stuff so. (Jack, Interview 3)

Although he acknowledges the risks, his former work roles are greatly missed: "...all the way through I really enjoyed my work and it's a shame that I can't do it now. And it does, it's something you lose" (Jack, Interview 1). Jack was well respected in his field and he wishes he could return to work not only because he enjoyed it, but also so he and his wife could continue to travel:

I go out and in all the companies like I say I was well respected in what I did and they kept bringing me back and bringing me back right up until this silly little thing happened, and I would love to go back and it'd be nice too, then we could go places... (Jack, Interview 3)

Alice also talks about being forced out of her job. She explains how she was assessing persons living with dementia one week and being assessed her self the next:

And just before I left we were turning our unit into an assessment unit for...umm, memory loss, and placement, and this type of thing, and we were doing the minimal and stuff like that. So ironically, here I was assessing others with minimal, and turning around a few weeks later, I needed the mini-mental myself (laughs). So, it's kind of ironic. (Alice, Interview 1)

Alice goes on to tell me that she was eventually forced out of her job: "And I was escorted out and just told point blank that I was incapable of working" (Alice, Interview 1). Not only did she lose the role, others failed to support her social identity as a nurse by emphasizing her losses instead of her remaining capabilities. These role losses are grieved. Participants reflect on how their lives could be different if they were able to continue to work:

I think it, I think like it would feel as if somebody took away your driver's license and you couldn't drive. I think it's the same thing. The same feeling. Because all of a sudden you're thinking, jees you know like I could be out there working and making good money and everything else. (Jack, Interview 1)

For these two participants, diagnosis of dementia and subsequent loss of jobs also led to a loss of income, affecting their ability to participate in some leisure activities:

You figure when you come out of, work, you know like I retired when I was 62 and then I did contract working until I was 60, 69? 69. And I was making good money. Really good money and everything. So we could do whatever we wanted to do. We could go to Japan, we could go here, we could go there, we could go, because we had the money and now we can't do that, like we don't have a lot of money now. (Jack, Interview 1)

In addition to work roles, leadership roles within one's community have fallen the wayside: "Well they used to ask me to lead in prayer or do something say something in public maybe. Um it wasn't a big problem, it is, it is now, and I just say I can't do it" (Charles, Interview 1). Alice finds it is more difficult to advocate by speaking in large groups, so she has given up that role in her community, although she continues to advocate in other ways:

But as far as public speaking, I think that role is very limited now. Umm...but, to stand up and speak, those days, I would have to really choose and have it...written down, because ah...the ability to remember, umm...what I previous said, is gone. (Alice, Interview 1)

Some leisure roles have also been lost. Alice used to volunteer to drive people to medical appointments, but had to give it up when she lost her license: "So, um...especially for the driving, driving people who didn't have their license and things like that. And now I'm really, really glad that I did, because driving, I loved" (Alice, Interview 1). Rita has given up some of her roles in the church, including the choir and reading to the children, although she tells me that this is not necessarily the result of her Alzheimer's diagnosis:

Um, yes I quit the choir, but that wasn't so much because of the Alzheimer's but more because I felt I was getting too old to be in the choir...I used to tell the kids

story in church, and I don't do that as often anymore because they have other people too who come in and said they would do it (Rita, Interview 3).

Jack had to give up his sailboat, being demoted from captain to crew member, affecting his view of himself as a sailor and a leader. He notes that perhaps he would rather not sail now because of the role change:

Yeah, like even like to go sailing and that now. Like, a like we, we had a boat and luckily I sold it and now I'm thinking that I wouldn't, I wouldn't know if I can ah, if I'd go sailing anymore, because if I go sailing it won't be, it will be on somebody else's boat, I'd just be like a crew. (Jack, Interview 1)

Loss of roles occurred in terms of family and relationships as well. Household or family tasks once valued and completed by the individual also changed, particularly with the loss of the driver's license. Charles talks about his discomfort of losing his license and the impact it has had on his role as a husband:

And um, giving up my j- my car, was very uncomfortable, and still is, because I...I like to think of myself as a gentleman and it's very difficult for me to stand downstairs in ...warm indoors while she goes out and gets the car, and bring it around to me. (Charles, Interview 3)

Rita used to love to cook and hosted dinner parties on a regular basis. Although she has made the choice to stop cooking, rather than being forced out of the role, it still feels like a loss to her: "And uh, that uh, that part does bother me because um, even though I don't feel like cooking anymore, it still seems like something I've lost you know" (Rita, Interview 1).

While relationships have strengthened in many situations, Alice has lost friendship roles. She tells me how her work friends are no longer part of her life: "...some disappear completely, some are denying it, umm...And the ones that are the worst are the ones that were in the medical field. They're the ones who've gone completely" (Alice, Interview 1). This may be due in part to the loss of her work roles. No longer being part of the work place may

have reduced her connection with some of her friends. None of the other participants felt that they had lost the role of being a friend as a result of being diagnosed with dementia.

These role losses leave the participants longing for parts of themselves that were central to their personal and social identities. They continue to be missed long after they are given up. However, as discussed above, participants focus on their remaining capacities and continue to do the things they can do well, taking pride in their continued abilities, demonstrating again how they live within the tensions of the paradox of challenge and hope. These role losses are grieved and regretted, yet participants do not let them overshadow the hope they feel about new or sustained roles.

Losing independence

In addition to loss of roles, most participants experience increasing dependence on other people, particularly family members. Independence was a valued aspect of their identities prior to diagnosis and losing that independence threatens the way they think about themselves. Loss of one's driver's licence is a key factor in losing independence as participants can no longer go where they wish, when they wish, once the license is taken away. Charles talks about how losing his license and subsequently losing his independence, makes him feel: "to have to be dependent on [my wife] just to go the, the grocery store or the drug store or whatever. Um...it borders on being uncomfortable" (Charles, Interview 1).

Rita lost her license as soon as she received a diagnosis. She tells me:

Actually that's, that's one of my sore spots, is that, umm, I don't go out like I used to. Umm, I used to drive down to the mall if you were bored. You could go down there, and. Or go visit somebody and uh, but now, I'm limited, because of no car. (Rita, Interview 1)

Losing independence can reduce opportunities for leisure engagement. Since participants may no longer go out on their own or are unable to drive to meet their friends, their loss of independence impacts their leisure. Jack notes how it is more difficult to go golfing with his friends because he can no longer independently get to the golf courses where they play:

I don't feel comfortable asking somebody to get a car and go somewhere, here or there, and, and if we always did do that, everybody went out in a foursome and we were playing out any place, and now I'm out of that group a bit... (Jack, Interview 3)

While participants do ask for help in order to maintain their leisure activities, they are sometimes reluctant to do so, contrasting with the many ways in which they enable participation in activities. Having to ask for help symbolizes a threat to independence and, in turn, a threat to identity. For example, Rita loves to shop, but she does not want to ask her family to drive her to the mall. She wants to do it herself, so she misses out on leisure because of her unease in asking for help: "I want to do it on my own, you know. And I think, that's kinda a, a shut down for me. It's not having that freedom" (Rita, Interview 2). Jack similarly does not want to ask his friends for a drive to the skating rink, so he does not skate as much as he used to:

Like when we always skated all winter you know all winter for the old guys we always went in the arena everyday and now I have to ask somebody well can I come with you? And I get, I get that I don't want to ask them all the time. Because they, can I go here, can I go there, so a lot of times when like I've got friends that would say, yeah come on with us and I don't want to do that. (Jack, interview 1)

Participants talked about loss of independence almost solely in terms of driving.

However, independence is also lost in terms of loss of income. Since Jack has had to leave his contract work, he no longer has the money to golf on certain golf courses:

Um...I don't have the freedom of, nor the money now, to uh, go where I want, when I want, and because before, like I used to play on...one of 17 golf courses...And we can go out and play it, we have to pay the, the things to ...it's not

free, you've got to pay your, your uh. But, we, we can, could do that. But I don't do that anymore... (Jack, Interview 2)

Alice in particular values her independence highly. She is still able to live in her own home, so she retains a great deal of independence. However, she has lost some of it, but has reconciled changes in her independence. In the following exchange, Alice and I discuss her desire for independence and how it has been altered:

Rebecca: So living here on your own is very important to you right?

Alice: That's, that's a good point. That, that is, that's yeah. I'm glad you brought that up. Because that's one of my most important. Yeah.

Rebecca: Your most important...?

Alice: Ss, um...goal.

Rebecca: Goal, okay.

Alice: To stay independent on my own as long as I can. Now that has changed. From being totally independent, to being independent with assistance. So I've conceded to that. I've conceded to that now. Because it's needed. So... (Alice, Interview 1)

Loss of independence highlights the paradox of challenge and hope. Participants draw hope and a sense of belonging from their relationships with others and they are happy that others are willing to enable their leisure experiences when needed. However, they feel threatened by having to ask for help and losing their highly valued independence.

Struggling with demeaning images and expectations

In addition to loss of independence, the presumptions of other people regarding abilities can threaten the identities of the participants. Sometimes other people believe that Jack, Alice, Charles, and Rita are incompetent and treat them as though they have very few remaining abilities. Alice tells me about a friend who tends to be patronizing when speaking with her:

“And umm, she very seldom calls, but when she calls, it’s like, ...umm, talking to me as a child, or I should this, or I should that” (Alice, Interview 1).

Occasionally, family members and friends discourage them from doing things, question their abilities to look after themselves, and give constant reminders to their loved ones with dementia. For example, Rita’s family reminds her to take her insulin after eating, even though she has never forgotten it:

And um, it’s pressure if you know you have to take it. And you feel like a child when somebody says “have you taken your insulin yet?” You sort of feel like well if I haven’t, um, you know I’ll remember. You do have a few minutes to take it after you eat, or, before. (Rita, Interview 3)

These reminders and assumptions undermine Rita’s sense of identity as she is no longer seen as a capable, independent person, but as someone who has dementia, and therefore can no longer look after herself. Rita also talks about wanting to go to the mall by herself but being discouraged from doing so by her family:

...I have a daughter-in-law who will say, “If you want to go to the mall phone me and I’ll take you”, you know. And, and then I had said to them... “I want to get on that bus someday and go by myself, you know. And get on the bus and come back. And then I’ll have more confidence if I do it once, you know, on my own.” But then they’ll say, “No no, don’t ever do that, 'cause you could be wandering somewhere” you know and, I think, “Oh where would you wander if you’re going to the mall?” But ah. In, in that case they do. They don’t think that I should go out on my own. And uh. But then. I’ll go for a walk by myself. And things like that. (Rita, Interview 3)

Rita tells me a story about staying with her son and daughter-in-law, who would not allow her to help out around the house which highlights how the presumptions of others undercut her capabilities:

I have a daughter-in-law who sort of says things like “You sit down mom” you know and “I’ll do this” and I stayed with her for a day or two when my husband was in the hospital and I would say “Let me do the dishes” you know or “Let me set the table”, and she’d say “No no you just go sit down.” And I find that an

irritation because I'm thinking you're saying I'm not able anymore and those are things that you can do, you know. (Rita, Interview 3)

When others assume the participants are incapable, the participants begin to question their own competence, and wonder if other people are right. They question their own abilities and fear that they may not be able to look after themselves, further undermining their identities as independent people. Rita tells me about her husband's response to her complaints that her children are too overprotective:

... maybe as [my husband] said, he said they're, they're worried for you because, they don't want you to die. They don't want you to, to leave them, you know and, and ah, I said "But that's not really good for, for you to be telling someone they're not doing the right thing", you know. Then you start worrying about it, you think well maybe I'm not. And, and ah. You always dread the time, that's another thought. (Rita, Interview 1)

Here, Rita begins to question herself and her own abilities simply because her children tell her not to do certain activities. When she questions herself, her fear of the future grows, further threatening her identity.

In some cases, other people threaten participants' identities by assuming their lives no longer have meaning or purpose. They make assumptions that all abilities are depleted as soon as one is diagnosed with memory loss: "I oft' times wonder if they feel that we become...like a nomad in a desert that still has no purpose in life, whereas I think the leisure activities show um, that we still have a lot to give" (Alice, Interview 2).

The experience of having dementia denied or normalized by others comes into play again as participants struggle with demeaning images and expectations. Discounting the dementia experience is demeaning and threatens the way the participants see themselves as people who cope very well with memory loss. While this is viewed as an indication that the participants are indeed coping well with dementia, there is still some resentment about the lack of regard

for the dementia experience. When the diagnosis of dementia is denied or normalized by others, stigma regarding dementia is reinforced. When others assume that the participants could not possibly have memory loss, they emphasize society's beliefs regarding dementia by focusing on its demeaning and debilitating features. While participants want to be seen as competent and capable people, they do not want others to deny their experience with dementia.

Accepting overreactions of others

As a result of demeaning images and expectations, participants experience overreactions of others along with feelings of being overprotected. Other people worry about the participants and unnecessarily check up on them to make sure they are safe: "Some of the ladies in the park worry about me. They think that I'm going to have Alzheimer's and think I am really having lots of troubles. And I haven't have, but they'll phone to see if Jack's okay" (Jack, Interview 1). The participants are still capable of many things, so this can be frustrating, as Rita points out: "And, and then that, that really irritates you, because you think, you know, I'm still an adult, and I'm capable of taking care of myself" (Rita, Interview 1). Alice also addresses the notion of overprotection, noting that her friends would rather do things for her: "So, umm...but they still would, will pref, prefer to go ahead and do it for me, or umm, take me by the hand than allow me to ...to do it" (Alice, Interview 1).

Paradoxically, however, the participants recognize overreaction and subsequent overprotection as a sign of love and concern, and try not to let it bother them too much. I ask Alice how it feels when her friends are overprotective. She says: "Sometimes it's very frustrating, even makes me angry. Umm...but, umm, I don't want to say anything because their intent is good" (Alice, Interview 1). I then ask her why she thinks they act this way, and she responds by saying: "They love me so much...Part of it is not knowing how, how to deal

with it. But, most of it is because they love me so much” (Alice, Interview 1). It is because of this love that participants are able to accept overprotection: “And the ones that...were very, umm...over protective, the one is still very overprotective, but we, I’ve reached a happy medium within myself with that” (Alice, Interview 1).

Losing confidence

Loss of independence and the negative perspectives of others combined with the changes experienced cause participants to lack confidence in themselves. Loss of confidence is linked to the struggle with demeaning images and expectations, since demeaning expectations lead to hesitation to do things independently. Losing confidence is particularly paradoxical since participants prefer to be viewed as independent people, yet the changes they are experiencing jeopardize their self-confidence. For example, Rita worries that she’ll get lost if she takes the bus to the mall:

But I think you get to feel that uh, you’re not as sure of yourself. Like I could get a bus right outside the door here, practically and go to the mall, and get on the bus and come home again, and they take you right to the door. But I think about it every once in a while and I think “Well what if I for- miss the bus coming home (laughs) or what’s going to happen?” (Rita, Interview 1)

She has also lost confidence in her ability to prepare a meal for a dinner party. She wonders if this is a result of memory loss:

And I don’t feel capable anymore, because people used to come in and say “Boy you’re really a good cook” you know. I’ve, that’s all I, now you wouldn’t say that you know. So, so you don’t feel as sure of yourself. And maybe that’s part of the Alzheimer’s, that you lose that feeling of confidence, you know, in yourself. (Rita, Interview 1)

Similarly, Alice sometimes feels like she does not have the confidence to go for a walk by herself:

And...I contribute that to just the path of the disease, because my confidence isn't the same. Umm, like I would walk for hours by myself. Now I notice I'm reluctant to go on my own. Umm...I still do it, but I'm not as confident. (Alice, Interview 1)

Jack questions his abilities more so now than ever before. He stops to think about whether or not he is doing something properly, whereas before the diagnosis he had a great deal of confidence in himself:

...all of a sudden this little disease comes up and now I'm thinking, I have to take second, maybe I'm not doing it right. And I was not shy on saying "Well this isn't what I would do in this situation" because I always said to everybody else whether it was kids that were playing hockey or whatever it was I knew what I was telling them was the right thing that was supposed to be happening, and now I'm sort of thinking I may have to take a second chance to see if I can do it right, before I tell them how to do it. Before I never had that problem at all. (Jack, Interview 3)

This loss of confidence can result in feeling inferior. Some participants feel badly about themselves and experience a lowered self esteem as a result of their changing abilities. The changes they are going through could have a negative impact on how they view themselves.

Charles says of his own self worth:

I think that inferiority complex is more than it did for the last number of years of my life. I started to say I feel like a dummy waiting to die. And I guess that's not too far off. Too far off from what I'm feeling. (Interview 1)

They know they are not the same as they had once been and can be critical of themselves for this. Alice tells me "...I'm always very hard on my self, umm...no matter how well I do, I want to do better. I'm my own worst critic...But it's worse now with the disease..." (Alice, Interview 1).

Different from the other participants, Rita finds herself suspicious of the intentions of her friends and family:

Um, I'm inclined to think um, if, if, now I know, just after I was diagnosed I know that word got around to some of our friends at the church and for a while there like was a group of them, not a group but maybe two or three people would come

up and say “How are you doing Rita?” you know, and “How do you feel?” and I’d get suspicious then that people think, you know what are you trying to tell me, you know and ah, that kind of thing would bother me, but then again you’ve gotta, you’ve gotta say they really just are being kind and it’s not that they’re nosy or anything, but you just don’t want to be expressed that way. So I guess that...kind of thing would bother me. (Rita, Interview 3)

Rita does not want to be pitied, and she fears that others are only being nice to her or spending time with her because of her diagnosis. While this may not be true, her feelings that it might be threaten her identity as a friend and as an ordinary person who loves to socialize and engage with others. She wants them to want to be with her for her cheerful personality and friendship and not because she has been diagnosed with dementia.

Identity threats come from a variety of sources and impact personal and social identities. Participants feel different about themselves because of their changing abilities and because of the way other people perceive them. They are sometimes prescribed a master status of having dementia instead of being seen for who they really are. Nonetheless, participants find hope in their journeys by sustaining and recreating identities. Alice tells me that although identity is indeed threatened, hope wins out through her analogy of weeds as beautiful flowers:

...like I’ll look at the wild daisies or the dandelions in a whole different perspective. More for their beauty than for what harm they may be creating to the environment so to speak, but I see the, I tend to see the beauty in things that were once considered...ugly, or a threat. They’re no longer a threat. Like say the weeds, they’re not a threat to me, they’re a beauty. They are there for a reason. Just as I may be considered a threat to society because I’ve got memory loss and I’ll create problems. The weeds are thought to be creating problems, but really they have their beauty too, so therefore in the journey of memory loss and dementia we have our beauty and our, and our sense of accomplishment and our dignity as well. So maybe that’s why they mean so much more now because some people consider we’re unfit and we’re a weed. So...we’re not (laughs). They just have to learn to accept us. (Alice, Interview 2)

Upholding Identities

Despite threatening assaults to identity, participants uphold their identities by finding ways to reaffirm them. The participants acknowledge the experience of memory loss and its impact on their lives, but they consider themselves to be the same people they were before diagnosis. For example, Rita describes herself as someone who has always been and will continue to be “an ordinary person”. The participants are proud of their abilities to cope with dementia in the ways that they do and they incorporate this into their identities. The participants want other people to know that they have many remaining abilities. When I ask Jack what was important for others to know about him, he says: “I think ...they have to know...that...they can do stuff, I mean like, that I can do stuff, and I do do stuff...” (Jack, Interview 1). Essences of upholding identities include *changing perspectives, reaffirming self through leisure, engaging in life through leisure, having purpose, feeling a sense of accomplishment, and creating enduring memories.*

Changing perspectives

Participants uphold identity by working to change the negative presumptions of others regarding loss of abilities. They communicate with others to inform them of their remaining capacities in order to change perspectives. For example, Rita changed her daughter-in-law’s attitude toward her by explaining that it is still important for her to contribute:

...and she, she said “But we don’t want you to have to do things now, you should be relaxing now”, and I said “No I shouldn’t.” I should be doing things, and um, I said “I think that I would be far better if you would just treat me like I always did and say sure you can do the dishes or let me do them”, you know and um, I think that a lot of them is how to get it across to people without hurting their feelings.... So she changed she let me do the dishes after (laughs). She said “Well if you feel like that you know, whatever’s going to make you feel good” you know. (Rita, Interview 3)

Some participants change perspectives by using their leisure to demonstrate their capacities and to demonstrate that their lives still have purpose and meaning. For Alice in particular, changing attitudes reinforces her personal and social identity as an advocate. As a nurse she advocated on behalf of her patients and now she advocates on behalf of persons living with memory loss. Alice's advocacy work has changed the attitudes of her family and friends:

Oh yeah. Um...occasionally, I say occasionally, people say well they used to say well, you know maybe you can't do that or maybe you can't, or maybe this or maybe that, and I'll say "Well, I'll buy it, I'll try it, if I can't do it, okay." But their expectations have changed and yes in the beginning, yes in the beginning their expectations were end stage. So with teaching and learning, that's changing. I still do have the odd person that feels like, can you still walk type thing. And um, that's the older generation. That's the generation before me that tend to think the end stage. Um, with teaching the um, our, my generation the younger generation are seeing a more pro- are taking a more proactive approach rather than saying "Okay now it's just over". So the perspective is changing. (Alice, Interview 3)

Although Alice's identity is threatened by the loss of her job, she retains the valued role and directs her efforts in a different direction, resisting threats to her identity as an advocate, overriding the master status of dementia. Through advocacy, she is working to change societal images and understandings of dementia.

Jack has similar experiences. He was always involved in his community, whether by coaching youth sports or sitting on a board of directors, helping others has always been a key part of Jack's identity. Jack tells me how he makes a difference in the lives of others living with memory loss by encouraging them to engage in meaningful leisure:

I'm one of the one's that started going and it went down when we were in [town] more nobody was dancin' at all and we'd sing songs and do all that part that was part of the exercise, your exercise and you hit the ball or the um, balloons and you go around and that's your exercise, hit it to the next person and all that (laughs) so I think that I've changed some of the things for the better that, what people can still do. I go to this one chap and he used to play drums in a parade and then he got

Alzheimer's. And then he didn't do anything and he didn't do so I got out and got the drums out so now every time he's there he's looking for the drums to play... (Jack, Interview 4)

Jack takes advantage of social leisure opportunities to tell others about dementia. It makes him feel useful to be able to share his experiences and ease the journey for other people:

I feel that it probably helps you and I know it helps me, make a, make a good, makes me feel not important but useful for other people who are having the trouble of it and how they react and um, I was out to a, ah, a retiree's thing out last night and I was, like they know I have Alzheimer's, and there was a whole bunch of people. There must have been about 150 people there, and this one would come over and say how am I doing, and I tell them "Well I don't see any big changes right" and it sort of makes me feel good because some of them have their mothers and their fathers or something are having Alzheimer's and a lot of people don't really...want to know about it you know... (Jack, Interview 3)

Jack intends to continue to help others with dementia even after death as he has plans to donate his brain to science to further biomedical research on dementia. This is just one more way that persons with dementia feel they can make a contribution:

...like we thought about, thinking about things like I'd like to give my body to some doctors, science yeah, or make sure they got the brain to see if they can find something about Alzheimer's because you don't know what Alzheimer's are until after, you have to wait until they cut you up and find out. I'd like to do that for somebody. (Jack, Interview 1)

Despite their efforts, participants are not always able to change attitudes. Sometimes other people are unwilling to change their opinion about what it means to live with memory loss:

And so then of course, I wanted to be an advocate, especially for the medical, but they don't want to hear it. They don't want to... "Oh yeah, there's days I forget too", is the most common. They just sort of put it on the shelf, and don't really want to ...umm...I think understand how to deal with our patients better and in a more kinder way, more understanding way. (Alice, Interview 1)

Participants can feel frustrated when they are up against people who do not want to change their perspectives. Nonetheless, the participants in this study value playing a role in changing the images of dementia so others will not have to suffer in the ways that they have.

Reaffirming self through leisure

In addition to changing perspectives, participants uphold their identities in the face of threatening assaults by reaffirming themselves through leisure. They emphasize identities beyond memory loss by demonstrating to both self and others that they are still the same people that they were prior to being diagnosed with dementia. This occurs in two ways: *sustaining valued aspects of self* and *emphasizing abilities*.

Sustaining valued aspects of self

The participants view themselves as the same people they were before diagnosis despite the challenges of memory loss and threats to their identity. They act out their identities for self and others to demonstrate this. Rita tells me how she is still the same person, incorporating her trademark sense of humour when she does so: “It’s a, it’s not an easy thing to deal with, but, but then, it is if you just think I’m just as, I’m just like I always was, you know. That’s how I feel about it. Except I can’t remember my husband’s name all the time (laughs)” (Rita, Interview 1). Participants wish to be treated as though they are the same people that they always were and want to be included in daily activities. Rita told her daughter-in-law who would not let her help out when she was staying with her: “I said ‘I just want to be a part of it you know, you feel like a guest when you’re sitting in the other room’” (Rita, Interview 3). Leisure is a space where they can be themselves despite the changes they are experiencing. Through leisure, they enact many of their previous roles and although these roles may be altered in some way, they remain meaningful for the participants.

Participants maintain valued aspects of identity in the same ways as they did prior to having memory loss. They describe themselves as having certain characteristics and these characteristics continue on despite the changes. Rita identifies herself as being “a cut-up”, and values her role of bringing humour to other people’s lives. She maintains her sense of humour despite the diagnosis, reinforcing her belief in herself as a person who is fun to be around: “She talked about that she has not changed much since diagnosis – she still feels like herself. She said ‘I was always kind of a cut-up and that hasn’t changed’” (Rita, participant observation field notes, games). All of the participants view themselves as being good friends to others. This role is apparent in the way participants support and are supported by their friends and enjoy spending time with them. When I ask Alice what her photo of her friend at Tim Hortons says about herself (see Photo 12), she responds:

...One who enjoys being with people. Um, caring and sharing, um...as you can tell by that photo, I’m very happy so obviously, um, it’s a very positive experience to be with, with, with people. I’ve always been a people person so I think this is when you’ll see me smile the most. When I’m with others. (Alice, Interview 2)

Some family roles also play out in the same way. Rita, a grandmother, continues to take this role very seriously. It is sustained in leisure as she spends time playing with her granddaughter. I ask Rita about the photo of her and her granddaughter and what it says about her (see Photo 16). She tells me:

A Grandmother (laughs) and, I, I guess that’s uh...that’s what it is, I ah... like with, dealing with Alzheimer’s, I, I think I am, my husband says this too, he says “You’re trying so hard all the time to make sure you can be funny with her, and uh, and play with her, and get down on the floor with her”, and, he says “You’re trying so much to stay so that you and her are close”, you know, and, and it’s true. I guess I do, you know. (Rita, Interview 2)

In this way, she projects her own identity as a grandmother and rejects a master status of dementia. With her actions – getting down on the floor with her granddaughter to play and

acting in ways she did with all of her grandchildren, Rita expresses her valued aspects of herself in the same way she always did, which helps her to feel like herself, not just a person with memory loss.

