COPING WITH EVERYDAY STRESSORS IN ADIPOSISS DOLOROSA: IS THERE A ROLE FOR LEISURE?

A Thesis

Submitted to the Faculty of Graduate Studies and Research

In Partial Fulfillment of the Requirements

For the Degree of

Master of Science

in

Kinesiology and Health Studies

University of Regina

By

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January, 2016

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Urmihal Mukherjee, candidate for the degree of Master of Science in Kinesiology and Health Studies, has presented a thesis titled, *Coping With Everyday Stressors in Adiposis Dolorosa: Is There a Role for Leisure?*, in an oral examination held on December 7, 2015. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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Abstract

Adiposis Dolorosa (AD) is a rare and painful disease characterized by multiple benign tumours (lipomas) that primarily occur on the trunk, upper arms and legs, but eventually spread throughout the body (National Organization for Rare Disorders - NORD, 2012). The lipomas press against nerves and cause cardinal, nerve pain - the most common symptom of AD. Pain is also accompanied by chronic fatigue, brain fog and generalized obesity (Hansson, Svensson, & Brorson, 2012). With no known cure, patients receive symptomatic treatment with substantial risk due to multiple medications (NORD, 2012). The complications of AD are burdensome and impact the overall quality of life (QoL) (Wortham & Tomlinson, 2005). Several studies have noted the positive role of leisure in coping and self-management of chronic illness (Castelli & Valley, 2007; Iwasaki, Coyle, & Shank, 2010; Kleiber & Hutchinson, 2010). Leisure may offer opportunities for creativity, participatory activities via clubs and organizations, social networking, spending time with family and loved ones, as well as enjoying personal space and freedom to recharge and look forward to life (Adams, Leibbrandt, & Moon, 2011; Hutchinson & Nimrod, 2012). Although the relationship between leisure and chronic illness is promising, leisure within the context of rare chronic illnesses has not yet been considered. The purpose of this study is to understand the lived experiences of individuals with AD and explore the role of leisure in coping with everyday stressors associated with it. Guided by hermeneutic phenomenology, telephone interviews were conducted with four persons with AD. Interviews were recorded and transcribed verbatim, and data were analyzed using detailed line by line analysis (van Manen, 1997). The findings indicate that amid the several negative life events brought about by AD,
leisure provided participants with time, space and meaningful engagements to cope with daily stress and symptoms. Amid changes in relationships, threats to identity, and the apprehension of living with a poorly understood illness, experiencing shared leisure with family, utilizing free time to relax, practicing religion/faith, making behavioural adjustments and pursuing meaningful activities such as advocacy of rare chronic diseases helped participants maintain a positive attitude and live well with AD.
Acknowledgements

I would like to thank everyone who brightened my life with their positivity and helped me complete my thesis. I am blessed to share this accomplishment with all of you.

I would like to thank Dr. Rebecca Genoe, for giving me the chance to learn from her and work with her. Your mentorship and guidance over the last forty months has been invaluable to my personal and academic growth. I am extremely grateful for the constant encouragement, patience and support you have selflessly showered my way. I hope to internalize your work ethic someday. I could not have wished for a more considerate supervisor than you.

I would like to thank my participants for offering their time, energy and wholehearted support. I am very grateful that you chose to share your knowledge and insights with me. Without you, this would not have been possible.

I would like to thank my committee members, Dr. Cory Kulczycki and Dr. Brenda Rossow-Kimball. Your advice and suggestions brought new perspectives and added to the richness of my research. I am very appreciative of your understanding and approachability.
Dedication

I would like to take this opportunity to honour my late birth parents, without whom, I
would not have been. I am grateful to have inherited your resilience.

I would like to dedicate this to my adopted parents who show me every single day what
unconditional love truly means. Words cannot do justice to my sentiments for you.

Last but not the least I want to thank Shishir, who gave me the chance to begin a new life
chapter. You are truly my better half in every sense. Your continuous support means more
than I can ever convey. You taught me self-acceptance and self-love, and to be a whole
individual without depending on anyone or anything to complete me. You inspire me to
be a better person. And for that I am so very grateful.
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Chapter 1: Introduction

The journey of a thousand miles begins with one step - Lao Tzu

1.1 How It Began

My relationship with leisure and rare chronic illness germinated from a few personal experiences. Growing up, I had a fairly turbulent childhood, with my biological mother passing away an hour after my birth, and my father consecutively taking to alcoholism to drown his sorrows. He eventually committed suicide when I was 14. I had two, much older, biological brothers. However neither sought to have a relationship with me. My wonderful uncle and aunt adopted me as an infant to give me as normal an upbringing as they could. Yet, their own marriage has consistently been troubled and abusive, causing me to internalize my distresses. To escape the unbearable realities surrounding me, I would often spend time in solitude, shut out from the rest of the world. Savouring these moments of peace, I drowned myself in reading, evening walks, imaginary friends, music, dance, and plays.

The role of leisure in my life became pronounced in adulthood when I became a caregiver to my ailing adopted parents. Between working full time as an attorney and nursing them back to health, leisure became the sanctuary that provided me with breathing space and respite. Some of the (positive) paths I took to shelter myself from the negative emotions associated with caregiving included spending time with friends, playing racket sports and word games, and traveling. I recall cherishing the moments I got away from my everyday responsibilities for they let me forget my burdens temporarily. After a few years, my adopted parents began their journey towards recovery.
I was extremely happy for them, and yet my brush with leisure ignited a spark in me that would lead me on this academic journey.

The fact that I had little knowledge about health studies did not deter me. I became adamant to study the quality of life and the importance of leisure in the lives of older adults living with grief of widowhood (stemming from my biological father’s loneliness after my birth mother’s death) and chronic illness (shaped from my adopted parents’ experience with comorbidities). Thus, my journey towards this Master’s degree began with an email to Dr. Genoe in May 2010, enquiring about her willingness to supervise me. My research topic however, did not remain the same because of my own experience with chronic illness. At the age of 24, a few months prior to my arrival in Canada, I learnt that I was suffering from a rare chronic illness called Adiposis Dolorosa (AD). The abrupt diagnosis left me shocked, confused and very afraid. Although I was relieved to have a name to my deteriorating health (I have been experiencing symptoms since I was a child but nothing abnormal was ever identified), I was terrified at the idea of battling a mysterious illness without known cause, cure and treatment. My plans to arrive in Canada were suddenly jeopardized, however, instead of abandoning my goal, I decided to alter my research and consider exploring this little known disease within the context of leisure.

Once I arrived in Canada in August 2012, I was exposed to endless possibilities and methodologies in the intriguing world of research. I spent countless sleepless nights, mulling and considering the different angles of inquiry that would best fit my interests. I was at one point, quite unsure if I had set out on the right path due to lack of adequate literature and information about the number of individuals inflicted with AD. As well,
the question of how or where I would locate potential participants remained unanswered for a long time. Several meetings with my supervisor and other faculty members reinstated my faith and provided me with the encouragement to begin this research. After a shaky start, I finally had the confidence to not second guess my choice of topic and tread a lesser known path that awaits understanding from a subjective point of view. Thus, my master’s thesis exploring leisure and AD commenced.

1.2 Rationale of the Study

Persons with AD face numerous challenges on a daily basis and, at some point, have to come to terms with the fact that they have a lifelong association with a chronic condition. Embracing a host of physical, mental, emotional and socio-economic changes can be a slow, self-motivated process involving considerable adjustments and effort. Recovering from the trauma associated with the diagnosis of chronic illness requires healing and positive transformation. Recovery usually involves a holistic, person centered strengths based approach that focuses on self-direction, respect, hope, connectedness, peer support, empowerment, spiritual fulfillment and meaningful life that includes education, employment and leisure (Sells, Borg, Marin, Mezzina, Topor, & Davidson, 2006; U.S. Department of Health & Human Services, 2006). Leisure has the capacity to provide time, autonomy and opportunities for self-reflection through narration of past achievements, sharing experiences on support networks, pursuing a hobby, developing new skills or nurturing old ones, or creating new identities or reshaping old ones. With the help of leisure, individuals with AD may be able to balance roles and responsibilities as per existing capacities (Halding, Wahl, & Heggdal, 2010; Hutchinson & Nimrod, 2012; Jones, Kimberlee, Deave, & Evans, 2013).
Leisure can also be useful in continuing engagements that were left unattended in youth and adulthood due to time and family commitments. Leisure activities continued from the past are known to generate positive feelings and help individuals with chronic illness rearrange personal and social priorities (Hutchinson, Yarnal, Staffordson, & Kerstetter, 2008). Most importantly, leisure has the capacity to create avenues for non-physical or less physically demanding tasks that also double up as expressive, creative, social, spiritual and cultural pursuits (Iwasaki, Coyle, & Shank, 2010). In the event of illness related disabilities, leisure can be modified to accommodate the needs of the individual. For example, women with arthritis pain partaking in creative arts could replace physically engaging tasks with less demanding activities (such as being a critic or overseeing supplies) than actually engaging in the creation of arts that may take up more energy. Thus, by creating new roles through leisure, the urge to go out and be productive still thrives (Hutchinson, Bland, Kleiber, McCormick, & Iwasaki, 2008). These elements may be crucial in sustaining the coping efforts of the AD community.

I believe that the relationship between AD and leisure is important because leisure has the potential to contribute towards a meaningful life by remedying the challenging and stressful aspects of life (e.g. coping with/healing from) as well as enhancing the positive aspects of life (e.g. improving quality of life [QoL], focusing on satisfaction). Additionally, leisure can optimize positive emotions, promote self-awareness and enlightenment, and offer opportunities to develop harmonious connections (Iwasaki, 2008). Leisure may help individuals with AD cope with negative life events such as disruption, adaptation, stress and vulnerability arising from challenging conditions such as disabilities, trauma, loss of a spouse and failed
relationships (Kleiber, Hutchinson, & Williams, 2002). It can especially be beneficial in transcending negative life events by developing patterns of stability, control and deflection to encourage patterns of self-protection; exercise choice and freedom to separate the stressors (and hence use leisure as a buffer); generating optimism and hope about the future; and directing leisure activities towards self enhancement, restoration and personal transformation by being reflective and letting go of things and situations that do not help the individual grow (Kleiber et al., 2002). Leisure can offer distractions when life becomes difficult or threatening for individuals with AD (Kleiber & Hutchinson, 2010). Furthermore, leisure may help in the preservation and restoration of the self by reaffirming/validating personal beliefs and values, expressing enduring personal characteristics and preferences, choosing convenient substitute activities, reinstating former self-beliefs, and having social space to let one’s guard down (Kleiber & Hutchinson, 2010).

1.2.1 Purpose of the Study

Given the paucity of research regarding leisure and AD, the purpose of this phenomenological study was to understand the daily life experiences of individuals with AD and the role of leisure in coping with stressors. This study was guided by the following research questions:

1) How do persons with AD experience the illness?

2) How do individuals with AD experience leisure?

3) What role does leisure have in the lives of persons living with AD?

4) What role does leisure play in their lives with regards to self-management of symptoms and overall wellbeing?
5) What leisure barriers do persons living with AD experience? How do they address those barriers?

I proposed my research in October, 2014 and began collecting data in January, 2015. I started analyzing the data soon after and continued the analysis until July, 2015 as I wrote the final draft of my thesis. I interviewed four individuals with AD to understand how they experienced the illness and whether leisure helped them manage stress and symptoms.

1.2.2 Potential Contribution of the Study

I hope the findings of my study will: a) contribute to the limited literature on rare chronic illness, especially AD; b) add to the pool of knowledge exploring the relationship between leisure and chronic illness; c) add to the research on the importance of self-management in chronic illness; d) assist organizations such as the National Organization of Rare Disorders (NORD), Canadian Organization for Rare Disorders (CORD), and the medical/rare disease community at large by sparking research and funding interest in the area of rare chronic diseases; and e) allow the medical community as well as persons with AD and their loved ones to gain further insight into this baffling disease.

1.3 Understanding Rare Chronic Illness

According to the World Health Organization (2009), sixty-three percent of all deaths worldwide are caused by the persistent and degenerative nature of chronic illnesses. Chronic illness can trigger a host of physical, emotional, psychological and social adjustments that can cause life-altering events. Rare chronic illnesses (also known as orphan diseases) are chronic illnesses that are not well-known. Although rare chronic illnesses lack popularity, their impact on the life on an individual and the healthcare
system cannot be overlooked. Rare illnesses, including those of genetic origin, are life threatening and chronically debilitating in nature, often involving disability and premature death (EURORDIS, 2014; National Institutes of Health, 2010). They are of such low prevalence that special combined efforts are needed to address them (European Commission, 2012). It has come to light that there are approximately 7,000 different types of rare diseases in the world, with more being discovered each day (National Institutes of Health, 2010). It is estimated that approximately 350 million people worldwide live with a rare disease, with 50% of the rare disease population comprised of children (National Institutes of Health, 2010). Global Genes Project (2009) informs us that 95% of rare diseases do not have a single FDA approved drug treatment and 30% of children with a rare disease will not live to see their fifth birthday. Rare diseases are responsible for 35% of deaths in the first year of life and approximately 50% of rare diseases do not have specific support or research supplementing their condition (Global Genes Project, 2009). It is suspected that if all individuals affected with a rare disease live in one country, it would be the world’s third most populous nation (Global Genes Project, 2009).

Due to a lack in awareness and knowledge about rare diseases, many symptoms amongst health care practitioners remain unknown. Therefore, diagnosing a rare medical condition represents a major medical challenge in itself.

1.3.1 Understanding Adiposis Dolorosa

Adiposis Dolorosa (AD) is also known as Dercum’s disease, fatty tissue rheumatism, Juxta-Articular Adiposis Dolorosa, or lipomatosis Dolorosa Morbus Dercum's. It is a progressive, debilitating chronic condition that is touted as one of the
ten most rare and painful diseases in the world (National Organization for Rare Disorders - NORD, 2012). First described in 1888 by American neurologist Francis Xavier Dercum, AD is an unusual syndrome with unknown etiology and cure (Thorofare, 1892). It is typically characterized by multiple painful fatty deposits (benign lipomas) that mainly occur on the trunk, upper arms and upper legs of the body (National Human Genome Research Institute, 2012). Persons affected with AD experience varied symptoms such as nerve pain, chronic fatigue, brain fog, and memory impairment. Emotional disturbances such as depression and confusion in addition to early dementia are not uncommon (Hansson et al., 2012). Other disorders associated with AD include breathlessness, anxiety, palpitations, insomnia, heartburn and loss in cognitive alertness, making everyday living exigent and agonizing (Wortham & Tomlinson, 2005). Although it is up to 20 times more common in women, 16% of the reported cases occur in males (National Institutes of Health, 2010). AD is also commonly seen in persons between the ages of 45-60 years, although it may occur in women who are younger than the specified age group (McGevna, 2015). A survey including patients with AD revealed that 85% of patients developed symptoms before the onset of menopause (McGevna, 2015).

In chapter 2, I speak more at length about AD and discuss literature that establishes a positive connection between leisure and chronic illness. In chapter 3, I describe the methodology of this study and the involved research processes of participant recruitment, data collection and data analysis. In chapter 4, I present the finding of this study. Finally, in chapter 5, I discuss the importance and value of the findings and how they expand our understanding of the relationship between leisure and AD. Prior to this study, how individuals living with AD experience the illness remained unknown. As well, the role of
leisure in coping with AD was wide open for inquiry. In my conclusion, I address these gaps before closing with a list of recommendations that could have practical bearings in rare disease management and future leisure research.
Chapter 2: Literature Review

2.0 Introduction

I will commence this chapter by familiarizing readers about AD. I will then highlight the importance of self-management in AD to expand our general understanding of this study. Following this, I will explore the challenges of this illness and summarize the vagueness and paucity of knowledge in this area of health studies. Finally, I will discuss the beneficial and therapeutic nature of leisure in coping with chronic illness, thereby indicating a possible connection between leisure and AD.

2.1 Adiposis Dolorosa

In chapter 1, I described the debilitating nature of AD. In addition to the aforementioned challenges, persons with AD also experience insecurities related to their body. The multiple painful fat nodules cause anatomical disfigurement which may result in physical and emotional scarring (Leung & Wong, 2012). From personal experience, I am aware that trauma of such kind can cause low self-esteem and social reclusion. Furthermore, individuals with AD face tremendous restrictions in diet and are discouraged from engaging in most forms of physical activity. Unfortunately, even the mildest form of physical activity is known to aggravate the condition (Wortham & Tomlinson, 2005). The multitude of changes related to chronic illness can result in loss of identity and self-belief. In light of such constraints, passive leisure such as reading books, introspection, and watching movies or television may support cognitive and intellectual functioning that are associated with good mental health (Herzog, Ofstedal, & Wheeler, 2002; Hultsch, Hammer, & Small, 1993) and reinstate a person’s current abilities.
2.1.1 Nature and Origin of AD

To date, researchers continue to speculate and investigate the causes of AD. The only known lead in etiology is the sudden appearance of the symptoms together with the incidence of a slight increase in the number of inflammatory cells in the fat. This could point toward the disease being, in part, an immune defense reaction (Skagen, Petersen, Kastrup, & Norgaard, 1986). It is suspected that the sympathetic nervous system may play a role in the origin and development of the pain which is a classic symptom of AD (Leites, Davtian, & Emanuel, 1972). This characteristic was established in an independent study on detailed necropsy conducted by Winkelman and Eckel (1925), who noted the involvement of a ‘pluriglandular’ component, which eventually led to the discovery of pain sensations – the most fundamental symptom associated with AD. In medical terminology, a pluriglandular component may indicate factorization or decomposition of several glands and/or their secretions (The American Heritage Medical Dictionary, 2007).

Limited literature dating back several decades indicates the possible presence of a dominant gene with variable expressivity. Lynch and Harlan (1963) examined two families with AD and the presence of a dominant gene was discovered. It was deemed that this dominant gene could well be a potential cause of the disease as well as a factor that considered the gender of the person before the illness struck. Cantu, Ruiz-Barquin, Jimenez, Castillo, and Macotela-Ruiz (1973) conducted a pedigree analysis of a five member family consisting of both males and females affected by AD and noted the presence of an autosomal dominant inheritance that may be responsible for the illness. After the analysis of the family histories of the participants, it was noted that the illness
seemed to have a more established pattern in the grandmother-daughter lineage. Unfortunately, Cantu et al.’s (1973) findings were limited to a single case diagnosis and it has been well over 40 years since this theory was initiated. Over half a century ago, Steiger, Litvin, Lasché, and Durant (1952) indicated the possibility of a specific endocrine factor of etiologic importance whilst studying the potential causes leading to AD. Unfortunately, similar to Cantu et al., (1973), there was no further research to further establish the validity of these findings.

Currently, research involving AD is very inadequate, resulting in limited understanding of this condition. Due to the obscure origin of Adiposis Dolorosa (AD), a cure has been difficult to determine (Brodovsky, Westreich, Leibowitz, & Schwartz, 1994) and individuals with AD are compelled to lead a life marked by constant uncertainty and fear. The majority of available literature about AD offers varied and irresolute results established decades ago. The deteriorating effects of AD can impact the overall quality of life (QoL) of persons diagnosed with this rare chronic condition and may prevent individuals with AD from leading a productive and satisfactory life. Amidst rapid evolution of science and healthcare, further research exploring the phenomena of AD is needed.

2.1.2 Characteristics and Symptoms

In addition to the symptoms mentioned above, persons with AD also experience weakness, muscle and skeletal stiffness, migraines and difficulties with sleep (Tomlinson, 2005). Additionally, easy bruising, diabetes, fibromyalgia, illness associated trauma, lethargy, high blood pressure, painful adipose tissue, and unexplained swelling in various areas of the body are known to be associated with AD (Hansson, Svensson, &
Brorson, 2011; Yousefi et al., 2012). The multitude of symptoms can not only make diagnosis extremely challenging but also perplex physicians. Reflecting on my personal encounters with several doctors and past experiences, it has become quite clear to me that AD is not only complex and misunderstood, but also lacks acknowledgment from the public and medical community alike. This denial of an illness can make the patient’s experience of an illness all the more traumatic. In the absence of a specific route of diagnosis, patients and physicians rely heavily on symptomatic treatments to identify as well as manage the progression of AD.

Cardinal nerve pain is the most commonly experienced characteristic of this disease. Patients often describe the pain as abrupt, jagged and of intense neuropathic nature, often equivalent to that of pressing nerves, insertion of hot knives or pain that causes temporary spells of immobility (Brodovsky et al., 1994). The immobility and physical challenges are mainly due to the presence of multiple tender painful fat pads (also known as juxta-articular adiposis dolorosa) over various parts of the body (De Silva & Earley, 1990) causing persistent nerve pain. These symptoms are usually treated individually with substantial risk of side effects due to multiple medications (National Organization for Rare Disorders - NORD, 2012). AD patients are also at a high risk of sudden death resulting from cardiac failure and/or multiple organ failure due to the lipomas forming too close to the vital organs and causing malfunction or complete shutdown. Cardiac failures are the most common cause of abrupt death due to abnormal blood pressure levels and excessive strain on the heart in addition to the symptoms. Therefore, from personal experience, I am aware that once an accurate diagnosis has
been made, individuals with AD are advised to periodically monitor their health and report unusual symptoms via journaling and self-awareness.

2.1.3 Diagnosis and Treatment

To diagnose AD, physicians match symptoms with other illnesses and narrow them down to potential prognoses. Patients are then asked to go through several tests and doctor visits to determine the most plausible answer, which unfortunately is usually not AD. Magnetic resonance imaging (MRI) scans, ultrasounds and biopsies of lipomas are most commonly used to detect anomalies (Tins et al., 2013). These tests are usually conducted with intent to rule out well-known diseases. Astonishingly, in the era of constant medical and technological advancement, the entire diagnostic process for AD remains cumbersome, and some people may have to wait up to a decade or more to reach a diagnosis. By the time AD is accurately diagnosed, the disease usually advances and makes management of the illness extremely challenging.