The participants identify a variety of roles that they have maintained, including being a mother (Alice), being a nature lover (Alice), being physically active and fit (Jack), being a poet (Rita), being adventurous (Rita), being a reader (Charles), and being independent (Alice). For example, Jack plays out the valued role of physical activity in the same way he did prior to diagnosis as well. Jack included some photos of himself preparing for his first golf game of the season to demonstrate the importance of golfing, and physical activity in general, to his identity (see photos 21 and 22). Golfing is a frequent activity for Jack:

... I think I must of played and ...uh...200 uh...two hundred....nine hole at least. And some of them were just the 18 hole. And uh...and this is when my wife brought me to move from our house over to the golf course. And uh...and then I went out and played. (Jack, Interview 2)

I ask Jack more about the photo:

Rebecca: So what does golfing say about you as a person?

Jack: That I'm being, being uh, very active....Very active...

Rebecca: Is that important for your identity?

Jack: And it is, yes it is. (Jack, Interview 2)

Participants resist both threats to their identity and the ascribed status of having dementia by finding ways to sustain valued aspects of themselves and acting out roles that are particularly meaningful to their identity in the same way that they always did.



Photo 21: Jack prepares for golf



Photo 22: Jack and his golf clubs

As a result of the numerous challenges that the participants face, not all roles can be maintained in the same way. Other roles that are meaningful to the participants' identities both before and after diagnosis of dementia play out in new ways. Alice, a former nurse who nurtured and advocated on behalf of her patients, continues these roles in new ways in her leisure time. Instead of nurturing her patients, she takes care of her cat and her plants. Alice took a photo of her cat and explains the meaning that her cat has for her in helping her maintain the caring roles she finds meaningful (see photo 23):

And when I first got her she was extremely timid, she didn't know how to play...And she had been very very sick, so it has taken a long time to create that trusting bond. Which having been a caregiver is even more important to me

because I'm still doing that caring and that giving. So it meets a lot of needs for me. (Alice, Interview)



Photo 23: Alice's cat

Alice also decided to start feeding birds on her balcony when she moved from her house to her apartment, an activity which allows her to nurture and gives her purpose, as she says when she describes her photo of the birds (see photo 14):

But no that is brand new and that is something I decided to do because of the journey of memory loss that I thought being close to nature and being giving was only going to help myself feel good and have a purpose. (Alice, Interview 2)

In addition to caring for the birds and her cat, Alice talks about the tasks associated with nurturing her plants (see photo 24):

So um, and actually you have to really remember to water it, remember to fertilize it so there's a lot of things, um, that you have to remember to do to keep the plants

going, and I don't have anyone else to do it so I'm responsible, I have to keep my plants alive if I want them. (Alice, Interview 2)



Photo 24: Alice's plants

Looking after the plants is her responsibility alone and so she must rely on herself to undergo a series of steps required in providing care. While this helps her to play out the same role in a new way, it is also a way of exercising her brain and of accomplishing something particularly meaningful.

Alice also continues her role as an advocate which began for her as a nurse. Now she turns her advocating efforts to herself and other persons living with memory loss:

Always, umm...no matter what stage I'm at, I'm hoping I can...allay...fear in the everyday person. Umm, ...and allay the fear in people that have been newly diagnosed, that, like any disease process, it's up to us to make the best of the journey, best, you know, the best. Do the best we can with what we've got. So, I'll always be an advocate. (Alice, Interview 1)

Alice's photo of her cat represents her success as an advocate on behalf of people with memory loss since she was able to change the minds of the people at the SPCA regarding the abilities of persons living with memory loss (see Photo 23). I ask Alice if she believes her actions will change the way people with memory loss are perceived:

I'm hoping it will. Now since then, I've heard of a senior who was declined a dog because of her age. So I'm hoping that they'll see people with memory loss as still capable. So there's another place, I guess when I really look at it, I did advocate for people with memory loss. And we won. And we won (laughs). With the support of others. (Alice, Interview 2)

In this way, she is able to experience lifelong roles that she continues to value, albeit in new ways, directing her efforts in different directions while garnering the same benefits.

Jack also finds new ways to play out his identity. As previously discussed, Jack was formerly a competitive sailor, but can no longer sail safely, so he turns his competitive nature towards himself. Instead of trying to beat others, he tries to best himself. Golfing allows him to be to do so: "...it's very competitive, but it isn't competitive because you're really only fighting with yourself. (Jack, Interview 2) (see photos 21 and 22). Jack is able to use leisure activities to maintain his competitive nature. By using leisure to find new ways to perform values that are central to one's identity, the participants are able to resist social and pathological threats to identity.

In addition to demonstrating valued aspects of identity, leisure provides a space for participants to reaffirm their identities beyond their diagnosis of dementia for themselves. It reminds them that they are not just people with memory loss, but many other things as well. Alice speaks about leisure's role in reaffirming her identity beyond memory loss, noting that it gives her a sense of individuality and self worth:

Um...because it does two things, physically, it gets me on the move. And um, psychologically, it ah, gives me a new perspective even if I change a little bit in

one day or do a bit of a project one day, or recall something, it's given me hope and dignity that I am still an individual. And I'm still worthy. (Alice, Interview 3)

Alice included a photo of a jigsaw puzzle that she was working on over the course of our interviews. Puzzles are an important means of exercising her brain, but more importantly, the photo reminds Alice of her self-motivation and stick-to-itiveness. For her, the photo of the puzzle represents her persistence, her adaptability, and personal growth along her memory loss journey (see Photo 25):

That I have patience, persistence, drive...ability to adjust to what the journey's doing to me at that particular moment. Um, adapting...seeing beauty in it. And it also indicates, even though you're living alone, there's a lot you can do. With self motivation. I think that's one thing it shows, persistence, self motivation. (Alice, Interview 2)

Alice refuses to give up activities or give up on herself when she struggles. She keeps trying with the hope that she may one day succeed. She tells me about playing computer games despite the fact that she often cannot complete the current level:

Now I'm not even able to accomplish the first level. And, I'm working on that for weeks, it seems like about three months, but it's probably only about six weeks. But I haven't been able to zip through that one. But I keep trying, 'cause one of these days I might. (Alice, Interview 1)



Photo 25: Alice persists with a challenging jigsaw puzzle

Alice's walks in her community further reaffirm her identity by reminding her that she is indeed a member of her community, not necessarily shoved aside because she has memory loss. Her photos (see Photo 26 and Photo 27) of her walking route remind her that her small community is a safe place for her to engage with others and remain active:

And you go downtown and what's really nice is there's always someone to talk to. You say hello and a conversation ensues. It's just amazing what you find out...And then I'll sometimes go down the street and meet people that are visiting and want to know where something is. I don't think, there's very seldom a time I go downtown and meet somebody that is new and just...yeah. And one day I was coming home with some birdfeed, I was coming through [the park] and a gentleman said 'yeah you feed birds too' and we got talking about the wild turkeys where he lives. So you just, you never know. And that's one advantage that I find I have in the small town. (Alice, Interview 2)



Photo 26: Alice's community



Photo 27: Alice's community

The families and friends of the participants also reaffirm identities. Rita tells me how her family treats her as though nothing has changed, reaffirming her identity as part of the family:

Um...it's good to keep the connection with them, because ah, one thing I really appreciate about my family is that they uh, they never, we never talk about Alzheimer's or anything, you know. And uh, and I think that's very healthy for, for people, like I think you should let them bring it out themselves if they want to. But I think that you can, there's a lot of people who get stuck in it, you know, and think poor me. You know, and the future doesn't look very good, and everything, where, when it does, you know, there's you can go on living for a long time, as long as you keep your spirits up and you're, you're okay with it, you know. (Rita, Interview 2)

Spending time engaging with family in leisure activities provides a space for participants to have their identities reaffirmed by their loved ones. However, this is particularly paradoxical for Rita, since she also experiences overprotection and negative presumptions about her remaining abilities from her family. Although they undermine her identity, they also reinforce it by respecting her decision not to dwell on having been diagnosed with dementia.

Alice's family reaffirms her identity in the way they treat her with dignity and respect, encouraging her independence:

Even if it's going to the store "Well mom, we're going to the store, is there anything you would like or would you like to go?" and then we adapt it to whether I feel I can go, or not, and...they'll come by and pick up the money or whatever and they'll go and get the groceries on a bad day, or they'll go and they'll guide me. (Alice, Interview 3)

Alice included a photo of her granddaughter, which symbolizes Alice's new role of being a grandmother (see Photo 28). While this is a new identity role for Alice since being diagnosed, it emphasizes her identity outside of memory loss as one who plays an important role in her family. The new role of grandparent reminds Alice to keep fighting dementia: "This is the grandbaby, number one (smiles broadly). Oh she's just...giving me another purpose to keep trying" (Alice, Interview 2). Although Alice sometimes questions her abilities to help

look after her grandchildren, her family supports her in this endeavor, reminding her that she is indeed very capable:

...I said to [my son], I said “Well there was a day when I could really help you with [granddaughter] and what to expect”, I said, “A lot of that I’ve forgotten”. He said, “Don’t under estimate yourself mom. There’s still a lot in there that you don’t realize you have.” (Alice, Interview 3)



Photo 28: Alice and her granddaughter

Reaffirming self beyond identity also occurs outside of family relationships. Charles reaffirmed his own identity when he created a reading box to hold a book so that he can read in his easy chair (see photo 29). The box is particularly meaningful to Charles because it represents his identity as a person who works to solve his problems:

Oh I’ve always been one to figure out how to cope with a problem, and to me it was a problem that disturbed me and I, what can I do? Well, we, okay, I’ve got the answer. We made our own, built up that thing with Styrofoam so it’s very light. (Charles Interview 2)

Leisure is a space for the participants to be themselves despite the threats to identity that experience. It is through leisure that participants are able to act out familiar and valued roles,

whether in the same ways they always did or in new ways. Participants assert their identities beyond memory loss, resisting stereotypes and assumptions of memory loss.



Photo 29 – Charles created a stand to help him read

Emphasizing abilities

In addition to sustaining valued aspects of self, participants reaffirm self by emphasizing abilities. Participants focus on the positive aspects of their lives, and, in turn, celebrate their remaining capacities in order to tackle life with memory loss for themselves. Doing so helps them to manage the changes that they face. However, by emphasizing abilities through leisure, participants resist threatening assaults to identity and accentuate capacity by pointing out all the things they *can* do, resisting the threat of presumptions of others. Not only is focusing on the positive important for tackling life with memory loss, it is vital for sustaining identities. Leisure becomes an important space for participants to demonstrate capacities that they can no longer perform in work roles. I ask Alice whether participation in leisure changes the way

other people see her, and she believes that it does: "...those that don't have the disease see it as an amazing that um, I'm able to do *something*" (Alice, Interview 2).

For Alice, emphasizing abilities contributes to her identity as an advocate as she uses her leisure to demonstrate her capacities, which in turn changes perspectives:

...I think the leisure activities show um, that we still have a lot to give. Or even if um, I'm doing my crocheting or whatever, and that's exhibited, or I show friends what I've done. It's amazing. You know, especially when it comes to something I've never done before. So I think in that aspect it's sort of like an advocacy. (Alice, Interview 2)

The participants had to teach me about their own leisure activities so I could participate with them, and in doing so, they demonstrated their skills. Jack emphasized his abilities by teaching me how to putt: "Jack commented on the ball only a couple feet after he hit it and was able to predict whether his hit was too weak or too hard, or too far either left or right of the hole. He would then compensate for the next swing" (Jack, participant observation field notes, putting).

Charles and I discuss how his leisure helps him demonstrate his continued abilities in our third interview. As a result of positive feedback from others, Charles is motivated to continue to engage in meaningful leisure, which demonstrates to others that he copes well, an important aspect of Charles' identity:

Charles: The very fact that people affirm me, what I'm able to do in leisure, makes me want to continue and it, it...I guess I think of myself as being a person who can be identified as someone who can cope quite well with change. It feels good to have them say "I didn't know you had it" or it's hard to, hard to see.

Rebecca: Okay, so by staying involved with the things that you do, that helps people to see that you're a person who copes well with change?

Charles: Mmhm.

Rebecca: Is that right?

Charles: Yes. Same exactly. (Charles, Interview 3)

Participants want to show others that they are still independent, self-determined individuals, resisting the notion that they can no longer take care of themselves. While Alice once got angry with friends who were overprotective and reluctant to allow her to try new things, she now asks to try new things to show them that she is able to complete the task: “Umm...I used to get very angry with them, say ‘Oh never mind’. You know, and just, ‘Just leave me alone.’ Now, it’s where I, I’ve learned that ‘Yes, I can do that, or yes, that’s okay. But, would allow, would you let me try this?’” (Alice, Interview 1).

While Jack has lost some independence, he has altered leisure so he can be independent in a new way. Golfing at the golf course next to his retirement community affords him some of the independence lost when he lost his license and Jack included two photos of himself getting ready to golf (see Photo 21 and Photo 22). I ask Jack why golfing was important for him:

Last year it was really important, because it was ah, it was something I could go, like I was telling before, I only walked from my house over the, the golf, golf ah, place, and that means that [my wife] doesn’t have to come and pick me up and go, and everything. (Jack, Interview 2)

Being able to golf independently by going to a convenient golf course allows Jack to play out the valued leisure role of golfer. He emphasizes his remaining abilities by showing others that he is indeed still capable to do things on his own.

Rita takes a slightly different approach to emphasizing abilities to uphold her identities. Rita avoids openness about her diagnosis so that others will focus on her capacities and not make assumptions about her abilities. She tells me that although her family is supportive, she does not want friends and acquaintances to know about her diagnosis so they think that she is the same as she always has been:

I would rather people didn't know that I had Alzheimer's you know, and um, but it's not a big thing with me, because my family just accepted it and they don't think I'm any different than I was before and so I get a lot of encouragement from them with it. But there are times you hope that somebody doesn't notice anything different about you, you know. But I haven't run into that really that people have said oh you're not like you were before. (Rita, Interview 4)

Rita hides her diagnosis in order to resist threatened identities – if people do not know she has memory loss, they cannot threaten her identity.

Participants demonstrate their capacity, counteracting the belief that they are purposeless or unable to do things. They find ways to continue to perform tasks or activities, and are thus able to demonstrate capacity, overriding the master status of dementia.

Engaging with life through leisure

In addition to demonstrating self through leisure, participants uphold identities by engaging with life through leisure. Although the participants encounter challenges in their leisure, they largely view it as a positive aspect of their lives. It plays a vital role in sustaining their feelings of hope as they use leisure to practice and demonstrate their identities. Jack, Charles, Alice, and Rita continue to be interested in and connected with life. They seek out novel activities and familiar leisure pursuits as continued opportunities for growth and development. Jack talks about the wide range of activities he is involved in, and how they make him feel connected to the world around him. If he ever feels uncertain about what to do with his time, leisure can fill the void:

And then all of a sudden something comes up and you know I go, in this place where we are, on Monday we play crokinole at one o'clock. On Tuesday we play um...carpet bowling. On Wednesdays we have stretch and balance...it's a wonderful thing because everyday I've got something I can do. (Jack, Interview 1)

Essences of engaging in life through leisure include *seizing opportunities, sustaining social personae, appreciating the simple things in life, having fun and enjoyment, renewal, filling time, and claiming space.*

Seizing opportunities

Participants take advantage of new opportunities that come their way since being diagnosed with dementia. Two of them have started new activities that provide new interests and goals. Alice started to play computer games, reading fiction, and feeding the birds. She tells me how reading has opened a new door for her (see photo 30):

I've never been a reader but it's given me a new extension, and it's a new extension of leisure that I can take the book with me if I'm at a doctor's office, if I'm going to visit someone, I can take it with me. Um, it's just opened another whole field.
(Alice, Interview 2)

Jack has also started new activities, including crokinole (see photo 31), carpet bowling, and bocce ball, since being diagnosed with dementia, which provides him with ways of combining physical and mental activity, activities he has always valued.

Alice notes that it is important to take advantage of opportunities, even when she feels too tired or lacks motivation to get involved in leisure activities. The photo of herself and her friend having coffee reminds her of the importance of taking advantage of what opportunities come her way (see Photo 12): "So this photo is really significant of how important it is to go and not say no go" (Alice, Interview 2).



Photo 30: Alice reading



Photo 31: Jack has started to play crokinole

Participants seize opportunities for learning and building skills, which enables them to participate in daily life, both with family and friends, and on one's own. Alice learned how to use a computer after she was diagnosed with dementia and is able to maintain contact with friends and family through email as well as do her committee work. Alice took a photo of her computer to emphasize the importance of this new skill in her life (see Photo 8):

Um, I'd used a computer a little bit at work, we were just starting to get into them...but when I got sick, surprisingly, my niece and my eldest son, and my friend's son all got together and decided that it would be so great for me to have a computer to learn how to email because I was involved in the committee...and just general, keeping in touch, communication. And also enhancing skills - skills, and lo and behold, my eldest son was so supportive in this that it really shocked me but the three of them got together and we got a used monitor, a used hard drive, a used keyboard, and all different types, and they all got together and got it working. (Alice, Interview 2)

Alice also works to build her skills when doing puzzles (see Photo 25). Although she finds puzzles difficult, she breaks each puzzle down into smaller sections to complete it:

And I did finish that one. That was where I had to go back down to number, to 500 pieces and work my way up again...And I finished it and the pieces were all there. And it got easier um...as I figured out a strategy to do certain items in the puzzle. Like the bright items, and then slowly all the blues came together. So once I picked one colour, then as I progressed it seemed to get easier. (Alice, Interview 2)

She believes that this technique allows her to build her skills and she will be able to try a more difficult puzzle: "I knew if I completed 500 pieces it would only um, enhance my, it would only encourage me to try the 750 and then the thousand again" (Alice, Interview 2).

Participants also seize opportunities by learning from others, particularly younger family members. Rita talks about leisure in terms of shared learning with her granddaughter. They learn from each other as they interact in leisure activities:

...I think when I think about her we play cards together, and, and um, we draw things and stuff like this you know, and she teaches me a lot (laughs). I think I'm teaching her something...because she's always got something on her mind that

she wants to do you know, and, and so that's good. That keeps her, us thinking, yeah and keeps us busy. (Rita, Interview 2)

Alice similarly experiences mutual learning with her young niece and nephew:

I do it with my niece and nephew...they help me learn, it's sort of a reversal. And um, actually I cherish it. I don't see it as a negative. I see it as them understanding what the disease will do because just they'll come along and help me with something and it's not condescending or anything. (Alice, Interview 4)

Engaging in leisure with grandchildren and other young relatives provides a mutual learning experience in which participants teach about the experience of dementia. It is a space where they can experience acceptance and gain knowledge from the younger generation, helping them to feel part of the world around them.

By seizing new opportunities, participants are able to remain actively engaged in their lives through leisure. In trying new things and building new skill sets, they resist the assumptions that they should not try new things.

Sustaining social personae

In addition to seizing opportunities, participants engage in life by using leisure to sustain social personae. They find ways to sustain roles that require support and interaction with others, what Sabat (2001) refers to as Self 3. Self 3 may be at greatest risk since social personae require support and interaction from others. Earlier, I discussed how living in relationships helps the participants to tackle life with memory loss, including challenges in their leisure. Being together helps to instill a sense of belonging. However, being with others is also vital to actively engaging in life and plays a key part in terms of upholding identity, particularly social personae. Leisure is a way to spend time with family and friends and have an active social life. It helps the participants to feel like they are still a valued part of their social groups and can contribute to relationships while enjoying the company of others. Jack

says being with family is the most important thing to him right now: “Central to my life right now? Uh...I think...probably, my life is my life is probably central to my life, my family is very important to me” (Jack, Interview 1). Here, Jack indicates the importance of having family relationship roles. By sharing their leisure time with other people, participants have fun, catch up with others, and meet new people. Rita and I spent much of our leisure time together socializing. After our walk around the block we chatted about a wide variety of things:

We sat down in [the living room] and chatted for a while. We talked about the economic problems with so many factories closing down and moving south, we talked about the price of gas, and the Democratic Leadership race in the US. She asked what I thought of Obama, and she told me that she thinks he is very smart, and she really likes him. I said yes, I thought he seemed like he would be a good leader. She commented about his comments regarding working together instead of bringing each other down. She thought Hillary could learn something from him. (Rita, participant observation field notes, walking)

In this conversation with Rita, I learned that she continues to be interested in the world around her. Instead of disengaging from social and political issues, she socializes with others to share her opinions on current events.

Charles and his wife spend time with friends by playing games, and Charles included a photo of playing games with friends to demonstrate this (see Photo 13). He tells me what the photo represents for him: “um...socializing. Um. It’s fun (laughs). And it’s also, yeah, it’s something, yeah socializing, spending time with friends” (Charles, Interview 2). Similarly, Jack included a photo of himself eating out with friends to demonstrate the value he places on spending time with friends (see Photo 32):

This is ah, we go out a lot for lunch with our friends...we go from restaurant to restaurant. Not necessarily in any particular one at any particular time. So that’s just a picture of us ...when we were having a...lunch, with this other couple. Because we do go out quite often, really quite often. (Jack, Interview 2)



Photo 32: Jack has lunch at a restaurant with friends

Rita engages with life in part through her close relationship with her six year old granddaughter. This relationship is particularly valued for Rita and her husband, who enjoy sharing their lives with their granddaughter:

Uh...I think my relationship with this little girl of ours...um, is a key thing, because, um. We spend a lot of time with her. And she comes over and stays over night and, um. She's really done a lot for me, because she's a very bright kid too... So she's kind of a central part of our life. And she calls everyday. And we tell stories over the phone. And she's just a real gem. (Rita, Interview 1)

Rita also engages through life when spending time with her children:

Uh, or we'll drive like, my daughter lives in [town] and we often go down there...on the Sunday or something, and go out for dinner, and... yeah, no we, we have a good connection. I'd miss that if it, if it wasn't like that, I, I you know, you talk to some people who say their kids are so busy they haven't got time for them. But that doesn't seem to happen to us... (Rita, Interview 2)

Through these relationships, Rita is supported in playing out her social roles of being a mother and a grandmother. Not only do relationships support participants to engage in leisure and other meaningful activities, being with others is a way of maintaining active engagement with

life and provides a space for participants to act out familiar and new social roles. This, in turn, allows participants to resist roles that are ascribed when one is diagnosed with dementia.

Appreciating the simple things in life

In addition to sustaining social personae, participants engage with life by appreciating the simple things. Facing a great deal of loss, and grieving those losses, allows participants to be aware of and appreciate the aspects of life that are meaningful for them:

But it's not all a bed of roses. There are those down days too. And those down days are very intricate part of the disease process, but they have to be, you have to allow yourself to have them, for me personally, I allow myself to have them because then I appreciate the good times more. (Alice, Interview 2)

Simple pleasures are enjoyed more so than they were prior to the dementia diagnosis. Alice took a photo of her plants partly to demonstrate how she appreciates simpler things in her life now (see Photo 24). She explains how she finds beauty where she might not have noticed it before:

I think now since the memory loss I appreciate something like this even more. The little things mean more and are much more significant. Because when you, when you don't have a problem with your memory you take things for granted and now every little thing, like even the weeds look pretty... (Alice, Interview 2)

Jack and Charles also find they enjoy and appreciate the natural environment a great deal.

Appreciating small things can refer to the acts of others as well. Rita not only appreciates a sunset or a good movie, she appreciates invitations to go out more now than ever before:

Um, I know if a friend calls and says would you like to go to the show, or would you like to do something, I just jump to anything that's outside of here you know (laughs). Not that I feel tied in here but it's um, it is kind of a tie down with him being not well and um, I don't like to leave him too long, but he is coming along very good. It's just you have to get out and see other people and go other places every once in a while. Um, I guess in that sense I do. I do enjoy a sunset, I do enjoy things like that very much, or a good movie, and um, um, things along that

line. Yeah I would say that way. I would rather watch a funny movie than a serious one you know. (Rita, Interview 4)

Participants use their leisure time to appreciate the simple aspects of the world around them.

As such, they find a great deal of pleasure in their lives despite the challenges they face.

Having fun and enjoyment

In addition to being a space to appreciate the simple things in life, leisure provides a space for participants to have fun and enjoy themselves. The participants describe their leisure as fun, regardless of the other benefits of their activities. As a result of his variety of leisure activities, Jack really enjoys his life despite having memory loss:

And um...I'm very fortunate. I don't know if you ever knew that, my wife tells me I have the life of Riley. Because Riley used to have everything, you know like in the old days, it was always the life of Riley and that's what I'm doing now. I'm just enjoying it. Doing well, really. (Jack, Interview 1)

Alice included a photo of her friend playing Yahtzee, and looking at the photo reminds her of having fun (see Photo 19):

I tend to lose a lot in Yahtzee, but we laugh a lot. It, its just fun. It's not whether you win or lose, it's doing something together. And she enjoyed it because she hadn't done it in a long long time and I hadn't done it for a while, so it, it just enhanced, um, having fun. (Alice, Interview 2)

Previously, Alice spoke of the value of Yahtzee for exercising her brain, but here she tells us that it is more than that – it is a pleasurable way to spend time. Charles spends a great deal of his time reading because it is enjoyable. He appreciates the sense of enjoyment that leisure has:

I allow myself to do the things that I enjoy doing without feeling guilty about it in any way. Um, the reading is a good illustration of that, spending as much time as I do and also having the mechanism to make it comfortable, and yeah, in those days I can continue to enjoy what I was doing before, and sometimes some new ways, leisure. (Charles, Interview 4)

Leisure activities can bring excitement to their lives as well as enjoyment. Rita went to see a concert of her favourite singer, and she tells me how excited she was to be there and how much she enjoyed it:

I love to go out, I love to, to, like I said this thing with Anne Murray was a real highlight for me it was great, and ah my daughter said to me the other day...she says dad was in to the office to talk to them, they're just down the road and she says your mother was just like a little kid going in there (laughs). She was bouncing around there, she keep hitting me on the arm (laughs). And ah, I was really excited that night, and those kind of things are great, so. And that's a leisure thing, you know, you are just sitting there and it's really nice. (Rita, Interview 3)

Participants describe themselves as being fun loving. Leisure is a space for them to act out this role, reaffirming aspects of self that are valued. When I ask Charles what playing games says about his identity, he responds by saying: "yeah, fun loving" (Charles, Interview 2) (see Photo 13). Similarly, Jack has always enjoyed life and continues to do so even now. Leisure helps him to do this: "So I had *such* a good life. And I don't want to lose it. And that's why I want to stay in leisure and enjoying my life" (Jack, Interview 3).

Participants describe their time as going by very quickly when they are engaging in leisure: "It makes the days fly by" (Charles, Interview 3). Rita talks about how quickly time goes by when she is playing with her granddaughter (see Photo 16):

It seems to go quite quickly. Yeah. She's a very busy little girl, she's always got something new to, to do or to work with, and. And uh, it, it seems like you're with her for a little while and then the times gone, you know, because uh, she's always keeping you thinking about something, or, doing something, or reading a book, and stuff like this you know. (Rita, Interview 2)

However, low energy levels can end a leisure activity causing time to slow down: "The time goes quickly, but the fatigue sets in so we know it's time to move on" (Alice, Interview 2). As a result of draining energy, participants cannot participate in leisure as much as they once did. When one feels good and engaged in meaningful leisure, time goes by quickly, but

when challenges become too great in leisure, time slows down, participants become tired, and they must leave the activity behind for a while.

Leisure's inherent sense of fun helps participants focus on the enjoyable aspects of their lives instead of dwelling on the losses and threats to identity that they experience. It reinforces their views of themselves as fun-loving people who like to have a good time and enjoy life.

Renewal

In addition to having fun, leisure is a time for renewal. Leisure is associated with freedom, which is relaxing: "That gives you that freedom to relax. It's almost like a freedom to be carefree" (Alice, Interview 3). Leisure can relieve stress through a change in environment or activity. Alice tells me how leisure can give her a new sense of energy:

So, but, so the leisure, if I'm having a bad day, at what they call my work, then if I do something that's leisurely, like take a walk or do start something totally different that will bring me back to a point of a new beginning...Or it's like, I guess, the only thing I can compare it to is like if I'm studying really hard for an exam, it's like walking away and having a break and coming back. That would be the best way to describe it. (Alice, Interview 3)

Alice provides an example of how taking a break and engaging in a leisure activity can help refocus on a task:

Um, let's see, now oftentimes if I'm feeling down and I go for a walk then I come back and approach my daily activities like maybe um, because I'm trying to get ready for a garage sale and downsize, I'll pick out something to sort of okay, which box does that go into? And it's a long drawn out process because of the memory loss now, but getting away from something and coming back, it, there again, the word refreshes, so and it's also intermingled. (Alice, Interview 3)

Participants often feel relaxed and most comfortable when engaging in their favourite leisure pursuits. Since fatigue sets in more quickly now, participants engage in a restful or passive leisure activity instead of constantly being active. Jack will take a break and watch golf on television when he gets tired in order to relax: "But for leisure, for leisure stuff, like I take it

easy now too. I take off, like if, like Mike Weir is playing golf today, so I lay down on the couch and splay back, watch and relax” (Jack, Interview 3). Using leisure for resting helps participants to continue to engage in other activities such as housework or other chores. It allows them to recoup some of the energy that is lost as a result of memory loss and allows them to engage in other meaningful leisure. Leisure that is aimed at renewal is important for maintaining active engagement in life and other forms of meaningful leisure.

Filling time

Sometimes, leisure is meaningful because it makes time pass quickly and is a way to avoid boredom. With the loss of other valued roles, particularly work roles, participants find they have more time for leisure than ever before in their lives. This time can be difficult to fill since job loss is accompanied by a loss of income, and therefore participants have less money to engage in desired leisure pursuits.

So...like, you're trying to figure out what, what works well in the leisure time of being in, in a fact, ah retired. Because once you're working you don't have time to do the wor, do, do, to have leisure. And then when you're off the ah ...when you retire, all of a sudden you got all the time, but you don't have the money. Before that you had the money, but you don't have the time. (Jack, Interview 2)

Participants will often pick up a small activity when they have a few minutes to spare, or if they have nothing else to do, such as an electronic game or a crossword puzzle. Rita included a photo of herself doing a crossword puzzle (see Photo 6): “I don't sit at it for days, or a long time, it's ah, I usually keep one out and if you're bored, or sitting around, I would pick it up” (Rita, Interview 2). Alice and Charles also talk about filling time with leisure by reading. This points to the multiple meanings that leisure can have for the participants, since these activities are used to keep their minds active and resist progression of dementia, as well as reduce

boredom and maintain active engagement in life. Charles tells me: "...I would be bored if I didn't have anything that I enjoy doing" (Charles, Interview 3).

Engaging in leisure to fill time provides a sense of purpose for participants. Instead of doing nothing, they choose activities that demonstrate their abilities and that they believe will slow the progression of memory loss to avoid boredom. Participants recognize, however, that this may not always be the case as their memory loss progresses. They are aware that as dementia progresses they may lose the ability to do their favourite activities. Engaging in meaningful activities to fill empty hours counteracts frightening awareness that one may no longer be able to participate in valued activities.

Claiming space

Finally, participants engage in life through leisure by claiming space. The participants designate their own private spaces within their lives, where much of their leisure occurs. Doing so allows them to live their lives with memory loss more comfortably. They know where things are and can arrange them for their convenience. Having personal space distinguishes oneself from others.

These spaces instill feelings of safety and hominess. Several of Charles' photos show him in his own space, an easy chair in one corner of his apartment, where he has access to the telephone and all of his leisure activities, including books and electronic games (see Photos 4, 5, 30). He says of the photos: "Well, the fact that it illustrates that I like to have my own chair. That's my corner. And if I keep it messed up, [my wife] doesn't feel nearly as concerned as if I clutter somewhere else. That's my, that's my corner" (Charles, Interview 2). He goes on to say of the space: "Other than that it makes me feel good. I've got this space that's mine and um, I'm pretty well right at the phone, I don't have to jump and run" (Charles,

Interview 2). Rita and Jack also have their own spaces in their homes where they can engage in leisure or just have quiet time if they need it. Rita took a photo of her den, where she spends much of her leisure time (see Photo 33). She says of her own space:

That's where I usually go. [My husband] bought a new TV here, and every time I touch it I seem to do something wrong with it (laughs), you know, so it's better I leave it alone. And, and then we have another TV in the other room, so usually he watches his sports here, and I, and I'm in the, the den. And I like it in there, because uh, now I've got the phone there if I wanted to talk, and...and it's comfortable. (Rita, Interview 2)



Photo 33: Rita spends time in her den

Participants design their space to incorporate their favourite leisure activities conveniently into their lives. Although Alice has her own space because she lives independently, she arranged it to enable engagement in a series of leisure activities and recognizes the importance of having personal space when living with memory loss:

But the proximity of everything, it's sort of, I've sort of got it set up like I progress from one thing to another because if you look at it, I get up in the morning, I have my computer and activities, I'll have a puzzle or ss, or things that I'm sorting through in the table, and then I'll go to the living room where I'll have my books and my puzzles, the other puzzles, and the TV....So I've made it as a circle. You know and then I can divert by that, because oftentimes if I'm sitting in here doing a puzzle or reading or whatever, I'll still see the birds out the balcony. So, and then,

I'm sitting here it reminds me to water my plants because I'll see the droopy leaves. So one thing reminds me of another, so having your space. I've always had my space, because I'm living alone. But I can certainly understand where it is extremely important to have, the individual with memory loss to have their very own room. They set it up, and they put it the way they want it. Their space. (Alice, Interview 2)

Unfortunately, it can be difficult to maintain one's private space for leisure. Rita lost her space between the time we played Skip-bo together and our follow-up interview. Moving into an assisted living facility meant having to give up much of her space, which Rita regrets:

Actually I didn't want to move into this place. We were in the condo, and I was quite happy there but the family all thought that we should get into a place where we get our meals here and there's somebody there to take care of you...it's very nice here...but this place isn't as big as even our condo was and as soon as we were looking at this place I said "Well, that's fine but it's not big enough really, there's not enough space here for us," which would bring in a place where I used to go and do my typing with my computer and work on it sometimes and I really enjoyed that, well there's no place now to really set anything up like that. So that's the kind of thing I miss. I would like to have a spot to go and do things like that, but there just isn't the space... (Rita, Interview 4)

Rita emphasizes the value of having one's space for leisure, since having to give it up means she no longer has the same opportunities for leisure that she did before.

Engaging with life is vital for the participants to maintain positive attitudes and helps them to resist threats to identity by providing continued roles and new activities that emphasize strengths instead of point to losses. Charles summarizes how active engagement in life is important for his identity: "And I guess I also pride myself in the fact that I am trying to continue to enjoy life" (Charles, Interview 3). Being able to seize new opportunities and being recognized for doing so reinforces the identity of being capable people who can still contribute in a variety of ways to the world around them.

Having purpose

The fourth essence of upholding identity is having purpose. Leisure is purposeful for the participants when they use it to fight the progression of memory loss and as a way to contribute to their families and/or communities. Charles notes that leisure gives life purpose and meaning: "...reading is the core of how I spend my time and I enjoy that and with the reading magnifier um...it, it helps to make my life enjoyable...And other forms of, yeah, I think life has purpose and meaning" (Charles, Interview 4). Leisure can be purposeful in terms of work and motivation, but sometimes participants find leisure lacks purpose and feelings of meaninglessness result.

For some participants, leisure's purpose is to improve skills and fight memory loss, making leisure work-like in nature. For Alice, the line between leisure and work is blurry. She views her leisure as work because of her belief that it will help her maintain her independence. Leisure has replaced her work roles, and she defines leisure as purposeful work in terms of function and independence. By replacing work roles with leisure, Alice is able to resist threatened identities.

Yeah, it's replaced my work, my employment. So, the thing is with the disease, the whole picture, the whole concept has changed, because I'm um, quote new normal. Like I'm still very high functioning, but I have to alter what I do in leisure or work or just daily activities to sort of work on my weaknesses so I can enhance my lifespan of longer...and higher quality of memory. Because what I do leisurely, quote work, either can enhance or decrease my memory loss. Or not, it can either improve it or decrease it. (Alice, Interview 3)

She tells me that she has difficulty distinguishing between leisure and work because of leisure's importance for her well-being. She has a leisure routine designed in a task-oriented way similar to a work environment in order to maintain her abilities. Her adoption of work-

like leisure helps fill the void of the loss of work roles for Alice, providing her with a similar routine and goals for her day. It is a means to an end:

Like I'm having a very difficult time differentiating between leisure and work. So to speak. And I think that's due for the, to the fact of the way I sort of constructed it within my own mind. Because I've combined the two...So leisure, defining leisure is really difficult for me. Because when you first asked me I thought what is leisure? Well, yeah the things I do for fun. Well everything I do is for fun, with a work connotation in it. (Alice Interview 3)

Alice explains this further for me:

Alice: That's what I've had trouble with, because see I'm mixing the two up. Like I'm looking at leisure as almost work. Because I think because of the disease process I have to work at it constantly in order to keep it stabilized. So leisure has sort of taken the place of employment, so leisure is my work. That's, but it's...

Rebecca: Is it still leisure?

Alice: Yes, because it's fun. That's the only way I can describe it because, it's, it's, it's leisure, if I was normal, it would be normal fun things, but because of the disease there's the work element in it. To keep me functioning. So there's that difference with the disease process, it's almost like a leisure-work combination. Because it's still, you still have the fun aspect of it, I'm still being productive, and I'm still interacting, but I have to work at that because of the disease. (Alice, Interview 3)

Participants use leisure as brain exercise and keeping fit, as discussed previously, giving a special purpose to leisure – as a tool for slowing further memory loss. Although their activities that exercise the brain are fun and enjoyable, they serve a greater purpose.

In addition to work-like activities, leisure is purposeful in the lives of the participants because it is motivating. Alice sometimes lacks motivation to do daily chores or personal care activities. Participating in leisure can give her the motivation to continue to engage in activity:

Because I'm sort of at a stage now where I have a fear, fear to try. It kind of creeps in there, so it's a 24/7 job just to try to decrease that fear level in order to have the positive to move on. So...um...leisure is really not leisure. Because it's such a motivator for me. It can be if I use it in the right context. (Alice, Interview 3)

Leisure gives Jack a reason to get out of bed in the morning. Having something to look forward to helps him to focus on the positive aspects of his life. I ask Jack if leisure helps him manage life with memory loss and he tells me:

It makes me feel better every morning. Every morning I get up and think “What can I do today?” you know, and then I go out and I go out for a walk around our place and then I go out and play golf and that makes it get up and go. So it’s moving and talking and everything, and so far, I still think that I can do almost everything that I ever have done. (Jack, Interview 2)

Jack stresses this again in his third interview:

Leisure is very important, yes it is. Why is leisure important? Because you’re doing something. You do it because you enjoy it and then it makes you feel good. And it gives you a reason to get up in the morning when you can’t do something that you used to be able to do, like, like like I used to get up every morning, go to work at six in the morning and work long hours and everything else. (Jack, Interview 3)

Again, this demonstrates that participants resist the assumptions of others that they have lost a great deal of ability and have nothing to do. Leisure gives them a reason to have hope and continue on in life, and to actively engage in the world around them.

When participants find it difficult to maintain active engagement in life or activities lack meaning, they experience meaninglessness. Rita sometimes feels like life lacks meaning: “...I don’t know where I read it in one of the books that I had that that’s a common thing for people with Alzheimer’s, they can get in a flash and sort of feeling that life’s not worth it you know” (Rita, Interview 3). While we walked together, Rita acknowledges that sometimes her activity choices lack purpose or fulfillment for her:

She told me she thinks it is important to have a leisure activity, or something to focus on when this happens. I asked her if she had found one that was important to her, and she thoughtfully said that she hadn’t. (Rita, participant observation field notes, walking)

Similarly, when Alice experiences a set back that affects her cognition, leisure becomes meaningless to her as she focuses on regaining energy and ability. She tells me she focuses on survival and leisure becomes a lower priority:

...I had a little stroke episode a week and a half ago, and now um, I'm re-learning everything, so right now nothing has a particular meaning its like I'm surviving. So but as I get through that where my speech is clearer and this time it really hit my cognitive, so the sequencing, and it really hit the writing. Um, so um...I'm really not concentrating on the leisure as much as trying to recoup. (Alice, Interview 4)

Feeling a sense of accomplishment

The fifth essence of upholding identity is feeling a sense of accomplishment. Leisure is a venue for achieving goals and being successful. All participants experience accomplishment in their leisure to varying degrees. These feelings of accomplishment reinforce their identities and instill a sense of pride and confidence.

Participants set goals for themselves in order to have something to aim for and improve upon. This provides them with direction and motivation for tackling dementia. Alice sets goals in order to accomplish something each day:

Like my goal is each day accomplish one thing. Minimum of one thing. Whether it be do the dishes, do a puzzle, umm, do the computer, umm, go for a walk, umm...something. Something in the positive realm or call somebody that I haven't talked to in a long time, or try my knitting, or try my crocheting, or try, something new, there, that I have to do one positive thing a day. At least one. Even on my worst day, there has to be, even if it's cleaning the toilet, it has to be one accomplishment per day. No matter how small. (Alice, Interview 1)

Setting and achieving goals can lead to a cycle of accomplishment. As one goal is met, the participants feel that they can continue to accomplish other tasks as well. Alice's photo of her computer highlights her accomplishments in terms of gaining new skills (see Photo 8): "It has opened a whole brand new field of excitement. And a big accomplishment for me

personally. Big, big, big, big, big, big” (Alice, Interview 2). Her accomplishments emphasize that life after dementia can continue to be a time of growth and development.

And it’s almost like, look what I’m doing, look at what I’m accomplishing. And you know maybe without the disease I wouldn’t have tackled the computer to the same level. I may have just let it be. Yeah like, so there’s life after diagnosis. (Alice, Interview 2)

Jack’s photo of a jigsaw puzzle emphasizes how solving the puzzle, piece by piece, feels like an accomplishment (see Photo 7): “And, and, and then finally when you put that last piece in, jeez it feels good” (Jack, Interview 2).

When leisure is related to feeling a sense of accomplishment, participants experience increased self worth, pride, and sometimes elation at having been successful in the face of their challenges. Rita feels good about herself when having figured out a particularly difficult crossword puzzle: “And you get a great sense of uh, strength when you realize you’ve done right” (Rita, Interview 2). Charles talks about his sense of accomplishment in leisure in terms of solving his leisure-related problems. He describes the photo of his reading box and the sense of accomplishment that finding a way to continue to read increased his sense of self worth (see photo 29). I ask him how it felt to create his reading box and solve the problem of not being able to hold a book steadily, and he responds: “It really relieved some of my frustration. Because I hadn’t found an answer, but I found a way to make it easier...it helped my self worth. That I found a way to work around it” (Charles, Interview 2). Furthermore, being able to accomplish things in leisure increases Charles’ self-confidence. In our third interview, Charles tells me that accomplishments in leisure time help him to feel better about himself: “Yes, I think it’s a cycle. That being able to, that being able to and purposely continuing to do those things that I enjoy in leisure, helps me to feel more positively about myself that I can...still do what many others cannot” (Charles, Interview 3). Alice takes

greater pride in her accomplishments more now than ever before, and celebrates them by sharing them with her friends and family:

...I would say now when um I accomplish...something very positive, I'm very verbal about it, and usually before I wouldn't. And it doesn't have to be to the same level of perfection...that I would do a craft before. Or umm...anything, like you know, I'll phone my kids or my best friend or whatever "Guess what I got finally done", you know, like. Uhh...I can't say it's, it's not bragging, it's a sense, a sense of accomplishment. Whereas I wouldn't have done that before. (Alice, Interview 1)

The feeling of accomplishment is so much greater when experienced within the face of memory loss: "It is, it's almost a high" (Alice, Interview 3). Through accomplishments, participants are able to resist assumptions of being purposeless and incapable. They celebrate not only their abilities, but their courage to continue to try difficult things despite the challenges and their abilities to work with their memory loss to find new ways of doing things that are meaningful for them.

Creating enduring memories

The final essence of upholding identity is creating enduring memories. The participants wish to leave behind a positive memory of themselves. They want to leave behind a legacy that goes beyond having dementia. Types of memories left and how the participants go about creating them differs across all four participants. Nonetheless, participants use leisure to create memories of themselves for their loved ones. For example, Rita's most valued role is that of grandmother, so she is writing poems for all of her grandchildren to remember the times they had together:

Yeah, um...I think um, the only thing I can think of is I'm doing some poetry now to each one of my grandchildren and I've got about 49 of them, (laughs) you know not really that many, I think there's about 12, 13, 12 is it, and I'm, I'm doing sort of a collage of it, so they have something to remember the memories that we've had together, and they're just on memories that I've had of each one of them you know

because they're all different. And some of them you're very close too, and other ones you sort of gotta work yourself into their life and, but it's um, that's very helpful because it brings back the memories of when they were young, when they were born and that sort of things. That that's very comforting to me, to do that kind of thing. (Rita Interview 3)

Poetry is an important part of Rita's identity as she defines herself as a person who loves poetry. She uses this aspect of herself to create enduring memories:

I love, I love poetry. I love reading other people's poetry, and um, and I like writing it. Ah, I feel really good when I'm typing it out and, and uh, and it may not be all good, it's you know, but, to me it's good, because it's done, done something for me, and my kids like it, and you know, that's I've given it to friends, and stuff like that. And, and um, they don't tell me that I sound crazy, so. (Rita Interview 2)

Reflecting on pleasant times with her grandchildren and using poetry as a means of sharing her memories with them is comforting for Rita. I ask her if writing poetry helps to emphasize her role as a grandmother and she responds:

... it's true, you feel as if when they read these, they'll know that I wasn't really all that different when I went away you know, so I think that's, that's a very good point, I think it helps a lot, this idea. (Rita, Interview 3)

Thus, by creating enduring memories through poetry, Rita upholds her identity by finding ways to preserve valued aspects of herself. She resists the possible loss of her future identity by creating enduring memories for her family to remember her by.

Alice uses her leisure to show her capacity and change the way people think about memory loss. She wants her family and friends to remember her as someone who does not give up, but who fights despite the challenges she faces. The new activities she has adopted and the purpose she finds in leisure provide her with a means of leaving a legacy. Alice wants to be remembered for the positive example that she sets for her family and friends:

It's leave, leaving behind the legacy that I tried to make the best of the disease process. It's leaving a positive legacy...And...for those around me, or that meet me...will have less fear of the disease with other people. With their family or friends. Um...yeah. The dignity. Encouraging the dignity, and I expect dignity.

Umm...I request dignity. If somebody wants to help me...that's going to ...make me feel embarrassed or ashamed. I will quietly suggest another way so I have a little bit of my own dignity. That I did, ah, maybe one percent of the job instead of somebody doing it completely. Or making it...in the public, especially in the public. Umm, if they want to overprotect...I'll still try to reinforce that respect and dignity. So I think that's, yeah. A positive legacy...for those around me that they can carry with them the rest of their lives so if they meet someone with memory loss, they can umm... umm, know how to deal with it in a positive manner. And especially my great nieces and nephews, cause they're the young generation. And they're the easiest ones to teach. (Alice, Interview 1)

Alice keeps trying in all of her leisure activities partly because she believes this sets an example for others and will encourage others living with memory loss to avoid complacency in their lives: "...but no, I think as I go along in the journey it's more of a fight than ever because um, by setting the example it's only going to help somebody else" (Alice, Interview 3). Alice continues to push herself. She provides an example of playing Yahtzee with her friend and adding the numbers in her head in order to set a positive example of fighting dementia:

Like for example my girlfriend came up and played Yahtzee with me. I was telling you she used the calculator and I used my brain. So there's another example of comfort zone or do I challenge myself. Take your pick. You can look at both sides. But for me it would be an easy way out and I, life has never been easy and why would I change it now. And what kind of example am I setting for those around me if I don't challenge the disease. Like for me that's me personally. (Alice, Interview 3)

Charles also uses leisure so that others remember him as someone who faced a challenge and solved his problems. His creative ways of solving some of his leisure problems are a testament to this, and he believes that solving these problems reinforces his identity. His reading box is an example of this (see photo 29):

Oh I've always been one to figure out how to cope with a problem, and to me it was a problem that disturbed me and I, what can I do? Well, we, okay, I've got the answer. We made our own, built up that thing with Styrofoam so it's very light. (Charles, Interview 2)

Similarly, Charles took a photo of his magnifier to represent how important problem solving is to his identity (see Photo 17): “Um...it’s a good illustration of my personality in terms of if something’s good, make it better” (Charles, Interview 2). Charles reinforces to those around him that he is a person who works to solve problems instead of letting them get the better of him, and he wants to be remembered as such. Charles also wants to be remembered as a supportive friend. Other people see Charles and his wife as people who want to make a difference: “...people accept us for being open to help others as much as we can” (Charles, Interview 1). He reiterates this in the third interview:

I think that [my wife] and I are known as...enjoying...friendship and being a friend. I simply say to have a friend you have to be friendly. That’s certainly true. But um, I think both of us are known as having caring personalities and wanting to do for others, and that continues on and I want it to... (Charles, Interview 3)

Finally, Jack’s legacy comes in the form of helping others. Jack is social and friendly and he wants to talk about his experiences of dementia in order to make other people understand the disease and feel more comfortable. He sees his role as helping others come to grips with their own memory loss or that of their loved ones. This plays out in his leisure lifestyle as he uses his group leisure activities, such as golfing and playing games, to talk with others about dementia. He tells me a story about chatting about his experiences of memory loss with a stranger in a hardware store:

I uh, I had a, a friend and I went out and there was a chap that was in this antique store...And his mother was having dementia and this guy was in the store and we got talking and I said well I’ve got Alzheimer’s...And we got to talking and it came out that his mother was having dementia and she had gone in and saw the doctor and the doctor said you got dementia, gave her a pill and that was it. And I got talking to him and I talked to him for an hour...And he said well how about this and how about that? And he got out the door he felt so good about what he should be doing about his mother, just from me talking to him, not that I did anything important, but I directed her to the Alzheimer Society and it just made me feel real good and told him some books that he could go to and get at the Alzheimer Society and look at the books and the rest of it. And it just made me

feel really good. And that's what I want. I want to do things that I can do now before I can't do it. (Jack, Interview 1)

Jack explains that it is important for him to share his experiences with others. He wants his experience with memory loss to be used in order to ease the way for others, including other care partners and persons living with dementia:

I'm able to know what I am doing. Right now that's what I'm trying to do. Ever since I found out about Alzheimer's I'm trying to make sure that anything I can do to help someone and be very proactive of telling people what Alzheimer's that I know about that can help, that's basically. (Jack, Interview 1)

Jack uses his social leisure as a way of helping others and emphasizing his identity as an advocate and as being supportive of others. In speaking out, he is breaking the silence that has long existed in dementia. By engaging in meaningful leisure, participants create enduring memories of themselves so that they will be remembered as who they are, and not merely remembered as victims of dementia.

In sum, the participants in this study engage in meaningful leisure in part to be able to resist threats to their identity, whether from family and friends, from loss of abilities and independence, or from wider social stigma associated with dementia. Engaging in meaningful leisure emphasizes that the participants' lives have purpose, that the participants can accomplish things, that they continue to enjoy life, and they work to change perceptions of dementia. Alice describes the importance of engaging in meaningful leisure in our second interview:

I would say it's one of the most important things you can do because through that you can advocate, you can enjoy yourself, you can um...just do anything and the leisure activities, whether it be walking or making something or being with friends is all so important as to your own self fulfillment, your self satisfaction, your, your inner growth, within the disease, your advocissy [advocacy] in showing friends, anybody, stranger what you can still do, and um, it's an outlet, it's, it's a game in a way because um, once you, it's like monopoly, you start at go, and, and, when you hit go to jail, well okay that's the day you're having bad and you go back to go and

you start trying again. So in a way the leisure activities only enhance the journey because it's, it will address wherever you are at what level in your journey, it will only help you um, the only word I can think of is further the cause, but a sense of fulfillment...But, no journey is, leisure is um, ultimate to success and satisfaction. And your self worth and dignity and respect. All in one. (Alice, Interview 2)

Leisure has a range of meanings for the participants, and they choose valued activities that help them to resist assumptions that they are no longer capable people. They uphold valued aspects of identity and remind their loved ones of who they really are.