Since the root cause of AD remains mysterious, much attention is devoted towards symptom management. As chronic pain is the most challenging symptom of AD, most patients are unable to function without long term pain management. Some pain management techniques include the use of steroids, intravenous lidocaine, peroral mexiletine or similar analgesic treatments. However, the aforesaid treatments only provide temporary pain relief (Petersen & Kastrup, 1987). Persons with AD also have the option of seeking medically invasive treatments such as liposuction, surgery and excision to remove painful fatty tissues (Hansson et al., 2011). Unfortunately, the majority experience relapses and even multiplicity of the lipomas within a span of one to three years (Brodovsky et al., 1994). The surgical removal of adipose tissue has limited effect
on the QoL in AD patients, unless accompanied with adequate self-management and lifestyle changes (Berntorp, E., Berntorp, K., Brorson, & Frick, 1998). To manage the condition, some patients have been known to use water beds to ensure restful sleep, hot and cold compresses, and manual massages or pumps to drain the lymphatic system (Lange, Oelzner, & Uhlemann, 2008). Individuals with AD are also advised to make use of adequate comfort and mobility aids such as wheelchairs, walking canes and scooters when necessary (Fat Disorders Research Society, 2014). As a precautionary measure, they are also asked to refrain from any strenuous forms of physical activity and exertions. A controlled diet that mainly comprises of lower consumption of animal and dairy products is recommended to control pain flares, inflammation and rapid progression of the illness (Herbst, 2012). However, such decisions are best taken on a case to case basis, after careful consideration of the individual’s medical history and bodily needs.

2.1.4 Impact on Quality of Life

Eiser and Morse (2001) define quality of life (QoL) as a multidimensional concept that encompasses broad domains of our existence. These domains not only envelop an individual's functional status and physical, psychological and social functioning, but also his or her overall satisfaction with life and health (Spilker, 1996). Persons with AD live with a host of ailments that have a direct impact on their overall wellbeing. Such circumstances can have a profound impact on their state of mind, causing loss of interest and pleasure; feelings of guilt and hopelessness; and even decline of cognitive abilities. While some researchers have documented a declining QoL in chronic illness caused by different aspects such as disability, depression, and anxiety
(Livneh, 2014), limited research notes how individuals with rare disease cope with a dwindling QoL when little help is available to them.

2.2 Living with Chronic Illness

Being diagnosed with a chronic illness can be life altering. The progressive and debilitating nature of chronic illness can create several mental, emotional, psychological and social challenges. I am personally acquainted with many individuals who have undergone massive changes in personality and daily activities since being diagnosed with a chronic condition. A chronic ailment can limit mobility and independence, whereby previously enjoyable activities suddenly become tiring and arduous. With changes in ability and/or senses, self-confidence and self-worth may plummet to an all-time low (Nimrod, Kleiber, & Berdychevsky, 2012). Personally, what makes a chronic illness threatening is not the statistics associated with it, but the probability that life may never be the same again. Although chronic illnesses can be managed to some extent with medications and lifestyle changes, there is usually no permanent cure.

Chronic illness is often thought of as synonymous with disabilities, damaged body image, and lack in bodily functions (Corbin, 2003). While chronic illness and disability may be used in conjunction, the World Health Organization (WHO, 2016a, 2016b) distinguishes the two phenomena to avoid confusion and provide clarity on the terms. According to the WHO’s (2016a) International Classification of Functioning Disability and Health (ICF) model, a chronic illness is defined as a non-communicable disease (NCD) that is not passed from person to person, is of long duration and generally progresses slowly. On the other hand, the ICF defines disability as functioning in multiple life areas, wherein the disability is seen as a result of an interaction between a
person (with a health condition) and that person’s contextual factors (such as environmental and personal factors), and that the disability touches the functioning of an individual at various levels including their body, person and societal levels. Additionally, according to the definition, disability indicates impairments in body functions and structures, limitations in activity, and restriction in participation (WHO, 2016b).

Unfortunately, the roots of chronic illness seep deeper than biology. More often than not, suffering is more than a physiological and psychological response (Morse & Carter, 1996). Persons with AD live with the knowledge that a host ailment has permanently taken residence within their bodies. This may result in them having to reconstruct their life psychologically as well as emotionally to accommodate this new information and eventually build a life that their current life skills and resources. Each time a new challenge comes up, a new adaptation must be considered. For example, an individual who enjoyed gardening before AD may be unable to pursue it anymore due to everyday stressors. Therefore, they may have to find their way around the obstruction and substitute the activity with a more suitable choice. Indeed, periodic adaptations mean tearing down old identities and building new ones time and again. The constant changes and adaptations may consequently result in a collapsing of identity with regards to the self as well as the body (Charmaz, 1983). According to Charmaz (2005), the process of adaptation includes three major stages: (1) experiencing and defining impairment (2) making bodily assessments and gradual identity trade-offs, as patients with chronic illness weigh their losses and gains and revise their identity goals, and (3) surrendering to the sick self by relinquishing control over illness and by flowing with the experience of it. The above summarization indicates that almost every aspect of an individual’s life
undergoes changes in chronic illness. Getting in stride with these adaptations may consume large amounts of time, energy and motivation. From personal experience, I can confirm that individuals with chronic illness are forced to lead lives than are very different from people who do not have chronic illness. For example, a social outing for someone with chronic illness may call for long periods of physical and mental preparation. Before deciding to step outside, several factors such as energy level, comfort in social settings, dietary restrictions and mental preparedness to meet and greet individuals in a positive state of mind must be addressed.

Charmaz (1983) noted that individuals with chronic illness are forced to confront restricted lives, social isolation, discrediting behaviour, and the onus of burdening others. More often than not, their illness is accompanied by several debilitating “companions,” the most common of them being depression and sadness (Katon & Sullivan, 1990). For individuals with AD, chronic anxiety and fear may also result from knowing that their disease does not have any specific treatment. Amid daily stressors and painful living conditions, it was not uncommon for individuals with chronic illness to feel a sense of disconnect from the self and others (Charmaz, 1999). Akin to the definition adopted by Turner (1976), Charmaz defines the self as the organization of attributes, sentiments, values, and characteristics through which people choose to define themselves. Thus, the disintegration in connection with the self and others in chronic illness may result in crumbling identities. The loss of personal and well as social identities could be attributed to the fact with individuals battling illness often experience the body as a hindrance, feel isolated in illness, and struggle for normalcy (Öhman, Söderberg, & Lundman, 2003). Loss of strength, energy, and power are also common characteristics of an illness
(Öhman et al., 2003), thereby further affecting confidence and the ability to take care of oneself and others. In illness, a person may feel vulnerable and dependent, which can affect ongoing life plans (Öhman, et al., 2003) and result in feelings of reduced capacity and limitation (Toombs, 1992).

Regardless of chronic illness, good health and wellbeing form the primary goals of all human needs. For individuals with AD, peace of mind can largely depend on fostering residual health and hoping for a positive future. It is however, important to be aware that hope is a subjective connotation and may mean different things to different people. For example, the definition of hope differs between a person with terminal cancer and with someone with a non-terminal disease (Perakyla, 1991). Duggleby et al. (2012) explain that in chronic illness, hope indicates a dynamic future focused entity that is situational in nature and involves choice/will. Therefore, for someone with a long term illness such as AD, wellbeing may simply mean hoping to find a pace that accommodates daily life without the illness flaring up or turning in to the most dominant life experience (Olsson, Skär, & Söderberg, 2010).

The needs of an individual with chronic illness are like any other. We all crave meaningful work, loving families, supportive friends and joyous engagements to feel accomplished and fulfilled. I truly believe that a large portion of how we see ourselves is often attached with the way others see us, and that judgment may become the ground on which we evaluate ourselves. However, the challenges brought about by a chronic illness may be so all consuming that seeing the self in positive light amidst debilitating health and negative mental thoughts may become challenging. Duggleby et al. (2012) point out that positive reappraisal was an integral part of hope for persons with chronic illness.
Leisure can provide individuals with AD the self-affirmation they need by maintaining and expressing identity (Haggard & Williams, 1992), managing uncertainty and fear (Folkman, 2008), and prevent constant dependence on others. Shared leisure may provide persons with AD the opportunity to give and receive love, get noticed for their efforts, and take on roles and responsibilities that garner appreciation.

### 2.3 Self-Management Strategies in Chronic Disease

Chronic illnesses are suspected to become the leading cause of death and disability by 2020 (Griffin, 2000; Lopez & Murray, 1996). Therefore, effective individual and population self-management strategies (different from self-management programs) for chronic conditions that include necessary interventions taken by the patient to take care of their medical condition (in addition to what healthcare practitioners do) can assist individuals with chronic disease to create order in their lives (Kralik, Koch, Price, & Howard, 2004). Newman, Steed, and Mulligan (2004) describe self-management as a substantial responsibility that entails regular intake of medication, lifestyle modifications, being actively involved in preventive self-care, and taking important health decisions on a daily basis. Effective self-management strategies require active patient participation in everyday care of the symptoms of illness, medical treatments, as well as maintaining general health and preventing progression of their condition in the form of regular self-care (Novak, Costantini, Schneider, & Beanlands, 2013).

In a study examining the meaning and experience of self-care by adults living with chronic conditions (Kralik, Price, & Telford, 2010) participants described the process of self-care as transformational (with regards to themselves and maintaining a
sense of order around them) and identified four central themes associated with self-care. The themes were (1) **Self-care as a sense of being and becoming**: This process involved identifying psychological and physical responses to illness, and adapting, planning, pacing and managing daily life around illness; (2) **Self-discovery through self-care**: As participants learnt about the illness, they learnt to adopt a new vision of themselves as well as their lives. For example, letting go of trivial fears and maintaining or improvising their sense of humour helped many individuals in this study, cope and manage their daily challenges more effectively; (3) **Self-care as a process of learning**: At this stage participants learn to respect and listen to their body and practice forgiveness, compassion, courage, determination, resilience and acceptance of imperfection; and (4) **Reclaiming a sense of order and creating a new vision for the future**: In this theme, participants revealed that self-care included a combination of biomedical knowledge and self-knowledge collected from within their life context. They used this knowledge to make more informed choices and take decisions that made them happy. Connecting with other chronically ill patients allowed participants to network and empathize with individuals in similar situations, and learn to deal with guilt, uncertainly and limitations. Regaining control over their lives mainly included generating positive emotions that allowed them to appreciate beauty and exclaim wonder at nature and its many elements.

The Early Rheumatoid Arthritis (RA) Help Seeking Experience (ERAHSE) study examined the help-seeking process from symptom onset to one year after diagnosis of RA (Townsend, 2011). Thirty-eight adults from British Columbia between ages 30 to 70 were recruited through medical offices and arthritis websites. The data were gathered through in-depth interviews and thematic analysis revealed that they were eager to fulfill
social roles and maintain favoured identities. Emerging themes included self-management as: (a) illness work, i.e., carrying on with occupations in order to avoid disruption of daily life and continue roles and leisure activities even amidst lack of support and daily frustrations; (b) daily life work, which indicated positive attitude, pacing, resting, reorganizing tasks and family support amid constant medications; and (c) identity work, which was the ability to continue with meaningful occupations to support identity and the self (Townsend, 2011).

Considering the increase in incidence of chronic illness, several programs and initiatives have been put in place, with an increased demand for allied health professionals to support individuals with chronic illness in their efforts towards self-management (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). However, more often than not, chronically ill patients are left with no medical or social support, and end up feeling frustrated and helpless. People often do not have access to materials or information to channel their strengths, or initiate adequate knowledge transfer with health professionals. Currently, health systems are efficiently enabled to encourage chronically ill patients to maximize their existing capacities. Therefore, rather than formal care and self-management being mutually exclusive, it may be beneficial if they are regarded as interconnected resources (Townsend, 2011).

Although chronic illness management may seem daunting and complex, with combined efforts between healthcare practitioners and patients, efficient self-care programs can be implemented to place to gain maximum leverage over one's health (Townsend, 2011). Active participation over one’s health matters can encourage better patient-health practitioner collaboration and result in reduced healthcare costs. While
caring for my ailing family, I noticed that self-care can also result in an enhanced QoL for the care recipients and provide much relief to caregivers. If self-management strategies become a pertinent part of health care goals set by my medical communities, the experiences of individuals with chronic illness (with regards to personal transformation and healthcare objectives) may become more achievable.

2.4 Leisure

Chronic disease self-management is a complex but vital part of living with a chronic condition. Leisure engagement may provide one means of self-managing chronic conditions. Below, I will discuss leisure and its potential role in coping with and self-managing AD.

Leisure is typically defined as preferred, enjoyable activity in the free time context (Kleiber, 1999). Leisurely pursuits could involve a wide array of activities including, but not restricted to, leisure-time physical activities such as walking, jogging or periodic exercises; and social engagements such as spending time with friends and family or joining a local club. Additionally, leisure can include cognitive activities such as solving puzzles; engaging in creative arts for expression (Kelly, Cudney, & Weinert, 2012); and simple, passive activities such as watching television. For some individuals, doing household chores such as laundry or washing dishes could be a source of leisure as well. Payne, Ainsworth, and Godbey (2010) point out three dominant characteristics associated with leisure including free time, defined activities, and an existential condition or state of mind. Kleiber and Hutchinson (2010) describe leisure as a source of positive distraction for individuals with illness disability. This especially holds true in matters of daily stress management, an escape from negative emotions, and offering a
source of hope (when reminded of the goodness in illness disability, their strengths, capabilities and enthusiasm to look forward to things). They explain that leisure can be beneficial when used as a means of self-restoration (by providing reassurance, space, alternate activities and validation), a source of strength and support (by focusing on self-determination, endurance and companionship), and a source of personal transformation (encouraging self-expression, filtering the negatives out, controlling the mind and embracing positive thoughts).

Several studies indicate a positive connection between leisure pursuits and chronic illness management. The Grove Hotel in Bournemouth, UK that serves as a holiday destination for people with cancer and life-threatening illnesses is an example of the positive relationship between leisure and chronic illness (Dean, 2012). The majority of the hotel residents have advanced cancer and other life limiting conditions, and to comfort and assist the residents in their quest for leisure, the hotel provides round-the-clock nursing services. Ms. Gray, a former nurse who lives in Bournemouth, says. “I walk in and my spirits are lifted and the staff come up to me and say it is lovely to see me again. It is so nice to come here as it is a hotel – not a care home, or a hospital, or rest home” (p. 1). For many chronically ill patients, the end of life may spell doom, engulfed in loneliness and fear. In such times, to make a haven out of a leisure space that offers solace, friendship and genuine care may be comforting. Although leisure is best defined on a personal level, it is very useful in understanding human behaviour by learning what people do in their free time. People often pursue hobbies or vocations that reflect their interests and values. Some studies have found that leisure behaviours are indicative of an individual’s personality (Haggard & Williams, 1992). For example, from my teaching
experience, I have observed that students who use their free time to volunteer within the community are often committed to nurturing principles such as compassion, humanity, and kindness.

Rare diseases such as AD involve everyday stressors that can heavily compromise QoL and impact one’s overall wellbeing significantly (Garrino, Picco, Finiguerra, Rossi, Simone, & Roccatello, 2015). In recent years, a call to move away from a deficits approach to a strengths-based approach has emerged (Anderson & Heyne, 2012). Anderson and Heyne argue that focusing on strengths is more effective in creating change than focusing on deficits. When we focus on strengths, the individual becomes the expert of his or her own life (rather than viewing medical professionals as experts) and the individual is seen as a resourceful person rather than simply being labeled by a particular diagnosis. Leisure can act as a stress survival strategy for individuals with AD, helping them build on their strengths and resilience by acting as a coping mechanism for stress as well as offering itself as a resource for managing stress (Iwasaki, Mactavish, & Mackay, 2005). Various studies have indicated that in recent times, leisure has become a psychosocial phenomenon wherein different leisure activities such as jogging, camping, visiting friends and listening to music possess underlying meaning and functions that result in reduction of stress (Iwasaki et al., 2005). Leisure empowerment (leisure activities that provide a sense of validation and control) and leisure palliative coping (a ‘time-out’ that allows rejuvenation and relaxation) are specifically self-protective strategies that can encourage self-determination and opportunities to find new directions and meanings in life (Iwasaki et al., 2005; Kleiber et al., 2002). Juniper (2003) suggests that humans do not live in voids, but instead have
relationships and (short-term or long-term) interests that can generate support and therapeutic benefits when properly organized. These factors can be transformed into person-centered leisure lifestyles that proactively engage individuals to identify their strengths and work on developing their psychological resilience to adapt to stress (Iwasaki et al., 2005; Juniper, 2003).

Insights on the role of leisure in stress and coping can provide valuable knowledge into the different ways in which leisure can contribute to countering stress (Iwasaki et al., 2005). This information is important because it can assist in the development of self-coping strategies that may have the ability to lessen the impact of stressors that marginalized communities such as persons with AD are forced to live with on a daily basis. Regardless of the nature of one’s leisure activity, by using leisure to volunteer, share humour or laughter, dance, or simply reserve ‘leisure space’ for oneself, many people intentionally create channels to recharge themselves emotionally, physically and psychologically, thereby showing strength, perseverance and a sense of balance (Iwasaki et al., 2005). By pursuing empowering activities such as social, cultural, spiritual, altruistic engagement during one’s leisure time, one can engage in meaning creation, and emphasize on their own strengths than fixate over healing damage (Iwasaki et al., 2005).

For the purpose of this study, I have described leisure within a voluntary, individualistic or subjective context, wherein people may enjoy non-obligatory activities during their free time.
2.5 Leisure and Chronic Illness

Coping with the daily challenges of chronic illness can be overwhelming, pushing an individual to question their capabilities. Individuals with chronic illness also experience a loss of identity and experience self-doubt (Barnett, 2005). Recent research highlights the therapeutic nature of leisure, especially in coping with stress and negative life events. Coping involves affective, cognitive and behavioural responses to situations appraised as stressful (Lazarus & Folkman, 1988).

Leisure can help individuals with a chronic illness cope in several ways. These include generating positivity; acting as a buffer; creating avenues for distraction; creating roles and responsibilities as per existing capacities/capabilities; providing channels for creative pursuits; offering time, autonomy and opportunity; provide a sense of belonging; lend a sense of survivorship; assisting in the maintenance of cognitive health; and aiding in the improvement of overall QoL. According to Hutchinson and Nimrod (2012), leisure participation can assist individuals with chronic conditions to live well and manage their symptoms. Considering the voluntary and stress free nature of leisure, it can also offer a plethora of recovery channels and lend itself as a mode of coping in chronic illness. Perhaps the most attractive quality of leisure is the chance to make choices that reflect free will and autonomy. For individuals living with chronic illness, this freedom of choice can act as a strong foundation on the basis of which further independence may be gained. Moments of relaxation, enjoyment, temporary escape and distraction may boost self-confidence and contentment when considering positive life circumstances. Leisure may play a key role for active living and provide pathways toward recovery, health
promotion and life-quality enhancement in individuals with chronic illness (Iwasaki et al., 2010).

In addition to offering avenues for positive distraction and fostering hope (Hutchinson, Loy, Kleiber, & Dattilo, 2003; Hutchinson, Yarnal, Son, & Kerstetter, 2008; Kleiber, Hutchinson, & Williams, 2002; Son, Kerstetter, Yarnal, & Baker, 2007) leisure can also improve or maintain one’s overall health by offering opportunities for meaningful participation (Dupuis, 2008; Kelly, 1993). Leisure is known to act as a buffer from immediate stressors and maintain mental stability and restoration/rehabilitation of health (Hutchinson et al., 2003). Leisure can also be an excellent source of mental distraction, an escape from the monotony of home and hospitals, a channel for personal growth beyond disability/illness, a source of meaningful motivation, and an outlet for positive activities that offer opportunities for accomplishment and a sense of purpose. Continuing former leisure engagements can preserve a connection to the past, which may, in turn, help persons with chronic illness relive or recollect positive stories or events, or find threads that lead towards self-transformation (Hutchinson et al., 2003). Leisure can also generate moments that offer optimism, competence, independence, structure, acceptance, and a sense of belonging to cope with daily hassles and normative life stressors (Iwasaki & Mannell, 2000).

The role of leisure in the lives of AD patients may be immense, considering its ability to offer a wide range of coping opportunities. By allowing adjustments, diversion and rejuvenation in free time, persons with AD may experience the benefits of leisure through some of the ways listed below.
2.5.1 Generating positivity

Living with a chronic illness can lead to several negative emotions, which may result in a cascading effect on the growth and personality of an individual. I have personally experienced this as I continue to battle AD. There is empirical evidence indicating that leisure not only contributes to overall physical, social, emotional and cognitive wellbeing but can also lend itself as an economical channel to generate positive emotions and hope for the future (Caldwell, 2005). Participation in leisure activities promotes mood enhancement and moderates the relationship between stress and psychological wellbeing (Iwasaki & Mannell, 2000).

A great deal of importance is drawn to the accrualment of positive emotions in the coping process, especially amongst people living with severe and chronic stress (Folkman, 2008). Amidst growing evidence of the effectiveness of leisure as a coping resource for people living with chronic conditions or disabilities (Hutchinson et al., 2003; Shannon & Bourque, 2006), the common factor that binds health, wellness and QoL together is “the aspect of the positive” (Payne et al., 2010, p. 16). Experiencing positive emotions can prove to be a beneficial form of physical, social and emotional support that runs supplemental to medical care. Personally, having the opportunity to experience positive interaction and support significantly contributes to my resilience and personal growth amidst challenges associated with AD. Gilda’s club of Greater Toronto similarly, plays a significant role in the lives of individuals living with cancer (Glover & Parry 2009). Ancillary to medical support, Gilda’s club offers physical, social and emotional support to individuals diagnosed with cancer by offering free services and recreational activities such as yoga classes, workshops, lectures, monthly potlucks and
art therapy in a home like setting. The club thus offered a common platform for individuals with cancer to come together and connect in a home away from home (and hospitals) along with the opportunity to empathize with other cancer patients who are undergoing similar life circumstances. This practice helped the members of the club focus on positive interactions and relationship building, thereby generating positive elements of hope, understanding and friendship.

2.5.2 Leisure as a buffer and distraction from challenging circumstances

In addition to generating positivity, leisure can act as a buffer in chronic illness, especially when coping with life changing circumstances, traumatic life events or/and transcending negative life events (Hutchinson et al., 2003). Leisure can provide opportunities for self-protection, self-restoration and personal transformation by offering: a) positive distractions to manage daily stress and escape from negative emotions by being a source of hope (for example when reminded of our strengths, capabilities, goodness in life and enthusiasm to look forward to things); b) self-restoration by providing reassurance, space, alternate activities and validation; c) a source of strength and support by focusing on self-determination, endurance and companionship; and d) offering a chance towards personal transformation by encouraging self-expression, filtering out the negative life events, and controlling the mind by focusing on positive thoughts (Kleiber, Hutchinson, & Williams, 2002).

The inherent interest and enjoyment connected to leisure provides opportunities to develop meaningful engagement and experience self-expression and creativity, which may in turn serve as protective factors and contribute to better health and wellbeing (Caldwell, 2005). Leisure engagement does not only serve as a buffer, but may assist
persons living with chronic conditions to reduce boredom, take their minds of pressing issues, provide things or events to look forward to, and distract themselves from everyday immediate stressors. This can occur in several ways, including: a) assisting in the maintenance of mental stability and restoration/rehabilitation of health; b) by offering an escape from the monotony of home and hospitals; c) help them grow beyond their disability/illness; d) motivate them to find meaningful, positive activities that offer avenues for accomplishment; e) preserve a connection to the past which may help them relive/recollect positive stories/events or find threads that lead towards self-transformation; and f) provide a sense of purpose (Hutchinson et al., 2003). Leisure has the power to distract, generate optimism about the future, and preserve a sense of self in the face of trauma (Kleiber et al., 2002). Iwasaki and Schneider (2003) state that the degree and manner in which individuals experience stress and the ways in which they cope with stress strongly influence their daily choices and outcomes, specifically those related to leisure.

2.5.3 Creating new roles and responsibilities per existing capacities

Older adults and persons living with health constraints often experience barriers that prevent them from participating in or enjoying recreation and leisure activities (Hutchinson, et al., 2003). However, some researchers argue that constraints often exist in a beneficial relationship with leisure activity patterns and should therefore be studied for potential positive effects (Kleiber, McGuire, Aybar-Damali, & Norman, 2008). Leisure can create several avenues for expressive, creative, social, spiritual and cultural pursuits with non-physical or less physical demands that help people cope with their condition (Iwasaki et al., 2010). Some literature suggests that leisure can offer new roles
and abilities, while taking into consideration the limitations of an individual in chronic illness (Nimrod, 2008; Nimrod & Kleiber, 2007). For example, to overcome loneliness and social isolation, older adults and/or persons with chronic illness can engage in correspondence through email or letters to get in touch with loved ones and share their challenges and good moments. Nimrod and Kleiber’s (2007) leisure innovation theory suggests that leisure in later life may facilitate healthy aging because it “can be growth promoting and liberating . . . while at the same time generally protecting a sense of internal continuity” (2007, p. 1). Adopting new leisure activities may therefore lead to healthy aging through personal growth and renewal of interests in addition to reconstructing new or existing identities and increase meaning making in life (Liechty, Yarnal, & Kerstetter, 2012).

In a study examining how older adults with arthritis experience leisure, Janke, Son, and Payne (2009) observed the social, emotional and physical challenges individuals with arthritis have to deal with on a daily basis. However, in spite of the barriers, participants identified various strategies associated with the Selective Optimization with Compensation (SOC) model (Baltes & Baltes, 1990) that helped them experience positive health outcomes. The SOC model outlines adaptation or modification of leisure pursuits with activities that accommodate an individual’s abilities and needs. It states that adapting to challenges and creating positive outcomes can occur by selecting personal goals that match or optimize an individual’s available resources (Baltes & Carstensen, 1996; Lang, Rieckmann, & Baltes, 2002). Hutchinson and Nimrod (2012) explain SOC in the following terms. Selection refers to the decision to reduce or limit activities in order to preserve remaining resources for more important goals (e.g.,
abandoning lawn-mowing to save energy for other, perhaps more enjoyable, forms of gardening). Optimization involves refining and focusing efforts and resources to achieve desired goals (e.g., creating a plan for gardening to prevent overdoing it). Compensation refers to adapting how desired goals are achieved in the face of constraints (e.g., hiring someone to mow the lawn when it is too difficult to manage personally).

Using the SOC model, Hutchinson and Nimrod (2012) examined leisure related goals of older adults with chronic conditions and the strategies they used to not only successfully manage their chronic health conditions, but also to live well. Personal interviews conducted with 18 community dwelling older adults (9 men and 9 women, aged 58 to 87 years) with a variety of chronic conditions resulted in descriptions of changes and continuity in participants’ leisure engagement following the onset of their chronic condition. This led to the construction of four themes - drawing on existing resources for continued involvement; setting leisure-based goals; using strategies to get more out of life; and more than managing: living a life of meaning. The authors concluded that even in the face of what others may see as formidable impairments, if people can continue to maintain core valued relationships, feel some sense of purpose, and remain engaged in some form of personally meaningful activity, they are more likely to be quite satisfied with life, regardless of the severity of their health condition.

Thus, leisure can provide individuals with chronic illness the time, autonomy and opportunity to reflect on past achievements, storytelling, sharing experiences on support networks, pursuing a hobby, developing new skills and creating or reshaping their identities by promoting active engagements that assist them to move beyond the silhouette of chronic illness. Leisure can also provide opportunities for individuals
experiencing disabilities to pursue socially valued normal activities and develop new meaningful relationships or reshape/create new roles for themselves by engaging in activities that satisfy the urge of going out and being productive (Hutchinson, Bland, Kleiber, McCormick, & Iwasaki, 2008).

2.5.4 Coping through creative pursuits

Many individuals with chronic illness use creative artwork to experience feelings of capability and satisfaction (Shaw & Wilkinson, 1996). Artwork can give rise to symbolic meanings and sensuous pleasures that can help individuals cope with the repercussions of chronic illness. Observing the artwork of 12 women living through various stages of cancer, Reynolds, Lim, and Prior (2008) realized that participants used art to resist the psychological and social disruptive effects of cancer. Participants relied heavily on their creations as a means to convey meanings, inspirations, and subjective significance associated with their lives and ongoing mental state. The participants therefore engaged in creative arts to remind themselves of their vitality rather than their illness. Art helped them focus on positive experiences and develop social connectedness with others. Their creations emphasized their existing capabilities and allowed continuity of the self (Kelly et al., 2012).

Noting the “master status” role chronic illness plays in the lives of individuals battling chronic conditions, Reynolds (2004) examined the role of textile art in coping with physical impairments. Her study found that creative art was not only a flexible route to pursue an activity of choice, but also temporarily block illness related symptoms. Pursuing textile art empowered the participants and endowed them with the power of choice, independence, right amount of challenges, the chance to socialize, unearth
hidden abilities, and nurture existing skills or develop new ones. Reynolds, Vivat, and Prior (2011) also unearthed a similar finding in their study that showed persons with RA adopting various strategies to maintain participation in visual art by making health adaptations. The strategies incorporated by participants included a) devising more accessible creative spaces; b) planning, designing, and anticipating new creativities activities that evoke feelings of choice and control, especially during flares in symptoms; c) maintaining a positive attitude; and d) finding ways to accommodate their arthritis. One participant stated, “I had no materials or money for materials but I was always a compulsive maker of things. And I used to blow eggs and paint on them, or get stones and paint on them” (Reynolds et al., 2011, p. 36). Her statement indicates that creative self-expression helps persons with chronic conditions cope with life changing events and reminiscence life journeys by depicting them through artwork.

Leisure may offer individuals with AD the time, opportunity, and means to create and hone new or existing talents, and engage in play to feel refreshed and whole. Engaging in creative pursuits may also result in social connectedness when artwork is shared through social networking sites or the Internet. Lastly, receiving positive feedback and encouragement on their artistic creations may be a fruitful way for individuals with AD to boost self-esteem and self-confidence.

2.5.5 A sense of belonging and survivorship

Observing the relationship between leisure and wellbeing, Mock, Fraser, Knutson and Prier (2010) noted that greater frequency of physical leisure participation in adults with Rheumatoid Arthritis (RA) was associated with higher ratings of mental and physical health. A sense of belonging was also identified as a major component in
enhancing activity participation amongst participants, contributing to wellbeing and opportunities for social leisure regardless of the level of disability. Connecting with others helped the adults overcome seclusion, low self-confidence, loss of identity and reduction in feelings of self-worth. Feeling positive about oneself can also arise when an individual feels positive from surviving traumatic episodes in everyday life. Examining the triumph of overcoming breast cancer, Parry (2008) notes that survivorship is a dynamic process that spans through a person’s living memories including their treatment as well as learning to live well despite the knowledge that the ailment may strike again. Exploring the role of dragon boat racing (DBR) as community leisure, Parry (2008) saw that DBR not only provided breast cancer survivors with psychological and emotional support, but also presented them with an opportunity to use DBR for coping and vitality. Many participants even expressed a sense of spiritual awakening due to feelings of appreciation for daily living and nature that arose during the activity. Shared leisure can thus let individuals with long term illness fit in, boost self-worth, and generate optimism that can help them accept the illness, defy the illness, and learn to live well through expansion of social, emotional, physical, mental and spiritual dimensions.

**2.6.6 Maintaining cognitive health and overall quality of life**

Leisure that involves the use of sensory organs can be beneficial in helping persons with AD maintain cognitive functioning and wellbeing. Activities such as learning a new language or mastering problem solving skills can become more interesting and less demanding when enjoyable and also maintain cognitive wellbeing. Research indicates that individuals have power over their abilities to influence their own cognitive health through mental, social and psychological behaviours (Castelli & Valley,
By participating in leisure activities of their choice, persons with AD can not only exercise control over their wellbeing but also prevent diseases, reduce cardiovascular risk, enhance QoL, and maintain mental and cognitive health (Freire, 2013; Jones, Kimberlee, Deave, & Evans, 2013; Millington, 2012; Paluska & Schwenk, 2000). Engagement in physical activity is an effective strategy in attaining, regaining, or maintaining cognitive health from birth to adulthood (Castelli & Valley, 2007). Therefore, persons with AD may benefit from leisure time activities to physical, social, and emotional wellbeing.

Leisure can contribute to remedying the negative (e.g., coping with/healing from) as well as enhancing the positive (e.g., improving QoL, focusing on satisfaction) by optimizing positive emotions, promoting self-awareness and enlightenment, developing harmonious connections and creating or reshaping identities (Iwasaki, 2008). Leisure is also known to support an individual's pursuit to overcome negative life events such as disruption, adaptation, stress, and vulnerability arising from challenging conditions such as disabilities, illnesses, trauma, injury, relocation, loss of a spouse, “empty nest” syndrome and failed relationships (Kleiber et al., 2002). Leisure activities can take a focal point when life becomes difficult or threatening for individuals with chronic illness (Kleiber & Hutchinson, 2010). Amidst daily challenges, leisure activities may assist persons living with AD in several ways. Leisure may help preserve or restore positive self-perceptions by reaffirming or validating personal beliefs or values, allowing expression of enduring personal characteristics and preferences, offering convenient substitute activities, and reinstating the belief that they are fundamentally still the same.
before the onset of illness (Kleiber et al., 2010). Moreover, leisure may also provide persons with AD with personal and social space to be themselves (van Manen, 1997), experience the joys of life without discomfort or a sense of inadequacy, and come to terms with the illness.

Individuals with AD are surviving a traumatic illness on a daily basis. This in itself may foster emotions of pride and self-worth. Engaging in self-introspection during leisure time and reinstating self-belief may reinforce strength, replenish energies, and generate motivation to nurture health and wellbeing through enjoyment and meaningful activities.

2.6 The Potential Role of Leisure in AD

Chronic illnesses have dramatically risen in the past several decades and are expected to rise further in the near future (World Health Organization, 2009). Incorporating behavioural changes that include personal/lifestyle, social, environmental and community related alternations could be an excellent way of addressing society’s many pressing public health issues (Payne et al., 2010). The positive role of leisure in coping with chronic illness has already been established by several researchers. However, whether the benefits of leisure apply to AD, remains wide open for examination. Leisure may provide individuals with AD the opportunity to establish support networks and social groups/clubs; offer multiple-co-existing routes of expression via creative arts, cognitively challenging pursuits, or activities that are open for perusal with minimal physical exertion; create opportunities by taking on the role of advisor, life coach, tutor, or any other role that takes into account their existing capabilities and allows the promise of a constructive future; and offer opportunities to exercise autonomy
and independence by choosing activities that suit their taste and comfort. A better understanding of what individuals with AD experience and what role leisure plays in their lives may encourage self-management and autonomy in individuals with rare chronic illness.

Understanding leisure amongst people living with AD could help us understand the aspects that support this particular community’s quest to live well. The insights gained from this study could then be shared with others who are interested in integrating resources and energy to enhance the QoL of this community. Ideas springing from this research could create greater awareness and sensitivity amongst the general population and medical communities. This study could also stimulate further interest in leisure and rare chronic illness research.

Leisure may provide persons living with AD with time, autonomy and opportunity; a sense of belonging; a sense of survivorship; the ability to maintain cognitive health; and a chance to improve their overall QoL. Through behaviours such as social networking, developing bonds through shared activities, leisure may provide channels for emotional regulation and meaningful activities thereby revitalizing life and sustaining coping efforts. Leisure may play a quintessential role in health promotion and disease prevention by offering simple and affordable solutions in the form of simple and pleasurable engagements, medically sensitive programs and effective public policies. Additionally, the findings of this study may create a humanistic, holistic and person-centered environment where the experience of living with a rare chronic illness is not stigmatized.
Limited research on AD is affecting medical knowledge and awareness, rendering diagnosis to be a major medical challenge as the majority of the symptoms remain unknown amongst health care practitioners. Combined with a lack of financial or market incentives to treat or cure rare diseases, a serious danger to the public health care system and the lives of individuals affected by a rare chronic disease exists (NORD, 2012). Furthermore, to my knowledge, no previous research has explored the lived experiences of individuals with AD. Moreover, considering the complex nature and multiple symptoms associated with this condition, how individuals with AD cope with its impact on their daily living and how they self-manage the physical, emotional and mental stress associated with AD has not been considered. Gaining a better understanding of how individuals with AD experience and manage this illness in the absence of adequate support and information is required to better meet the needs of those living with the illness. The multiplicity of symptoms in AD can make the illness more complicated to manage. Nevertheless, self-management interventions may go a long way in managing their health more effectively.

To broaden our understanding of the nature of AD, how people living with AD cope with this illness in the midst of everyday challenges such as movement restrictions, unequal access to health care and social consequences accompanying progression of the illness is vital. Investigations into the everyday lives of persons living with AD and the role of leisure in coping with this illness may help to illuminate pathways that lead to the understanding of non-medical, alternative self-management approaches. Research into the experience of chronic illness such as AD may provide insights that may assist in promotion or maintenance of meaningful living and wellbeing in life.
2.7 The Role of Leisure in My Life with AD

Leisure has played a significant role in my life in coping with AD. Initially its presence was fairly unconscious, however, with time it helped me come to terms with the illness and make me appreciate my current abilities. Leisure gave me opportunities and time to contemplate on what I can do instead of what I cannot do. For example, a large part of my identity is connected with work and daily productivity. AD often makes it challenging for me to keep up with personal and professional demands due to fatigue and migraines. This leads me to wonder how long I can go on without succumbing to the disease. Looking back at my former life, I become aware of my fluctuating abilities. Consequently, I end up analyzing myself in a very critical fashion and suffer from an eroding identity. Leisure helps me take time off from everyday pressures and readjust focus on my strengths and abilities rather than limitations and challenges. I use leisure resources (such as the SOC model) to compartmentalize my physical, mental and intellectual resources in accordance. I use my free time to constantly learn about emerging health and wellness trends. This helps me manage the illness and slow down the progression of the disease. I have incorporated several diet, lifestyle, natural exercise (walking and biking) and leisure time pursuits (doodling, painting, playing music) that are suitable for the wellbeing of my body, mind and spirit. Leisure allows me to connect with those parts of my soul which are periodically buried in self-doubt and anger.

A large part of my leisure time activities involve chatting on the phone with my friends and family, traveling, reading, practising Zen Buddhism, and advocating animal and humanitarian rights. While traveling helps me bask in the glorious elements of nature and meet diverse travelers who distract me from my incapacities, practising
meditation and mindfulness helps me stay connected to my strengths. Advocating for the rights of animals and marginalized groups gives me purpose and makes me realize that irrespective of AD, I can continue to pursue my passions as per my current capabilities. For example, instead of joining my peers in physically demanding activities, I use my knowledge of law to oversee documentation. The constant pain and fatigue does make daily living extremely challenging. I find myself extremely vulnerable to depression and emotional lability time and again. Leisure helps me find a sacred space and time for myself that is wholeheartedly devoted to positive readings and therapeutic cooking. To me, the individualistic and voluntary nature of leisure has the potential to heal, rejuvenate and contribute to wellness and overall QoL.
3.0 Introduction

Due to the complex nature of AD, individuals living with this illness may experience leisure differently than persons living without chronic illness. To incorporate flexibility in understanding leisure experiences within the context of a rare chronic illness, I have adopted a qualitative research methodology because it aims to understand general experiences and occurrences taking place in the midst of a particular event (Bogdan & Biklen, 1998). More specifically, I chose to incorporate hermeneutic phenomenology because it involves understanding and interpreting the lived experience of an individual (van Manen, 1997). Below, I describe the qualitative approach I adopted in detail, followed by a discussion on phenomenology. Then, I discuss the process of participant recruitment, data collection, data analysis and how trustworthiness of the data was addressed.

3.1 Qualitative Research

Qualitative research focuses on interpretation of phenomena in their natural setting to make sense of the meaning people bring to these settings (Denzin & Lincoln, 2009). One aim of qualitative research is to understand singular interactions within a particular situation to unravel the characteristics of the situation, explore the meaning brought by participants, and what is happening to them at the moment (Patton, 1996). I believe that human behaviour is an outward projection of the world we experience inwardly. Therefore, to me, qualitative research methodology is appealing because it allows room to make intricate observations that are pertinent to understanding subjective experiences of individuals living with a chronic condition. A qualitative approach also permits rich data collection with the aid of participants’ experiences and stories that will
reveal the subtle nuances of daily living (Reynolds, 2004; Strauss & Corbin, 1990). Fraenkel and Wallen (2009) describe qualitative research as an approach in which the researcher investigates the quality of relationships, activities, situations or materials. The authors incorporate certain characteristics that distinguish qualitative research from quantitative research. These characteristics include: (a) the natural setting is the direct source of the data and the researcher is the key instrument; (b) data are collected in the form of words and/or pictures; (c) researchers are not only interested in the product but the process as well; (d) the process of data analysis by researchers is an inductive process; and (e) researchers are concerned about the ways in which participants make sense of life. Since one primary aim of my study is to understand and explore specific phenomena, (i.e., understand the lived experiences of individuals living with a rare chronic illness and explore the role of leisure in coping and self-management), a qualitative study design is appropriate as it will answer my research questions effectively. Moreover, qualitative health research provides a multidimensional understanding of a person’s experience of a health condition that goes beyond the everyday or common sense awareness and which leads to a more informed, nuanced, and empathic practice (Curry, Nembhard, & Bradley, 2009).

3.2 Phenomenology

I chose a phenomenological approach because I was curious to learn how persons living with AD made sense of their experiences and the way they transformed those experiences into consciousness, both individually and as shared meaning (van Manen, 1997). Langdridge (2007) defines phenomenology as both a philosophy as well as a family of research methods concerned with exploring and understanding human
experiences. Phenomenologists aim to gain a deeper understanding of the nature or meaning of our day to day experiences and are concerned with the study of lived experience or the lifeworld (van Manen, 1997). Husserl (1970) described the life-world as the ‘world of immediate experience’ and the ‘world that is already there’. He makes a critical historical and phenomenological distinction between our theoretical attitude to life and our natural pre-theoretical attitude on life on which all theorization is based and ultimately derived. He further states that the natural attitude of the life-world is always ‘pragmatic’ and always directed at the world ‘toward this or that, as an end or means, as relevant or irrelevant, towards private or public, and daily required or obtrusively new’ (p. 281). Considering our non-participating spectators or surveyors of the world, Merleau-Ponty (1962) describes the lifeworld as the demand for certain awareness, a certain kind of attentiveness and will to seize the meaning of the world. Husserl (1970) argues that every lifeworld shows certain pervading structures or styles that need to be studied. He further gives the term an existential connotation in phenomenology that studies our modes of being or ways of being in this world. Yet others such as Wittgenstein approach the term lifeworld from a linguistic stand, explaining it to be a notion of “form of life” and “language game” (Gier, 1981).