Summary

Jack, Alice, Charles, and Rita experience memory loss within a paradox of challenge and hope. Their lives are filled with many challenges, yet they search out and experience hopeful, meaningful lives. While challenge and loss are synonymous with memory loss, feelings of hope must be cultivated through one's attitude, one's relationships, and a sense of willingness to fight the disease. The participants experience loss and frustration while finding ways to enjoy life. Charles notes that he sometimes feels "like a dummy waiting to die" (Charles, Interview 1), yet in his follow-up interview he indicates that his life has purpose. This demonstrates how the participants' journeys of memory loss are characterized by a contradictory and changeable experience. The participants use leisure as a space to fight the challenges, both in terms of changes in abilities and in terms of threats to their identities, and as a result, their lives are intertwined with threads of challenge and hope. Alice summarizes this with the following quote:

But on the other hand, when I do have my down days, they may be somewhat worse, because I know the end stage. I've seen it so often, that if I start to feel down, it really hits...and umm...So, um...as I say the journey is really a learning experience...and...it's affected me, and frustrated me and I've been angry at times, which is normal. Umm...I've gone through all the gamuts of emotions with losing my abilities. And umm...then trying to turn around put a positive side

on it. So that is the key, is turning it around and trying to bring it...into the proper focus, a more positive focus. That's a, that's a 24-7 challenge. (Alice, Interview 1)

The experience of leisure within the memory loss journey is itself paradoxical. Having lost former roles leaves time for engaging in meaningful leisure, yet other losses make participation more challenging. Although participants use leisure as a space for sustaining hope, their fluctuating abilities highlight the losses they experience. I ask Charles how leisure plays into some of the changes he has experienced:

I'm not sure how to answer it. Um, ah, just give me a minute. Well positively it gives me time to, time to read and enjoy that. Um, it gives us...time to...enjoy our walks and um, table games. Negatively it um, certainly is difficult. I can only walk for about half an hour where I used to be able to walk for a couple of hours. Um, I miss that very much on our walking, when we're out doing our pole walking, which I told you about. And we were out this morning for 25 minutes, I could have gone for another half an hour I *think*. (Charles, Interview 3)

The diagram of the flower that summarizes the participants' experiences within the paradox of challenge and hope (Figure 1) was inspired by, and preferred by, the participants of this study because it is a symbol of hope and of continued growth and development in the face of change. The diagram shows how each essence of the participants' experiences, and its respective subthemes, combines with the other essences to form the paradox of challenge and hope. The participants of this study truly live their lives within a paradox of challenge and hope as they work through the challenges that memory loss creates and by doing so, find meaning in life. Life has changed but participants have found ways to adapt to those changes and "live" with dementia.

Chapter 5: Discussion and Conclusions

This study expands our understandings of the subjective experience of leisure within the context of memory loss. It contributes to a small but growing body of research that is moving away from biomedical and clinical approaches to dementia to a focus on the “lived” experience of dementia from the perspectives of those living with it. This research is particularly unique because of its emphasis on leisure in the lives of persons living with dementia. Through interviews, photos, and participant observation, it was revealed that persons living with memory loss experience leisure within a paradox of challenge and hope. Leisure provides meaning in the face of change. I now situate the findings of this study within the current literature and demonstrate how our understandings have expanded as a result of this research. I first discuss the implications of this study in terms of our current knowledge regarding the subjective experience of dementia. Second, I explore how the participants use leisure to cope with stress that results from living with memory loss. Following this, I explore insights that have been gained in relation to identity and dementia. Next, I discuss leisure’s role in the lives of the participants of this study as it relates to, and expands, our knowledge of leisure as resistance in the context of memory loss. I then consider how this study contributes to our understanding of personhood and relationship-centred care. Finally, I explore my own research journey along with the practical implications and future directions of this study.

Understanding Life with Memory Loss

Life with dementia is full of uncertainty as it presents many challenges (Clare, Rowlands, & Quinn, 2008). However, participation in meaningful activity indicates that, as Alice suggested, there *is* life after diagnosis. In this section, I explore how these findings both reflect

and diverge from the existing literature in terms of the experience of symptoms, coping with memory loss, and the overall complexity of life with memory loss. Additionally, I consider the findings in relation to the lifeworld existentials (van Manen, 1997) to increase understanding of the lived experience of memory loss.

The participants in this study experienced many of the symptoms commonly associated with dementia, such as changes in cognition, judgement, problem solving, and memory. People living with dementia are aware of changes in memory and cognition (Beattie et al., 2004; Ohman et al.; Phinney, 1998). Symptoms vary as memory loss progresses, although we have yet to fully understand the experience across the course of the dementia journey due to a lack of longitudinal research. Rita, who had only been diagnosed one year prior to the commencement of this study, experienced the symptoms of dementia as a memory problem and considered them to be minimal or normal (see Gillies, 2000). However, for Jack, Charles, and Alice, memory loss was not minimal and they were aware of their symptoms and fluctuations in abilities (see Phinney, 1998).

Persons living with dementia are creative in the ways that they cope with the symptoms that they experience (Clare, 2002; Clare, Rowlands, Bruce, Surr, & Downs, 2008; Harman & Clare, 2006; Harris & Durkin, 2002; Ohman et al., 2008; Parsons-Suhl, Johnson, McCann, & Solberg, 2008; Sorensen, Waldorff, & Waldemar, 2008). Sorensen et al. suggest that persons living with dementia used "...a spectrum of coping strategies to preserve personal dignity and value" (p. 297). One such strategy includes having hope that the diagnosis is wrong. Another strategy involves avoiding worry about one's memory problems (Clare, 2002). These particular strategies were evident in the way that Rita questioned her diagnosis throughout our interviews, and her indication that she tried to avoid thinking about having memory loss. She

often denied the pathology of the condition, as Gillies (2000) suggests people often do in the very early stages of dementia. Rita stayed away from situations that might have highlighted her memory loss (see Harman & Clare, 2006) and preferred not to talk about memory loss with other people (see Van Dijkhuizen et al., 2006). The participants, however, underwent what Keady and Gilliard (1999) refer to as an active process of learning to live with dementia. Jack, Alice, Charles, and even Rita reconciled the changes that were occurring, drew upon the support of their care partners to live with dementia, and subsequently felt as though they were in control of their situations at least most of the time.

Keeping an active mind is valued by persons living with dementia for staying on top of the disease (Phinney, 1998). Participants chose mentally stimulating leisure activities that were enjoyable. These types of activities were purposeful and led to feelings of control over their memory loss journeys, contributing to a sense of hope while living with memory loss. Making decisions about what types of leisure to engage in helped the participants to feel as though they were working hard to fight dementia. Coping with memory loss by remaining mentally active contributed to a sense that leisure itself was meaningful, and one's leisure choices could be both enjoyable and beneficial.

A positive attitude has also been acknowledged as a means of coping with dementia (Harris & Durkin, 2002). Persons living with dementia continue to feel optimistic and live life to the fullest (Keady, Williams, & Hughes-Roberts, 2007). Jack, Alice, Charles, and Rita adopted positive attitudes because they believed that failing to do so would lead to feelings of depression which could be very difficult to overcome. Focusing on their remaining abilities and the aspects of their lives that they were particularly satisfied with, such as having supportive friends and family, sustained positive attitudes. Beard and Fox (2008) also found

that focusing on one's remaining abilities was important for managing life with dementia. Harman and Clare (2006) suggest that some people may have difficulty deciding whether they should accept dementia or fight it. The participants in this study for the most part opted for both. Being optimistic about their lives helped them to do so. They all sought to fight memory loss by remaining actively involved in life, yet they reconciled, to varying degrees, the reality of their diagnosis and their subsequent changes in cognition. Their positive attitudes contributed to their feelings of hope about their lives and counteracted the losses they were experiencing.

While hope was a predominant feature in the memory loss experience for the participants in this study, Parsons-Suhl et al. (2008) found that a diagnosis of dementia "...was like a death sentence; as their memory got worse, they were also thrown into a future that would be similar to death" (p. 40). This suggests that having a positive attitude is not necessarily part of the memory loss experience for all of those living with dementia. One's attitude may be fluid – immediately at diagnosis, it might seem more like a death sentence, but as people reconcile the diagnosis, having a positive attitude might be possible. As well, it may be easier to have a positive attitude on good days than on bad days. This emphasizes the complexity and fluidity of the experience of memory loss. Although future memory loss was feared, Jack, Alice, Charles, and Rita believed that acquiescing to such negative thoughts about their lives would not be a particularly useful coping strategy. Instead, in an ongoing process, they fought hard to keep these negative feelings at bay and focused on the positive aspects of their lives.

Humour has also been found to be a valuable coping mechanism in dementia (Parsons-Suhl et al., 2008; Snyder, 2001). Having humour can help with the hassle of forgetting (Parsons-Suhl et al, 2008). Jack, Alice, Charles, and Rita often relied on their senses of

humour to remain positive while living with dementia. They made light of their mistakes and joked about forgetting names. As well, there was a sense that having humour about dementia enabled them to accept it and move on with their lives in new ways.

Another valuable coping mechanism involves drawing upon practical strategies to serve as memory cues (Clare, 2002; Gillies, 2000; Parsons-Suhl et al., 2008; Phinney et al., 2007; Preston et al., 2007; Van Dijkhuizen et al., 2006). Using calendars and notebooks, and being consistent in placing things in the same place helped the participants remember important things. These techniques are fairly common in the literature, and help persons living with dementia to manage their memory loss. Using practical strategies contributed to a sense of hope as participants were able to tackle the changes that they faced.

The variety of symptoms experienced in dementia, combined with the ever-changing abilities that must be adapted to, make life with dementia complex. Memory loss is experienced as a balancing act between losses and remaining abilities (Keady, et al., 2007; Pearce et al., 2002; Steeman et al., 2007). Steeman et al. (2007) point to complexity of life with dementia when they suggest that persons living with it focus on the positive aspects of their lives and minimize losses in order to balance feelings of being devalued, lonely, uncertain, shameful, and useless. Similarly, Sorensen et al. (2008) highlight the complexity of dementia with their tentative theory that states that "...patients protect themselves against awareness of decline in dignity and value by adapting to the consequences of AD" (p. 291). Their participants found ways to cope with dementia by adopting a variety of strategies to maintain well-being. Jack, Alice, Charles, and Rita revealed the complexity of life with memory loss as they, too, worked to balance feelings of hope with the losses they faced. In leisure, they balanced their losses by focusing on abilities and demonstrating that they, as

persons, still had worth. This balancing act led to a range of emotions, from embarrassment and frustration, to pride and enjoyment when challenges were overcome. However, leisure will become increasingly difficult as dementia progresses and threatens their remaining skills and abilities, making the balancing act more challenging. Sorensen et al. found that feelings of well-being in dementia are associated with the ability to manage everyday life and being useful, while anxiety is associated with old age, lack of a cure for dementia, and worrying about the progression of dementia. Alice, Charles, Rita, and Jack experienced well-being when they were able to manage daily life and make contributions to their families and communities, but, at the same time, they feared what their futures might hold.

The essence of the experience of dementia occurred within the tensions between challenge and hope, and while losses happened to the participants, they actively responded to challenges to counterbalance the changes with a sense of hope. The complexity of life with dementia was also apparent in the contrasting ways memory loss was experienced. For example, Rita's family supported her and did not treat her like she had memory loss, yet they questioned her abilities, which threatened her identity. It was also revealed in the way the participants felt both pride and frustration when people told them they did not appear to have dementia. Memory loss brings with it conflicting emotions, abilities, and relationships, and this study continues to increase our understanding that life with dementia is complex, contradictory, paradoxical, and ambiguous.

While it is evident that the findings of this study align well with previous research, further insight can be gained by considering the lived experience of dementia in terms of phenomenology's four lifeworld existentials. van Manen (1997) argues that despite great variation, all lived experiences ultimately occur within lived space, lived body, lived time, and

lived other. Consideration of memory loss in terms of the lifeworld existentials deepens our understanding of the complexity of the phenomenon.

Lived space

Lived space, or spatiality, refers to the experience of space, or the space in which participants felt comfortable and at home (van Manen, 1997). Participants valued having a quiet and comfortable area to call their own. Charles and Rita included photos of themselves engaging in leisure activities in their own space, suggesting that personal space was indeed meaningful for the participants. Charles defined his small space in terms of a comfortable chair and easy access to his favourite leisure activities. Rita chose to engage in her leisure in her den, where she knew how to operate the television and could comfortably read and work on her crossword puzzles. Alice lived alone and had designed her space in a comfortable, convenient way that made her feel at home. Jack had a designated quiet space in the bungalow that he shared with his wife. These lived spaces were experienced as comfortable, relaxing, and safe. Having comfortable space in which to engage in leisure activities enabled their participation. It provided room for their puzzles and games and a place to relax and rejuvenate when energy was depleted. However, when Rita lost her space to call her own, she was unable to engage in activities that required space, leading to a discrepancy between leisure that was meaningful for her and that which she could actually engage in.

Lived space went beyond personal space created for quiet time and leisure activities. For Rita, lived space did not always have such a positive connotation. She felt isolated as a result of losing her license: "...I would, I would like to be out more, and I would like to be among people more. But, but you find you're limited if you don't have the transportation" (Rita, Interview 1). Similarly, de Witt et al. (2009a) found that participants felt "closed in" when

they lost their drivers' licenses. Rita in particular sought out experiences away from her own space, eager to be part of the world around her, visiting her children, eating out, going shopping and spending time with friends.

Although perhaps not as frequently as they might have liked, all participants left their comfortable spaces to pursue other leisure activities. They appreciated the natural environment around them. Alice valued the outdoors more than ever, paying attention to the birds and the wildflowers in ways she had never done before diagnosis. Awareness of lived space was heightened when access to meaningful space was threatened and could no longer be taken for granted. This was apparent when Rita moved from her condo to the retirement home and expressed how much she welcomed the chance to get out with family and friends. Since her opportunities to be in public spaces were reduced, she took advantages of all offers to spend time with other people away from the retirement home. It was also apparent in the way Alice sought out opportunities to interact with the outdoors and found a great deal of pleasure in doing so. Alice recognized that she may not always have the opportunity to feed the birds or go to the park as her dementia journey progresses, so she took advantage of every opportunity to do so.

The experience of lived space could be negative when homelike settings and communities became confusing for participants. Awareness of where their bodies were in lived space changed with dementia. This was apparent in our participant observation sessions. Jack was unable to find his way back to his house after we practiced putting. He felt somewhat confused and frustrated, but Jack turned around and retraced his steps until he recognized his surroundings. Alice felt disoriented in her own apartment when she woke up in the morning (see Phinney & Chesla, 2003). While having a space of one's own was comforting, one's lived

space was beginning to narrow, since going beyond it could lead to uncertainty and the fear of, or reality of, becoming lost. de Witt et al. (2009a) reported that the women in their study acknowledged benefits to getting out of the house, but they sometimes felt uncomfortable going out. Furthermore, they felt like they no longer belonged as part of a particular group or in a particular setting. As well, Clare, Rowlands, & Quin (2008) found that persons living with dementia in residential care felt confined, much in the way Rita felt when confined to her own home for long periods of time. This suggests that lived space may become increasingly smaller as dementia progresses and participants transition to long-term care.

Lived space was paradoxical. Leisure activities occurred in designated spaces that instilled a sense of comfort and hominess. However, these spaces could also feel confining if opportunities for leaving the space were lost. Additionally, participants' experiences of space could be disorienting. For the most part this occurred in environments that were less familiar to the participants, but could also occur in familiar locations.

Lived body

Lived body, or corporeality, refers to one's experience of one's physical body. It addresses how self is revealed through physical presence, whether intentionally or unintentionally (van Manen, 1997). Considering the experience of dementia in terms of embodiment provides a deeper understanding of the experience of dementia (Kontos, 2003; 2004; Phinney & Chesla, 2003). Kontos' (2004) findings indicated that selfhood persists outside of cognition and is instead grounded in corporeality. The findings of this study support recent research that has explored embodiment and dementia.

Phinney and Chesla (2003) characterized the experience of dementia as a breakdown in bodily flow – bodies slow down in dementia, and people with dementia feel lost in the world

and have trouble finding their way. They experience “being a blank” and are unable to find thoughts and words that make it possible to engage in reflection. Phinney and Chesla suggest that lived body changes for the worse, describing dementia as a “...breakdown of a deeply embodied sort” (p. 296). Phinney and Chesla also report that participants experience a slowing down of conversation. Jack, Charles, Alice, and Rita experienced embodied fatigue. They found themselves slowing down in their activities and ability to use equipment, especially in terms of driving. Their lack of energy led to a slowing down in physical activity. Jack pointed out that sometimes he felt like his get up and go had diminished. Charles included a photo of himself sleeping to demonstrate that he is frequently tired and falls asleep while reading. Their difficulty accessing thoughts was reflected in slowing conversation. Time was needed to formulate words that participants knew that they knew but could not access (see Truscott, 2003).

The participants of this study did not acknowledge a great deal of change in terms of their own lived bodies. Although they noticed changes in energy levels and felt their bodies tiring easily and slowing down, participants were unable to pinpoint how they experienced their bodies while engaged in leisure activities. At this point in their memory loss, their forgetfulness and changes in cognition were more apparent than changes in their physical presence. Nevertheless, Charles noted that the experience of dementia is physical when he says: “I can feel it. Sense it” (Charles, Interview 1), indicating that participants experienced a physical knowledge or awareness of the presence of dementia that went beyond cognition.

Charles, who had also been diagnosed with Parkinson’s disease, may have experienced lived body differently than the other three participants. He admitted to having difficulty discerning between symptoms of dementia and symptoms of Parkinson’s. He noted changes in

his capacity to participate in many physical activities. He lost his job as an apartment building superintendent due to his inability to use a screwdriver and a lawnmower because of symptoms of Parkinson's: "and then I was diagnosed with the Parkinson's, and I couldn't get the screwdriver into the right spots anymore and couldn't chase after the lawn mower so I resigned" (Charles, Interview 1). The physical nature of the symptoms of Parkinson's also impacted Charles' leisure. Physical activities that he once enjoyed, such as playing basketball and riding a bicycle, were no longer possible as a result of Parkinson's disease. Even reading became more challenging:

And I can't hold a magnifying glass because of the Parkinson's and it shakes like crazy. And so I have reading glasses, and in order to be able to sit there magnified four times and so I've made up an apparatus where I have a piece of...Styrofoam, and then with a holder that holds the book. And that way without it the book is shaking...and ah so this is the way that I can read. (Charles, Interview 2)

Participant observation revealed more about the experience of lived body than the interviews. Facial expressions indicated concentration or intentness in focusing on an activity. I observed this when Alice and I were crocheting dishrags: "Alice...held the dishrag fairly close to her face, and her brow was slightly furrowed, lips in a straight line while she concentrated on making the correct stitches" (Alice, participant observation field notes, crafts and games). However, what I found to be most revealing about corporeality was my own experience of participating in new leisure activities with participants. I had to learn how to use my body to participate in these activities. This was particularly evident when Charles and I went pole walking.

Charles told me to try to walk by swinging opposite arms and legs, which for me proved quite difficult... The pole walking felt awkward. I had a difficult time getting my hands and feet to move opposite each other. I felt like I spent a lot of time thinking about walking rather than just relaxing and doing it. I told Charles

this and he said it was like that when he first started. It takes a long time to get used to it. (Charles, participant observation field notes, pole walking)

Of course, had I continued on with pole walking over time, I am certain that my body would become used to this way of walking and I would spend less time thinking about walking and the action would seem natural and effortless. I would likely lose awareness of my physical presence within the activity. Participants may not have this advantage as their memory loss continues to progress. They may have needed to relearn physical activities each time they tried them. Additional time is likely required in order to develop a more comprehensive understanding of the lived body in the context of dementia as the disease progresses.

Phinney and Chesla (2003) suggest that people living with dementia disengage from their everyday activities as a result of embodied breakdown. However, Jack, Alice, Charles, and Rita's continued participation in daily activities contributed to feelings of hope about their current and future situations. Using one's body to engage in everyday activities, leisure or otherwise, was valued and resulted in feelings of self worth. Participants had not yet experienced the collapse of involvement evident in Phinney and Chesla's research. This may change for the participants as their memory loss progresses.

Lived time

Lived time, or temporality, refers to the way that time is subjectively experienced. Phenomenologists question how the passage of time *feels* to the individual, as well as the individual's experience in time in terms of reflecting on the past or thinking about the future (van Manen, 1997). Parsons-Suhl et al. (2008) stated that "the experience of forgetting was one in which either their sense of time or remembering things happening in time was lost" (p. 37). Time was experienced in a multitude of ways in this study. Time could be filled and

made to go quickly through meaningful leisure, which participants used to avoid boredom. Often participants spent a great deal of time in their favourite activities. For example, Jack played golf up to five times each week and Charles read for more than four hours each day. Although time passed quickly when engaged in leisure, this feeling could abruptly change, and when fatigue set in, time crept along slowly, sometimes almost to a halt. In some cases, participants could no longer spend as much time as they would like to in valuable activities. For example, Alice noted how when she felt tired, she was required to extract herself from the activity, no matter how much she enjoyed it. Lived time was influenced by lived body since reductions in leisure time resulted from increased fatigue.

Temporality was occasionally lost all together for the participants. Alice noted that time was irrelevant, and unless she had an appointment or meeting scheduled, time passed her by unnoticed. Jack experienced a loss of awareness of time passing as well. He had difficulty understanding how time was passing. Telling time became confusing. He could no longer recognize that 10:20 was the same as 20 minutes after 10. Charles had difficulty setting the time on timers or watches to remind him when to take his medication. Charles reported feeling surprised when his wife announced it was time to go to choir. Memory cues such as clocks, watches, calendars, and pill boxes for their medication were useful for the participants to manage their current time, but not always effective.

Time must also be considered in terms of the past and the future. With memory loss, there is awareness of a future that is not particularly hopeful. Participants perceived the future as fearful, and had visions of themselves wandering in nursing homes, unable to recognize family and friends (see de Witt et al., 2009b). As such, there was a sense of urgency to life and importance placed on living in the moment. There was a focus on what one could still do with

the time one had remaining in terms of current abilities. While participants were afraid of what the future might hold, they were also hopeful about the future in terms of medical advances that may further slow the progression of memory loss. The connection between the past and present may also be lost for some persons with dementia (Parsons-Suhl et al., 2008).

Temporality could be experienced in terms of forgetting the past, which threatened identity and being-in-the-world. At this stage, Jack, Alice, Charles, and Rita were able to reflect on their past stories. They told me in great detail about their lives prior to diagnosis during our first interview. They did not appear to have lost the connection between present and past.

However, I suspect that as their memory loss continues, the connection between present and past may become fuzzier.

Lived time is paradoxical and complex when living with early stage memory loss. Temporality was altered in memory loss and losing a sense of time could be frustrating or bothersome for participants in some cases, but in other situations, lack of awareness of time was not relevant. Living in the moment became more important as future and recent events were forgotten and could not be planned for or reflected upon. Again, this was not necessarily negative, as participants took the time to truly enjoy particularly meaningful moments in their lives, such as spending time with friends, or enjoying the natural world.

Lived other

Lived other, or relationality, refers to our relationships with others in the space we share with them (van Manen, 1997). The experience of lived other is particularly paradoxical since relationships were affected in a variety of ways. The changing nature of relationships has been considered in the literature regarding the subjective experience of dementia (Harman & Clare, 2006; Phinney et al., 2007). Participants were supported by, and in turn, supported their family

and friends. Indeed, living in relationships became critical to “living” with dementia. Relationships with others were valued by, and enriched the lives of, the participants. However, the nature of relationships changed to some degree as participants relied more on their care partners than they did before. This could cause discomfort for participants who preferred to continue to do things themselves, such as driving the car. Nonetheless, for the most part, participants appreciated the support they received from their loved ones, which helped them maintain active engagement in meaningful leisure activities. Participants were able to remember rules to games that might have otherwise been forgotten, socialize with friends and family outside of the home, and generally maintain their preferred activities. They included photos of themselves engaging in leisure with family and friends to demonstrate the importance of sharing leisure and the support that they give and receive within the context of leisure and relationships.

I reflected on my own experience of relationality when analyzing the data I had collected with Charles. In the excerpt below, I considered how the support of Charles’ wife helped us both to participate in one of Charles’ favourite leisure activities, playing games with others:

During much of the participant observation I was not only participating but often learning the game as we went along. This is true for both Golf and Phase 10, so Charles and I both struggled to remember the rules and identify the patterns on the dice, while [his wife] supported us both in her gentle way. This provides some insight into what it must be like to play a game like it is nearly new every day, yet the difference at this point is that I would get into the routine after a while and become quicker at identifying the patterns, whereas Charles continued to need assistance in identifying the patterns. (reflexive journal)

While participants felt supported in their relationships with others, they also occasionally experienced overprotectiveness. Family and friends became concerned for the welfare of the participants, and were hesitant to allow them to do activities on their own. Thompson and Sobolew-Shubin (1993a) define perceived overprotectiveness as “a perception on the part of

the ill adult that he/she is overhelped, induced to be dependent, shielded from stress, and generally not treated as an adult” (p. 87). Perceptions of overprotectiveness can occur when older adults receive support from others (Cimarolli, Reinhardt, & Horowitz, 2006). The persons’ capacities are underestimated and there may be attempts to restrict activities (Kuijer et al., 2000). Cimarolli et al. suggest that overprotection can lead to increased disability as a result of threats to personal autonomy. Perceived overprotection has been linked to increased rates of depression, reduced feelings of control, and reduced motivation to do things for oneself (Cimarolli et al., 2006; Kuijer et al., 2000; Thompson & Sobolew-Shubin, 1993a; Thompson & Sobolew-Shubin, 1993b). Participants in this study experienced overprotectiveness when their family and friends prevented them from doing things or overreacted to a particular incident. Jack’s story of the neighbours calling his wife to ask if Jack was safe is an example of this. It is unclear whether overprotectiveness led to feelings of depression and/or reductions in control. Nevertheless, overprotection from others emphasized the stigma associated with dementia by pointing to the participants’ deficits instead of their remaining abilities.

Although participants were bothered by overprotectiveness, they also perceived it as a sign of love – their friends wanted to protect them and make sure they were safe. However, participants would prefer to be treated as though nothing had changed, as Rita expressed with her story in which she told her daughter-in-law that she still wanted to be asked to wash the dishes and be part of the family. Overprotectiveness in relationships undermined participants’ sense of identity and shook their confidence in their own abilities. Lived other is thus experienced in paradoxical ways as feelings of love and responsibility towards the participants both supported and threatened the identities of the participants at the same time.

Lived other was also influenced by one's willingness to disclose the diagnosis to others. Some people are willing to disclose diagnosis, while others are not (Ohman et al., 2008). Being open can be advantageous as it leads to support from others (Beard & Fox, 2008). Disclosure can be empowering, can foster compassion, can justify behaviour, and allow one to ask for help (Beard, 2004), and most of the participants in this study preferred to be open about their diagnosis for these very reasons. Additionally, being open allowed participants to relate to other persons living with dementia, and to work towards changing attitudes and misunderstandings about dementia. Beard and Fox found that sharing experiences in support group environments generated friendship. Phinney et al. (2007) suggest that persons living with dementia find relationships with their peers to be particularly meaningful, and Jack, Charles, and Alice stressed how much they appreciated being able to share their experiences with others who may be feeling the same way.