It is interesting to note that the term ‘life’ may be devoid of literal sense until we attach meaning to it – either in a personal or abstract fashion. The particular ‘meaning’ given to life by an individual through his or her many experiences explains a phenomenon. Although an individual experiences a phenomenon in a particular and unique way, that phenomenon is still experienced within a shared context (Smith, 2007; Smith, Flowers, & Larkin, 2009). To elaborate, individuals with AD experience the
illness in their own unique fashion but the phenomenon of experiencing AD is also shared by other individuals who have been diagnosed with this disease. Since phenomenologists interpret the various consistent and inconsistent phenomena of life experiences, this approach was ideal to gain better comprehension of leisure and overall wellbeing in the lives of people living with AD. A phenomenological approach helped me understand a participants’ firsthand experience. The findings of this study can be utilized by health care professionals as well as the family of persons with chronic illness to assist their loved one’s quest for a meaningful life.

3.2.1 Hermeneutic Phenomenology

The roots of phenomenology branch into several categories. I strove to understand the meaning, value, essence or significance (whether less, more or none at all) that participants attached to their lived experiences. This study is therefore guided by hermeneutic phenomenology for its ability to explore lived experience and lived meaning (van Manen, 1997). Lived meaning is defined as the way a person experiences and understands their world in a real and meaningful fashion (van Manen, 1997). It describes nuances of a situation that are only experienced and fully understood by the individual going through the experience (van Manen, 1997). Hermeneutic phenomenology also embodies the theory and practice of the interpretations of the meanings of texts (Rennie, 1999). Schleiermacher’s proposition states that a detailed and thorough interpretation of text, directed towards both a linguistic analysis as well as a psychological analysis (particularly looking at what is said and how it is said) would reveal the meaning of the text whilst at the same time revealing something of the (un)intentional motivations of the original author (Moran, 2000; Smith et al., 2009).
Hermeneutic phenomenology finds its rationale in the fact that human existence is close knit and bound together by the world we live in. This is because the emphasis is on the world lived by the person and not the world as something separate from the individual (Valle, King, & Halling, 1989). This kind of an inquiry asks, “What is this experience like?” as it attempts to unfold meanings as they are lived in everyday existence (Laverty, 2008). The focus of phenomenology is therefore on understanding the meaning-making process of human experiences as it is lived (Polkinghorne, 1983). Since the ‘life world’ is understood as what we experience pre-reflectively, without resorting to categorization or conceptualization, and quite often includes what is taken for granted or those things that are common sense (Husserl, 1970), it seems reasonable to assume that at the very crux of experiences, everyday human experiences commonly are bound and close knit in a plethora of meaning-making processes. To cope with the challenges that come with the common lived experience of people bound together by language, culture, things and relationships (Larkin, Watts, & Clifton, 2006), hermeneutic phenomenology is strongly inclined towards the researcher’s texts since an enquiry into the study starts from the researchers themselves. It is more concerned with a state of being wherein being is the enquiry into the nature or meaning of that phenomenon (van Manen, 1997).

### 3.3 Participant Recruitment

According to Polkinghorne (1989), an appropriate sample size for a phenomenological study is 5 to 25 participants. I made several attempts to recruit a minimum of five individuals. However, after a long wait and subsequent consultation with my supervisor, I recruited the four participants from USA who responded to my
invitation. The small sample size was not a deterrent in any manner as it allowed rich, deep descriptions that may not have been otherwise possible with a large pool of participants (Morse, 2000). All participants were diagnosed with AD for more than a year and had the ability to converse in English (Please see Table 1 for participant demographics). They were recruited online via Facebook, where I had posted the letter of invitation (Appendix A) on my timeline as well as an online support group for AD, after receiving permission from the group administrator. Once the participants reached out to me, I provided them with the consent form and study fact sheet with my contact information (Appendix B). I requested them to read the information carefully and contact me for further information or clarification. Once participants confirmed their interest to partake in the study and emailed me their consent forms, I arranged telephone interviews with each of them at their convenience. I offered participants the choice of traditional telephone interviews as well as Skype. However, knowing that video calling could trigger potential body image issues or physical discomfort, I informed them that they could opt for audio Skype only. I commenced recruitment only after receiving ethical approval from the University of Regina’s Research Ethics Board (Appendix C). I have included a profile of each participant below (please see table 1 below).

Table 1: Participant Demographics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Location</th>
<th>Marital status</th>
<th>Employment status</th>
<th>Experiencing symptoms since</th>
<th>Current age</th>
<th>Age at diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Richard</td>
<td>U.S.A</td>
<td>Married</td>
<td>Retired / Self-employed</td>
<td>Several years</td>
<td>58</td>
<td>50</td>
</tr>
</tbody>
</table>
3.3.1 The Internet and Illness Experience

Individuals with chronic illness adopt various strategies to cope with and manage their illness. Over several decades, the Internet has developed into a medium that allows people with similar or different illnesses to connect, bond and share information (Conrad & Stults, 2010). The Internet boom has transcended the illness experience from private to public and changed the experience of illness for many individuals. For example, low income groups use the Internet to access medical expertise that is being offered over various websites to the public at large including higher income groups (Ayers & Kronenfeld, 2007). My personal experience with the Internet has made me understand the empowerment that an individual with a chronic disease may experience by having the opportunity to participate in chats, forums, exchange emails, explore common platforms to share stories, meet potential friends, provide input, and maintain anonymity at the same time. Today, the Internet has the potential to empower patients with knowledge and options by offering information previously limited to medical experts only (Conrad & Stults, 2010). This in turn may give an Internet user (for example an individual with chronic illness) easy access to relevant information as well as some control of their health. Additionally, the Internet continues to play an active role in encouraging social support groups and illness social movements in bringing about a
change in illness experiences of patients by protesting against false medical claims and unfair healthcare practice (Conrad & Stults, 2010). It has the ability to bring together individuals from different background into collective groups to share and learn more.

Although the Internet offers vast resources for almost all kinds of information, it is important to note that it does not replace a physician’s expertise (Ayers & Kronenfeld, 2007). It is best to use the Internet in conjunction with a physician’s guidance as this technological medium could easily turn in to a double edged sword by influencing individuals looking for affirmation or clarity to defy physician orders (Ayers & Kronenfeld, 2007). To elaborate, persons with AD are often on multiple medications due to the many symptoms associated with the illness. However, after joining an online support network, they might become aware of the many side-effects associated with multiple doses of varied medications and therefore refuse to comply with the orders of their general practitioner. This may clearly be the case where the Internet has a more powerful impact than a medical practitioner, which may in turn prove to be fatal.

Although the Internet has assisted several individuals with chronic illness to connect, share, grow and learn from each other, knowing what kind of information to lean on from the Internet and what to overlook is a thin line all technologically savvy individuals need to be aware of.

For my study, the Internet played a significant role in ensuring smooth connectivity with participants. The Internet and social platforms such as Facebook have not only been very dominant in taking the virtual experience to whole new levels (Conrad & Stults, 2010) but also helped me communicate with participants without invading their personal space. Currently, advanced technology, innovative
communications media, and increased global accessibility have made the Internet a very viable choice for research and to let people follow a cause, create a difference, or pursue an objective. The universal nature of the Internet has turned it in to a collective forum to bring together different minds and knowledge. Therefore, for the purpose of my study, recruiting participants over the Internet was ideal.

3.4 Data Collection

Data were collected using active interviewing via telephone. This type of interview was carefully selected after giving due consideration the geographical disparity, lack of research funding, and protection of AD patients from any potential body image issues that may come up during face to face interviews. The initial interviews lasted approximately 90 minutes in length followed by 15 minutes of follow up interviews. Interviews were semi-structured and included flexible, open-ended questions to leave room for meaning to develop. I asked probing questions such as, “What does living with AD mean to you?” or “What does leisure mean to you?” to allow perceptions and understanding to stem from participants instead of me. This not only prevented deductions from erupting prematurely and also gave me the chance to adapt the questions and explore the topics without causing discomfort to the participants. The complete interview guide for this study can be found in Appendix D.

I conducted follow up interviews with participants a month after my initial data analysis. The aim of the follow up interview was to confirm my interpretations and give participants the opportunity to add any thoughts that might have emerged since our initial conversation. Examples of the type of follow up questions I asked included: Is there anything that you would like to add, modify, delete or change in the transcript? Since
our last conversation, has anything changed? Did you do anything different? Is there anything else that you would like to share with me? The data collected from the follow up interviews were combined with the data from the initial interviews and thematically analyzed again.

All interviews were digitally recorded and transcribed verbatim. I emailed a transcript of the interview to each participant to allow them the opportunity to edit, remove or add any thoughts. Excluding some minor editing, none of the participants requested any changes. As well, no major event relevant to AD had occurred in their lives since the first interview. Only one participant mentioned that she had, since our initial interview, traveled to another city with her family for camping with the help of mobility aids. Once all participants conveyed their satisfaction about the content and quality of the transcripts, I began outlining my findings. Below, I have explained active interviewing in detail.

### 3.4.1 Active Interviewing

Within our society, information is constantly generated via mass media, group talks or any form of human service (Silverman, 1993). Interviews are a structured way of making an inquiry into another’s life. Interviews may be formal or semi-formal, standardized, quantitatively oriented, or aimed at free flowing conversation (Holstein & Gubrium, 1997). I consciously decided to use active interviewing due to its departure from traditional and conventional forms of knowledge seeking. In active interviews, respondents actively construct and interpret meaning while interacting. Active interviews can therefore be defined as a form of interpretive practice involving respondent and interviewer as they articulate ongoing interpretive structures, resources and orientations.
with what Garfinkel (1967) calls ‘practical reasoning’ (Holstein & Gubrium, 1997). As the active interview takes places, meaning-making revolves around the how and the what of experience through interpretive practice, as well as the procedures and resources used to apprehend, organize, and represent the participants’ authentic experiences (Holstein, 1993; Holstein & Gubrium, 1994). In active interviewing, the “meaning” attached to the everyday life experiences of individuals with AD reflects relatively enduring interpretive conditions, such as the interviewer’s research topics, and local ways of orienting to those topics (Gubrium, 1988, 1989; Holstein & Gubrium, 1994, 1995). Those resources are astutely and adroitly crafted to the demands of the occasion, so that meaning is neither predetermined nor absolutely unique (Holstein & Gubrium, 1997).

A very interesting aspect of active interviewing is the transformation of the role of the participant after the interview (Holstein & Gubrium, 1997). Several times before an interview commences, researchers imagine the participant to fit a certain picture or criteria. However, in an active interview, the subject behind the interview questions emerges as part of the project as the participants respond (Holstein & Gubrium, 1997). Just as the process of meaning-making emerges as the interview ripens, the personality of the individual behind the “participant” comes forth over the course of the interview. Within the interview itself, the subject is fleshed out – rationally, emotionally, in combination, or otherwise – in relation to the give-and-take of the interview process and the interviewer’s broader research purposes. The interview and its participants are constantly developing and the respondent does not simply ‘break out’ talking – they actively construct and assemble answer (Holstein & Gubrium, 1997). The active interviewer’s role is to incite the respondent’s answers, virtually activating narrative
production. Holstein and Gubrium (1997) further explain that while the role of standardized interview is to attempt and strip the interview of all but the most neutral impersonal stimuli, the role of the consciously active interviewer is to provoke responses by indicating or even suggesting narrative positions, resources, orientations and precedents. Schütz (1967) describes this as the interviewer’s attempts to activate the respondent’s stock of knowledge and bring it to the fore of the discussion in ways that are appropriate to the research agenda.

While interviewing individuals with AD, the active interview provided flexibility to allow the interview to explore alternative perspectives and stocks of participant knowledge (Holstein & Gubrium, 1997). Rather than focusing on expected answers, active interviews gave me the chance to encourage the respondents to reveal their authentic answers, as diverse and contradictory as they might be. Thus, as an active interviewer, I had the opportunity to set the general parameters for responses and constraints in addition to provoking answers that were pertinent to my research interests. Without telling the participants what to or what not to disclose, I encouraged them to conceptualize issues and make connections. To answer my research questions effectively, the method of active interviewing was most suitable for my project.

3.5 Data Analysis

Data analysis in qualitative research can be an overwhelming task. Pope, Ziebland, and Mays (2000) observe that data can include field notes, interview transcripts, and the researcher’s reflective notes. The data I collected during my study included all the above and incorporated line by line analysis using van Manen’s (1997) phenomenological strategy as well as Interpretive Phenomenological Analysis (IPA)
(Smith et al., 2009). The primary aim of the data analysis was to focus on the common experiences of the participants.

Following closely on the lines of hermeneutic phenomenology, IPA aims to examine how individuals make sense of the life experiences that hold meaning to them (Smith et al., 2009). Using IPA, researchers often aim to comprehend what elements make a phenomenon or experience special or unique to the person experiencing it. For example, through this study, I intended to focus on grasping what it is like to experience AD. While I already understand some elements of living with AD because I am experiencing the illness myself, I find it imperative to state that just as every sentient being on this planet experiences life in a manner that is unique, an illness is experienced differently by each individual (although they may cluster together under common symptoms or the label of a specific kind of disease). In addition to understanding the lives of participants with AD, I also wanted to understand what leisure meant to each participant. Instead of seeing the phenomena, in this case the experience(s) of AD and leisure, as a general event, I thought it was best to interpret each participant’s experience(s) exclusively and emphasize the themes or occurrences that are most common to them. To define and limit what I found, I employed the established methodological framework of IPA to understand the events, objects, people, circumstances, situations and experiences in the lives of self-interpreting beings (Taylor, 1985), namely my study participants.

Smith et al. (2009) state that interpretive phenomenological researchers are often interested in looking at how an individual makes sense of major transitions in their life, such as moving homes, having children, experiencing trauma, or any other life event that
holds significance in an individual’s life. The attempt of the researcher to analyze data is a journey of interpretations, harnessing the energies of the researcher and the words behind the story. Since one aim of IPA is to dig deeper into a person’s exact experience(s) and the resulting sense that emerges from the assimilation of the experience by the person, IPA studies often have a small number of participants (Smith et al., 2009). This part of penetrating the similarities and differences between the stories of a small group of participants is known as idiographic IPA. Thus idiographic IPA attempts to explore every participant’s account before producing any general statements (Pietkiewicz & Smith, 2014). Smith and Osborn (2007) note that IPA usually involves double hermeneutics, or a two stage interpretation process, meaning that the participant is not only trying to make sense of the world but the researcher is also trying to make sense of the participants making sense of their world. During the interviews, there were several instances when the participants and I paused to digest the meaning of the words discussed. At first, I confounded myself into thinking that my pauses were merely a sign of courtesy – a gesture allowing the participant to breathe, reflect and come back to our conversation. However, as the interview progressed (and my transcripts indicate), the participants were, on several occasions, trying to make sense of the gravity of their own words as they narrated their lived experiences to me. After the data collection process, I listened to each audio recording multiple times to understand the meaning behind the words and listen to the tone and timbre of the participants’ voices for traces of emotions that failed to come across in text. To my surprise, I realized that concurrent to their narration my own voice bore traces of my efforts to grasp the weight of their words. Whilst striving to understand the intensity of their experiences, I was clearly becoming
aware of my own emotions/interpretations in the process. Thus consistent with phenomenology, IPA is concerned with understanding what both the participant and researcher bring to the table. It is a crystallized contribution of both parties that comes forward in the findings of a study.

Finally, I chose IPA because purposeful sampling gave me the prospect to interview a group of individuals to whom the research questions held significance. As my research topic is rare and automatically defines the boundaries of the relevant sample, the homogenous sample of participants who partook in this research allowed me plenty of opportunities to conduct a case by case analysis, thereby allowing the findings to be applicable to larger populations since the results were based on strong scrutiny and not generalized claims (Smith & Osborn, 2007). Participants were interpreted to be homogenous on the following characteristics: a) they were experiencing a common phenomenon of AD, b) they had similar experiences in living with AD and experiencing leisure (which became the themes of this study); c) they shared similarities in terms of background (all participants were parents and/or grandparents, were forced to retire from their careers due to AD, were living with AD for several years before they received official diagnosis, sought self-care and treatment for AD and lastly wished to live well with AD).

In addition to IPA, I incorporated van Manen’s reflective, thematic analysis that included the steps listed below.

The first step involved listening to the recorded interviews and reading individual transcripts and field notes several times (van Manen, 1997) to get a sense of the lived experience as a whole. I read transcripts multiple times, and each sentence or sentence
cluster was considered to understand what it revealed about the phenomenon being described. Data analysts go through the data (interview transcripts, field notes, journals) to highlight significant statements, sentences or quotes that provide an understanding of how the participants experienced the phenomenon. Moustakas (1994) describes this step as the process of horizontalization. Thematic analysis of data includes repeatedly reading raw data to identify common themes (van Manen, 1997). The second step of data analysis involved coding or noting and/or underlining significant statements. Bradley, Curry, and Devers (2007) state that an inductive process of reading and re-reading the data helps the researcher develop one or multiple themes to code and categorize data. Themes reflecting the essence of the participants’ lived experience soon began to emerge, and I worked on developing them further. Third, I created clusters of meaning from these significant statements, developing them into themes. Although human experiences are dynamic and subjective in nature, van Manen (1997) explains that predominant themes that present an overview of the life world eventually emerge. He states that a theme captures the phenomenon one is trying to explain. Bradley et al. (2007) describe themes as fundamental concepts that characterize specific experiences of individual participants, and spot recurrent unifying concepts or statements about the subject of inquiry. Morse (2008) defines a theme as a meaningful “essence” that runs through the data. Like a segment of music running repeatedly during a musical, a theme is a similar tone that runs or appears through the data over and over again. Themes are, therefore, the basic strategy of analysis in phenomenology, where the purpose is to elicit meaning or the essence of the experience of the participant (Morse, 2008).
As themes began to emerge, I considered recurrent themes as potential commonalities and lifted appropriate phrases to describe the meaning of the themes (van Manen, 1997). Development of themes arose when I began to uncover the basic topic that the overall narrative was all about. I compared themes across all data for commonalities and differences. Overall themes that best describe the essences of the participants’ lived experience were identified. Then, I used interpreted themes to write descriptions of what the participants experienced (also known as textural description) (Creswell, Hanson, Plano, & Morales, 2007). The textural descriptions are the main components or features that account for the basic integrity and consistency of the writings. Creswell et al. (2007) describe them as the conditions, situations, or context in which the participants experienced the phenomenon. Once the textural descriptions were outlined, I wrote a detailed description that conveyed the essence of the phenomenon. I incorporated identification of analytical categories and themes that emerged from the data, and these categories and themes focused on particular participant phrases, incidents, or behaviours and experiences. I then described the essence of the phenomena and verified my interpretations with all participants in the follow-up interview to member check and ensure that the findings are valid and capture the intended essence of the narrations. (van Manen, 1997).

The data analysis process was an ongoing, repetitive process that began at the early stages of data collection and continued throughout the study (Bradley et al., 2007). Apart from minimizing the margins of errors, this practice also allowed questions to be refined and new opportunities of inquiry to develop.
3.6 Trustworthiness of Data

I employed several strategies that entailed certain traditional criteria for appraising trustworthiness of a qualitative study (Guba, 1981). These include a) attention to its credibility, which measures the congruency of study findings with others’ experiences; b) transferability, which is the extent that study findings are applicable to other situations and populations; c) dependability, which is a test of whether or not the study can be replicated; and d) confirmability (equivalent to objectivity in quantitative research) that describes the extent to which the researcher has described his or her preconceptions.

To ensure credibility, I involved myself in prolonged engagement with the participants (Lincoln & Guba, 1985). Prior to the commencement of the interview, I spent considerable time on the phone getting to know the participants to establish trust and confidence between us. Discussing the research with them also gave me the opportunity to learn about their backgrounds, test any misinformation, and examine details that were relevant to the study (Lincoln & Guba, 1985). This was achieved through the initial as well as follow up interviews. To further strengthen the analysis, I triangulated several sources of data to build and justify the themes of this study (Shenton, 2004; Creswell, 2009). This included transcripts, field notes, and a journal reflecting my personal thoughts. Triangulation can be defined as an “attempt to map out, or explain more fully, the richness and complexity of human behaviour by studying it from more than one standpoint” (Cohen & Manion, 1994, p. 254). Additionally, I took every effort to be sensitive to the questioning that I ensued with the participants. Being cognizant of the trials and traumatic incidents associated with a chronic illness helped
me be empathetic towards participants without allowing emotions to cloud my judgment. I ensured that my interactions during data collection were given proper consideration and all dialogue gathered during data collection was equally scrutinized (Walsh, 2003).

To ensure transferability, I provided a thick description of the study, documenting the time and context in which the results were found, interpreted and concluded (Lincoln & Guba, 1985). This was achieved through the two interview structure of active interviewing, consequently allowing readers to have proper understanding of the phenomena being investigated and compare my research with instances that emerge in their own situations (Shenton, 2004), as well as allow future researchers to take decisions about the transferability of the findings to similar contexts.

To address the issue of dependability, I described every process of my research in detail, thereby allowing other researchers to repeat the work, if necessary, although not with the intent to gain the same results (Shelton, 2004). By employing a two-interview process in addition to a detailed step by step guide of the research study, I included an in-depth coverage of how the projected was planned and executed, what was done on the research fields at all times, and how the effectiveness of the process of inquiry was achieved (Shelton, 2004).

The last aspect of trustworthiness, which is the element of confirmability, was achieved by audiotaping the interviews. This helped me capture the participants’ articulations in an accurate manner and consider the manner in which their words overlapped with what they actually intended to say (Lincoln & Guba, 1985; Shelton, 2004). I also engaged in member checking with participants (requesting them to go through the transcripts and my interpretations carefully) and continually attempted to
critically scrutinize and address the question of meaning as constructed by the participants by collaborating with my academic supervisor. Together, we ensured a methodological rigour throughout and at all times remained open and sensitive to the unpredicted and unexpected (de Witt & Ploeg, 2006).

3.7 Reflexivity

To ensure trustworthiness, I was also reflexive throughout the data analysis process to ensure transparency and validity. In preparation for my research, I maintained a personal journal of thoughts that I referred to for candour, reflection and guidance during data collection and analysis. Periodic reliance on the information in my journal helped me assess, gauge and understand how I am influencing my research. Holland (1999) defines reflexivity as “that which turns back upon, or takes account of, itself or the person’s self” (p. 2). This practice of holding oneself accountable can be a strong foundation to create awareness and consciousness around the work we do. There are different kinds of reflexive methods that a researcher can adopt to keep her research transparent and reflective of its spirit. Walsh (2003) categorizes reflexivity into four distinct categories, namely personal, interpersonal, methodological and contextual reflexivity. Personal reflexivity involves detailed expressions of the researchers’ assumptions, expectations, reactions and unconscious responses that could influence the research process (Finlay, 1998). This method of reflexivity particularly holds meaning in hermeneutic phenomenology where the analyses not only includes data received from participants, but also the researcher’s data, attitudes and perceptions before, during and after the process (Walsh, 2003). In interpersonal reflexivity, I am expected to be aware of my relationship with the participants at all times. Methodological reflexivity states that
one’s deductions should be identified prior to the research process so that the researcher can gain deeper insight into the nature and understanding of the experiences sought (Walsh, 2003). The final component to reflexivity, according to Walsh (2003) is the contextual aspect that strives to acknowledge the cultural and historical element privy to a phenomenological study.

Irrespective of the type of reflexivity a researcher chooses to incorporate during ongoing research, the foundation of a reflexive practice advises one to continually take into account one’s personal experiences, belief systems, motivations, as well as tensions, and assess how these factors may impact the work that one is engaged in (Fraser, 1993). Myerhoff and Ruby (1982) define reflexivity and its reflexive knowledge as,

The capacity of any system of signification to turn back upon itself, to make itself its own object by referring to itself: subject and object fuse . . . Reflexive knowledge then contains not only messages, but also information as to how it came into being, the process by which it was obtained. (p. 2)

A reflexive methodology, therefore, at all times demands the conscious and deliberate inclusion of the full self (i.e., the researcher self and the human self) throughout the research process (Daly, 1992a). This involves continuous, intentional, and systematic self-introspection (Daly, 1992b) that begins even before a researcher enters the intended field of study or begins data collection. Reflexive methodology recognizes the researcher’s connectivity with the world around her or him and involves the use of empathy throughout the research process. It embraces the direct acknowledgement of our personal feelings into the analysis, using emotions and experiences documented in personal research journals to support or refute our initial assumptions or perspectives and
to help us understand the lived experiences of others (Kleinman & Copp, 1993). It means asking ourselves how we felt during different stages of the research and why we felt a specific way. It identifies those aspects of the research that were difficult and those that were easy, and sheds light on the reactions associated with emotional issues that came up during the research process (Dupuis, 1999). These aspects expose the phenomenon under study (Kleinman & Copp, 1993; Krieger, 1991).

Being reflexive also means weaving those emotions and personal experiences into our writing to help make the phenomenon under study come alive for our readers (Dupuis, 1999). A reflexive research methodology recognizes the active, collaborative role that both the participants and researchers play in the meaning-making process and demands a move towards the notions of active interviews as described by Holstein and Gubrium (1995) in experiential as well as participatory research. Such research recognizes the importance of developing extended, trusting relationships in qualitative research and explicitly incorporates self-disclosure on the part of the researcher throughout the research process (Dupuis, 1999). Finally, adopting a reflexive approach means learning to report our research and to write our stories and theories in different ways (Dupuis, 1999).

As reflexive researchers we must detail explicitly in our written accounts how the research process developed over time, how research-design decisions were made throughout the process, and what factors affected those decisions (Dupuis, 1999). We must outline how the analysis procedures were conducted and what questions were asked of the text during the analysis phase. We also must describe how our human selves and our personal experiences influenced the decisions we made and our interpretations of the
data (Dupuis, 1999). As Johnson and Altheide (1990) argued: “Unlike the novelist who is not compelled to tell the readers the how of substantive claims, the reflexive social scientist seeks to more completely share the claims-making process with readers” (p. 32). We, as data-gathering instruments, must outline the specific process by which we gathered the data (Myerhoff & Ruby, 1982). Daly (1995) suggested that we can begin to do this by using the active, first person in written accounts and by claiming interpretations as our own through the use of phrases such as “I responded to these comments with the idea that . . . or what I believe they were saying was”. A reflexive research methodology explicitly incorporates the researcher and her or his experience into the analysis process and into theory-building endeavors, and it demands the conscious and deliberate inclusion of statements and disclosures of the self and personal experiences in written accounts of the research (Daly, 1992b).

Critically examining the removal of the researcher’s self from their work, Dupuis (1999) observed that this dilemma was not only common amongst researchers in leisure studies, but in a variety of other disciplines as well. This may be understandable considering that the investments of a researcher into their projects not only reflects their knowledge of the study, but also evokes the world of personal experiences, interactions and subjective thoughts, patterns, prejudices and preconceived notions of the individual’s lifeworld. Repressing one’s emotions and feelings about their work may not be realistic, and therefore calls for a channel that would allow the researcher to have the opportunity to observe their notions, expectations and sentiments via journals, notes, or reflexivity. Krieger (1991) stressed that a suppression of the self and individual perspectives may not be a good idea since stifled ideas may only give rise to surface conformity in research.
Berg and Smith (1988) noted that the suppression of the emotions and personal experiences of the researcher results in the loss of a wealth of information about the lived experiences and social worlds of the people we are studying. Several researchers have therefore illustrated the need for the more direct use of the self in the assistance of illuminating the phenomena under study (Dupuis, 1999). Daly (1992b) described how the deliberate use of his self and his personal experiences with infertility and adoption throughout his research project assisted him in unraveling the experience of infertility for his participants.

Meaningful, useful, and rigorous qualitative research means addressing the two sets of criteria used to assess qualitative research: trustworthiness and authenticity (Guba & Lincoln, 1989, 1994; Lincoln & Guba, 1985; Manning, 1997). Having the ability to immerse in credible, honest and authentic research does not mean extracting oneself from the inquiry, but rather using both the research self and the human self throughout the research process, particularly in our reflexive writings (Dupuis, 1999), to do our work in a mindful and professional manner.

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 (Dupuis, 1999). Being reflexive in this domain required me to consider how the result of my study may impact individuals living with AD, contribute to the literature on rare chronic illness, enhance the medical community’s understanding of lived experiences of individuals living with AD, and add to our knowledge in leisure research by presenting the multidimensional role of leisure in coping with a rare chronic illness such as AD.
3.9 Ethical Considerations

Individuals with AD may be considered as a vulnerable population given the nature of their condition. When attempting to make sense of the lived experiences of individuals with Adiposis Dolorosa and understand the role of leisure in their lives, several opportunities for introspection as well as recollection of the onset of the illness and their journey so far, arose. While the majority of the participants provided this kind of information without hesitation (since their names will be replaced with pseudonyms), there was potential for participants to feel some trauma or emotional challenges while narrating their experiences. To keep the process of interviewing smooth and the experience of narrations comfortable, I offered a detailed explanation of the study to the participants and allowed them to learn the research questions in advance. I advised them to contemplate their decision of participation carefully, before they choose to volunteer. During the interview process, I made every effort to frame the questions as sensitively as possible, and empathize with them. I also ensured that they at all times were aware that they had the choice to take as many breaks as they require amidst narrations, and could also withdraw from the study without explanation.

Prior to the commencement of this study, ethical approval was obtained from the Research Ethics Board at the University of Regina (the ethics approval can be found in Appendix C). Once approval was obtained on meeting all standards of conduct, participants were provided with adequate information about the study and their voluntary participation was confirmed prior to the first interview. Participants were informed about their rights which included a) right to withdraw from the study at any given point in time without any liability; b) right to not disclose any information they do not feel
comfortable discussing; c) right to privacy and confidentiality throughout the study; d) right to choosing time and method of communication. Prior to data collection, I emailed the consent form (Appendix D) to the participants for their perusal and proceeded with the interviews only after receiving their approval to partake in the study.
Chapter 4: Findings

4.0 Introduction

This research was eye opening for me in a multitude of ways. Prior to embarking on the data analysis process, I was frightened that my personal prejudices would cloud the rationale of this project. However, actively engaging in reflexivity, member checking with follow up interviews, multiple meetings with my supervisor, and taking breaks between reanalyses helped me move past my anxieties and dive deep into the data.

The findings of this study reveal two contrasting dimensions that co-exist amid life with AD. They are that of challenge and hope. While AD caused several barriers in daily life (including leisure) on a regular basis, leisure ushered in a flurry of positive emotions and coping mechanisms that helped participants look forward to life. Living with AD meant challenges with diagnosis, loss of identity, daily stressors, hurdles in leisure and life, struggling for continuity, experiencing substantial personal transformations, maneuvering through a varied range of paradoxical emotions, and learning to cope with the illness in the absence of adequate awareness, knowledge and guidance. On the other hand, experiencing leisure meant cherishing personal relationships, appreciating life, helping others, and basking in the sweetness of positive emotions. Leisure created a sense of balance and control to neutralize the catastrophic effects of AD and offered participants some breathing room amid the chaos of chronic illness. Amongst various leisure activities, spending time with family played a strong, central role in offering support and helping participants cope with AD.

Engaging in religious pursuits, peace and solitude, soul searching and contemplation of current and future dreams were other forms of leisure behaviours that
brought purpose, meaning and direction. These periods of rumination led to greater heights of self-awareness and in turn, better self-management, as participants understood their needs and dislikes better. For example, all participants realized that the side-effects of multiple medications were taking a toll on their emotional stability and mood. This insight helped them develop compassion towards themselves during downtime and handle their emotional wellbeing better. Participants were also aware that they were undergoing changes in their personality because of the pain and daily stressors. Becoming aware of these changes encouraged them to consciously make decisions that brought happiness and meaning. Engaging in significant activities such as taking care of family, especially their children, as well as serving their community were identified as activities that let participants cope with the negative effects of chronic illness without overstretching themselves. Being there for others generated positive feelings that helped them feel valued and appreciated. Experiencing contentment amid AD gave participants hope and optimism. Thus, as participants narrated profound experiences that swung between distress and optimism, the paradox of pain and hope came forth. The themes and subthemes of this study are listed below in Table 2.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
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<tbody>
<tr>
<td><strong>Theme A</strong></td>
<td>▪ Struggling for medical diagnosis and validation</td>
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<tr>
<td><strong>Experiencing AD</strong></td>
<td>▪ Living with chronic pain and chronic fatigue</td>
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<td></td>
<td>▪ Living with daily stressors and constant change</td>
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<td>▪ Experiencing identity crises</td>
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<td>▪ Dealing with weather implications</td>
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<td>Theme B</td>
<td>The role of leisure in AD</td>
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<td></td>
<td>▪ Using leisure to cope with symptoms</td>
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<td>▪ Finding identities through relationships</td>
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<td>▪ Using former and new leisure habits to escape AD</td>
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<td>▪ Preventing further deterioration of AD</td>
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<td>▪ Making behavioural changes to sustain wellbeing in AD</td>
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<td></td>
<td>▶ Eating well and maintaining physical movement</td>
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<td>▶ Understanding potential triggers</td>
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<td>▶ Forgoing familiar routines</td>
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<td></td>
<td>▪ Staying active and looking forward to life</td>
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<th>Theme C</th>
<th>Addressing barriers in leisure and life</th>
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<tr>
<td></td>
<td>▪ Pursuing meaningful activities</td>
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<tr>
<td></td>
<td>▪ Staying positive and appreciating life</td>
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4.1 Experiencing AD

While each participant was at a different stage of the illness and experienced AD in their own unique way, their stories overlapped in several places. Experiencing AD meant experiencing diagnostic challenges, everyday stressors, crumbling identity, struggle for continuity, chronic pain and chronic fatigue, barriers to leisure and life, lack of awareness and support, and learning to self-manage and cope with the illness without adequate information. Living with AD also meant obstructions to employment, reduced social life, estrangement from friends and intimate relationships, and decline in physical independence due to loss in mobility and motor control. The experiences of participants were diverse as well as similar. I chose the most recurring and common themes for inclusion in this chapter and have discussed them at length below.

4.1.1 Struggling for medical validation and support

A vast portion of our interviews revolved around the challenges of diagnosing and treating AD. Since rare diseases are not very common and have been researched
negligently, Richard, Catherine, Pamela and June explained that healthcare professionals were inexperienced and confused about diagnosing and treating this little known illness. The lack of awareness and knowledge led participants to go through years of diagnostic ignorance and errors, as they watched their condition worsen. It took participants several years to find answers to their deteriorating health. By then, AD had caused tremendous physical, mental and emotional damage. When I asked June how long it took her to receive a diagnosis, she responded, “It took me nine years to get diagnosed. They kept telling me nothing was wrong with me”. Pamela shared a similar story,

I went everywhere for a diagnosis. I had tumours in my breast and of course you know you think it’s going to be cancer and I went everywhere and I ended up going to the University of Washington and they could see them on the mammogram they could feel them but they couldn’t see them on the ultrasound and so they knew that it wasn’t cancer....they did not know what it was. I was finally diagnosed in the year 2006.

From their experiences, it became clear to me that lack of familiarity with rare diseases such as AD makes diagnosis extremely challenging. Moreover, even if a doctor suspects an anomaly, they might still be unable to help, because concrete diagnostic tools to detect AD do not exist currently. Almost all participants of this study are living with comorbidities such as multiple sclerosis (MS), cogan’s syndrome, fibromyalgia, chronic fatigue syndrome, rheumatoid arthritis (RA) and madelung’s disease. Most of them were diagnosed with other illnesses before they were diagnosed with AD. The presence of other pathogens in the body not only fogged symptoms of AD but also perplexed physicians further. Participants explained that several symptoms of the aforementioned
illnesses are very similar to the symptoms of AD, and therefore, identifying each illness took numerous years. AD was diagnosed last in all participants. By then, the disease had progressed radically and participants were lost in an ocean of tests, medications and confusing predicaments.

Because I was so old when it happened... I was 60 when I was diagnosed. And um I was 45 when I got (these illnesses).....When my world crashed and my world fell apart....there is no better way of explaining it....I did not uh in fact these last 15 years I did not recognize them, it's like they are there, not there. I was so sick, so horribly sick, so definitely sick, and it was because all of these different diseases were attacking me and umm when ok wait a minute...what was I talking about? Oh I was so sick... (Pamela)

Prior to the diagnosis of AD, all participants were aware that their bodies were no longer their allies and that something obscure and painful within their physiology was causing them immense distress.

I first noticed these tumours at about age of 27. And at that time I just had one that was particularly sore. It was in my left breast. And I checked with the doctors to make sure it wasn't anything serious. And it didn’t seem to be but it was painful. (Catherine)

Recollecting her suspicions about AD, June, who was diagnosed at the age of forty-four, said to me,

I was diagnosed with AD when I had my son. I was 30 years old then. I could tell something had changed with me... I have been dealing with it for almost 14 years but not chronically.
Richard realized something was wrong when he started experiencing sudden weight issues and had difficulty partaking in physical activities.

*I was a pretty active person physically. There was a time when I could run miles.*

*I think I have had this for a long time and I did not realize that I had this ...I had a personal trainer for a while and after working out, my legs felt so miserable.*

*And I thought why should my legs feel fatigued so easily?*

Becoming aware of their failing health, Catherine, June, Richard and Pamela immediately began making efforts to find out the cause of their dwindling wellbeing.

Catherine said to me, *I did a whole lot of tests and I found out that I was basically covered with them (tumours) and there wasn’t anything I could do about them. And so uh that just kinda left me on my own.*

Although the initial tests revealed the presence of benign, painful tumours, nothing suggested the presence of AD. Suspecting that there was more than what meets the eye, participants sought answers from multiple specialists, but in vain.

*All I kept hearing was nothing is wrong with your test. We can’t find anything wrong. All you have is Rheumatoid Arthritis. If you want you can work. I did not find any doctor to get me to take care of my pain. So I have been really struggling, suffering for years.* (June)

As doctors had no experience with rare diseases, they refused to acknowledge AD, agonizing participants and making them feel invalidated. The absence of medical validation also led to familial tensions as loved ones grappled to understand an illness that even physicians had trouble accepting.
My husband kept asking me to go to the doctor and said, “Nothing seems to be wrong with you. Are you sure something’s wrong with you?” And I believe my husband was convinced nothing was wrong with me. That it was all in my head....

And I think that is one of the reasons why he left. (June)

In between convincing doctors and family members about AD, participants realized that the burden of making decisions relating to their physical and mental wellbeing rested solely on their shoulders. Not knowing a better course of action or who to turn to for advice, they took judgment calls on their health without knowing the repercussions that would follow. For example, Catherine noticed that some of the tumours on her body were turning extremely painful and had begun to obstruct her motor skills. She therefore decided to have them removed. The doctors, not being aware that surgical removal of lipomas causes them to multiply, followed Catherine’s decision without second guessing the ramifications of the procedure. The results of the operation were unfortunately, extremely detrimental.

..... I had the surgeries done when the tumours would get very painful and they would obstruct my motor skills. I had 48 of them removed. What I found out through these years was that that was a big mistake because they grow back, and they grow back multiplying. So where I had those tumours removed, I would not only have those tumours grow back but I would have multiple tumours. So I started getting this situation where these tumours would just grow though my muscles and my nerves.....My scars didn’t heal properly for years, I had constant itching. It really aggravated the situation.
The progression of the illness, unintended medical ignorance and lack of guidance left the participants feeling distressed and helpless. Left with little support and information, they eventually began researching the Internet and found out about AD themselves.

*I basically self-diagnosed myself on the Internet and I made sure I took one of my siblings with me so they could hear that something is wrong with her. I think they didn’t want anything to be wrong with me but at the same time they also wanted something to be wrong with me.* (June)

Fervent Internet searches and visiting one health practitioner after another allowed participants to collate information about AD and subsequently educate their current doctors about the illness.

*I was actually the one who ended up telling my doctors about it who diagnosed me with it. And it was a whole lot of research that I gave them. I went to several specialists who finally said you know what, you have AD. It is the only thing we can think of.* (Catherine)

Unfortunately, despite their efforts to research and self-diagnose AD, they received little consideration or support from health practitioners (although by this time, their family and friends had begun acknowledging AD). Recalling her encounters with physicians, Catherine said to me, “And the doctors told me we have never heard about this, we don’t know what to do about it.” Although Catherine, Pamela, Richard and June realized that their doctors had their best interests at heart and were perhaps unable to assist them in the best manner possible due to lack of adequate material and resources, they were dejected to learn that their physician was unwillingness to discuss or even acknowledge the existence of AD despite the information that they had provided. The dearth of
validation caused irreparable delay in the diagnosis and eventual treatment of AD.

Sounding disappointed, June said to me,

*When I discussed my lipomas with him (the doctor) and asked him why do they hurt? He said some people just have them. I told him I don’t just accept that as an answer. There is some reason people get them. I thought he would be willing to treat me when I got back, but he kept saying you don’t have lipomas all over and I kept telling him that I have them all over me! I mean you can see them. They are getting to where you can see them now.*

Participants explained at length that being unacknowledged was a heart wrenching experience. Regardless, they continued their efforts to find a compassionate doctor who would take their inputs into consideration and collaborate with them to manage AD.

They went on to inform me that several years passed between the emergence of the first symptoms of AD and finding the whereabouts of a doctor who was willing to treat them. However, they opined that despite the hurdles and disappointments it was important to maintain open dialogue with doctors and be self-educated about possible symptoms to self-manage AD in the best manner possible.

### 4.1.2 Living with chronic pain and chronic fatigue

Participants found chronic pain and fatigue to be the biggest factors that impacted daily living and leisure experiences. Reflecting on the impact of chronic pain and fatigue on his current life, Richard shared,

*Today was a horrible day for me. You know I could have just closed my eyes and it was really busy today. I shouldn’t have been out. I should have been home today watching TV and closing my eyes. I can’t sleep. It’s probably the medicine*
but I can’t nap. I can’t sleep……I am fatigued enough that I don’t want to open my eyes.

Describing the chronic pain specifically, participants said that the pain was debilitating, burning, and disabling to the point of incapacitating them from living a normal life. Recalling the effect of the pain on her wellbeing, June said to me, “Seriously, I was about to lose my mind because of the pain….I have been on pain meds now. I can’t do anything. I am on the couch all the time”. The constant pain and fatigue affected June’s daily activities as well.

...and even if you take the meds and it gets the pain under control, you will have all this fatigue. There is nothing that helps me with the fatigue. There is nothing that comes close to describing my normal self. I was just a workaholic. I would be doing something all the time. That’s what made me feel good. Taking care of my household, my children, I was just a do-er. I was doing something all the time and I was a massive ardent gardener. I mean I was never in the house during the summer time. As soon as the weather got warm, I would put my hands and feet in the dirt and that’s what I wanted to do and now I can’t even pull weeds anymore.

Living with multiple health conditions was challenging and participants longed for some pain-free time to enjoy the company of their family and friends without constantly struggling for normalcy. The constant pain and fatigue were also major barriers to personal enjoyment and career goals.

I used to be the head secretary for the principal in a very large high school.... and I got sick....and it hit me hard and fast. I tried to work.....umm, I tried to
work part time, and they finally said, "We are done with you, you gotta go".

(Pamela)

Not wanting to give up on their aspirations, participants tried to work part-time despite the chronic pain and fatigue. However, after a certain point, even adjustments were ineffective and they found themselves stretching their limits with adverse effects.