Conversely, persons living with dementia may find disclosure leads to stigmatization (Harman & Clare, 2006; Snyder, 2001). Rita chose to keep her diagnosis to herself because she feared that others would treat her differently (Snyder, 2001). Rita tended to be suspicious of others' reactions to her when they knew that she had dementia, worrying that they were being nice to her only because of her diagnosis. She did not want others to feel sorry for her. Similar to Rita's experience, Langdon et al. (2007) found that people with dementia revealed the diagnosis to their families but kept it from others in order to avoid misconceptions. Both disclosing and not disclosing diagnosis were motivated by the desire to feel comfortable interacting with others.

The experience of dementia in terms of lived other was paradoxical for the participants. They liked to spend time with other people and valued the support they received. Such support

enabled them to remain actively engaged in their favourite activities. Nonetheless, these relationships could cause discomfort and frustration for participants when relationships were paternalistic and overprotective. A desire to avoid threats to identity prevented disclosure for Rita, but a desire for support led to being open among Jack, Alice, and Charles.

The findings echo those of previous studies in terms of the experience of dementia, coping with the symptoms of dementia, and the complexity of living with memory loss. However, this study also expands our understanding of the experience of living with dementia in terms of the lifeworld existentials. Responding to dementia occurred within all four lifeworld existentials, but particularly within lived other and lived space as participants drew upon the world around them to live meaningful lives with memory loss. Considering the findings in relation to the lifeworld existentials highlighted the paradoxical experiences of the participants as simultaneously challenging and hopeful.

Leisure as a Means of Coping with Dementia

In addition to increased understanding of the subjective experience of dementia, this study provides insight into how persons living with dementia use leisure to cope with stress. Leisure plays an important role in coping with stressful events (Iwasaki & Mannell, 2000). It can be used to maintain continuity with the past while embracing new opportunities for growth and development (Kleiber et al., 2002). This study demonstrates that persons living with memory loss find many ways to cope with the stress of having an illness that affects cognition. Participants used problem-focused and emotion-focused coping to manage their stress in living with memory loss (Folkman, 2008). Problem-focused coping occurred when participants found practical solutions to manage their problems, such as exercising their minds, or adapting their leisure to prolong engagement. It also occurred when they sought out and accepted

support from others. Emotion-focused coping occurred when participants reconciled with the changes that were occurring and maintained positive attitudes. However, participants also drew upon other ways of coping with stress. In this section, I discuss how the participants used meaning-focused coping by drawing upon Folkman's (2008) stress and coping model. Following this, I address how the participants of this study used leisure to cope with their situations in terms of Kleiber et al.'s (2002) work on continuity and transformation. Finally, I discuss how participants coped with challenges in their leisure specifically by drawing upon Baltes and Baltes (1990) theory of selective optimization with compensation.

Meaning-focused coping

Folkman's (1997, 2008) stress and coping model provides insight into how the participants find meaningful ways to cope with the stress of living with memory loss. Folkman's (1997, 2008) research revealed that positive emotions can occur when coping with a stressful event: "...positive emotions and negative emotions co-occurred during the intensely stressful experiences of caring for a dying loved one and then actually losing that person" (Folkman, 2008, p. 3). Jack, Alice, Charles, and Rita similarly experienced the co-occurrence of both positive and negative emotions as they coped with a variety of stressors that resulted from living with memory loss. For example, they experienced frustration, grief, and embarrassment while also experiencing enjoyment and pleasure, and were generally happy with their lives. While it may be considered unusual or surprising that the participants experienced both positive and negative emotions while living with memory loss, Folkman's (1997, 2008) stress and coping model indicates that positive emotions are often used to cope with stressors. The model includes meaning-focused coping, which is believed to lead to positive emotions and restore coping resources:

Meaning-focused coping is, in its essence, appraisal-based coping in which the person draws on his or her beliefs (e.g., religious, spiritual, or beliefs about justice), values (e.g., “mattering”), and existential goals (e.g., purpose in life or guiding principles) to motivate and sustain coping and well-being during a difficult time. (Folkman, 2008, p. 7)

There are five categories of meaning-focused coping: benefit finding, benefit reminding, adaptive goal processes, reordering priorities, and infusing ordinary events with positive meaning (Folkman, 2008). Benefit finding refers to the discovery of benefits to coping with stress, such as growth in wisdom, greater appreciation for life, and improvements in the quality of relationships. Jack, Alice, Charles, and Rita found some benefits to having to cope with memory loss, particularly in terms of a greater appreciation for life, and positive relationship changes. As well, they gained feelings of competence as they learned how to cope with the changes they were experiencing, which they also deemed to be beneficial. Folkman argues that when a stressful situation is ongoing rather than resolved, as is the case with dementia, there is “...a co-occurrence of positive emotions generated by benefit finding and the negative emotions associated with the unwanted outcome” (p. 8). Positive states can assist with problem focused coping by affording people with the opportunity to consider negative information and choose which problems to solve. For Alice, Charles, Jack, and Rita, finding benefits to having been diagnosed with memory loss helped them to cope with the changes they were experiencing. For example, Alice considered her diagnosis to be a blessing in some ways because it allowed more time for leisure. As well, having bad days resulted in greater appreciation of better days.

The second category, benefit reminding, is not dissimilar to benefit finding (Folkman, 2008). Benefit reminding refers to the ways in which one reminds oneself of the possible benefits that may result from a stressful situation. Reminding oneself of the benefits can lead

to a better mood (Tennen & Affleck, 2002). Jack, Charles, Rita, and Alice frequently reminded themselves of the benefits of having memory loss and tried to focus on the positive aspects of their lives. For example, Jack focused on the advantages of receiving and accepting a diagnosis so he could make plans and continue to live life to the fullest. Alice also reminded herself of the benefits and considered how well she had learned to cope with memory loss when going through a new grieving period or transition along her journey, which helped her to feel positive about her situation.

Adaptive goal processes are a third strategy for meaning-focused coping. This occurs when people recognize that former goals are no longer appropriate and replace them with new, meaningful goals. This may reduce stress that results from the inability to attain an old goal. Alice and Jack set new goals for themselves upon the realization that older goals may no longer be possible to achieve. Doing so helped them to cope with the changes and continue to look at their lives positively.

Reordering priorities is another common response to stressful situations (Folkman, 2008). Jack and Alice both talked about changing their attitudes when diagnosed with memory loss, as well as their priorities. Jack said that he accepted it and took a different view of life right then. He prioritized his leisure time, deciding to focus on his golf, and gave up work and sailing. Alice similarly altered her priorities to live in the moment and appreciate the simple things in life. She gained a great deal of pleasure from the world around her by rearranging her priorities to take notice of things she had once overlooked. Although reordering priorities can be beneficial for individuals, Folkman also notes that this process can be stressful when meaningful goals and activities must be given up.

Finally, Folkman (2008) suggests that meaning-focused coping can occur by infusing ordinary events with positive meaning. A positive event, such as watching a movie or receiving praise, can be particularly meaningful when dealing with stressful events. Alice found meaning in ordinary events, such as watching the birds on her balcony, and looking after her cat and her plants. She spoke about her new appreciation for weeds, which she perceived as beautiful, rather than threatening. Accomplishments in leisure and other aspects of life were also more meaningful after diagnosis than they had been before. All participants found time spent with family and friends to be particularly meaningful, more so than they had prior to diagnosis.

Jack, Alice, Charles, and Rita used meaning-focused coping in order to experience positive feelings along with the many negative feelings that resulted from the chronic stress of living with memory loss. It is perhaps through meaning-focused coping that they were able to experience hope throughout their journeys of memory loss. Previous research on meaning-focused coping appears to have explored caregivers' experiences of stress and coping. For example, the concept arose out of Folkman's research with caregivers of men living with AIDS in the 1990s. However, this research provides new insight into meaning-focused coping as the participants experience positive emotions and attach meaning to their stressful experiences in order to cope with them. Leisure activities were an arena for the participants to cope with the changes in their lives in positive ways. They found pleasure in their leisure and recognized the benefits of having to live with memory loss in terms of their ability to participate in leisure activities. They felt that having been diagnosed with memory loss was meaningful as it gave them the opportunity to grow and cope in positive ways, as well as help others who may need to understand what it is like to live with dementia. By looking at the positive aspects of life

with memory loss, the participants placed meaning on their experiences and were able to cope effectively with the changes that occurred.

Continuity and transformation

Leisure is particularly important for coping with a traumatic life event by providing continuity with one's past and helping one transform (Hutchinson et al., 2003; Kleiber et al., 2002). Kleiber et al. proposed four functions of leisure for transcending negative life events. The first two are related to self protection and the remaining two are related to self restoration and personal transformation. In this section, I explore the four propositions and ways in which this study both supports and contributes to them.

In terms of self protection, leisure activities provide diversion from negative life events (Kleiber et al., 2002). While Alice, Jack, Charles, and Rita did not explicitly discuss diversion from thoughts of memory loss among meanings of leisure, they pursued diversionary activities that might have allowed them to avoid thinking of themselves as persons living with dementia, such as watching television and movies, reading, and spending time with friends. Such activities may have given them respite from frightening awareness regarding their futures, the disquieting emotions they experienced as a result of memory loss, and thinking about the loss of independence and valued roles that was forced upon them as a result of their diagnosis.

The second proposition suggests that diversionary leisure can lead to an optimistic attitude about the future. Kleiber et al. (2002) state that "...leisure has the power to restore hope for one's future despite dire circumstances" (p. 227). Engaging in leisure helped participants to cope with memory loss by affording protection of their perspectives of themselves. It also played an important role in creating hope for the future, particularly since the participants were no longer able to work. Leisure provided an important space to find

continued purpose and meaning in life, and build a sense of hope for the present and the future. Success in familiar leisure activities built confidence, leading to future success and a sense of optimism for the present and the future.

Kleiber et al.'s (2002) final two propositions suggest that leisure can aid in reconstruction of a life story that is continuous with the past and that leisure activities may lead to personal transformation. These two propositions appear to be especially salient for persons living with memory loss. Leisure can aid in reconstruction when it provides a sense of normalcy. For example, Charles' love of reading was a life-long leisure pursuit, and his efforts to maintain this activity helped him to sustain his identity as someone who loved to read. Jack pursued physical activity all his life and continued to do so. As well, participants engaged in activities with lifelong friends and family, which connected them to their pasts. Kleiber et al. argue that "resumed involvement in familiar leisure...thus serves to affirm one's identity and reinforce valued aspects of one's previous life" (p. 228). In this study, leisure affirmed identity and reinforced valued aspects of life as it is used to maintain identity. Jack, Alice, Charles, and Rita drew upon their resources to perform valued roles in both familiar and new ways in order to sustain personal and social identities.

In their final proposition, Kleiber et al. (2002) suggest that participation in leisure activities following a negative life event can be used for personal transformation: "While reestablishing some semblance of a former lifestyle creates a degree of continuity that is stabilizing, the changes created by the event may be liberating for the discovery of new alternatives" (p. 230). Alice in particular discovered new alternatives for herself since being diagnosed with dementia. She became a strong advocate on behalf of other people living with dementia, learned to use a computer, and developed a greater appreciation for the natural

environment. Many of her photos depicted these new alternatives. All participants were creative and worked with their care partners to find ways to live with any new changes that arose. They considered their abilities to adapt and solve their problems as a strong and integral aspect of their new and shifting personal identities. They transformed themselves to live meaningful lives with dementia by altering their expectations and their leisure activities. While participants transformed as they tackled life with dementia in a daily basis, doing so provided a sense of continuity – it showed they had not changed after all, that they were still the same people they were before diagnosis, and, in fact, had grown and were stronger because of their experiences.

Kleiber et al.'s (2002) work was developed based on research that has explored persons who have had physical accidents or a chronic illness, not memory loss. A sudden physical accident can drastically alter one's life immediately. Memory loss is more gradual. It has a different type of stigma attached to it due to the belief that cognition is vital for humanness. Changes creep in and may go unnoticed until diagnosis and, even then, participants acknowledged that they were not always aware of what was changing them. Participants both fostered continuity of identity while being open to and actively engaging in new aspects of the self. Alice and Jack became engaged in new activities that were meaningful to them and provided opportunities for transformation (e.g., advocacy). Participants also wished to hold on to who they were. Charles and Rita in particular appeared to seek out opportunities for continuity rather than transformation. This may be due to the progressive nature of dementia and participants' recognition that the challenges they face will become progressively more difficult. It may also be due to threats on identity and the need to resist these threats and affirm to self and others that valued aspects of the self still remain despite dementia. Nevertheless,

Kleiber et al.'s four propositions regarding self protection and transformation highlight the link between leisure and identity when experiencing a negative life event. This study contributes to further development of the propositions by considering them in terms of an insidious condition that requires ongoing adaptation. The paradox of challenge and hope is supported by Kleiber et al.'s suggestion that leisure can lead to a sense of optimism when coping with a negative life event. Kleiber, Reel, and Hutchinson (2008) indicate that the four propositions compose a continuum, moving from distraction to transformation. However, the paradox that pervades the journey of memory loss suggests that these propositions are not necessarily a series of stages for the participants to go through, where one starts to cope with the negative life event through diversion, which can lead to a sense of optimism and hope, followed by reconstructing identity to maintain continuity with one's past and transforming oneself to incorporate new aspects of one's identity. Rather these four propositions can occur simultaneously, or may shift in importance over time as abilities fluctuate, and good days and bad days are experienced. They will likely occur again and again as participants must constantly incorporate new challenges and identities into their lives, mourn new losses, and learn new ways to tackle life with dementia.

Overcoming challenges in leisure

In addition to meaning-focused coping, the findings of this study provide insight into how persons living with memory loss address challenges in their leisure. They not only use leisure to cope with the stress of living with dementia, but they also find ways to cope with changes in their ability to participate in leisure activities. Sorenson et al. (2008) state that the participants of their study "...wanted to participate in the daily activities and social life to a degree adjusted to their present level of functioning" (p. 297). The same was true for Jack,

Alice, Charles, and Rita, who overcame many challenges to continue engagement in meaningful leisure. Many of their photos demonstrated that challenges could be overcome (e.g., Charles and his magnifier and reading box, Jack playing darts by himself, Alice's jigsaw puzzle). Baltes and Baltes' (1990) model of selective optimization with compensation (SOC) provides a framework to consider the ways in which the participants altered their leisure to continue to participate. SOC suggests that as people experience age-related changes, they choose among preferred activities and drop others in order to maximize their strengths in those preferred areas (selection). Selection can be active or passive and intentional or unintentional (Baltes & Carstensen, 1996). Then, older adults optimize their abilities in the areas they have selected (optimization). They enrich their resources, which leads to enhancement of functioning (Baltes & Carstensen, 1996). Finally, they compensate for constraints by drawing upon internal and external resources to accommodate losses in order to continue to participate in their chosen activities (compensation). Compensation involves using alternate means to achieve the same goal. When combined together, the three components provide a way to conceptualize how older adults adapt to loss (Baltes & Carstensen, 1996). "If implemented together, the use of the processes enables people to master their goals despite, or perhaps even because of, losses and increasing vulnerabilities" (Baltes & Carstensen, 1996, p. 405). The model accounts for both losses and personal growth in later life (Baltes & Carstensen, 1996, 2003). The diagram in this research (see Figure 1) emphasizes continued growth and development regardless of memory loss. Alice, Charles, Jack, and Rita chose which activities to continue to participate in and which to drop. For example, Jack dropped sailing because of safety concerns, and focused on golf, which is less risky. Similarly, Rita decided to stay with Skip-bo instead of learning how to play bridge. They optimized their abilities in these

activities by practicing their skills. In order to continually succeed in their preferred leisure activities, the participants drew on a variety of resources to compensate for their losses. It is in compensation that understanding of the participants' creativity in coping with the changes that dementia brings comes to light.

In terms of internal compensation, participants altered activities so that they could continue to meet the demands. For example, Alice chose less challenging puzzles and tried to build up her confidence to attempt more difficult puzzles. Competitive activities became cooperative, or competition was turned towards one's self. Jack stopped competing against others in darts because he was afraid he would injure someone. Instead he opted to practice darts on his own and compete against himself. As well, participants internally compensated for their losses by altering their expectations of themselves. Instead of dropping activities when they became more difficult, participants changed their goals to fit their current abilities. Alice demonstrated this in her unwillingness to give up computer games even though she could not make it through all of the levels she was once able to conquer. Instead, she changed her goal to get through the first level, and celebrated her accomplishments when she did so.

Participants also relied on external sources of compensation. These were either interpersonal or technological. They relied on other people to support them in leisure. Charles depended on his wife who reminded him how to play the games they have played for years. Rita asked family members and friends to drive her when she wanted to go shopping. Jack depended on the other members of his foursome in golf to point him in the direction of his golf ball. Charles was particularly resourceful in using technology to enable participation in leisure. He used a magnifier to read, and he created his reading box so he could read while sitting in his chair or on his balcony instead of at his magnifier. As well, Charles and his wife used the

poles for walking so that Charles would not have to use a cane. He was able to walk further and found going up and down hills much easier with the poles.

Kleiber, McGuire, Ayber-Damali, and Norman (2008) suggest that limits to leisure activities may be beneficial. They argue that “persisting with an activity in the face of obstacles strengthens one’s sense of self and one’s identification with the activity” (p. 348). Participants in this study defined themselves in terms of their ability to solve their problems. Charles’ adaptation of reading allowed him to continue to pursue this activity and he remains deeply committed to it. Another benefit of limiting activities involves increased attention to other goals. When one activity is dropped in favour of another, one may be able to achieve new goals. For example, when Jack gave up his contract work, he was happy to focus on improving his golf game. The third benefit involves discovery of unintended capacities. Alice, after being forced out of her job, focused on her leisure, and learned of her capacity to use the computer and write poetry about her experiences. She also learned of her passion and capacity for advocacy. The fourth benefit refers to changes in attitudes toward leisure and life. Participants in this study appreciated the small things in life, celebrated their accomplishments, no matter how small, and generally felt satisfied with their lives despite having memory loss. Optimizing abilities in some areas and not others allows for participants to indeed be successful in their endeavours. Kleiber, McGuire, et al. (2008) suggest that there is a paradox between constraint and benefit and this appears to be the case for the participants of this study. By engaging in the process of SOC, participants negotiated their constraints and found their lives were richer.

Through selection, optimization, and compensation, participants were able to cope with memory loss to continue to engage in meaningful activities. They used their resources to adapt

both activities and their expectations of themselves. The model provides insight into how the participants adjusted their activities to maintain involvement, but the study contributes to the model as well. My findings show that SOC can continue in the face of memory loss. While Baltes and Carstensen (2003) suggest that even very frail older adults can engage in SOC, they indicate that the more resources one has, the better one is able to engage in this process. However, Alice, Jack, Charles, and Rita have revealed that SOC occurs in the face of one of the most feared and stigmatized diseases of later life, demonstrating that continued growth and development occurred in memory loss as participants drew on a wide variety of resources in order to maintain involvement in valued leisure.

This research provides insight into and expands our current understandings of leisure and coping with stress. Leisure does indeed play a significant role in coping and living with memory loss. Previous work has demonstrated that this is true for persons living with physical disabilities, but these findings indicate that persons living with an illness causing dementia also use leisure to cope with stress. Doing so helps them to feel more positively about their lives and gives meaning to their experience of memory loss.

Negotiating Identities Through Leisure

When I began this research, I set out to understand the role of leisure in the enhancement or re-creation of identity. Above, I discussed the ways in which participants used leisure to cope with stress related to life with dementia. I demonstrated how Kleiber et al.'s (2002) work on transformation of identity applies to the participants of this study. Leisure plays a key role in sustaining and recreating identities in other ways as well, and participants draw upon these to negotiate threats to their identities.

Identity is typically defined in terms of personal and social identity. Personal identity refers to consistencies and inconsistencies with one's past, as well as similarities and differences compared to other people (Hewitt, 1991). Social identity refers to identification with a particular group (Kleiber, 1999), and develops over time as the individual participates in life and social groups (Hewitt, 1991). As discussed in Chapter 4, personal and social identities were both supported and threatened by both diagnosis of dementia and by relationships with others. Beard and Fox (2008) suggest that other people questioned the autonomy and competency of persons with dementia, which in turn, threatened identity roles such as parent or partner. Alice, Jack, Charles, and Rita received similar threats but were able to resist them by successfully tackling life with dementia. By taking a proactive approach and adopting a "fighting spirit" (Clare, 2002), participants tried to prevent their diagnosis and subsequent changes from assaulting their personal and social identities. Nonetheless, there is no doubt that their identities were affected by dementia – after all, they experienced a loss of valued roles and independence which undermined their confidence.

Participants enhanced new and continued identities by engaging in meaningful leisure activities. Leisure allowed them to play out valued roles in new ways. Furthermore, since many of their abilities in leisure remained, or could be easily supported by others, participants were able to protect valued aspects of their identities that were leisure-related prior to being diagnosed. For example, Jack was able to maintain his personal identity as a physically active individual. Additionally, by addressing the challenges that they faced, the participants emphasized their identities as individuals who were capable of managing a multitude of challenges. When combined with acceptance from other people, participants were supported in their social identities. Charles noted that by tackling his problems successfully, and

subsequently having his actions affirmed by others, he reaffirmed his identity as a person who solved his own problems in the face of adversity. His photo of himself using his reading box was his favourite since it demonstrated his abilities to others.

My findings demonstrate the importance of maintenance and preservation of valued identities in the dementia context. Furthermore, they indicate that leisure plays a significant role in identity for persons living with dementia. In this section, I explore how participants negotiated their identities in the face of memory loss. I begin by discussing how the participants were both affected by and overcame the master status of having dementia. I then explore the findings in relation to Sabat's (2001) work on the social construction of identity in dementia. Third, I explore leisure's role in fulfilling Harris and Sterin's (1999)

core values of identity in memory loss. Fourth, I discuss how the findings of this study relate to understandings of leisure and identity. Finally, I explore the role of leisure in creating memories for family and friends.

Overcoming a master status

Charmaz (1995) suggests that when an individual is diagnosed with a chronic illness, he or she is assigned a "master status". Upon diagnosis, participants in this study were assigned a master status of having dementia. Beard and Fox (2008) studied persons with Alzheimer's disease attending support groups to explore how they tried to combat the master status of dementia. They suggested that the label of dementia had both advantages and disadvantages as "...study participants navigated the label both as a resource and a potential detriment" (p. 1519). The label could occasionally be advantageous for Jack, Alice, Charles, and Rita if it explained their unusual behaviour to others. It could also be detrimental when the master status threatened their identities and participants were viewed solely in terms of the dementia

label. This was apparent in the overprotection by some of their family members and friends. As well, losing valued roles as a result of dementia undermined their previous identities and highlighted their diagnoses as part of their identity. Nonetheless, participants were often able to override this master status by being themselves. They found ways to act out personal and social identity roles that served as a reminder that they were themselves first, and a person living with dementia second. Leisure roles that replaced work roles provided a means of overcoming a master status of dementia. In leisure, participants did not consider themselves first in terms of their diagnosis, but rather in terms of valued roles, such as athlete, advocate, friend, spouse, and grandparent. They included photos of themselves in these roles that demonstrated their identities beyond dementia.

Openness provides insight into how participants reacted differently to the master status of dementia. For Jack, Alice, and Charles, disclosure led to being supported to be oneself within the context of relationships. Instead of being open with others about her diagnosis, Rita tried to keep it hidden and avoided thinking and talking about dementia so that people would not change their perspectives about who she was. Rita preferred not to draw on support of others, but instead maintained identity by believing that nothing about her had changed. Avoiding disclosure of her diagnosis allowed her to present herself to the world in a positive way. She was able to circumvent the stigma and overprotectiveness that the other participants experienced to some degree, but unfortunately, her relationships with her family were occasionally stigmatizing and she felt as though they no longer considered her to be a capable, independent person. Overcoming a master status was challenging, but possible when supported by others.

Considering identity as a social construction

Further insights can be gained about identity and dementia when identity is considered to be a social construction. Sabat (2001) breaks identity down into Self 1, Self 2, and Self 3. Self 1 refers to personal identity, which is expressed by using first person indexicals. Sabat suggests that Self 1 remains to the late stages of dementia. The participants in this study maintained their personal identities in telling their stories, where referrals to self were numerous. There was no indication that Self 1 was eroded at this point in the participants' journeys of memory loss.

Self 2 refers to beliefs about personal and physical characteristics. Participants had strong senses of who they were. They believed in their abilities to address the challenges in their lives and viewed themselves in certain ways, such as being fun-loving, having a good sense of humour, being an ordinary person, and being a good friend. Leisure helped them to maintain these beliefs by providing a space to emphasize their capacities and abilities. However, Self 2 was threatened when they began to question their abilities or lose confidence in themselves. For example, Rita sometimes doubted that she could manage her diabetes on her own when her family questioned her ability to manage it herself. As well, Charles was questioning his capacity to participate in choir. He believed he was beginning to require too much support to remain in the group without bothering the other members.

Finally, Self 3 refers to social personae, which are constructed in many different situations. Each persona is associated with a set of performed behaviours and requires others to respond to that behaviour appropriately. Self 3 is most likely to be threatened if the individual is not supported in valued roles that comprise one's personae. Many valued roles have been lost and more may be lost in the near future. Jack and Alice were no longer

supported in terms of their work identities. Charles ceased participation in leadership roles in his community because of changes in his ability to talk in front of a group and discomfort in speaking out because of uncertainty of what he might say. However, leisure became a space for participants to be supported in their personae. In social groups, Jack was able to maintain the view of himself as a golfer and physical activity enthusiast. Alice was able to maintain her personae as an advocate and nurturer through leisure by taking care of her cat, her plants and the birds on her balcony, and advocating on behalf of herself and other people with dementia. Participants were also supported to maintain family and friendship roles. Others continued to interact with them in ways that supported their identity as part of relationships. Many aspects of Self 3 were maintained for participants with the cooperation of others in the context of leisure.

By drawing upon Sabat's work on the social construction of identity, the findings of this study demonstrated that identity was not lost in dementia, but continued on in old and new ways with the support of others. People in early stage dementia try to maintain identity and add new aspects of their identity while adapting to change (Clare, 2002; Harman & Clare, 2006; Pearce et al., 2002; Steeman et al., 2007), suggesting that identity is not static, but ever-changing over the dementia journey. Leisure has not previously been explored as a space for maintaining identity while adjusting to change in memory loss. This study supports the notion that identities continue on in the face of memory loss, but it is unique in demonstrating that leisure is a space for both sustaining and recreating identities in this context.

Although the findings of this study indicated that leisure was a space for persons living with early stage memory loss to sustain and create identities, they also indicated that leisure can threaten identity. When loved ones questioned participants' abilities, opportunities to

participate in leisure were reduced. I saw this with Rita in particular, whose family did not believe she could take the bus to the mall. As a result, she was unable to go as frequently as she would have liked, threatening her view of herself as an independent person. Furthermore, activities were altered and participants were required to adjust their own expectations of performance in activities in order to accommodate fluctuating abilities. This may strengthen Self 2 in relation to how the participants see themselves as being able to solve their problems. Conversely, it may threaten identities that are directly linked to leisure roles if fluctuating abilities can no longer be accommodated and beliefs about one's own abilities are eroded. Presently, engagement in meaningful leisure enabled participants to negotiate changing identities. This may become more difficult as participants continue on their journeys of memory loss and face greater challenges, emphasizing the dialectical and paradoxical nature of identity that it can be sustained and threatened at the same time. Now that I have considered the findings of this study in terms of the social construction of identity, I turn to leisure's role in meeting identity values through leisure.

Meeting identity values through leisure

Harris and Sterin (1999) identified values of self identity for persons with dementia, including meaningful productivity, primary autonomy, and comfort and security. Leisure provided a space for persons living with memory loss to engage in activities that address these values. Leisure activities were often productive, especially since the participants used their leisure to fight dementia by engaging in activities that were believed to prevent decline. Freedom of choice is inherent to leisure (Kelly, 1983), and participants were autonomous in making decisions about how to spend their leisure time. They were able to engage in some leisure activities on their own, without having to rely on a care partner. This was particularly

evident in Jack's autonomy in golfing alone. He could independently join a foursome without having to depend on his wife to drive him to the course and pick him up. Leisure was also a space for comfort and security as it occurred in physical spaces that the participants identified as safe. For most participants, leisure was shared with friends who understood the challenges of memory loss and who encouraged engagement in leisure that supported one's remaining capacities. Leisure was a space to safely practice one's remaining abilities where risk of failure was relatively minimal. Its relatively non-threatening nature allowed participants to figure out how to balance the losses that they were experiencing with their remaining abilities.

The findings of this study also add a relationship component to Harris and Sterin's identity values, since relationships and their related roles were particularly meaningful to the participants and their identities. Living in relationships was useful for sustaining social identities and affording opportunities to play out valued aspects of the participants' identities. Leisure provided a space for participants to connect with family and friends in ways that were fun and enjoyable. It allowed them play out valued roles such as being a friend, a parent, and a grandparent. The addition of relationships to Harris and Sterin's identity values lends itself to a deeper understanding of identity in memory loss, particularly since relationships play such an important role in the lives of the participants.

Leisure and identity

In addition to Harris and Sterin's (1999) identity values, this study reflects and contributes to our current understandings of the role of leisure in identity formation. Kleiber (1999) suggests that leisure plays an important role in identity formation across the life span.

Kleiber (1999) argues that leisure is a space for both identification and differentiation. Being with others establishes a sense of belonging to a group that is different from other groups. The participants in this study were supported in their identities by being part of groups, such as their families, friends, and in some cases, groups of persons living with dementia. At the same time, part of identity involves individuation, in which the person makes themselves distinct from the group. Leisure enables individuation by allowing for alternative ways of thinking and being. In this study, leisure allowed participants to continue to identify with others and consider themselves to be part of a group, yet it also allowed them freedom to think about themselves in new ways, particularly with Alice, who found new aspects of herself in leisure after diagnosis.

Kleiber (1999) argues that leisure has the greatest impact on identity formation in terms of individuation. He suggests that leisure contributes to identity when it provides opportunities for new interests. Again, Alice explored new interests after diagnosis, indicating that leisure did indeed provide a space for sustaining and recreating identity. Kleiber also suggests that leisure is important to identity formation when new interests are personal and reflect other values. Alice's emerging interests were carefully aligned with her personal values of advocacy and nurturing that were closely linked to her nursing career. Third, Kleiber suggests that identity formation is supported when recognition from others supports interests. The participants spoke of the support and encouragement they received in their leisure pursuits,

helping them to sustain identities. Fourth, he suggests people develop capacities that in turn reinforce possibilities. This component may be more difficult for the participants of this study as their abilities change, but when they were successful in their activities, they gained confidence and often felt that there were indeed other possibilities for them. Fifth, identity formation is supported when the person is committed to the activity. Jack, Alice, and Charles exhibited commitment to their preferred activities. Jack was dedicated to playing golf and engaging in regular physical activity; Alice was committed to her advocacy work and pet and plant care; and Charles was committed to his choir and reading. All participants committed themselves to using leisure to stall decline. Finally, Kleiber argues that leisure plays a role in identity formation when one feels comfortable in the social world related to a particular activity. Participants in this study did not always feel comfortable in group activities because of their fluctuating abilities, but Jack in particular felt safe golfing even with strangers providing he could remember the etiquette of golf. Leisure continues to play an important role in identity formation even when one has been diagnosed with an illness causing dementia.

Creating memories

A unique finding to emerge from this study involved the creation of enduring memories. Alice, Charles, Jack, and Rita used leisure to create positive memories of themselves for their families. They wanted their families to remember them for who they were instead of who they may become as their memory loss progresses. Leaving behind a positive legacy of oneself was an important part of their meaningful leisure. It was yet another way participants used leisure to sustain their identities and resist negative perspectives regarding memory loss. To my knowledge, this finding has not previously appeared in the dementia literature. Some work has explored the importance of memory boxes in long-term care (Hagens, Beaman, & Ryan, 2003).

Hagens et al. held reminiscence sessions with residents and wrote poems from the words of the participants. These poems, along with other meaningful objects were placed in the memory boxes. The boxes helped staff to learn about their residents and led to communication that affirmed personhood. Alice, Charles, Jack, and Rita chose to create memories of the present for themselves and their families through leisure. They did not rely on others to initiate memory making, but decided for themselves how they wanted to be remembered, and engaged in leisure activities that would help them achieve that goal. Other research has explored how mealtimes serve as a space for reminiscing about the past, celebrating, and passing on values and traditions to younger generations for persons living with dementia and their partners in care. Mealtime is used as a space to sustain family identities (Genoe et al., in press). Leisure similarly serves as a place to pass on values and traditions and create positive long-lasting memories of oneself for loved ones.

Turning to the family leisure literature, the notion of purposive leisure provides insight into creating memories (Shaw & Dawson, 2001). Rather than being freely chosen, leisure is a space to achieve goals set by parents. One of these goals includes creating a sense of family. This is done in part by creating positive memories of time spent together. Parents choose leisure activities that they believe will result in positive memories for their children. This differs from my findings, as participants chose leisure to create positive memories of *themselves* for their children, grandchildren, and friends, yet supports the notion of purposive leisure since the participants have goals for their leisure that goes beyond freely chosen activity. It expands our understanding of the meaning of leisure for persons living with dementia.

By creating positive memories of themselves for their families to remember them by, Jack, Alice, Charles, and Rita resisted threats to identity and sustained valued aspects of their identity. This theme warrants more exploration in future research as greater understanding of the desire to, and means of creating positive memories of self could lead to alterations in leisure practice.

In sum, although participants received a master status when diagnosed with dementia, they were able to express their identities through leisure. Personal and social identities were supported through leisure activities when living with memory loss. Furthermore, leisure provided a space for productivity, autonomy, and safety and security, and relationships for persons living with dementia. This research expands our understandings of identity within the context of dementia. I now turn to further exploration of the role of leisure for persons living with memory loss.

‘Not Just a Nomad Wandering in the Desert’: Leisure as Resistance

Previous research regarding leisure as resistance indicates that older adults without memory loss use leisure to resist ageist stereotypes and age-related changes (Dionigi, 2002, 2006). Whether this was true for persons experiencing memory loss was unclear before I began this research. However, I believe that exploring leisure as resistance is vital for understanding the experience of memory loss since persons living with dementia face both ageism and the stigma of dementia. In Chapter 4, I revealed that participants used leisure to resist the progression of memory loss. In addition, identity is threatened for the participants of this study, yet they fight against this stigma by engaging in meaningful leisure. I now explore how this study contributes to our current understandings of leisure as a space for resistance.

First, I discuss how persons with dementia used leisure to resist stigma and progression of dementia. Second, I explore the link between leisure, identity, and resistance.

Weathering the sandstorm: Resisting progression and stigma of dementia

Marginalized individuals and groups often use leisure to resist dominant ideologies (Shaw, 2001; Wearing, 1995). Through leisure behaviours and interactions, people can challenge the ways that power is exercised (Shaw, 2001). Clare (2002) suggests that persons living with dementia who accept their diagnosis often actively fight the challenges they face. This can occur by being active and doing everything one is still able to do (Phinney et al., 2007). Rita, Alice, Charles, and Jack took a similar approach to their lives since being diagnosed with dementia. They were able to weather the sandstorm of negative assumptions combined with the inevitable progression of dementia. For example, Rita often spoke of fighting the disease through her sense of humour and positive approach to life. Actively engaging in the world demonstrated to others that the participants' lives had purpose. Their leisure provided a space for engaging in behaviour and interactions that resisted commonly held negative beliefs about persons living with dementia. Indeed, leisure might be the *only* space for participants to challenge power relations at this stage in their lives since they have lost valuable work and community leadership roles.

Resistance was both intentional and unintentional (Shaw, 2001). In terms of resisting the progression of dementia, resistance was intentional. Participants purposely chose activities that they believed would defend against further memory loss (see Phinney, 1998). Indeed, Jack, Alice, Charles, and Rita included photos of themselves engaging in mentally stimulating pursuits to demonstrate how they tried to slow progression. Mental activity was valued by persons living with dementia and believed to be important for maintaining ability (Beard &

Fox, 2008). Other researchers have shown that older adults intentionally resist aging bodies through leisure (Dionigi, 2002, 2006; Hurd, 1999). The older athletes in Dionigi's (2002, 2006) research purposely chose competitive sports to resist their aging bodies, believing that participating in sport kept them young and warded off unwanted age-related changes. As well, the women in Hurd's (1999) study intentionally chose physical activities in order to avoid "being old". Of course, the participants in this study had more to contend with than simply old age. Leisure directed towards preventing decline provided them with feelings of control over their fluctuating abilities. In contrast, Ohman et al. (2008) report that persons living with dementia felt that they could not affect the progression of the disease, and avoided memory training. Ohman et al.'s participants intentionally chose *not* to resist progression of dementia since they felt it would be ineffectual. Jack, Alice, Charles, and Rita may have been different as a result of their extremely positive attitudes and their willingness to fight dementia to the best of their abilities.

Participants also resisted stereotypes associated with dementia. This type of resistance was largely unintentional, as they appeared to be unaware that their actions might be resisting dominant negative views of dementia. Frequently, participants engaged in leisure for its own sake without recognizing its potential for changing attitudes and perspectives. For example, Rita wrote poetry to remind her grandchildren of who she was before experiencing memory loss. In doing so, she resisted stereotypes of dementia. She demonstrated that persons with memory loss are still capable of completing complex tasks and drew upon her own memories to show that she remembers much of her life. This resistance was unintentional, as Rita was surprised, although pleased, when I asked her if she felt that writing poetry was a way of reminding others that she is not just a person with memory loss. Engaging actively in life was

valued among all participants and demonstrated to others that dementia was not necessarily related to withdrawal from the world. Jack did not continue to engage in physical activity with the intention of changing others' attitudes, but rather to maintain physical health and fitness. However, in doing so, he demonstrated that living with memory loss did not have to be equated with disengagement. During our participant observation session, a neighbour stopped and said hello to Jack. When Jack told her he had Alzheimer's, she was shocked by his abilities. In fact, frequently participants received comments from others that they did not appear to have dementia, or that they were managing their memory loss very well. This may be due in part to their active engagement in life. They were able to change perspectives on dementia by being open about their experiences and demonstrating to others that early stage memory loss is not just about loss and decline, but also includes hope and personal growth.

While resistance was largely unintentional, Alice consciously chose to advocate and change people's perceptions of memory loss. When she adopted her cat, with the support of a close friend, she demonstrated to powerful others that people with memory loss are in fact capable. The participants were eager to demonstrate to others that they still had many abilities, and success in leisure activities provided a means of doing so. Alice emphasized that leisure showed her friends and family that she was capable. Similarly, Jack wanted people to know that he could still do things. The participants worked to change the negative perspectives of their family and friends, and often these intentional acts of resistance occurred within leisure.

Resistance can also be individual or collective (Shaw, 2001). Individual resistance occurs when individuals resist their own situations and it impacts only themselves. Collective resistance transpires when groups act together to resist dominant ideologies. With the exception of Alice, who works with other people with memory loss to resist negative

stereotypes through her advocacy, resistance was largely individual. Resistant acts within the sphere of leisure revealed that life had meaning. Participants demonstrated to others that they were still capable individuals who continued to be themselves despite the challenges they faced. However, Shaw (2001) suggests that an individual's act of resistance can be both individual and collective as it can change presumptions not only about the individual, but about the group as a whole. When Alice adopted her cat, she believed that her actions would affect other people with dementia and hoped that in the future, the SPCA would think twice before refusing to give a pet to someone living with memory loss. Alice hoped this act was one of collective resistance, not only benefiting her, but changing perspectives so that all persons with memory loss could be perceived differently. Alice, Jack, Charles, and Rita wished to be treated in the same ways they were before their diagnosis, and they proved to others through their leisure-related accomplishments that they had many abilities. In doing so, they may have opened others' eyes to the reality of life with dementia, highlighting the differences between early-stage and end-stage dementia. Although it is difficult to know how successful they were at changing attitudes in this study, their actions were both individual *and* collective acts of resistance.

Ideally, resistance should lead to feelings of empowerment and social change. Demonstrating capacity through leisure led to self-confidence and greater willingness to try other activities. For example, Alice worked on a 500-piece jigsaw puzzle and gained the confidence in herself that she would be able to try a 750-piece puzzle next time. Through leisure activities, participants felt they could have some degree of control over the rate of decline by participating in mentally stimulating activity. They made their own choices about how to spend leisure time and were supported in these choices by others. They used their

leisure to remain productive and engaged in life, which became more difficult as they lost valued work and community roles.

Finding an oasis: The intersection of identity and resistance

Leisure provided an oasis in which participants were able to be themselves. They worked through identity dilemmas and resisted the master status of dementia imposed upon them by their doctors, family members, and friends. Wearing (1998) argues that resistance leads to the creation of new and alternative identities. It allows individuals to challenge imposed definitions of self. Wearing maintains that leisure can be a space for “...reconstituting the self and rewriting the script of identity. There is room here for subjectivities other than those that are ordinarily prescribed for one” (p. 146). In choosing leisure that demonstrated productivity, autonomy, and capacity, participants both sustained and created leisure identities that were more positive than the label of dementia implies. Furthermore, resisting identity loss through leisure allowed participants to break Cheston and Bender’s (1999) cycle of identity loss by providing them with new roles, decreasing risk for neurological degeneration, and in turn, maintaining capacity to perform remaining roles.

By resisting stigma through engagement in leisure that allows for making decisions, emphasizing abilities, expressing feelings and fears, and identity continuity and transformation, Jack, Alice, Charles, and Rita were able to resist negative views regarding dementia. Morell (2003) argues that empowerment is associated with the ability to define oneself rather than accepting definitions provided by others – self-definition is an act of resistance. While the older women in her study did not have dementia, they resisted being identified with disability and death and they refused to view themselves through an ageist lens. They emphasized that learning continues with new experiences and that capacities grow as life changes. Similarly

Jack, Alice, Charles, and Rita resisted being identified solely in terms of their diagnosis of dementia. They continued to learn and grow through leisure and by adapting to their fluctuating abilities. They experienced new things and embraced life and all that it had to offer. They defined themselves in relation to their leisure activities and family roles. By defining their identities on their own terms, they resisted others' definitions of dementia and the assumption that identity is lost.

Leisure was a space for Alice, Charles, Rita, and Jack to resist both the progression of dementia and negative stigma associated with memory loss. All four participants sought out ways to resist the progression of memory loss by engaging in mentally stimulating activities. They also resisted negative attitudes and assumptions that threatened identities by trying to change attitudes of their family and friends regarding their remaining abilities. Jack, and especially Alice, sought out ways to change negative stigma that society attaches to memory loss by advocating on behalf of themselves and others living with memory loss.

By continuing to actively engage in leisure and educate others about their experiences, participants changed perspectives about what it meant to live with dementia. They embraced life instead of withdrawing from it, and in doing so, they established that memory loss does not have to be associated with so many negative stereotypes. It is not the death sentence that Ohman et al.'s (2008) findings suggested. Participants preferred to be seen in terms of their abilities rather than their losses, and leisure allowed them to demonstrate, as Alice suggests, that they are not just purposeless nomads wandering in the desert. They had much to give and gain in their lives and current situations.

Contributions to Personhood

This study was guided by Kitwood's (1997a) personhood approach to dementia care. As such, I focused on the abilities and experiences of memory loss, not on deficits associated with dementia. Kitwood's intention was to develop a holistic approach to dementia that considered the person's psychosocial environment, which is overlooked in the dominant biomedical model. While personhood is useful for ensuring that researchers include the voices of people with memory loss and focus on lived experience rather than deficits as a result of dementia, it has received a great deal of criticism. Kitwood's work has been critiqued for overlooking persons living with dementia in the community. Some suggest that leaving personhood until one enters long-term care is too late (Cheston & Bender, 1999b; Morton, 1999). Additionally, the approach is criticized for its failure to consider reciprocity of care (Dupuis et al., 2008; Nolan, Grant, Keady, & Lundh, 2003; Nolan et al., 2002) and agency among persons living with dementia (O'Connor & Bartlett, 2006). Kitwood's assertion that personhood is bestowed upon one person living with dementia by others fails to recognize persons with dementia as being persons in their own right. Clearly, a broader notion of personhood is required, and the findings of this study can be used to expand understandings.

Rather than having personhood bestowed upon them by others, personhood was inherent in the participants in this study. They lived in the context of reciprocal relationships and they sought out meaningful leisure in which they could be autonomous. They chose to engage in purposeful activity that helped them feel in control of their lives and contributed to a sense of hope for the future. Kitwood's (1997a) work moves us towards a more positive perspective of dementia, but places responsibility for personhood squarely on the shoulders of others. While Kitwood indicated that his approach focuses on abilities, he failed to recognize

the capacity of persons living with dementia to take responsibility for their own situations and care. The participants in this study lived in the context of relationships, and received a great deal of support from family and friends, yet they took responsibility for their own lives. Their optimistic attitudes and willingness to fight dementia came from within. When they were not supported by family and friends and received threats to identity, they fought these threats. Kitwood would suggest that personhood is lost as soon as it is not supported by others, but the participants of this study showed that they could fight for their personhood on their own terms, and leisure provided a space for them to do so.

Personhood has been criticized for its failure to recognize agency among persons living with dementia. In response to this oversight, calls have recently been put forth to consider the notion of citizenship in dementia research (Baldwin, 2007; Bartlett & O'Connor, 2007).

Bartlett and O'Connor state:

One of the main boundaries of personhood is its lack of political dimension. In cognate literature, including social gerontology, critical psychiatry and disability studies, a citizenship lens is used to promote the status of discriminated groups of people to that of an equal citizen, with the same entitlements as everyone else. (p. 108)

Bartlett and O'Connor go on to critique personhood for failing to: "...recognize a person with dementia as social actor, capable of exerting power and influence" (p. 110). I have considered the political nature of leisure and explored how it is a space for participants to resist stigma. The participants of this study exercise power in their own lives, and use that power to change the way other people perceive dementia. Bartlett and O'Connor call for research that includes citizenship and ideas about agency and structure, and this study begins to consider aspects of citizenship, agency, and structure in the lives of persons living with dementia, revealing leisure

as an ideal space to broaden our understandings of personhood. Leisure becomes a space for recognizing and supporting humanness.

Engaging in Leisure Together: The Reciprocal Nature of Relationships

Since relationships played a prominent role in the lives of the participants of this study, I have considered the findings in terms of a relationship-centred care approach to dementia. Relationship-centred care recognizes both the uniqueness of individuals and the interdependence that shapes lives (Nolan, Davies, Brown, Keady, & Nolan, 2004). Nolan et al. (2003) suggest that relationship-centred care allows for focus on both intra and interpersonal dynamics of caring relationships. Positive relationships are based on a balance between independence, dependence, and interdependence. Nolan et al. (2003) suggest that in order to achieve a caring relationship, there must be a balance of mutuality and respect. They suggest that this can be achieved when the care partner and person with memory loss are able to reciprocate within the relationship. Reciprocity may be as simple as positive emotional feedback from the person living with memory loss (Ronning, 2002).

Jack, Alice, Charles, and Rita were indeed both unique and interdependent. Their relationships with family and friends were reciprocal and they took pride in the fact that they could still contribute. Although Alice sometimes doubted her knowledge, her sons recognized her abilities and sought her advice. In doing so they acknowledged both her uniqueness and her ability to contribute to their lives. Alice and Rita both learned from and taught the children in their lives. Charles liked to be able to help his wife with the chores around the apartment. All participants considered themselves to have close friendships, and leisure served as a space to act out reciprocity of support. In leisure, Rita spent time with a friend who was recently widowed. Jack and his wife served as supports for another couple who were living with Pick's

disease. Participants and their loved ones spent leisure time together and encouraged each other while doing so. The findings support the relationship-centred care approach to dementia. Furthermore, they highlight the possibilities of leisure as a space to nurture such relationships.

From Plunging into the Ocean to Basking in the Sunshine: Reflecting on the Research Journey

Now that I have explored how this research contributes to the current literature, I turn to my own role in the research process. Dupuis (1999) calls for greater reflexivity in leisure research, arguing that our understandings of the experience of leisure are enriched with the use of self in leisure research. Reflexivity shows how the researcher is part of the social phenomenon that she wants to understand. It is a space to examine personal and theoretical commitments to see how they impact the research. Reflexivity is a key component of crystallization, shedding yet another perspective on the phenomenon in question. In this section, I include excerpts from my research journal. I address the research process I experienced and how I came to understand the participants' experiences of leisure. In doing so, I explain my own journey throughout the research process. My first journal entry was written near the beginning of the research journey when I was immersed in the proposal process. Since it sets the stage for the study and acknowledges my own viewpoints, I have included the entire entry.

September 11, 2007

My partner, Chris, and I spend a week or so every August at his parents' cottage in Nova Scotia. The cottage is on a cove that is part of St. Margaret's Bay, not far from beautiful Peggy's Cove. This year the weather was a mixture of bright sunny days interspersed with fierce rain storms. The sunny days were pleasant, but not warm enough for lounging on the

beach or swimming in the ocean. Each day I looked longingly at the water trampoline moored to the wharf. Since Chris' cousin told me that the trampoline was great for lounging, all I wanted was to climb onto the trampoline and bask in the sunshine. The chilly breeze, and 50 feet or so of freezing cold salt water stood in my way. The combination of cold rain, and only moderately warm days had reduced the water temperature to a mere ten degrees Celsius. Finally, the day before we left, the weather was warm enough to consider wading in. Chris ventured in first – having grown up spending summers at the family cottage, he was used to not only the cold water but the sharp stones that littered the ocean's floor. I eased my way in, nearly crying out in pain between the frigid water and the rough stones digging into my tender feet. The cold water physically shocked me. My heart rate changed and my muscles clenched involuntarily. But I persevered and eventually waded out to the trampoline, climbed on, and basked in the warm sunshine while the water quickly evaporated off my skin. I sat out there for quite a while feeling warm, relaxed, and generally content. I was pleased with myself that I'd braved the Atlantic Ocean for an hour or so of sheer enjoyment in the beauty of the world around me and the gentle rocking of the waves underneath the trampoline. After a while, Chris' friends showed up for barbecue, and it was time for me to join them on dry land. Upper Canadian that I am, I had forgotten that since the tide was low when I ventured out, it would be considerably higher on the way back in to the beach. My walk out had been a slow and gradual immersion into water no higher than my waist, but going back I had to plunge in all at once, chin deep. If I thought the shock was bad the first time, it was much worse the second time. I raced for the shore as fast as I could and was greeted at the beach with a warm and fluffy towel, and eventually I returned to normal body temperature. Although the water shocked me, made me cry out in pain, and I considered turning back more than once on the

trip out to the trampoline, there is no doubt that it was worth it for the sake of the pleasure of basking in the warm Nova Scotia sun. I suspect next year I'll venture out again to experience the deep relaxation that comes from being on the water.

A few weeks later, as I began to work on my dissertation proposal, grappling with notions of crystallization and criteria, and representation in qualitative research, the image of my afternoon on the water struck me as an apt metaphor for my academic experiences so far. This life I have chosen has often frustrated me, and made me want to cry out in pain. On more than one occasion I have considered heading back to shore, but in the end I suspect (I hope) the agony leads to more positive feelings – of doing something worthwhile, of grasping some new abstract concept that has eluded me for so long, of feeling that I've finally done something I can be proud of. I also suspect (and have experienced so far) that these positive feelings are relatively short lived, that I'll inevitably plunge neck deep into situations that take me out of my comfort zone. So I bask in those good feelings when they are present, and look forward to them when they are looming on the horizon. I imagine my dissertation research journey will continue on in this vein – moments of joy and happiness, alternating with moments of confusion and frustration. It is with this metaphor firmly planted in my mind that I begin to journal about my research journey.

This study has been percolating in my mind since shortly after I arrived at UW to begin my PhD. It has evolved over many funding application proposals, through my course work and as I worked on my comprehensive exams. It is with Sherry's guidance that I have come this far and have been able to formulate this proposal. But it is a project that started out as a meaningful and it has since grown multiple layers for me.

My own values have grown and changed since beginning this degree, influenced by both my academic and personal life. My research with the Eating Together Study has given me the opportunity to meet courageous people who are living with and fighting against dementia. While they grapple every day with changes in their lives, they find ways to live their lives to the fullest, whatever that may mean to them. As a result of dementia, they have come to appreciate the small things in life that once went unnoticed. In some cases they've learned how to de-stress their lives by focusing on the simple things, and focusing on the things that they value most. From them, I have learned the importance of cherishing every day, and of appreciating the small things. I am not always particularly successful at this – the stress of the academic life I find often gets in the way of my ability to really live my life to the fullest, but I am learning how to do so.

These changes in me come from more than just the research I have been involved in. My mother passed away just before Christmas last year. She was 61 years old. Her short life again brought into my view the importance of really living everyday; of appreciating what I have and not worrying so much about what might be missing from my life. I remember talking with my sister shortly after returning back to school in January about how we were focused on our own eventual death, and how it was impacting our decisions. “Well, I may as well eat that piece of chocolate cake since I’m just going to die eventually anyway”, I joked. While chocolate cake may seem trivial, other decisions are not; decisions about how to live one’s life as if it might completely change at any minute. My mother’s death was not sudden, and we watched her world close in on her as she progressed through her illness. It didn’t change in a minute, but it certainly changed. I don’t know how my mother perceived her life near the end, but I don’t think she experienced a great deal of pleasure in it. I’m not sure if she experienced

“leisure moments” as time went on. She couldn’t concentrate on a novel, she couldn’t hold the newspaper, she couldn’t sit in one spot and knit, she certainly couldn’t weed the garden. She couldn’t even talk on the phone to us, her sister, her cousins and friends. She was always a social person, and I suspect that was the hardest thing for her to give up. She did some yoga. Apparently she watched a lot of CSI Miami. She spent a lot of time eating in order to keep up her strength.