I am trying to help him (brother-in-law) you know. I am there at 8 o clock every morning and doing a lot of stressful things. I really thought I could do it but I have seen it's making me worse. I am really struggling with the fatigue and I am sure it's because I am pushing myself too much. (Richard)

Richard and Catherine continued to remain involved in family business. Pamela and June however, had to quit their jobs due to several health complications. June faced severe financial difficulties as a result of unemployment.

I mean I am not trying to get disability so I can sit on my butt! I just physically cannot [work]! I have zero, zero, zero income! I have to rely on everyone else. I sold almost everything I owned just to get my medications. I am tired of selling my stuff to get my medication.

Despite seeking pain management to regain control over their lives, participants found themselves worn down easily, making it harder to manage AD.

4.1.3 Living with daily stressors

In addition to facing difficulties with diagnosis, dealing with the lack of support from doctors and family members, and battling chronic pain and chronic fatigue on a regular basis, participants also had to encounter numerous daily stressors. While every participant had unique challenges, AD impacted their daily lives in similar ways causing
physical, mental, emotional, financial and social hardships. I have discussed the most commonly recurring daily stressors below.

All participants were undergoing tremendous upheavals in their personal lives (such as childbirth, illness, surgeries, bankruptcy, divorce, widowhood, and spousal abandonment) when the subtle indications of AD began emerging. They noticed that it was during these intense periods of hardship that AD transmuted from a dormant to hyperactive state and led to a sudden explosion of tumours in different parts of their bodies. Richard noticed the sudden appearance of AD when he was grieving the loss of his first wife and raising his children as a single parent. Richard believed that the emotional stress of losing his first wife put his physiological system under duress and triggered the eruption of AD. Identifying the trigger, he told me “I believe that there were so many stressors that were so powerful in my life at the same time that caused my immune system to weaken and my body couldn’t fight that anymore”. Catherine first started noticing the tumours when she underwent knee surgery, a physical stressor.

So when they were sewing me (from the surgery) I noticed that when they touched me, they (tumours) really hurt.....And then they (tumours and pain) started spreading just all over the place. And at that point, with the stress in my system, it seems like the tumours just exploded in me. And my life changed within months.....I just started getting so many tumours I literally stopped counting...So I had hundreds and hundreds of tumours and I counted up to a 1000....and I just thought forget it. Now I just wanna find a place where I cannot find them you know.
The sudden appearance of AD threw participants off track and caused several challenges that they were not prepared for. Giving me an example, June explained the abrupt effect AD had on her career and consequently financial freedom. Catherine, Pamela and Richard also shared similar stories that demonstrated their helplessness. Besides financial hardships, AD also impacted their marriage, causing day to day strains in intimacy. Speaking of his needs, a very emotional Richard said to me,

...my needs are not just sexual or physical intimacy. It's uh spiritually, emotionally, those needs are more important than the physical ones because that has changed for me. The important thing is can the other (spouse) help you with the pain. Or when you get lost with someone but that's just physical. But that's nothing if you don't have anything emotional. I am not a person that will mind lying down with someone. I just want to be with someone. I don't know if this is the disease but I just long for that....and I don't know what is so wrong to want to have that someone be my everything.

The strain on marriage was felt by the other participants as well. Catherine felt an uneasiness creep into her marriage, when her husband, innocently quizzed her about her changing physical appearance (caused by AD),

First of all, you know, I was suddenly gaining all this weight and he (husband) was like “Catherine, what's going on? You know we don’t even have unhealthy food here”. And I was just shocked and thinking this is the weirdest stuff I have ever seen. These are just huge big tumours and they are measuring inches and inches on me.
The unmet personal needs and fluctuating body changes anguish ed and confused participants. However, with continued efforts, Pamela and Catherine managed to hold their marriage together. Despite repeated attempts to communicate with his wife, Richard’s needs were still not met. June unfortunately suffered the most, when her husband refused to work on their marriage anymore, and subsequently asked for a divorce.

4.1.4 Experiencing identity crises

During the interviews, participants often sounded anguished when discussing AD. I periodically took pauses to offer them support (by extending my empathy and understanding), suggested calling back at a later time, and/or reminded them that the option to quit the study was available to them at any point. However, all participants chose to move forward with our conversation, during which I got the impression that AD had an undeniable prominence in their life (something I instantaneously related with). Although Richard, Catherine, Pamela and June worked very hard to consciously disengage from AD’s looming presence, their struggle to reduce its significance was not successful all the time.

Yeah so with that and my extreme weight gain no one liked looking at me. So my friends didn’t come over because they didn’t like seeing me. Everything, everything, everything fell apart. I couldn’t go to my son’s house. I couldn’t travel. I couldn’t uh.... It’s not that I didn’t want to. It wasn’t that I wasn’t able to it’s that I literally, physically could not do it and at the same time - this really had an effect on me too. (Pamela)
Experiencing AD meant constant medications to treat the chronic pain and fatigue, relationships taking continuous time and efforts to limit misunderstandings and confusion, the need to habitually educate themselves and their families about AD, and the necessity to adapt to the continual curveballs thrown by AD. Furthermore, living with AD also meant not getting the chance to spend time with family due to downtimes and periodic bouts of sickness.

This year, I was so excited when I started having grandchildren and I was so sick I thought I was gonna die and I was preparing for that. I was so sick. And I was ready to...I knew I was just gonna be dead. And the grandchildren came and it would just break me because I couldn’t spent time with them, I couldn’t hold them and I couldn’t do things with them. (Pamela)

The many restrictions hindered normal living and often compelled participants to wonder about their individuality, especially when they drew parallels between their current and former selves. For example, Richard noted, “We are farmers…and I have been back and been with my brothers and helped him a little bit during a couple of harvest seasons and ....I miss that...I miss that part of my life”. Pamela also added, “ I got sick in 2000.....and then I had to quit work 8 months later and I have... my world fell apart when I had to quit work and that was everything to me”. Losing their well-established self was a painful process that involved much denial, grieving and acceptance.

I have gone through a couple of things......well it’s probably phases unfortunately that are created in anger and denial...I think sometimes those are equated with people grieving and I don’t think that’s necessarily true. I think with an illness such as ours .....It’s funny I didn’t see myself doing it at first. I had to look back
and probably you know I definitely see the anger and denial...but the disease makes you so aware of its presence that you can’t you can’t...at least I can’t.

(Richard)

The process of losing their former roles and responsibilities was extremely trying for participants because prior to the diagnosis, they were very active in their personal, professional and social pursuits. As AD progressed and incapacitated them from staying involved in those activities, they were forced to lead more docile lives. Catherine shares,

_I used to be very very active uhm did a lot of camping and hiking with the family – we enjoyed a lot. You know we were very active. And then I couldn’t do that._

Even standing at a certain position, like sweeping the floor or doing the dishes, _the big sciatic nerve that runs across your back to your leg, uhm, I was with these tumours and I could feel that this position really stings after a while. And then I found out when I was sitting on these tumours and they were stabbing at my arms and I was losing some of the strength in my hands. When I would hold the steering wheel when I was driving, my hands would go numb._

Sharing her ambitious nature and former life that was full of purpose and direction, June told me,

_I am basically on the couch all the time because I just cannot do anything, I was the kind of person who got up all the time, took a bath, made supper and everyone went to bed and I was always on my feet doing something all the way to quarter to nine. And now I am lucky if I can get up and get one or two hours’ worth of activity._
The repercussions of AD including loss of employment, inability to perform simple tasks due to intense pain and fatigue and lack of adequate support led participants to lead very different lives that were often marred by high levels of frustration and inadequacy. An example of a very massive deviation for all participants was the change in caregiver responsibilities. For the longest time, all participants were very involved in their respective households, caretaking their families and juggling work concurrently. However, since the diagnosis of AD, they had to take a back seat from their demanding household responsibilities and be stripped of their role as caregivers.

*As you can imagine as a mom, you know you learn to multi-task and be responsible for all kinds of things. He (her husband) had to take over some of that....And so he found himself for the first time ever, taking care of me sometimes where uh that had never been the case. I had always been the nurse....I had always been the caregiver..... So that was kind of that adjustment at hand.*

Richard shared a similar experience,

*.....Because of my illness you know, it is difficult to make it think about being on my own or being alone because I don’t even know....even though I can do everything. But you know those things are a lot more difficult when you are sick.*

Losing the role of caregiver and nurturer caused participants to feel like burdens on friends and family. Additionally, when their spouses took over household chores and responsibilities, participants found it hard to adjust to the sudden role reversal at hand.

*I was terribly sick and then two weeks later 9/11 happened and my life was like the towers....everything that I had thought that I had had crumbled down and I*
had nothing left. I had no friends, I had nothing. My world became 1400 sq. ft. and my husband had to take over cooking. (Pamela)

Since participants relied on their everyday occupations for joy and fulfillment, being dismissed of these roles came as a major setback. Their identity was assaulted further when family members, without much thought, pointed out their changing physical appearance (the tumours can expand to large sizes and are often visible above the subcutaneous glands of skin causing physical distortions in shape). Catherine recounts, “So he [son] used to say, ‘Mommy you have Popeye muscles’ where I had tumours. And I had to adjust to that. I would have these tumours to the point where my whole physical shape started to change”. With their bodies undergoing changes due to AD, participants often felt attacked when commented upon by family and friends. Apprehensions regarding identity and changing appearances led to low self-esteem and body image issues, ultimately driving them to lead reclusive lives. Richard continued making efforts to maintain social relationships, although it was physically taxing for him to do so beyond a certain point. However, not all got the chance to experience social connectedness especially when friends refused to see beyond external appearances.

When my towers fell down [referring to her life going down like the 9/11 towers], my friends dropped me. I was no longer able to communicate. I was no longer able to do anything for once....I could not leave the house. They would come up to see me and I was unable to have a relationship. And then when AD came and I gained all this weight, they didn’t know what it was. I had a moon face (due to side effects of medications). (Pamela)
Faced with an avalanche of physical, social, economic and mental, participants experienced identity crises where they could no longer understand what their abilities were,

*I am trying really hard to accept the fact that this is my life and that I have limitations..... And I just won't accept it. I want someone to find something so I can be who I used to be....Which is a person who worked! Sixty hours a week, cleaned and took care of their house and their yard. I really think about these doctors and wonder who decided I am not going to work anymore and just sit on my butt??! (June)*

Forced to adapt a less active lifestyle, they experienced a loss of autonomy when they found themselves relying heavily on their near and dear ones for support and assistance,

....and so now I am you know I guess because of what I do and because of my illness you know, it is difficult to make it think about being on my own or being alone because I don't even know....even though I can do everything. (Richard)

AD also affected their leisure pursuits, as symptoms got in the way and hampered their flow,

*What used to take me just a little bit to do something, it can now take me 3-4 hours and in the meanwhile I will have forgotten what I was doing and start working on something else, which makes me forget and then I go on to something, I mean I can have all these projects [as hobbies] going with no success. (Pamela)*

The shift from former independent workaholics, passionate caregivers and active parents, to inert lifestyles lead participants to self-doubt their capacity to make meaningful
contributions to life, family and work. With changes in their personality, bodily functions and appearances, participants found themselves looking for ways to remain resilient and live well with AD.

**4.1.5 Dealing with weather implications**

A relationship between the weather and chronic pain and fatigue was identified during the interviews. All participants experienced increased pain and fatigue on days on which the weather was unfavourable (e.g., foggy, windy, cold, or with higher atmospheric pressure in the air),

> The weather has a lot to do with what I have noticed, not as much as whether it is cold or hot, what gives me a hard time is the acclimate pressure. When the storm comes in I am fine but it’s the pressure. (Catherine)

June found herself agonizing more with the symptoms in winter than summer, “Actually when the weather changes from summer to fall and the pain is…there is such a drastic difference and I have been trying to tell my pain doctor that its really hurting me”.

She added,

> The past three months I haven’t been able to get my pain under control and I haven’t been a very positive person. I have been very grouchy and angry and I don’t want to be like this. I want to get my butt off and work like everybody else. Everyone tries to tell me that they feel low too but they still do something when they feel good, but I try to tell them that I don’t feel good. I don’t feel better. The fatigue and pain isn’t as bad as it is in the summer time as it is in winter.
Besides influencing overall wellbeing, the weather but also affected social outings. Participants often found their plans to visit friends or attend church marred by unpleasant climatic conditions that caused pain,

*So I just recently, Sunday, early in the a.m., here where I live, we have this really heavy fog which you know creates a bit of pressure on you. And I just thought oh my word I can’t even go to church today because when that comes in on me I am just used to hurting me everywhere. So what has happened to me in the last year is tremendous migraines and uh up to the neck and shoulders and some of them under your scalp.* (Catherine)

Thus, living with AD also meant having to accommodate unpredictable weather conditions, with warmer weather being identified as more favourable for pain management.

### 4.2 The Role of Leisure in AD

The participants of this study faced overbearing challenges as they tried to make sense of their life after diagnosis. However, they faced some common difficulties such as living with chronic pain and fatigue, dealing with uncertainty and daily stressors, facing employment hindrances and social isolation, and battling dwindling self-esteem and changing identities. Experiencing stressors on a daily basis triggered the need to cope with the illness. They attempted to move past barriers by managing their emotions, resolving issues that could be addressed, and learning to come to terms with persistent challenges by finding meaning and positivity in them. Leisure allowed participants to engage in constructive behaviours and exercise control by choosing activities that were enjoyable and valuable to them. Taking the time to reflect on their strengths and abilities
gave participants the opportunity to work through negative emotions such as anger, denial and pain, and accept their current circumstances. Leisure was a cherished source of coping that took their minds off the overwhelming effects of AD. For example, participants used free time to invest their energies into family and friends, thus minimizing social isolation and maintaining a strong support system. Leisure time also meant researching AD and learning about the condition as much as possible to educate themselves, their family/friends, as well as their physicians. Knowing how AD affected their bodies allowed participants to make better health and lifestyle choices, which in turn helped them manage the illness. Finally, participants used leisure to let go of unnecessary obligations, pursue old and new leisure behaviours, maintain cognitive wellbeing, and escape AD from time to time.

4.2.1 Using leisure to cope with symptoms

AD often triggered emotional roller coasters filled with feelings of grief, compromise, anger and exhaustion. Richard, Catherine, Pamela and June frequently used their free time to get away from the overpowering presence of AD. Leisure offered quiet moments for relaxation, calming overworked nerves, and soothe symptoms of AD that caused high sensitivity on sensory circuits (that are often damaged due to the chronic and degenerative nature of AD),

*I come home and I get quiet. And that’s because this is the place I feel like being that person. I can be myself. I push with everything I am to make people around me happy and putting on a face to try and give to other people and I do give to other people but ….I think noise and light, there is a high sensitivity to them with AD.* (Richard)
Pamela experienced sensory overdrives often and craved solitude to get away from the chaos and noise of everyday responsibilities. Indulging in her preferred hobbies (nature watching and leaving bath and food bowls for birds in her yards) gave her the chance to heal and get away from prying questions, judgments and symptoms of multiple illnesses,

*I don't handle any...let me see, let me get the word...sensory...too much sensory.*

*Whether it is movement, whether visual, or my hearing or surrounding, uh, I go to episodes where I black out. I go down like a rag doll. I can hear people but I cannot open my eyes or respond. My reception is so heightened I have to be very extremely careful about what kind of situation I am in. I am no longer able to go to church because even with my eyes closed and ear plugs in you would not believe how much sense I felt when people are too close to you....the clock ticking and the music and the vibration on the floor and uh it’s just too much.....that was a hard thing for me to quit. So I what I like to do is.....my husband put in a giant window in the back of our house..... and I can sit here in my chair and I have ...we have birds and squirrels and that is my reality and love. It is on the west side of the house, so the sun shines in the house...and I...I am just sitting here watching.....we have these different kinds of birds that come and take baths and this bath water thing and then we have these squirrels that we feed and they play oh they are hilarious! So that's my leisure. It helps me heal.*

Spending time in solace gave participants the opportunity to let go of things that held them back. Furthermore, occasionally doing nothing in their free time allowed them to escape from the pressures of personal and social responsibilities and connect with life more deeply. To ensure that they were not drained by events that required too much
effort and energy, participants turned to relaxing activities to take their mind off the constant stress of chronic illness. For example, Richard enjoyed daydreaming because it took his mind away from morbid thoughts related to his health. Sharing his enthusiasm for daydreaming, he said to me, *I love to travel. And I don’t have to travel physically. I can look across the street and wish something…..and it is like I am transported there.* Catherine mentioned that reading during leisure helped her stay engaged in the flow of things and cope with chronic symptoms such as nerve pain,

> It helps me get out of the naggy kind of aggravating kind of pain that I really can’t…it depends on what stage of pain you are in. So sometimes I’ll read. I used to do this with my girls way before I knew it was AD…… So they were always reading Nancy Drew and other series before Harry Potter and all that kind of stuff (laughing). I used to read these books to my kids…..and we used to laugh and talk about it and we would discuss all the characters and stuff and I saw that reading wasn’t something that was kind of important…..to remembering all things….it was frivolous and fun, distracting me a lot. (Catherine)

Taking the time to focus on their strengths and individuality raised their level of self-awareness and helped them evaluate their life choices (and direction) clearly. According to participants, this was an essential step to wellbeing because taking a candid look at themselves helped them consider what they could do, the priorities they should maintain, the goals they wish to achieve, and the behaviours they need to let go of.

### 4.2.2 Finding identities through relationships

During the interviews, participants spoke at length about the importance of relationships in their lives. Relationships not only served as successful channels to
generate positive feelings, but also helped them cope with the daily stressors of AD. Furthermore, relationships also helped participants establish firm familial and social identities, thereby indicating that close connections had a multifaceted role to play. Participants regularly invested large amounts of time and energy in relationships as spending time with near and dear ones offered them with emotional comfort, a connection to their former self, and stability in self-image. Furthermore, roles and relationships stemming from outside of home, such as advocating on online social networks or contributing to community events helped participants shape their social identities. Connecting with like-minded people helped them feel secure and needed. Additionally, developing and maintaining stable relationships with others also took their mind off the obscurities of a long-term illness. While most participants spoke of their relationships with their spouses (or the lack thereof), the most satisfying relationship for Pamela, Catherine, Richard and June were the bonds of love they shared with their children and/or grandchildren. Discussing the centrality of family in her life, Pamela told me,

\[\text{My grandchildren...you know God, my husband, you know those are basics but this idea....This summer I was so blessed and so excited. Each of my grandchildren came for one week to stay with me. My grandkids...if you could say they are my life right now. They are my focus.}\]

Richard also spoke of his son very fondly several times during our conversation. He said to me, \[\text{“My son may have five things on play here recorded that people don’t normally listen to so I listen to him. We just get lost in the music. I guess that’s my leisure time”}\]. Spending time with his children allowed Richard to fulfill his emotional needs. Having
his presence appreciated helped him take his mind off AD temporarily and fill some of the gaps in his self-belief. For him, enjoying his life with his children and grandchildren were especially important due to the lack of intimacy with his spouse. Grieving over the absence of a deep emotional connection with his wife, he shared,

That (the children and grandchildren) has been my greatest gift. Without them I would not have been...I would not have been in the relationship I am in at this point because I am fulfilling some of that....so there is a little bit of me that is grieving because I don't have the intimacy on the spousal level but I do have it with my children.

Continuing relationships with family helped participants secure the role of a parent and/or grandparent. This, in turn, made them feel needed and gave them a stable self-image, a solid identity that they craved for after losing their old world to AD and other traumatic life events. June conveyed to the importance of her son’s presence in her life to me,

But the majority (of coping mechanism) is my child at home and he needs taking care of, that gives me a lot of inspiration. And it gives me reason to just deal with it. If it wasn’t for that, it would make me very sore.

She further adds,

My daughter is grown and she can take care of herself but there are still things she needs her mum for..... I mean of course my son needs mom for almost everything. He is 14 and he is growing to be a man. He is not a little tiny kid anymore....so...but I feel without those two things I honestly couldn’t tell you. I don’t know if there would be anything else to keep me going. I mean most of the
times I am just on my couch and never even go out so they definitely keep me going.

Participants were not always successful at perfecting their personal roles. This especially occurred when they were fighting emotional battles that plunged them into depression. Regardless, they continued making efforts to be good role models to their children because they did not want to let them down,

…but that was the hardest time for me then [to find out that she had AD and had passed it on to her daughters]. When I came out of that depression, it was through prayer for me. I haven’t stopped since then. I felt badly and I was worried and concerned. But I felt like I need to be a good example to my daughters.

Devoting themselves to the role of parents and grandparents helped participants bounce back from their setbacks in a more constructive manner. Additionally, partaking in activities outside of home gave them social identity. The combination of personal and social individuality provided them with the opportunity to appreciate their uniqueness and talents, and see the self beyond AD,

That’s really my strongest gift…to preach…. and speak publicly. I am an emotional one for sure…..and I use a lot of humour and people laugh and by the end people are crying…and everything in between. I think it is a gift. I think it is amazing to understand the gifts you have been given and to be able to give them others. How fortunate and blessed am I! (Richard)

Social associations were especially advantageous in the absence of emotional support as friends and acquaintances made up for the lack of emotional connection that participants
sometimes experienced with their partner. Feeling needed as a spouse, parent or grandparent bolstered the participants’ delicate egos, and helped them shift their focus to what they could do rather than what they could not do. Thus, meaningful relationships formed an effective coping mechanism for participants to cope with AD as well as strengthen their identity. Personal and social relationships contributed to their wellbeing. Participants therefore strove to spend maximum of their free time in the company of friends and family members who were important sources of joy, peace, positivity and hope.

4.2.3 Using former and new leisure habits to escape AD

Richard, Catherine, June and Pamela would often engage in former and new leisure habits to escape daily stressors, albeit temporarily. For June, leisure acted as a buffer whenever she longed to escape the chronic pain caused AD,

*I loved to read but I have been on the couch since mid-September and I haven’t been able to read one book..... The pain was so bad I couldn’t even read a book! I watch TV and play video games sitting on the couch.... because at least the video games take my mind off the pain a little bit.*

June seemed to struggle with her new self the most, as she explained her guilt of not being able to pursue her dream of opening a bakery. She said that she was trying to make peace with the illness. However, despite repeated attempts, accepting her current lifeworld was far too challenging,

*I have never been lazy all my life. I mean I feel guilty for sitting around on a Sunday. I was always doing something. I have never done lazy in my life. If someone honestly called me lazy, I would completely lose it. I have never been
called the L word in my life. And that’s how I started to feel myself. I wonder sometimes am I lazy? Am I depressed? Now that I am on these steroids, I hope to get things going.

To calm herself down and still feel productive, she often used her free time to engage in making and painting - leisure pursuits that she held dear long before she was diagnosed with AD. Baking and painting not only provided her with joy and purpose, but also doubled as resistance towards the unwanted presence of AD (interpretative field notes),

I moved to a new place in September and I am still trying to get my house in order. And now that I am on these steroids, I hope to get things going. But now I still make art and do painting.

Learning new skills and putting them to use were beneficial to distract Catherine because they contributed to maintaining cognitive wellbeing and escaping the persistent pain to create something positive,

I never did Sudoku before…..I saw that if I really was in a really in a lot of pain or just couldn’t deal with it, because I still have a lot of the pain but its toned down most of the time, but there are still times as I was telling you when there is a big fog moves in and I’ll blow it. So doing those puzzles distracts me enough and makes my brain work in a certain way that you know when you are doing certain activities,……you are either using right left or a combination of the brain…….and I find that doing that [Sudoku] really helped me. That I don’t have to read anything, I don’t have to remember or recall stuff. It’s just a matter of figuring out puzzles, you know, constantly.
Leisure was not always easy for Pamela, who either hated being idle or struggled to keep pace with her grandchildren. Nonetheless, leisure did contribute to her wellbeing especially when the presence of her grandchildren (a more recent occurrence in her life) generated positive emotions in her,

But I must admit with the last one I was just...I was so ...the last one was pretty hard. But they uh look forward to coming to grandma’s and the fact that they...I never...I never, never, never thought that I would have my grandchild at my house for days let alone for weeks. That was just a miracle for me. So that is where I get my strength to focus.

Making e-cards for people she cared about helped Pamela appreciate the gift of vision and engage in activities that she liked. During our follow up interview, she was excited to share her new leisure interest with me, One thing that I have found that I enjoy doing....like today there is somebody whose dog died, and there is someone whose grandpa died...so I like making those cards for them and that helps me.

Richard, Catherine, Pamela and June were very honest in their disposition and mentioned that getting away from AD was not possible at all times. However, they mentioned that the process of (re)considering life choices was vital to self-care because they often critiqued themselves for not achieving as much as they did before AD and it was therefore, important to stay connected with their core self to disallow the illness from breaking their spirit.

4.2.4 Preventing further deterioration of AD

Through continual self-education, participants became aware of the progressive nature of AD. This motivated them to follow the ‘use it or lose it’ rule to reduce risk,
prevent further deterioration and promote overall wellbeing. Highlighting the importance of staying engaged in activities of any kind, Catherine said to me, “Puzzles help me keep my mind active and I don’t have to work that hard....You know you either use it or lose it”. Learning new skills was also a way for participants to maintain cognitive ability, as stated in the section above. Due to visual impairment caused by MS, Pamela said that she could not read much at this time. However, she mentioned that she adapted around this limitation by listening to audio books to enjoy the gift of sound and maintain her auditory capabilities: “Because of my original diagnosis with my eyes I could not read. So I am on the blind tape and so I get books and tapes to listen to”. During my follow up interview with her, she added that she had found a new leisure activity that did not strain her eyes too much and at the same time allowed her to maintain her cognitive abilities. Sharing her new found love of the Internet, she said to me, I was very very lucky [referring to her ability to see since her vision was corrected]...umm....and it’s because I like being on the Internet to research. Participants also discovered the meaning of self-care and combined leisure as they learnt more about chronic illness, consequently deciding to pursue activities that were not too overwhelming,

She [daughter] loves music and if she is listening to music on a good radio channel or if I put on a musical for her to watch, I will sit with her on her bed and she just likes that. She has mum all to herself you know and we will watch the music in Shrek or anything.....It distracts you, you know. And I am just happy because she is happy and she has got her mom with her for a while. (Catherine)

Sharing his thirst for new knowledge, Richard mentioned, Most of my life is built around social interaction or time with my family or I can sit and keep on learning something. I
love to learn. I love history. When the burden of multiple illnesses became too much, participants worked around their limitations by using strategies that did not jeopardize their wellbeing and still engaged their senses,

One of [my hobbies] is to be on the Internet. Now that I can see better and now that I can handle [symptoms]...I love researching on the Internet. I find that I love researching and finding little gifts that they [caregivers] would like, you know something special. So I love doing that. (Pamela, Interview 1)

Former and new leisure activities kept the participants’ wellbeing in check and helped participants take their mind off the daily stress of AD. Leisure also helped them maintain a positive outlook and greet life with optimism. Non-strenuous leisure behaviours allowed participants to maintain the identity of a “Do-er” (i.e., to continue doing something). Additionally, by sharing their knowledge with peers on social networking groups they continued the art of active learning and coped with the resources that were available to them.

4.3 Addressing Barriers in Leisure and Life

Even though leisure was useful to cope with AD, chronic pain and chronic fatigue continued to be considerable barriers in participants’ lives and leisure choices. Richard, Pamela, Catherine and June believed that these two factors influenced the way they experienced life as well as leisure. Richard previously enjoyed physical activities such as going to the gym and running. However, since AD, he was unable to partake in his favourite workouts anymore. Catherine noticed how easily she fatigued while giving swimming lessons to her daughter. June found out that she was no longer able to engage in baking or gardening as her heart desired. Pamela was unable to do much on her own
without the guidance of caregivers or her husband. To dodge challenges and maintain some degree of control over their lives, participants adopted a number of strategies that allowed them to address the daily constraints imposed by pain and fatigue. These strategies include breaking down tasks into manageable portions, resting between activities, substituting difficult activities with simpler tasks, and continuing to generate positive emotions by offering their empathy and support to those in need. Additionally, researching new information and keeping abreast of updated information on AD also helped them create individual self-management plans. Two themes that were common to all participants regarding addressing barriers emerged from the data. I have discussed them below.

4.3.1 Making behavioural changes to sustain wellbeing in AD

Participants adopted a number of behavioural changes to manage symptomatic flares, maintain energy and prevent further deterioration of their health. Some of the strategies adopted included eating well and maintaining physical movement, understanding triggers, and forgoing familiar routines. I have explained the sub-themes below.

4.3.1.1 Eating well and maintaining physical movement

Richard occasionally engaged in light stretching and cardio whilst relaxing on the couch or listening to his favourite music. This not only managed his pain but also prevented him from slipping into sedentary mode. According to Richard, setting small, realistic goals was more important than giving in to AD altogether. Explaining his health routine to me, he said,
I still take pain medicines. I tried to go without it and I just cannot function, I cannot..... You know but I have also found that if I do...you know if I do push myself [to exercise] it gets your blood flowing and it relieves the pain somewhat.

Sharing her strategy on wellbeing, Catherine commented that eating healthy was a priority in her family. She believed that the best kind of foods were made from scratch,

My family and I eat really healthy and drink a lot of water and that’s something we have always done and that is to basically eat really healthy and stay away from junk. If it is raw or natural or made up from scratch including making our own bread, that’s just how we eat. My husband and kids stay away from junk anyway so I think that helps.

Furthermore, taking initiatives over health also helped participants exercise control over their wellbeing and engage in self-care,

I take modern herbs, vitamins and minerals and uh I have a caregiver that manages for me so uh I have spent a lot of time in what you call meditation..... I am unable to walk....I uh....(pause) the only thing I do physically is I am trying to stretch out my body. I think I'd like yoga...I really think I would like that or something like that. (Pamela)

Since AD, participants mentioned that they had become very self-conscious about their lifestyle choices and were inclined towards better self-management to maintain residual health.

4.3.1.2 Understanding potential triggers

Understanding potential triggers that caused anxiety or worsened symptoms was also discussed as an important precaution to overcome barriers.
Pamela explained that avoiding physical contact was one of her strategies to avoid collapsing to overworked sensitive, sensory circuits,

*I used to not be able to go for my haircut. She [hairdresser] had to come to my home and it used to be that every time she touched my hair I would black out so she had to cut my hair when I was passed out. So for years I basically chopped off my own hair because I could not do it.*

Identifying perilous circumstances also helped Pamela keep away from risky environments,

*I had to go to the dentist there were sooo many people there, I blacked out. I shut down and I have a wheelchair because I am unable to walk so I sat in my….chair and had a meltdown. Anytime I can’t control my surroundings I am putting myself in risk.*

Due to the complicated nature of AD, participants were unable to always pinpoint potential triggers. However, maintaining a journal of triggers helped them become aware of risky circumstances and take appropriate risk management strategies to gain control over their health.

**4.3.1.3 Forgoing familiar routines**

Adopting new behaviours and habits often meant foregoing former routines and leisure activities and accepting the limitations that accompanied chronic illness. For example, not getting the chance to spend time with family would especially frustrate participants,

*The disease makes me feel….these days I don’t even have the energy to even get myself presentable enough to go do anything. And if I do, my attitude is well, no*
one wants a sick person anyway. And I don’t even go do things with my sisters, because I feel like I would bring them down. They want to shop, shop, shop and I can’t even keep up with them in walking......They walk so much faster than I do and it doesn’t take me very long to get tired and I am gonna have to sit down right now....and I don’t want them to feel like I am gonna have to sit down with you. So it’s just I don’t even ask anything of people anymore. (June).

Participants were motivated to incorporate well-balanced routines that allowed them to manage AD and work around pain and fatigue. One way of making a positive behavioural change was by modifying daily activities to suit their energy and comfort levels and not miss out on things that added meaning to their lives.

Now they [grandchildren] know grandma doesn’t do good and that she sleeps a lot and so they would just lay in bed with me, uhm, when they got up in the morning they would play on my iPad and let me go back to sleep....and then when I got up in the afternoon that’s when we did our tea party. So that’s when we did whatever.....And then I had one week in between each of them to rest.

(Pamela)

Slowing down or taking adequate breaks throughout the day was also a good way to ensure they could manage the symptoms during their time off,

I turn the lights off, and I close the blinds. And noise...my son is a drummer and when he plays in volume and he plays with style and rhythm. And we love music. But I have to ask him to turn it down and he asks, dad what’s wrong and I tell him I can’t do that anymore. I want as much quiet. (Richard)
Additionally, the importance of taking a back seat from time to time, especially with children, was also identified as an important coping mechanism. Catherine quipped, “So I am a tough mom so if I am not feeling well, sometimes I have to learn and not be like a drill sergeant”. Coming to terms with restrictions in life and leisure was challenging for participants. However, doing so helped them understand their limitations, and take care of their physical and mental wellbeing accordingly. Pacing life around AD was thus identified as an important coping strategy,

We are all getting together for a big football game because Seattle won and it happened to also be my dad’s 88th birthday so we were having my cousins come over and I was pretty...I don’t want to say I was stressed out...but it was more than I can handle. I don’t know what I am gonna do.... but probably I will go in to the room with my grandchildren who will play a game or watch a movie because that is a centralized focus I can handle. But being out with everyone now the talking the laughing and the football game the uh uh that’s more than my limit.

(Pamela)

Stepping down from household responsibilities, although discomforting to participants, was also identified as another self-preservation tactic. Catherine, Pamela and Richard therefore, allowed their respective spouses to take over some of their responsibilities from time to time. Taking breaks from activities helped participants rest and take care of their needs and priorities. Explaining the reluctant handing over of kitchen duties to her husband, Pamela explained to me,

My husband does all the shopping and all the cooking because I am not safe around knives or kitchen because I forget what I am doing and I disappear. The
only responsibility I have now is unloading the dishwasher and filling the dishes at night after my husband cooks and umm that’s it.

Giving up control of domestic responsibilities did impact participants’ self-worth. However, allowing their partners to lend a hand gave them the opportunity to physically and mentally pace themselves and prevent excessive strain due to physical and professional commitments. Since work was an important coping mechanism that buffered participants from daily stressors and at the same time helped them retain financial independence, most participants tried to find ways to create work engagements that were suitable. This involved cutting down on the number of hours or reducing commitments as need be to ensure that they did not stretch themselves beyond their limits,

* I have stepped down from a large church and started this one in a downtown ministry so I have been a part of that. Umm, I am trying to do some things, work a little bit, but it’s uh it’s probably pushing a lot of what I can do physically. (Richard)

Staying busy buffered participants from symptoms and offered channels of emotional satisfaction: “I don’t pastor as much as I did...I don’t do full time anymore but I do preach on Saturday nights”. Taking frequent breaks and accepting pain management interventions also helped them battle downtime. Richard states, “Well I think pain management seemed to be pretty successful for me. And I wouldn’t have thought that. I was a very strong person. I [still] take pain medicines”. Developing new adaptability skills and problem solving techniques (such as cutting their own hair instead of succumbing to challenges) helped maintain confidence and fewer disruptions.
Behavioural adaptations also meant keeping an active check on attitude to keep negativity at bay. Taking a philosophical approach to life, Catherine advised me,

*You know what I would tell someone like you? If an opportunity presents itself, go for it. There will always be struggles. We are all going to catch something you know. There is no guarantee that something isn’t going to happen. The only guarantee is that something is going to happen. And my advice would be to pick the best that life has to offer and do the best you can with it!* (Catherine)

Making adjustments to overcome symptoms and live well with AD meant substituting intense physical activities with less strenuous engagements, relinquishing control and learning to take breaks amidst busy schedules to allow adequate rest, and switching cognitively straining activities with arrangements that were less draining (such as listening to soft music in a relaxing environment as opposed to straining vision while watching television or reading). Adopting new behaviours after diagnosis also encompassed structuring daily life with adequate attention to personal accommodation and accessibility needs. Participants found ways to alter their everyday (and leisure) behaviours to ensure sufficient rest as well as time in the company of loved ones without getting overwhelmed by AD. To ensure a well-balanced life that did not burden them with constricted schedules and day to day activities, they developed habits and lifestyle choices that did not exacerbate AD.

### 4.3.2 Staying active and looking forward in life

An interesting paradox emerged while discussing barriers and plausible solutions to life and leisure with AD. This intriguing theme consequently discusses the participants’ love-hate relationship with free time. On several occasions, Catherine, Pamela, June and
Richard reiterated the impact of symptoms on their daily life. However, whilst discussing their approach towards life after diagnosis, they mentioned that living life to the fullest, keeping busy, and making efforts to remain physically and mentally active helped them with pain management. Sharing his tale of paradox, Richard told me, “When I was working full time, because I had to, and also because I enjoyed it, pain management was so much easier”. Fascinated, I requested him to elaborate. He then explained,

*I was so in tune with things that made me happy when I was young and I felt so good …I could stay in there (farm). I could help my brother 12 hrs a day and I didn’t have very much pain.*

Participants explained that keeping busy helped them defy AD because idleness made their situation worse. Staying active not only helped them be productive, but also prevented mental stress caused by a slow and uneventful lifestyle,

*I just do what I can do every day and I am slowly learning that I have my limitations and I can do what I can do each day and if I can’t do anymore, I can’t do anymore. I don’t like it. I don’t accept this as being the rest of my life. I just don’t. Someone has to find something that will work. Where we can at least be 75% normal again…..or where we can at least work. I have been looking for something to keep me sane because I am used to working. I am used to taking care of my family. I have come to realize that logistically I am a lot more challenged than I realize I was. So I keep trying to find ways to stay sane whether it is painting, or mixing art or decorating cakes or whatever I can try to do to keep myself sane. At least that way I am doing something! (June)*
While rest was vital to the participants’ wellbeing and they enjoyed taking time off daily responsibilities, inactivity made it harder for them to fight AD. Large amounts of free time on their hands subsequently agitated them and shook their self-image.

*I don’t have anything that I have to do and that to me is a stress because before I loved working. I loved being busy, my whole family I realize now we didn’t have hobbies because for us it was projects and doing things and working and now...* (Pamela).

Working or being involved in meaningful leisure pursuits also allowed participants to replace undesirable thoughts with more positive emotions,

*To take away all the negative stuff I feel and replace it with positive and get a positive result, a beautiful result [through work or other meaningful engagement] and that way I feel like I am doing something rather than just sitting on the couch right?* (June)

Thus, staying occupied and busy in everyday life or leisure helped participants maintain a healthy state of mind and look forward to life with more optimism.

### 4.4 Learning to live well with AD

The participants of this study displayed a strong desire to live well. They attempted to do so by learning to manage their health, take care of their emotional wellbeing, and engage in healthy lifestyles that contributed to their overall QoL. For example, participants adopted techniques such as making an effort to stay connected with family and friends or engaging in effective decision making to maintain their existing strengths and remain positive in their approach to life. This also helped the handle panic, apprehension, listlessness and other negative emotions such as uncertainty, fear, pain and
isolation caused by the constant presence of AD (and other morbidities). Taking medications in a timely manner, evaluating the best possible treatments, staying positive and appreciating the many blessings of life, and pursuing meaningful activities were identified as additional strategies to live well with AD. Furthermore, keeping busy and engaging in leisure helped participants manage symptoms and select activities that could be paced around the illness. Participants handpicked activities that were close to their heart to nurture their existing talents and share them with the world. Examples of common activities include advocating for AD, raising awareness of lesser known diseases, practising personal faith/religion, reaching out empathetically to others to lessen their burdens, and contributing to the pursuits and success of others (such as volunteering for this study). I have discussed the sub-themes in detail below.

4.4.1 Pursuing meaningful activities

Despite the everyday challenges of life with AD, participants were keen on undertaking and contributing to meaningful activities. They craved engagements that held personal value and highlighted their current abilities. While every participant enjoyed several different pursuits, advocating for the rare disease community and practising faith/religion emerged as the common themes. These two engagements particularly created hope, positivity and motivation in them.

A recurring desire to create awareness and support for rare diseases, especially AD, dominated the discussion on driving factors that motivated participants to live well. Since participants had personally faced many obstacles with diagnosis and management of AD, they were keen to help others navigate through these roadblocks. Participants actively volunteered their time and energies into sharing up to date information on
social/support networks (such as Facebook). Their knowledge also included tips on diet, lifestyle, medications, insurance coverage and current rare disease specialists. These social platforms cater to audiences across the globe and help in raising awareness about lesser known illnesses such as AD. Advocating held much meaning to participants because the spread of knowledge meant opportunities for research, funding, better treatments and potentially a cure. June, an active member on various discussion forums and groups dedicated to the cause of AD told me,

_ I mean seriously…I am not giving up that someone will find something that works for us. We may not be able to 100% the same person we used to be. We still may require more sleep. We may not be able to be on our feet all the time…but something that will allow us who we used to be. If we can take organs from other people and make that work then why is it so hard to figure this out? Because there is no one working on it. There is no awareness._

Promoting the rare disease community gave participants the opportunity to use their existing skills (of virtual speaking and technological savviness) and help others manage the progression of the illness. Becoming aware of their contribution to my thesis, they championed me to continue my efforts as they seemed happy to predict that my work would become a solid medium to reach out to more than just the AD community,

_…I then look at what talents have been given to me and then I think you know how do I make the most of this? I think AD is an opportunity [to help others and spread the word]. I can appreciate AD and just even made myself aware, that right now, helping you with this stuff…. (Catherine)_
Extending a helping hand to others generated positive emotions in participants. Additionally, connecting with like-minded individuals provided them with social companionship, emotional support, and empathy from people who were going through similar circumstances.

In addition to supporting the rare disease cause, faith/religion also held meaning in the lives of participants. Practicing religion helped them cope with AD because visiting church, offering prayers, reading religious scripts and making like-minded friends helped them create a new positive world and self-image. Discussing the things that keep him going, Richard told me,

Well it has truly been my faith. It’s honestly been like.....I told someone that I was probably 21 years of age when I felt came to personally understand Christ’s forgiveness and love. And to me to administer to others, I really believed I was doing what God called me to do.

I understood that believing in God/religion helped participants focus on the larger picture (in an existential sense) and examine the life purpose. Religion also gave participants an avenue to express themselves and resist AD,

This disease does not define me..... I may have AD but AD does not have me. I think for me in my faith....I believe that God whether we call it heaven or whatever, but the eternal lives that people believe in that God has made all things right. And that we have a perfect mind, a perfect being, a body, you know, not like this thankfully, but we are eternal creatures, we are eternal beings, we are not limited to this body.....to this life, to this pain and one day we will be free and we
will try to live the best we can and we can try to get others to understand that
God does love us and we must express that love. (Richard)

Like Richard, rejecting the presence of AD in her life, Pamela strongly conveyed to me,

I learned something that has been vital to me. If I say I have AD then I am
acknowledging it and accepting it. If I say that my body has been accepted by
AD, I am not...welcomed it in to my life. This is a difference in saying I have AD.
Or the people that say...anything you say "I have" you, have said ok to have that
dictation over me. You are a dictator over me. So anything that I say or write...I
will say my body has been affected by....or you know....this is attacking my body.
So if someone says what disease do you have? I don’t have any disease! I don’t
have ANY. I have not...I have grandchildren but I don’t have any disease. I don’t
have any ...they do not have any authority over me! I have not welcomed them in
to my life. And when I see people you know when they write ohhhh I have this and
I have this and no you don’t! And if you do stop it! Don’t have it!