It is these two experiences, combined with an extremely supportive partner, that have changed my life. Before my PhD, my leisure was limited to social activities with friends, watching a bit of TV, and reading fiction. But having to deal with my mother’s illness and death, and frequently being immersed not only in interviews with persons living with dementia and in the literature surrounding dementia was a lot to take. As well, I was frequently fairly miserable with the workload and constant struggling with academia and feelings of inadequacy as a student. Changes had to be made in my life, and they came in the form of leisure. I renewed my interest in horseback riding and I take weekly lessons. Being at the barn gives me space to forget about everything else in my life. It takes all of my mental and physical concentration to take the horse through a series of jumps in the ring. I’ve also taken up photography, which allows me to creatively capture the beauty in the world. I am deeply satisfied when I take a beautiful photo. Photography is also a learning process for me, and I hope I can use my leisure time to continue to grow as a photographer. I continue to read fiction, which I find relaxing, helping me escape reality for a few moments each day. I largely value these pursuits for the break they give me from the daily routine. They remind me that I am not only a student, but there are many more aspects of my identity. As a result of my own

leisure pursuits, and my interest in leisure studies, this research is influenced by my belief in the value of leisure for adding meaning to a person's life.

The remainder of this section includes reflections on the research process, including data collection and data analysis. I use excerpts from journal entries to describe the processes I went through to uncover the paradox of challenge and hope with the help of the participants.

Making new friends: Data collection

One of the most personally meaningful aspects of the research process was the development of relationships with the participants. We spent a great deal of time together, not only talking about their experiences, but having fun while they taught me their favourite leisure activities. Data collection was certainly the one of the most enjoyable aspects of the research, although it was not without its challenges.

On the whole, interviews went very well in this study. Occasionally, they were cut short by the energy level of the participants, or by their comments that they were having a bad day and were having difficulty thinking. One interview with Rita was cut short because she had plans to go out with a friend. On March 26th, I journaled about how well my first interview with Alice went, although questioned the length of my interview guide. Alice and I had worked together previously, and had already built rapport:

Alice also told me she was having some trouble today because it had been a busy week so far, with lots of family and friends visiting. However, to me she seemed like her usual reflective cheerful self, and I thought the interview went quite well. She is expressing a good deal of enthusiasm for the study and told me about some of her leisure activities, like crafts, playing computer games, and walking. It seems like we covered a wide range of things in the interview and we talked for just over an hour and a half (I wonder if my first interview guide is a bit too long perhaps?). She was easy to interview and gave thoughtful and interesting answers. (March 26)

Interviews were challenging when participants felt tired or had difficulty accessing their thoughts. Much of this was my own fault. As data collection went on I began to get excited about the emerging findings, and sometimes my enthusiasm got the better of my interview skills:

Today I had my third interview with Charles. It was a tough one. Charles was feeling tired and I was asking particularly long-winded questions. I'm not sure how the interview turned out. I could tell that Charles didn't feel comfortable in it. We ended somewhat early, but we were mostly done anyway. I think the previous two went better, but I guess that is part of the long interview process. It was difficult to get at whether leisure is used to cope when living with dementia, or what it means, although I guess that can be hard to articulate for anyone. I left feeling somewhat dissatisfied with the interview, all the while acknowledging my own fault in all of this, wanting leisure to be perhaps more than it is for Charles. I felt like I wanted to answer the questions for him, and I wanted him to say what I wanted to hear, which he did not. I think I did okay in restraining myself though. Perhaps not the best researcher, but hopefully not the worst. At least I can recognize my own weaknesses right? (May 23, 2008)

Data collection was exhausting and did not always go as planned. I journaled after my third interview with Jack, which I felt had gone very poorly: "My mind is fuzzy and not clear, and I am completely exhausted for no reason. All in all it was not a great day for an interview, at least from my perspective..." (June 13, 2008). While interviews went well for the most part, I certainly felt myself plunged into the deep cold water when I lost confidence in my interview skills and felt I lacked the ability to collect rich interview data.

In addition to the interviews, the use of photovoice was both challenging and rewarding. Photos served as cues for conversation and participants expressed enjoyment in using the photos to talk about their leisure. Following my second interview with Charles, I wrote: "We chatted a bit at the end about how the photos went, and Charles seemed to think they were a good idea, and liked how they prompted him to show me how things worked"

(April 25th, 2008). A few days later I addressed both advantages and challenges in using the photos:

I think the photos are working out well as a “jumping off” place for discussion about leisure. They seem to serve as cues for what the participants want to talk about, although I am still finding the guide awkward and I don’t use every question for every photo. (April 29th, 2008)

I believe that photovoice added a unique element to this study and was very useful in data collection for allowing participants to recall the leisure activities they wanted to talk about. However, participants and their care partners expressed concern about taking the right photos, or even good photos. I reassured them that it did not matter what the photos looked like and there was no right or wrong:

I get the impression that Rita worried a little bit about taking the “right” photos, but I reassured her that they were fine. Again, they are mostly photos of her doing activities, such as her with her granddaughter, and her with her children. She is similar to the previous two participants in that she had someone take photos of her instead of taking photos of things herself. (April 29th, 2008)

After Alice’s second interview where we discussed her photos, I journaled about her comments regarding the meaning behind the photographs:

Alice also found a great deal to talk about in each photo. She commented on how each photo really meant more than she thought they would when she took them, even though she did put a lot of thought and consideration into what she wanted to take. (May 5, 2008)

The most challenging part of data collection for me was participant observation. I had a difficult time learning new activities *and* remembering all of the conversation, context, and events of each session. I journaled about the challenges throughout the process, but this excerpt spoke to my reservations about my observation abilities:

Today I had my last meeting with Alice. We did participant observation, including crocheting, rug hooking, and Yahtzee. Remembering three different activities over three hours is very difficult! I hope I’ve done the notes justice. It

seems to take me forever to write up my observing notes, and I still have no idea if I am doing them correctly. (June 16, 2008)

After completing six participant observation sessions, I began to address some of the insights this form of data collection added to my research. I noted how participant observation data differed from interview data and how it helped me to build rapport with the participants.

Participating in leisure with the participants...gives me a different insight into their lives. Not being recorded, and doing something fun with no real structure like an interview guide changes the nature of the interaction. We're having fun together rather than working together, and...it does shed light on different aspects of the participants' lives...They tell me about their leisure, and they tell me about their memory loss, but in talking to someone, in enjoying time with someone, without a constant focus on the study, other aspects of their lives come up...Also I like to think that the participant observation gives me some insight into what it is like to participate in some of these activities. In many cases, I did new activities that I had never done before. I had to be taught, and I felt slow and unsure of my moves, whether what to do next in a game, how to hold the equipment, etc. I was uncertain of the rules and needed to be reminded, and this is something that Charles in particular tells me is a problem for him (the others so far seem to be able to remember rules). I felt happy to have the support – to be supported to play a new activity with patience and kindness, and gentle reminders, as I am sure Charles must feel as well, as he has indicated with comments like “[my wife] is such a beautiful caregiver”. The difference is for me I can learn it, pick up the skills in a short while, and my speed gets faster, my reactions quicker, patterns jump out at me. (June 30, 2008)

Participant observation also gave me the opportunity to reflect on the embodied nature of leisure participation. It gave me a glimpse into the experience of leisure for the participants that I felt I could empathize more strongly with the changes they were experiencing. In the excerpt below, I reflected on what it must be like to find familiar activities changed to the point where one has to relearn them each time they try them.

Yesterday was my last meeting with Charles, and we went pole walking along [the river]. This was my first time pole walking, and it was kind of a strange feeling. My body felt awkward and stiff as I tried to negotiate the use of poles while walking. I couldn't seem to settle into a rhythm using the poles as I walked...It was like relearning how to walk in some ways, although probably not as difficult as actually learning to walk. It felt strange to have to think about walking, instead of just relaxing and walking like one usually does. Charles told

me it took a long time for him to get used to it too, so that made me feel a little better. I'm not sure how my own learning experience throughout this process relates to dementia. Learning these new activities, whether games, or something physical like yesterday, makes me wonder what it is like to have to relearn everyday, as some of the participants mentioned. Charles talks about forgetting the rules to the game, forgetting whose turn, etc. I have the opportunity to remember the rules, remember how Charles told me to walk with the poles...I can't help but reflect on my own learning process and wonder what it would be like to have to start over each time I try to do a well known activity. I was complaining to Chris not that long ago that I didn't feel like I was getting any better at horseback riding. I'm not getting stronger, not remembering the multitasking required to use my body to guide the horse. It's disappointing to me that I don't see progress within myself when I'm riding. What is it like to lose progress, to feel like you're starting all over again, when you know you did that same activity yesterday or a week ago? (May 29, 2008)

While each data collection tool provided its own challenges, they also contributed significantly to the findings of this study. By using all three methods, I had a mountain of data to analyze, and I now turn to addressing some of the joys and challenges of the data analysis process.

Drowning in data: Data analysis

Data analysis occurred simultaneously with data collection. Themes began to emerge early in the data analysis process. My first interview was with Jack, and I noticed the tension between positive and negative aspects of life immediately. After reflecting on the first three interviews, I began to think this might be a key essence of the experience, but was not yet sure:

I can see in Charles' speech the contradiction between the experience of the illness and having a positive attitude. This seems to come through in all the interviews, and I wonder if it is part of the essence of the experience of living with dementia. (April 9, 2008)

The theme continued to emerge as I delved into the detailed line by line approach for analyzing data:

My overall sense of the data at this point for Jack is that his experience seems to be characterized by juxtaposing a positive attitude with the experience of change. It seems his experience is contradictory in that he acknowledges negative changes, or losses, yet immediately places a positive spin on his life. It's almost

like a give and take of the positive versus the negative. Anyway, this is my overall sense of the first transcript. Sort of “This has changed, this is lost, but life is great because of this and this.” (April 22)

A month and a half after data collection commenced, I began to really struggle with data analysis. The fact that this was my first attempt at phenomenological data analysis became very evident

I have just completed my first attempt at analyzing P3’s first interview. Again this was a challenging feat! Discerning essences is more difficult than I thought. In comparison to the P1 data analysis that I have done, I think they are somewhat similar in that the lived experience continues to be about juxtaposing the positive and negative. Again, P3 acknowledges losses and changes but stresses the importance of having a positive attitude, and believes that he does indeed have a positive attitude to living with dementia. The juxtaposition is less obvious in this interview, yet I think it still remains. (May 3, 2008)

Once data analysis was nearly complete, I reflected on the process again, hoping I was doing justice to the stories of the participants in my analysis process:

I finally feel as though I am making some progress on the data analysis. Things are coming together; the pieces are beginning to take shape as a whole. However, at the same time I am struck by the complexity of their experiences and I worry that I cannot articulate this complexity. By separating the essences of the experience, is part of the experience lost? How do I tell their stories in such a way that reflects the contradictions, juxtapositions, and paradoxes that the participants experience on their dementia journey, and still produce a story that the reader can follow with minimal confusion? Richardson is absolutely correct in her assertion that crystallization provides us with a completely partial perspective of the phenomenon. I feel as though I lack the finesse in my writing to truly get at the intricacies of the participants’ experiences without losing something of that experience along the way. (Oct. 9, 2008)

Despite the challenges of data analysis, I loved being immersed in the rich data I collected.

The challenges were welcome ones, and I thoroughly enjoyed working through them. In

December, I wrote: “...the research is the fun part of my life right now, it fills me with joy and hope, and I enjoy working on it. It’s stress-free academia, at least for a little while” (Dec. 18, 2008).

Reflexivity sheds light on the research process and how the researcher both influences and is influenced by the research process. It allowed me to reflect on my own leisure and my experiences with the research process. It provides insight into the research process and how I came to thoroughly partially (Richardson & St. Pierre, 2005) understand the phenomenon of leisure within the context of memory loss. This section provided a very brief overview of my research journey. It was certainly worth the struggle, frustration, and feelings of being overwhelmed to arrive at this point. I hope I get to bask in the sunshine for at least a little while.

‘A Picture is Worth a Thousand Words’

A significant part of the data collection process involved the method of photovoice. As discussed in Chapter 3, photovoice is a participatory action research method with the ultimate goal of creating social change. Photovoice researchers and their participants display the photos for the public to learn about the phenomenon under question. Photovoice has potential for empowerment among those who participate in it. For example, Levin et al.’s (2007) photovoice emphasized hopes and dreams and expressed their needs through photos. It is my hope that photovoice could provide similar opportunities for persons living with dementia, and spread a wider message of understanding the role of leisure in the lives of persons living with dementia. In keeping with the spirit of photovoice, I have created a slideshow depicting the photos in a way that represents the paradox of challenge and hope. The photos are used with quotes from the participants, or summary statements of certain themes to demonstrate the many challenges that participants feel, juxtaposed with the ways in which they tackle life with dementia and continue to live out their lives with a sense of hope. The slideshow is included with this thesis on a compact disc. I hope to bring the slideshow outside of the world of

academia in order to share the findings with a wider audience who may gain new insights into living with memory loss, and in turn, change their perspectives regarding what it means to live with dementia.

Practical Implications

The findings of this study have many implications for practice. They inform our understanding of leisure's role in the dementia experience, something we knew very little about prior to this study. In this section, I outline some practical implications that apply to persons living with dementia, their care partners, and formal service providers, such as family support workers, staff who work in day programs, memory clinics, support groups and other service providers who have a role to play in the care that persons living with dementia receive.

We are now aware that leisure plays a central role in the lives of persons living with memory loss. We also know that leisure is multidimensional for persons living with dementia. In this study, participants chose mentally stimulating activities and physical activities to maintain their function. Information about these types of activities and their potential benefits should be made readily available for persons living with dementia and their families. In addition, leisure is often purposeful, and opportunities to contribute to families and community should be facilitated. Persons living with dementia should be made aware of the possibilities of using leisure to replace previously valued roles in order to maintain or recreate identity. At the same time, persons living with memory loss and their care partners must be aware of the need to frequently reassess one's abilities and expectations in leisure activity choices. Recognizing and accepting that change will occur assisted the participants to adjust their activities so they could engage in those that were still meaningful. They recognized that the changing nature of memory loss meant that they might not be able to engage in these activities

forever, so they found ways to enjoy them in the present. If persons living with dementia, care partners, and service providers can work together to support leisure engagement, persons living with dementia may be able to maintain their identities and resist negative assumptions.

Following Kleiber et al.'s (2002) propositions for leisure in the context of negative life events, leisure practitioners could provide opportunities for diversion in order for persons living with dementia to nurture feelings of hope about their lives. As well, they should consider the role of leisure in both continuity and transformation. Tools could be developed for persons living with dementia, their care partners, and formal service providers to think about the many roles of leisure in coping with a diagnosis of memory loss and its subsequent threats to identity.

Jack, Alice, Charles, and Rita chose a variety of leisure pursuits based on their lifelong interests. It is important for leisure professionals to facilitate leisure opportunities that are personally meaningful for their participants. Practitioners should avoid stereotypical activities. They should support participants in their activities, rather than taking over and doing for them. As well, responding to efforts to adapt leisure in order to continue to participate is important for persons living with dementia to maintain involvement over time. Leisure service providers should also ensure that new opportunities are available for persons living with dementia who seek personal growth and are eager to try new things.

Leisure practitioners are in a unique position to provide opportunities for resistance in the space of leisure. Persons living with memory loss used their leisure to reveal their strengths and capabilities to others, but also to build self confidence, instigating a cycle of further participation in activities. Leisure service providers should be prepared to support persons living with dementia who may be interested in advocacy. Awareness of community groups

who engage in advocacy is important. Opportunities to share experiences with peers and advocate as a group are also important for some persons living with dementia. Providing guidance that recognizes the capacities of the persons living with dementia and allows them to direct the process is vital for empowerment.

The findings in this study highlight the significance of caring relationships for maintaining leisure engagement. Care partners were instrumental in maintaining leisure involvement, whether it was support for beginning new activities, providing transportation, or providing cues for remembering the next step in an activity. Service providers should be prepared to support care partners, providing them with tools for encouraging continued engagement in leisure.

Nolan et al. (2003) proposed the senses framework as a means for care providers to put relationship-centred care into action. The approach includes six senses: sense of security; a sense of continuity; a sense of belonging; a sense of purpose; a sense of achievement; and a sense of significance. All senses are required for satisfying caring relationships. The framework accounts for the interdependencies that person-centred care neglects. Leisure practitioners working with persons living with memory loss are in an ideal position to implement the senses framework. Since leisure appears to be a space for reciprocal relationships to be supported, leisure can be used to meet all six senses. Leisure can be facilitated in safe, secure environments, where people feel free to be themselves. As well, leisure practitioners can provide opportunities that support continuity in one's identity and leisure preferences. By enabling leisure activities for family and friends along with persons living with dementia, we can create a sense of belonging. I have seen many times in this research how leisure is a space for achievement and purpose. Drawing upon the senses

framework may lead to leisure programs that support reciprocal relationships among persons living with dementia, their care partners, and formal service providers. Additionally, through shared leisure, all of those in the caring relationship may experiences each of these senses.

This study has broader implications for leisure practice as well. The findings indicate that it is time to move beyond segregated leisure programming for persons living with dementia. Community leisure programs and seniors' centres should include persons living with dementia in the program planning, implementation, and evaluation processes. A call for inclusive programming that allows persons living with dementia to build relationships, develop skills and abilities, share their strengths and capacities, and contribute to their communities is in order. Furthermore, recreation programmers in institutional settings could consider which types of activities are meaningful for participants and support the identities of residents. Clare, Rowlands, and Quin (2008) report that persons living with dementia in residential facilities felt bored. They wanted to have more independence and often felt angry about their situations in residential care. Based on the findings of this study, recreation programmers in long-term care can play a significant role in working with persons with dementia to determine what is most meaningful to them and how to best reduce feelings of boredom and independence.

We should also consider citizenship and personhood when facilitating leisure experiences for persons living with dementia. Baldwin (2007) links citizenship to narrativity. He suggests that "...we are narrative beings who find our Selves in the stories we tell about ourselves and the stories that others tell about us" (p. 223). Sometimes, people with dementia find their stories to be marginalized. Baldwin argues that narrativity requires agency and opportunity, which are often denied to people living with memory loss. Having the opportunity to tell one's story leads to empowerment. By adopting narrative citizenship,

Baldwin suggests that policy can become more inclusive of persons living with dementia. I listened to the narratives of persons living with memory loss, and in doing so, it is my hope that a better understanding of dementia was garnered in this study, and we can adjust our leisure practice based on the stories of persons living with memory loss, not on what leisure practitioners think is best, or what care partners think is best. Leisure practitioners can use recreation settings to encourage persons living with dementia to voice their own narratives. Leisure programs can provide a space for persons living with dementia to tell their stories and create new stories about themselves. Leisure practitioners should consider creating safe environments for persons living with memory loss to exercise agency and power.

Future Directions

My dissertation research begins to fill some of the gaps in our knowledge that I identified in Chapter 2, but many questions remain to be answered. In this section, I outline some suggestions for future research aimed at further developing our understanding of leisure within the context of memory loss.

In-depth exploration of each of the four lifeworld existentials would broaden our understanding of leisure within the context of dementia. I felt limited by my research design in trying to understand lived time, lived space, lived body, and lived other in depth. Further exploration of leisure in terms of all four lifeworld existentials may provide us with a clearer understanding of leisure's role in the memory loss experience. Collecting data over a longer period of time would highlight how the experience of the lifeworld existentials changes over the progression of dementia. Increased time spent in participant observation may have revealed more about each of the lifeworld existentials. Probes that further explored the four

lifeworld existentials would be beneficial for gaining a better understanding of how they are experienced as well.

Further exploration of meaning-focused coping would garner a clearer understanding of how person's living with memory loss maintain feelings of hope in the face of a great deal of change. Frequently, research that draws upon Folkman's (1997, 2008) model does so from the perspectives of care partners. Research that explores positive psychological states when coping with stressful events from the perspectives of persons living with memory loss could provide increased insight into meaning-focused coping and the experience of hope for persons living with memory loss.

Further research is needed to better understand how leisure can be a space for advocacy for persons living with dementia. Jack and Alice talked about using leisure to advocate on behalf of their peers. It was an important aspect of their identities and they wanted to change the way people think about dementia. Focusing on leisure as a space for advocacy would afford a better understanding of the experience and provide insight into how researchers and practitioners can support self advocacy among persons living with dementia. Furthermore, we need to consider what it really means to advocate. How do persons living with dementia perceive their actions of advocacy and what role does advocacy play in the personhood approach to dementia?

Bartlett and O'Connor (2007) call for research that shifts to include citizenship. This would ensure that notions of power are considered in dementia research. More specifically, they suggest that people with memory loss should be considered in terms of "power to instigate and shape the research identity" (p. 112). Future research regarding leisure and the experience of dementia should include participants in all aspects of the research process, not just data

collection. This study begins to address notions of citizenship in dementia, but drawing upon a citizenship lens could increase our understandings of dementia and provide a more inclusive view in which to explore the experience of memory loss, further expanding our definitions of personhood.

Further investigation is needed regarding the role of the caring relationship in meaningful leisure. Phinney (2006) notes that engagement in meaningful leisure is supported by family members who adjust activities to meet the abilities of the person with memory loss. The findings of this study similarly revealed that support from care partners is essential for participation in leisure. We have not yet explored the caring relationship in the context of leisure from a relationship-centred care approach (Nolan et al., 2004; Ryan, Nolan, Reid, & Enderby, 2008), expanding notions of personhood in dementia care. By drawing upon relationship-centred care, we could further explore reciprocity of support that occurs within the context of leisure and how leisure is used as a way to resist a master status or status viewed as undesirable by persons living with dementia. As well, it would be fascinating to explore the larger leisure network, including care partners, adult children, grandchildren, siblings, and friends of the person living with dementia and consider how all of these experiences interact. Furthermore, the participants in this study indicated that their relationships with their peers were particularly important. Future research exploring these relationships and the role of leisure in nurturing relationships would improve our understanding of this phenomenon and how to support persons living with memory loss and their loved ones to pursue meaningful leisure together.

The paradox of challenge and hope can be better understood by following persons living with dementia over a longer period of time. This study represents just one slice of time in the

participants' lives. It is unclear how the participants will continue to experience leisure within the context of memory loss over time. How do persons living with dementia remain hopeful as dementia progresses? Such research would address meaningful activity as memory loss progresses and people transition to long-term care. It is time to move beyond measurement of physiological responses and reductions in "problem behaviours" in dementia research. We need to explore how Therapeutic Recreation interventions can be truly meaningful experiences that emphasize capacity in long-term care. Participants expressed fear of moving into long-term care, and perhaps some of this anxiety can be abated by changing the culture of long-term care to address the concerns of persons living with memory loss and their families. As well, the theme of creating enduring memories warrants more exploration as greater understanding of the desire to, and means of, creating positive memories of self could lead to alterations in leisure practice.

Jack, Alice, Charles, and Rita are active participants in their lives who maintain particularly positive attitudes in order to live with memory loss. As a result, their experiences with memory loss may be particularly unique. Since they were recruited through support groups and a research group, they may already be different from persons living with memory loss who do not seek out formal support or look for ways to be involved in dementia research. Additionally, volunteering for a study focusing on leisure may indicate that they value their leisure pursuits more so than other persons living with dementia. Future research that aims to recruit participants who may not value leisure, who may have more difficulty sustaining leisure involvement, or have a more difficult time balancing the positive aspects of their lives with the negative aspects of living with dementia may provide different insight into leisure within the context of memory loss. Such research could continue to expand understanding of the paradox

of challenge and hope by seeking out a greater diversity of participants living with memory loss.

Finally, the method of photovoice provides unique insights into the experience of dementia, but other creative methods are needed to understand the experience of dementia as communication becomes more difficult with the progression of dementia. Flexible methods will be required for understanding the experience of dementia, keeping in mind the abilities of research participants. Experimenting with a variety of approaches may help researchers to find some unique ways of understanding the lived experience of dementia. There are many possibilities for future research emerging from this study. It is vital that we continue to explore the subjective experience of memory loss so that services can be improved for families living with it.

Conclusion

This phenomenological study explored the meaning and experience of leisure among persons living with early stage dementia from a personhood perspective. I set out to learn if and how persons living with memory loss use their leisure as a space for sustaining and recreating identity and as a space for resisting stereotypes of dementia and the progression of dementia itself.

The findings of this study revealed that the journey of memory loss was experienced in a complex paradox of challenge and hope. This paradox is composed of the changes that the participants faced in their day-to-day lives, including leisure, juxtaposed with the ways in which the participants face life with memory loss with a sense of hope.

The study captures the stories and experiences of four unique individuals who may not be representative of all persons living with early stage memory loss. The participants were

active people who valued leisure. The findings could be strengthened with the inclusion of persons living with memory loss who may not value leisure, or who find it more difficult to address challenges to sustaining leisure involvement. However the use of photovoice provided unique insights into the experience memory loss that may be more difficult to capture through interviews and participant observation alone. Photovoice gave the participants the opportunity to reflect on and record their leisure. This, in turn, served to remind the participants of what was meaningful about their leisure during our discussions. Additionally, the photos created a powerful message regarding the experience of memory loss that may change society's perspectives on dementia.

This study is unique in its focus on both positive and negative aspects of life with memory loss. Frequently, research on the subjective experience of dementia centers on the challenges faced and the way the symptoms are experienced, paying less attention to the dialectical nature of living with memory loss. In contrast, the findings of this study emphasize the complexity of life with dementia by calling attention to not only the losses experienced, but the benefits gained from learning to live with such a life-altering illness. Life with dementia is indeed complex, but leisure has a valuable role to play within that experience, contributing to a sense of hope and optimism in the face of adversity.

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Appendices

Appendix A: Telephone Script for Contacting Agencies

A = Agency contact; I = Interviewer

I - May I please speak to [name of agency contact]?

A - Hello, [name of agency contact] speaking. How may I help you?

I - My name is Rebecca Genoe and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I am currently conducting research under the supervision of Dr. Sherry Dupuis on the meaning of leisure for persons living with early stage dementia. As part of my thesis research, I am conducting interviews and participant observation with people living with memory loss in order to explore the meaning and experience of leisure and its role in maintaining identity in the lives of persons living with early stage dementia.

I would like to set up a meeting with you so I could tell you more about the study and discuss with you how you might help me recruit potential participants. Would you be willing to meet with me?

A - Yes

I – What time and date would be convenient for you?

A – (gives time and date)

I – Thank you for your time. Good bye.

OR

A – No.

I – Thank you for your time. Good bye.

Appendix B: Script for Meeting with Agencies

Preamble: My name is Rebecca Genoe and I am a PhD student in the department of Recreation and Leisure Studies at the University of Waterloo. I would like your help in recruiting persons living with early stage memory loss to participate in my research project, “The meaning of leisure within the context of dementia”.

I am conducting this study because although a great deal of research focuses on service providers and family members, understanding the perspectives of persons living with memory loss is vital for increasing knowledge regarding the experience of memory loss. I’m trying to find out how people living with memory loss experience their leisure. While research has shown that participation in planned recreation programs may be beneficial for persons with memory loss, little is known about the meaning and experience of leisure, or the benefits to and challenges of participating in leisure. This study will help myself, other researchers, leisure practitioners, and other professionals working with persons with dementia and their families to understand the role of leisure in the lives of persons living with memory loss. This information may be used to help other people experiencing memory loss and their formal and informal care partners to understand the benefits to and challenges of participating in leisure and better support persons with dementia in addressing their challenges and continue to maintain involvement in valued activities.

Here is a Fact Sheet explaining the study in greater detail.

(Go through Fact Sheet for agencies with staff member)

Do you have any questions about the study I have not answered? (Allow time for staff to ask questions)

I have brought along copies of an information letter which has all of these details along with contact names and numbers on it. I would appreciate your help in passing this information on to anyone who you think might be interested in participating in this study. More specifically I am hoping you might discuss this project with potential participants and ask if they would be willing to have me call them and tell them more about the study and determine their willingness to participate. Should they provide you with permission, I will then get their contact information from you and call the potential participant myself. I will assure the potential participant that participation in this study is completely voluntary and that they are under no obligation to participate. Would you be willing to assist me in recruiting participants?

A - No thank you.

OR

A – Sure.

I - Thank you very much for your time. May I call you in a week or so to see if you have found anyone who might be interested in participating? Once again, if you have any questions or concerns please do not hesitate to contact me at my research office number 519-888-4567, Ext. 38187.

A - Good-bye.

I - Good-bye.

Appendix C: Fact Sheet for Agencies



The Meaning of Leisure within the Context of Dementia *Fact Sheet for Agencies*

My name is Rebecca Genoe and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I would like your help in recruiting persons living with early stage memory loss to participate in my research project, “The meaning of leisure within the context of dementia”.

Why is this study being conducted?

- A great deal of research focuses on service providers and family members, but understanding the perspectives of persons living with memory loss is vital for increasing knowledge regarding the experience of memory loss and improving quality of life for those living with it.
- Research suggests that leisure is important to identity and resistance of negative stereotypes for marginalized groups, yet little is known about the role of leisure in the lives of persons with memory loss.
- I’m trying to find out how people living with memory loss experience their leisure. While research has shown that participation in planned recreation programs may be beneficial for persons with memory loss, little is known about the meaning and experience of leisure, or the benefits to and challenges of participating in leisure.
- This study will help myself, other researchers, leisure practitioners and other professionals working with persons living with dementia and their families to understand the role of leisure in the lives of persons living with memory loss. This information may be used to help other people experiencing memory loss and their formal and informal care partners to understand the benefits to and challenges of participating in leisure and better support them in addressing the challenges they face and their ability to maintain involvement in valued activities.

Who can participate in this study?

- I am looking for three or four persons living with early stage memory loss to become involved in this study.
- Participants should be 55 or older and living in the community.
- Participants should be willing and able to sign an informed consent form, and should be able to operate a camera with minimal assistance.

What will be asked of participants in the project?

- Participants will be asked to participate in three interviews about one hour in length. The first interview will explore experiences of living with memory loss. The second interview will explore leisure experiences using photos taken by the participants, and the third interview will discuss the role of leisure in the participant's life. With the participant's permission, I would like to audio record the interviews so I make sure I adequately capture their experiences and perceptions.
- A participant will be observed 1-3 times for an hour or two each time doing a leisure activity of their choice.
- Each participant will be given disposable cameras and asked to take photos of subjects, images, or spaces that are meaningful to or reflect their leisure. I will develop the film and give the participant a hard copy and a CD, and keep one set of photos and one CD for the study. These photos will be used in the second interview. With the participant's permission, photos will be used in my thesis, and any presentations or publications that result. Each participant will be given information letters and consent forms that must be signed by any human subjects the participants would like to photograph.
- After data collection and analysis, each participant will be asked to participate in a fourth interview or group session involving other participants to discuss whether or not my findings reflect their experiences.
- The fourth interview or group session involving each participant will occur within the same year and after all data collection and analysis has been completed. The session will be approximately two hours in length.
- As a thank you for participating in this study, participants will be given a \$20 gift certificate for a store, service or restaurant of their choice.

What is being asked of me?

- I would like you to provide information about this study to any person living with early stage memory loss who you think might be interested in participating in this study.
- For those persons who express interest in participating in the study, ask them if you may provide me with their contact information so I may contact them and speak to them directly about the study.
- I will give you letters and information sheets to pass on to potential participants.
- I will then ask you to provide me with contact information (name, telephone number) for potential volunteers who have expressed interest in becoming involved in this study.

What should you know about participants' involvement in this study?

- Participation is completely voluntary and participants can refuse to answer any questions.
- There are minimal risks to participating in this study. There may be some emotional stress as participants are asked to reflect on their experiences with memory loss. However, previous interviews with persons living with memory loss have indicated that talking about their experiences is very therapeutic. I will be working closely with Alzheimer Society family support persons, and if any participant experiences emotional stress, he or she will be referred to their family support person.

- All information provided is strictly confidential. Participants' names will never appear in any report, publication, or presentation resulting from this evaluation. Personal identifying information will be removed from all stored data.
- Information gathered will be stored indefinitely in a locked research office at the University of Waterloo, with the exception of paper records and audio recordings which will be erased after two years.

Who to contact should you have any questions about this study?

- Please contact myself, Rebecca Genoe if you have any questions or concerns about this study. I can be contacted at (519) 888-4567, Ext. 38187, or by email at mrgenoe@ahsmail.uwaterloo.ca. My advisor, Dr. Sherry Dupuis, can be contacted at (519) 888-4567, Ext. 36188, or by email at sldupuis@healthy.uwaterloo.ca.
- This project has been reviewed by, and received ethics clearance through the Office of Research Ethics at the University of Waterloo. Any comments or concerns can be addressed to this Office at 519-888-4567, Ext. 36005.

Thank you in advance for your help with this study!

Appendix D: Participant Information Letter

March 6, 2008

Dear Potential Volunteer,

My name is Rebecca Genoe, and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I want to invite you to participate in a study titled **The Meaning of Leisure within the Context of Dementia**. I am hoping to better understand what it is like to live with memory loss. Specifically, I am hoping to understand your leisure experiences and what leisure means to you. I am trying to find out what role leisure plays in the lives of persons experiencing memory loss.

Your participation in this study would include taking part in three or four interviews with me to explore what it is like to live with memory loss, and the meaning of leisure for you. It will also involve me observing you as you participate in your favourite leisure activity. To better understand what leisure means to you, I would like to provide you with a disposable camera and ask you to use this camera to take photos of items that reflect leisure for you. Your commitment to this study will involve between 5 to 10 hours over 6 to 10 weeks. **Please read the attached Fact Sheet carefully for the details of this project.**

If you decide to take part in this study, I will be asking you to sign a letter formally stating your consent to participate. Your participation is completely voluntary and you may choose not to participate. If you do participate, you may choose not to respond to questions if you wish and you may choose to withdraw from participation at any time.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at (519) 888-4567, Ext. 38187 or by email at mrgenoe@ahsmaail.uwaterloo.ca. You can also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567, Ext. 36188 or by email at sl Dupuis@healthy.uwaterloo.ca.

Thank you for your interest and considering participating in my study.

Sincerely,

Rebecca Genoe
PhD Candidate, University of Waterloo

Appendix E: Fact Sheet for Potential Participants



The meaning of leisure within the context of dementia

Fact Sheet for Participants

My name is Rebecca Genoe and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. I would like to invite you to participate in my research project, “The meaning of leisure within the context of dementia”.

Why is this study being conducted?

- A great deal of research on memory loss focuses on service providers and family members, but understanding the perspectives of persons living with memory loss is vital for increasing knowledge regarding the experience of memory loss and improving the quality of life of those living with it.
- I’m trying to find out how people living with memory loss experience their leisure. While research has shown that participation in planned recreation programs may be beneficial for persons with memory loss, little is known about the meaning and experience of leisure, or the benefits to and challenges of participating in leisure.
- Findings from this study may help me, other researchers, leisure practitioners and other professionals working with persons with memory loss and their families to understand the role of leisure in the lives of persons living with memory loss. This information may be used to help other people experiencing memory loss and their care partners to understand the benefits to and challenges of participating in leisure and better support them in addressing the challenges they face and their ability to maintain involvement in valued activities.

Who can participate in this study?

- I am looking for three or four persons living with early stage memory loss to become involved in this study.
- Participants should be 55 or older and living in the community.
- Participants should be willing and able to sign an informed consent form, and should be able to operate a camera with minimal assistance.

What will be asked of participants in the project?

- You will be asked to provide informed consent to participate in this study.

- You will be asked to participate in three interviews about one hour in length. The first interview will explore your experiences of living with memory loss. The second interview will explore your leisure experiences, and the third interview will discuss the role of leisure in your life. With your permission, I would like to audio record the interviews so I make sure I adequately capture your experiences and perceptions.
- You will be observed 1-3 times for about an hour or two each time doing a leisure activity of your choice.
- You will be given a disposable camera and asked to take photos of subjects, images, or spaces that are meaningful to or reflect your leisure. I will develop the film and give you a set and a CD of the photos, and keep one set and one CD of the photos for the study. These photos will be used in the second interview to discuss your leisure. With your permission, these photos will be used in my thesis, and any presentations or publications that result. You will be given copies of an information letter and consent form that should be signed by the persons you would like to photograph.
- Once the data have been collected and analyzed, you will be asked to participate in a fourth interview or group discussion session with other participants to discuss whether or not my findings reflect your experiences.
- As a small token of my appreciation for participating in this study, you will be given a \$20 gift certificate for a store, service, or restaurant of your choice.

What should you know about your participation in this study?

- Your participation is completely voluntary.
- You can refuse to answer any questions you want.
- There are minimal risks to participating in this study.
- All information provided is strictly confidential. Your name will never appear in any report, publication, or presentation resulting from this evaluation.
- With your permission, all interviews will be audio recorded.
- With your permission, anonymous quotations from the interviews may be used in my thesis and any resulting publications.
- You may withdraw from participating at any time by advising the researcher. You will still receive the \$20.00 gift certificate if you withdraw from this study.
- Data will be retained indefinitely in a secure location, with the exception of paper records, which will be destroyed 2 years after the completion of the study, and audio recordings will be erased 2 years after the completion of the study. Any personally identifying information will be removed from the stored data.
- An executive summary of the results of this study will be available to all participants once all the data from the evaluation has been analyzed.

Who to contact should you have any questions about the study?

- Please contact myself, Rebecca Genoe if you have any questions or concerns about this study. I can be contacted at (519) 888-4567, Ext. 38187, or by email at mrgenoe@ahsmail.uwaterloo.ca. My advisor, Dr. Sherry Dupuis, can be contacted at (519) 888-4567, Ext. 36188, or by email at sldupuis@healthy.uwaterloo.ca

- This project has been reviewed by, and received ethics clearance through the Office of Research Ethics at the University of Waterloo. Any comments or concerns can be addressed to this Office at 519-888-4567, Ext. 36005.

Thank you in advance for your interest in this study!

Appendix F: Telephone Script for Contacting Potential Participants

P = Potential Participant; I = Interviewer

I - May I please speak to [name of potential participant]?

P - Hello, [name of potential participant] speaking. How may I help you?

I - My name is Rebecca Genoe and I am a PhD student in the department of Recreation and Leisure Studies at the University of Waterloo. [Agency contact] gave me your name and told me she has spoken to you about my study. I am currently conducting research under the supervision of Dr. Sherry Dupuis on the meaning of leisure. As part of my thesis research, I am conducting interviews and observing people living with memory loss in order to explore the meaning and experience of leisure and its role in maintaining identity for those living with memory loss. Did [Agency contact] give you a copy of the information letter and Fact Sheet?

P- Yes

I - I would like to tell you more about my study. Is this a convenient time to talk?

P - No, could you call back later (agree on a more convenient time to call person back).

OR

P - Yes

I – I am interested in leisure in the context of memory loss because little is known about how persons living with memory loss experience leisure. I really want to talk to people living with memory loss because understanding their perspectives is vital for increasing our knowledge and finding better ways to support them and improve quality of life. Often researchers rely on family carers or service providers to understand memory loss, but I am interested in hearing your perspective. I'm trying to find out how people living with memory loss experience their leisure. While research has shown that participation in planned recreation programs may be beneficial for persons with memory loss, little is known about the meaning and experience of leisure, or the benefits to and challenges of participating in leisure. This study will help me, other researchers, leisure practitioners and other professionals who work with persons living with dementia and their families to better understand the role of leisure in the lives of persons living with memory loss. This information will be used to help other people experiencing memory loss and their care partners to understand the benefits to and challenges of participating in leisure and find better ways to support them in maintaining involvement in valued activities.

- I will be undertaking interviews starting in February 2008.
- The first interview would last about one hour, and would be arranged for a time convenient to your schedule. During this first interview, I will give you a

camera and ask you to take photos of items and images that reflect your leisure. I will pay for the development of the photos, and we will use the photos to discuss what leisure means to you and your experiences with leisure at a second interview. We will also set up a time to participate in a leisure activity of your choice together.

- I would also like to participate with you in a leisure activity of your choice on one to three different occasions for about an hour or two each time.
- After we talk about the photos, we will arrange for a third interview to follow up on our discussion. A fourth interview or group discussion session involving other study participants will then be conducted so I can share my findings with you and ensure that I truly understand what leisure means to you and the role it plays in your life.
- Involvement in this study is entirely voluntary and there are minimal anticipated risks to participation in this study.
- The questions are designed to ask you about your experiences with memory loss and the role of leisure in your life.
- You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time.
- With your permission, all interviews will be tape-recorded to facilitate collection of information, and later transcribed for analysis.
- All information you provide will be considered confidential.
- The data collected will be kept in a secure location and disposed of in two years time, except for electronic data, which will be kept indefinitely. Any personal identifying information will be removed before storing electronic data.
- You may withdraw from this at any time by advising the researcher. There will be no negative consequences of withdrawal from the study.
- If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact Dr. Sherry Dupuis at 519-888-4567, Ext. 36188.
- I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567, Ext. 36005.
- After all of the data have been analyzed, you will receive an executive summary of the research results.

Do you have any other questions about this study that I have not answered? (Allow time for potential participant to ask questions)

Would you be willing to participate in my study?

P - No thank you.

OR

P - Sure.

I - Thank you very much for your time. What would be a convenient time and place for me to meet with you for our first interview?

P – Gives time and place

I - Good-bye.

P – Good-bye.

Appendix G: Declaration of Informed Consent

I have read the information presented in the information letter and Fact Sheet about a study being conducted by Rebecca Genoe of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I have the option of allowing my interviews to be audio recorded to ensure an accurate recording of my responses. I am also aware that excerpts from the interviews and photos that I share with the researcher may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. I was informed that I may withdraw my consent at any time without penalty by advising the researcher or her advisor.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567, Ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES NO

I agree to have my interviews audio recorded.

YES NO

I agree to the use of anonymous quotations in any thesis or publication/presentation that comes of this research.

YES NO

I agree to the use of photographs I take for this study in any publication/presentation that comes of this research. Photos of people will only be included if there is permission from the persons in the photos to use their photo in the research and any resulting publication/presentation.

YES NO

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

Appendix H: Thank You Letter

MAREP/University of Waterloo

[date]

Dear [Participant's name];

I would like to thank you for participating in my PhD dissertation titled “The meaning of leisure within the dementia context”. The purpose of this study is to explore the meaning of leisure in the lives of persons experiencing memory loss. Your perspective and insight have provided invaluable information to this study.

The data collected during interviews, observation, and photos will contribute to a better understanding of what it is like to live with memory loss. My findings will inform researchers and service providers of the experience of leisure and the role it plays in the lives of those experiencing memory loss. It is my hope that this information will help us better support persons with memory loss maintain valued activities.

I want to emphasize that all information shared throughout the duration of this study will remain completely confidential and will be used only for the purposes of this project. I will be sending out a summary of the findings of the research for your interest once the study is completed.

I hope you will get in touch with me if you have any further comments or questions about our conversations or about the study in general. I can be reached at (519) 888-4567, Ext. 38187. I would also like to remind you that this study has been reviewed by the Office of Research Ethics at the University of Waterloo and has received ethics clearance. Any comments or concerns can be addressed to Dr. Susan Sykes, Director of the Office of Research Ethics at (519) 888-4567, Ext 36005. Thank you again for your participation in the project.

Sincerely Yours,

Rebecca Genoe
PhD Candidate
Department of Recreation and Leisure Studies
University of Waterloo

Appendix I: Final Feedback Letter

MAREP/University of Waterloo

[Date]

Dear [Participant],

I would like to thank you for participating in my research study titled “The meaning of leisure within the dementia context” that was conducted in 2008. This study examined the meaning of leisure for persons living with memory loss.

The data collected during my interviews with you, observation of your favourite activities, and photos you took have provided important insights into what it is like to live with memory loss and the experience of leisure for those living with it. I will be using these insights to help others better understand the experience of memory loss from the perspectives of those living with it. It is my hope that in doing so we can begin to break down the stigma associated with memory loss and highlight the continued abilities, desires and talents of persons with memory loss.

I have enclosed a summary of my findings for your interest. I hope you like the summary, and in particular I hope you will find that I have been faithful to the information you gave me and to the general experiences of leisure as you described them.

Please remember that any data pertaining to yourself as an individual participant will be kept confidential. Now that the data have been analyzed, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles and with practitioners through workshops and presentations at professional conferences.

As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567, Ext., 36005.

Sincerely,

Rebecca Genoe, PhD Candidate
Department of Recreation and Leisure Studies
University of Waterloo
(519) 888-4567, Ext. 38187

mrgenoe@ahsmail.uwaterloo.ca

Appendix J: Interview Guide for Interview 1

Preamble: Hi, My name is Rebecca Genoe, and I am a PhD student in the department of Recreation and Leisure Studies at the University of Waterloo. I am trying to understand what leisure means for persons living with early stage memory loss. The focus of this interview is to get to know you better and to understand what life is like for someone experiencing memory loss.

Rapport Building Questions – Getting to know you

1. Tell me a bit about yourself?
 - a. Tell me about your past – your jobs, community roles, family roles
2. What is important for others to know about you?
3. What makes you happy?
4. What makes you sad?

Grand Tour Questions

Yourself and your current situation

1. What is daily life like for you now that you are experiencing memory loss?
 - a. What are the challenges that you face?
 - b. Tell me about a specific time you experienced a challenge.
 - c. What positive changes have you experienced?
 - d. Can you give me a specific example of a positive change that you've experienced?
2. How do others think of you? Has this changed since you've started experiencing memory loss?
 - a. Have your relationships changed? How? (family/friends/co-workers/social group members?)
 - b. Tell me about how one relationship in particular has changed since you've been experiencing memory loss.
3. How do you think about yourself now that you have been experiencing memory loss?
 - a. How has this changed for you?
 - b. How have you adjusted to these changes?
4. What is central to your life right now?
 - a. How has this changed since you've been experiencing memory loss?
 - b. What is important about that?
 - c. How does it make you feel?
 - d. Tell me about a specific incident relating to what is central in your life now.

Appendix K: Interview Guide for Interview 2

Preamble: Last time we met you told me about yourself and what it is like to live with memory loss. Today, I'd like to talk a bit more about your leisure. We'll use some of the photos that you took to talk about what your leisure means to you. I have a series of questions I am going to ask you about each photo that you would like to talk about. Of all the photos you took, which ones most represent what your leisure means to you now?

1. What do you see here?
 - a. Can you describe what is in the photo?

2. What is really happening in this photo for you?
 - a. What is meaningful about what you see here?
 - b. What does this photo say about your leisure? Please explain.
 - c. How important is this in your life right now?
 - d. What benefits do you gain from this activity?
 - e. What challenges do you face in this activity?
 - f. Can you tell me about a recent experience you've had with this activity?

3. Where does this activity take place?
 - a. Can you describe the setting?
 - b. How does the setting make you feel?

4. When do you engage in this activity? (frequently, infrequently, time of day, time of week?)
 - a. Has this changed since you've experienced memory loss? How so?

5. How does the time pass when you are engaging in this activity? (fast, slow)
 - a. How has this changed since you've experienced memory loss?

6. Who do you do this activity with?
 - a. What is it like to do this activity with that person/people/self?
 - b. How has this changed since you've experienced memory loss?
 - c. What are the challenges in doing this activity with other people?
 - d. What are the positive aspects of doing this activity with other people?

7. Tell me about how you feel physically when you do this activity?
 - a. What does this activity require of your body?
 - b. Has this changed since you've experienced memory loss? How so?
 - c. Are there any physical challenges you face doing this activity?
 - d. How do you feel when you are doing this activity?

8. What does this photo say about who you are?
 - a. As a unique individual?
 - b. As part of your family?

c. As part of your community/social groups?

9. What does this photo say about how others see you?
10. How do you think others think about you? What role does leisure play in the way others think about you?
11. What is the purpose of this activity? Why is it important to you?

Appendix L: Interview Guide for Interview 3

Preamble: Last time we talked about some of your specific leisure activities and what they mean to you. Today we are going to talk about how leisure helps you cope with the changes in your life.

1. What role does leisure play in the changes you are experiencing? Explain?
 - a. Has leisure replaced other activities that may have been altered or lost? Explain.
 - b. Have certain leisure activities been dropped since you've experienced memory loss? Please explain.
 - c. Have you added any leisure activities since you've experienced memory loss? Please explain.
 - d. Can you tell me about an instance where leisure helped you to balance changes in your life?
 - e. Can you tell me about an instance where leisure hindered you in balancing changes in your life?

2. How do you address challenges you face in your leisure?
 - a. Do you have any techniques for managing the challenges? Explain.
 - b. What role do other people play in helping you to manage the challenges?
 - c. Can you give me a specific example of a time when you were able to address challenges in your leisure?
 - d. Can you tell me about a time when you were unable to address challenges in your leisure?

3. What expectations do others place on you/your leisure because of memory loss?
 - a. How do you respond to these expectations?
 - b. How do these expectations limit your leisure participation?
 - c. How do they enable your leisure participation?

4. What are the primary reasons you participate in the activities you do?

5. How do you use your leisure to alter how others see you?

Appendix M: Sensitizing Framework for Participant Observation

- Setting
 - Physical environment
- Social environment
 - Social interactions
 - Decision making patterns
- Physical appearance
- Affect (emotional expressions, facial expressions)
- Body language and gestures
- Social interactions (with researcher and others present)
- Involvement in the planned activity
 - What is being done
 - Who is involved
 - How the activity occurs
 - When things happen
 - Strengths
 - Challenges
 - Beginning the activity
 - Middle of the activity
 - Concluding the activity
- Involvement in any unplanned activity
 - Before the planned activity
 - After the planned activity
 - Interruptions/distractions during the planned activity

Adapted from Patton (2002)

Appendix N: Information Letter for Photos

University of Waterloo

My name is Rebecca Genoe, and I am a PhD student in the Department of Recreation and Leisure Studies at the University of Waterloo. Under the supervision of Dr. Sherry L. Dupuis, I am hoping to gain a better understanding of the meaning and experience of leisure for older adults. I am trying to understand the meaning and role of leisure in people's lives. More specifically, I'm trying to find out if leisure plays any role in identity and the resistance of negative stereotypes.

As part of this project, I have asked participants to take photos that represent what leisure means to them. These photos will then be discussed between myself and the research participant. With your permission, one of the study's participants would like to take your (or your child's) photograph because it reflects what their leisure means to them. Your photo may be used for the study and in research papers and presentations that arise from it, but your identity will remain anonymous. If you prefer that the photo not be used in reports or presentations, I will respect that as well.

If you have any questions regarding this study, please contact me at (519) 888-4567, Ext. 38187 or by email at mrgenoe@ahsmail.uwaterloo.ca. You can also contact my supervisor, Dr. Sherry L. Dupuis, at 519-888-4567, Ext. 36188 or by email at sldupuis@healthy.uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of this office at 519-888-4567, Ext. 36005.

Thank you for helping the research participants in this study.

Yours Sincerely,

Rebecca Genoe
PhD Candidate, University of Waterloo

Appendix O: Informed Consent for Photos

I agree to allow Rebecca Genoe of the Department of Recreation and Leisure Studies at the University of Waterloo to use my image, or the image of the child to whom I am guardian, as it appears in the photograph(s). I have made this decision based upon the information I received in the Information Letter and have had the opportunity to receive any additional details I have wanted about the study. By allowing the participants to use my image or the image of the child to whom I am guardian, I understand that it may be used for the study and for use in research papers and presentations that arise from them, but that my identity and the child's identity will remain anonymous. I also understand that this project has been reviewed by and received ethics clearance through the Office of Research Ethics at the University of Waterloo and that I may contact this office if I have any concerns or questions about the use of my image (or my child's image) in this study.

I agree to have the photo(s) taken.

YES NO

I agree to the use of the photos in research reports and presentations that come out of this study

YES NO

Participant's name: _____

Participant's signature: _____

Date: _____

Appendix P: Essences, themes, and subthemes

Essence	Theme	Subtheme
Struggling with change	Muddled thinking	Disconcerting forgetfulness Distracting concentration Losing access to thoughts Baffling environment Troublesome learning
	Fluctuating abilities Draining energy	Diminished strength and capacity Losing motivation and interest Feelings of inertia
	Frightening awareness Disquieting emotions	
Tackling life with dementia	Reconciling life as it is Battling through by being proactive	Stalling decline with activity Cuing memory Maintaining humour Avoiding stress and worry Being open (or not)
	Living through relationships	Supporting each other Being together to secure a sense of belonging Trusting in others Being accepted
	Being optimistic	Feeling hope for today and tomorrow Focusing on the positive Comparing self to others Normalizing experiences
	Prolonging engagement in meaningful activities	

Essence	Theme	Subtheme
		Seeking help to improve a situation Altering leisure
Threatening assaults on identities	Disappearing roles Losing independence Struggling with demeaning images and expectations Losing confidence	Accepting over reactions of others
Upholding identities	Changing perspectives Reaffirming self through leisure Engaging with life through leisure Having purpose Feeling a sense of accomplishment Creating enduring memories	Sustaining valued aspects of self Emphasizing abilities Seizing opportunities Sustaining social personae Appreciating the simple things in life Having fun and enjoyment renewal Filling time Claiming space