Identifying with this part of their journey, I told them that I often feel the same way and
relate to the frustrations of being assigned a “master status”. Hearing this, Pamela said to
me,

Right, and you are not [AD]! That needs to be ....If I could have a sign on me it
would say, I had a horrible time in my life falling apart. I was no longer who I
was and I didn't know who I was anymore and so I had to put a saying up and I
wrote, “My life is not who I was. My life is not who I am. My life is who God
wants me to be”.
Showing the importance of faith in helping her disconnect from AD, Pamela added, “And that had to be my focus. It was who I was. And it wasn’t this crumbled down thing that I was now. My focus had to be totally on what HE wanted me to be”. As I mulled over Richard and Pamela’s assertions, I realized that religion not only brought purpose, wisdom, hope and joy in their hearts, but also helped them forge a deeper bond with themselves during the good and bad times,

    So I have this belief that I am not just here accidently or just come in to being flying through the eons and we just bump in to each other.... There is a reason why I am here and so that helps me in that belief and that there is a reason why I am going through this. And there is something that my heavenly father wants me to become regardless of this challenge. And so I become you might say a co-partner in helping create myself and he has decided that I can choose what I am going to do with who I am. And if there is something I want to become, how do I do that? First of all, I just recognize that I have this belief and then I think I belong to my heavenly father and I am his daughter. (Catherine)

Neutralizing the effect of AD to some extent, keeping faith/practising religion not only helped participants transform their distress into meaning but also taught them gratitude and empathy. Counting her blessings, Catherine reflected, “I would have sympathy for people’s problems and conditions and pains and diseases you know. And now I have empathy and that is different from sympathy because you know now exactly what it feels like”. On more than one occasion, participants mentioned how fortunate they were to have the support of their family, friends and/or caregivers, and that finding benefits even in the most distressing situations made them thankful for everything they had,
I know sometimes things can get negative (referring to the online support group on FB) but you have to realize that not everyone has got your situation. I have read some of the statuses on the group that is just so heart rendering and I feel so blessed. Some of the ladies and gentlemen really have it tough. And when your family doesn’t understand, are non-supportive or even more so critical or leave them, it makes it so difficult. (Catherine)

The experience of religion and chronic illness made participants appreciate life more and become sensitive to the sufferings of others. Richard stated: “I was very fortunate to pastor, to reach out, to minister to other people, lots of people”.

Just as participants discovered the beauty of self-actualization and self-awareness during leisure, they realized that involving themselves in altruistic and empathetic pursuits in their free time helped them affirm their abilities, maintain positivity, and raise self-esteem,

Helping you really makes me happy....I wish I could do more ....I want to advocate as much as I can....you never know who it might help.....and that way, I also feel like I am doing something and not just sitting on the couch. (June)

As mentioned above, participants were especially excited to contribute to this research project and went out of their way to help me. I especially became aware of their caring traits, when I realized that Richard was having a bad day on the day of our interview and still did not pull back. Brushing off my gratitude and apologies, he told me: “I so appreciate any effort to help the sufferers of AD”. Lending their time and energy towards the success of others was a source of fulfilment for participants. They expressed on several instances that they looked out for opportunities to help others in
whatever manner, including providing advice and support – in person or on online networking groups and social media,

There are many people who don’t appreciate what I say on social media [about concerns related to fatality in AD] however, I don’t care anymore. The ones who don’t want to hear the truth [that certain kinds of diet, medications and lifestyle are not good for you] will not change my mind about helping the ones who want to. (June)

4.4.2 Staying positive and appreciating life

Staying young at heart was a life mantra that often served participants well, especially on days when the presence of AD was extremely overwhelming. Enjoying the simple pleasures of life, living in the moment, experiencing joy and happiness despite daily challenges, and seeing the world through young eyes helped participants maintain vitality and a positive attitude,

I am still feel very young....I am only 44 years old. I realize now I am still a very young at heart person....I mean I am very young at heart. I still love to watch teeny bopper things with my kid when she was underage....you know....do all that teenager stuff with her. I am still very young at heart.....and I also have a 14 year old who keeps me young at heart. Because I know what young people are like. I don't see myself changing. I will always be young at heart. I will never believe that I am old. I tell people that even when I am 80, I will be 20 years old. (June)

Sharing his appreciation of life, Richard shared that he loved making people laugh and smile, especially during church sermons. According to him, staying young at heart was
pertinent to learning about people and appreciating the many good qualities they brought to the table. These small enjoyments empowered him to maintain a positive attitude.

Exciting me with his enthusiasm for life, he chirped, “I just love to live! I just love life! I love learning! I love learning and hearing people and learning what makes them tick”.

Introspecting on his occasional preoccupation with AD, Richard stated that it was important to not lose sight of the many benefits life has to offer,

\[I \text{ think some get so caught up in treatment and treatment and uh what’s out there and uh some of those aspects and I wanted to say that we are not in our lifetime going to find something that is just going to turn this around...this is a disease we have to learn to live with until we stop living but you can consume yourself trying to look for a cure or just enjoy life.}\]

Following closely on Richard’s way of life, Catherine also chimed that despite chronic illness, it was important to find what remains unique in us and share it with the world,

\[If you have that opportunity to be a wife and a mother I would say go for it. Don’t let your fears hinder you. I would never want my beautiful daughters to not marry or to not have grandchildren myself because of AD. I think we all have something unique in us to offer and we must rejoice in that.\]

Participants believed that staying young at heart has nothing to do with chronic illness or the age-appropriateness of behaviours,

\[You know I found something that really helps me. I call them the 4 Bs. The four Bs for me are...One is belief, one is belong, one is become, and then the last one is because. And the last one “because” is broken off to “be in a cause” and to “be a part of it”. So I thought what’s my life’s cliché? What was I meant to\]
accomplish? And who was I meant to help? And what was I meant to do that only I myself am meant to do or be. I literally think to myself, how do I rejoice? And how can I take some joy in every situation? (Catherine)

Participants candidly opened up that multiple medications and side-effects of symptomatic treatments did dull their enthusiasm and shine periodically. To combat such situations, they would either spend their free time in the company of family and friends who appreciated their presence, or they would spend time in solitude to locate the main cause of their sourness. Actively striving to be happy helped participants avoid negativity. This in turn helped them cope with AD better and live well despite challenges,

The pain medicines doctors put me on....it made me a very bitchy person. I mean I was beyond evil. Rage, like roid-rage (steroid rage). I mean I was angry. I thought I was just being grouchy because it was Christmas time and I was going to be myself. My daughter couldn’t get off work and my son was with his dad. But when they started that patch and it was over after Christmas, I wondered why was I still so grouchy and mean? And it hit me it was the medicine. But because I am so young at heart, I will never be a negative person. (June)

The findings thus support the initial suspected contention about the relationship between leisure and rare chronic illness management. The results show leisure plays a role in coping with and self-managing AD by allowing them the time and opportunity to heal from everyday stressors, cope with the help of close relationships, use leisure to distract them from pain, and practice empathy and be there as a support system for others.
Chapter 5: Discussion and Conclusion

5.0 Introduction

This study sheds light on our understanding of the subjective experiences of leisure within the context of AD. This research is very unique because, to my knowledge, it is the first study that examines the relationship between an alternative, therapeutic resource such as leisure and a rare chronic illness like AD. This study adds to the small but growing body of literature that addresses the concerns of the rare disease populations and explores how one can live well with the gifts of today, whilst awaiting greater care and attention from medical and scientific communities. The findings demonstrate that persons living with AD experience many challenges in the form of constant stress, symptoms, and compulsive and voluntary adaptations. Living with AD means experiencing difficulties in diagnoses, learning to manage the illness, losing control over life and making amends to embrace positive behaviours to overcome daily barriers and accept this illness as a part of life. The interviews with participants revealed several insights about leisure as well, especially with regards to its role in coping with AD. The results consequently indicate that it is possible to live a meaningful life after diagnosis and that there is a role for leisure in rare disease management. I begin this chapter by considering participants’ accounts of their lived experiences about AD with regards to current literature on rare diseases. Following this, I will shift the lens on the meaning of leisure in the lives of participants including discussions on how participants used leisure to cope with the illness, manage the symptoms, create meaning and purpose, and look forward to life with positivity.
5.1. Examining Life with a Rare Disease: Challenges in Diagnosis and Healthcare

While rare diseases do not raise immediate alarms – perhaps due to a combination of lack of knowledge, awareness and diagnostic tools, the concerns related with these illnesses are no less pressing than any other long term, chronic condition. These diseases can strike between 6%-8% of the population during their lifetime. Even though this statistic may seem low, the total number of individuals affected by rare diseases is 30 million in the European Union and 25 million in the United States alone (Agazio et al., 2004; Schieppati, Henter, Daina, & Aperia, 2008). Regardless of the geographic region or statistics associated with rare diseases, there are some common characteristics that are inflicted on the community that receives a rare disease diagnosis. These diseases are chronic, debilitating, involve emotional and/or physical disabilities and consist of a comprised QoL, thus calling for constant attention and care from specialists (Garrino et al., 2015).

Realizing the vulnerability of the rare disease community, Schulenburg, Graf, and Frank (2014) noted that on the way to a diagnosis, patients often go through a series of tests and examinations. However, very often they neither receive appropriate treatment nor a name to their illness. Richard, June, Pamela and Catherine experienced substantial delay in diagnosis, treatment and care. Chasing one physician after another, participants found it challenging to find a doctor who was willing to acknowledge their symptoms, let alone confirm that they were suffering from AD and/or subsequently treat it. Not knowing what was attacking their health made it harder for them to treat or manage their symptoms. In rare diseases, where the possibility to find a cure is very difficult if not nearly impossible, managing the progression of symptoms and intervening swiftly to
avoid them from worsening becomes critical (Garrino et al., 2015). Not finding suitable answers to dwindling health and delay in diagnosis makes it harder for people with rare disease to control the pathologies of the disease or the remissions and degenerative relapses of the illness that are required together with long term treatment (Garrino, et al., 2015).

Like other rare disease populations (Schulenburg et al., 2014), medical unawareness and lack of adequate information systems also affected participants as they struggled to bear the consequences of their physician’s lack of knowledge. Participants narrated experiences in which they were left untreated, prescribed medications on a trial and error basis, or given drugs that were solely based on the discretion of the physician, with no input from them. I found Catherine’s story to be particularly worrisome because it demonstrated the price a patient has to pay due to medical ignorance. The doctors, not being aware that operating on lipomas might cause them to proliferate in numbers, supported Catherine’s decision to surgically remove multiple lipomas that were causing her pain. The error in judgment cost Catherine months of healing, scarring and regrowth of tumours that exploded all over her body and filled her stomach with lipomas, resulting in physical and psychological trauma. After mulling over Catherine’s experience, I reflected on my own and wrote the following:

March 12, 2015

Unfortunately, in August 2014, similar to Catherine, I also had the misfortune of facing medical negligence by a famous plastic surgeon who operated on my lipomas (under local anesthesia) and failed to educate me about their regressing nature. During the procedure, the surgeon relentlessly applied manual pressure to the targeted lipomas
to detach them from my subcutaneous skin, causing unbearable physical pain that tore through every nerve of my thigh. My cries and pleas to discontinue or at least pause the procedure fell on deaf ears as I lay hurting on the hospital bed drifting between consciousness and unconsciousness as his fingers continued digging deep into my flesh. The scarring and bruising remain testaments to my physical and emotional trauma. Even after a year of the incident, the thought of the nauseating pain makes me grimace and triggers migraines.

Catherine’s narration bore traces of similarity with my experience, where the wounds of the surgery dug deeper than physical injuries. Unfortunately, due to lack of literature and adequate materials to guide physicians, they are often left grappling in the dark, blundering their way to finding the best possible treatment for their patients in the absence of specific clinical trials, case studies or subjective experiences of drug variations to refer to (Garrino et al., 2015). The lack of available case studies and references may create more hurdles for patients inadvertently, as doctors who are unfamiliar with relevant information remain inept to lead their patients to physiological and psychological safety. June’s doctor declining to believe that her lipomas hurt and subsequently refusing pain-management is an example of lack of collaboration and trust, causing the patient to remain in the lurch and suffer for months, without any fault of theirs. June eventually handed in multiple opinions from specialists and changed several doctors, presenting each of them with research collated from the Internet. Her efforts paid off when she finally found a doctor who was willing to recommend pain management. June’s experience reveals that the lack of acknowledgment and understanding from physicians can create undue barriers for people living with chronic
disease who are trying to make sense of their physical and/or mental anguish on their way to potential treatment.

On the road to determining a disease, physicians often forget the central role they play, not only in the diagnosis, but also in the patient-physical relationship (Barbero, 1995). Indeed, there are doctors who work very hard to be patient and understanding towards the feelings of inadequacy and frustrations that persons with rare diseases experience (Garrino et al., 2015). However, when traits such as empathy, humanity, and helpfulness are not exhibited towards persons who are trying to make sense of their unusual diagnosis, finding physicians who do not give up and are genuinely interested in sharing whatever information they have on hand with patients and their families can go a long way in the management of mental and physical wellness (Garrino et al., 2015). The lack of understanding and empathy from health professionals can especially become barriers to a patient and their families’ mental wellbeing because opinions and advice related to health and safety outcomes are generally taken seriously and seldom second-guessed (Barbero, 1995). As well, since chronic illness often causes day to day caregiving responsibilities to fall on the patient and their families, the absence of effective collaborative relationships with health care providers can prevent patients and families from better handling self-care tasks (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

Barbero (1995) emphasizes the need for sufficient time and patience to allow avoidance of confrontations between families and their change in perception of their loved ones. He adds that the process of diagnosing an illness (or altering the diagnosis as new information emerges) needs a steady flow of information in addition to time and
recognition of the changes that are to accompany the announcement, even for family. The effect of a chronic diagnosis itself leads to major changes in the perception of the self by the individual who is diagnosed and, eventually the family's perception of the individual. The individual and their family, therefore, require time to process the implication and meaning of the disease, as the process of accepting and understanding a diagnosis involves clarification and interpretation with the physician over many sessions (Barbero, 1995). Thus, diagnosis can be conceived not solely as an activity of the physician, but also a parallel incorporation of a modified sense of self-evolution in and around the patient (Barbero, 1995).

Discussing the often overlooked centrality of individuals with rare diseases within the diagnostic and treatment process, Garrino et al. (2015) noted that individuals with rare diseases, like the participants of this study, are usually very well informed about their disease and the treatment possibilities. Their knowledge usually stems from reading texts, speaking with independent medical staff, researching over the Internet, or attending conferences on the subject. If doctors invite individuals with rare diseases for a discussion and allow them to act as mediators to their own health, elements of building a solid communication and relationship can then begin to come to the fore. Moreover, the collaboration and joint efforts can also make the individual feel like they have some autonomy and control over their health (Aymé, Kole, & Groft, 2008). Thus, if healthcare professionals become more sensitive and open channels of communication with patients, several individuals journeying through similar experiences as the participants, may be spared the physiological discomfort of living with symptoms that can be addressed much earlier.
On more than one occasion, Richard, June, Catherine and Pamela mentioned that whilst the uncertainty of an impending diagnosis was painful, the nonchalant attitude of physicians caused even further distress. The lack of validation or concern from healthcare professionals triggered negative emotions in participants, especially when, like most patients, they had absolute faith in the medical community’s abilities to solve any kind of health related problems (Cipolletta & Oprandi, 2014). It took participants several years of experiences with doctors, clinics and medical research centres rejecting their ill health and symptoms, or simply failing to identify the source of their misery, before finding a physician who was compassionate and caring about their needs. June, Catherine and Pamela had to travel to various cities across the United States to find answers to their deteriorating health. This revelation aligns with Schulenburg et al.’s (2014) observation that people with rare diseases are often so desperate for medical care and attention that they are willing to travel abroad to make arrangements for their treatment. This not only demonstrates the despondency of the rare disease community and their struggle for assistance with their health but also, from an economic point of view, displays the inequality of healthcare access (Schulenburg et al., 2014).

The monetary, physical and emotional cost of getting diagnosed with rare diseases are also so high that often by the end of the diagnosis, individuals are only left with pieces of the world that they were once familiar with. Although participants felt lucky to have the love and support of the dear ones and a team of doctors who were helping them manage their pain and symptoms at this time, they mentioned that the long and winding path to a diagnosis, symptom management and learning to live well with AD requires herculean efforts, time, endurance, patience, wisdom and support.
Living with a rare disease can be an agonizing process in itself as it can attack any organ or part of the human body (Garrino et al., 2015). Most successful interventions in chronic disease management take place when the doctors and healthcare team members ensure that the patient receives appropriate clinical and self-management support (Wagner, 1997). Lack of effort and guidance can add to stress and apprehension in the lives of individuals living with chronic ailments. Lippman (1997) states that health decisions should not be based solely on the opinion of the physician or health plan administrators. To regain some control over one’s own health, questioning the different available options of treatment and trusting one’s instinct also go a long way in locating the right kind of healthcare. Creating effective population based care, treatment plans, evidence based clinical management, adequate consultations (between the patient, their families and doctors), offering self-management support, and sustained follow ups are all crucial steps towards effective chronic disease management (Wagner, 1997). Through collaborative efforts between the individual, healthcare practitioner(s) and family members, healthcare costs can be reduced and lives saved. The process of chronic disease including misdiagnosis, potential prognosis, the need for positivity and hope, a plan of therapy as well the presentation of evidence related to the diagnosis has universal application (Barbero, 1995). Errors in diagnosing or treating a chronic illness can also cause difficulty in support programs, insurance policies, and suitable vocations to cope.

This clearly shows that there is an urgent need for restructuring the way rare chronic disease management is currently handled. The long range effects of an improper diagnosis can often influence behaviour and development because more often than not, diseases are complex with a great range of expression. The medical community,
therefore, should recognize that when an error is made and exists for protracted intervals, it is not a simple process to reverse (Barbero, 1995).

As participants in this study narrated their lived experiences, I realized that viewing themes on life with AD as a whole, the challenges of this disease are very complex. From delays in diagnosis, to everyday stressors including susceptibility to weather, physical pain, identity erosion, loss of opportunities and day to day battles, rare or orphan diseases are unique, misunderstood, and severely neglected (Garrino et al., 2015; Williams, 2011). The difficulty in diagnosing a rare disease and the accompanying unawareness of doctors is a matter of great concern. Additionally, it is also relevant to our healthcare system, because delay or inaccuracy in diagnosis only adds to the current burden, as persons with current or potential rare diseases scamper for medical care and attention from clinic to clinic. Considering the fragile and degenerative nature of rare diseases (or any chronic illness), it is necessary that people living with them receive adequate medical attention and healthcare, as they often result in serious disability and a comprised QoL (Garrino, et al., 2015).

5.2 Coping With AD Through Leisure

This study broadens and deepens our understanding of the subjective experiences of AD. It also provides insights into the role of leisure in stress and symptom management as well as identity formation. Leisure has been an evolving area of inquiry in stress and coping (Iwasaki & Schneider, 2003; Kleiber & Hutchinson, 2010). Leisure engagements that are personally expressive and allow continuity of significant past relationships have great importance in restoring meaning and direction (Nimrod & Kleiber, 2007). Such activities are also likely to reinstate perceptions of competence,
control and freedom after experiencing a negative life event (Hutchinson et al., 2003). These qualities are known to moderate the impact of stress on one’s wellbeing (Coleman & Iso-Ahola, 1993; Iwasaki & Mannell, 2000). The interviews with participants revealed many complex emotions associated with AD. Their narratives also chronicled positive transformations that occurred amid their attempts to make sense of their lives. Participants experienced the joys of continuing to share and spend time with family, enjoy old and new leisure habits, and take on roles and responsibilities within and outside their homes. Their leisure habits also helped in the sustenance of identity which became a crucial element in coping and living well with AD. A stable self-image helped participants have faith in their capacity to control the illness. These positive transformations continue to act as practical solutions that assist participants to transition to their normal routines, indicating that they found ways to cope with and manage an illness that affected their physical, emotional, mental, sensory and motor capabilities.

In the sections below, I discuss a number of coping methods that were adopted by participants. This study is meaningful in the sense that it brings together several coping models that highlight the similarities and differences in coping strategies of each participant. Since every participant had a personal coping style that was unique and no one coping model could do justice to their experiences, I begin this section by first placing my findings within the current literature, beginning with Kleiber et al.’s (2002) work on leisure as a means of coping with negative life events, which applied to my study in a multitude of manners. Then, I discuss additional coping methods that participants drew on to engage in meaning making whilst coping with AD. Third, based on the insights that I have gained from the study, I will discuss how participants used
leisure to shape their identity and overcome barriers in life and leisure. Finally, I will discuss the practical implications of this study and make recommendations on future research.

5.2.1 The role of leisure in overcoming barriers

Kleiber et al. (2002) identified four functions of leisure (discussed in Chapter 2) in transcending negative life events. They were: using leisure to buffer and distract the self from negative life events; engaging in leisure to generate optimism and hope for the future; choosing leisure activities that promote self-protection and continued familiarity with past engagements; and directing leisure activities towards self enhancement, restoration and personal transformation. Participants experienced all four elements that helped them manage barriers in the form of everyday stressors. Richard often engaged in daydreaming to escape AD. The fleeting moments of freedom protected him from the constant presence of AD and helped him heal his shaken world in a more positive manner.

Passive mental escapes or even temporary escapes to distract oneself from the negative (Ulrich, Dimberg, & Driver, 1991) allow people to be refreshed and better handle problems (Iwasaki & Schneider, 2003; Kleiber et al., 2002). Catherine enjoyed spending time with her family at every possible chance, because these opportunities meant distraction from negative emotions and chronic pain. She cherished sharing jokes and humour with her husband because the laughter and joy demonstrated that AD did not control her life. Experiencing shared leisure generated positive emotions and provided an optimistic outlook towards life. Pamela enjoyed nature and the company of her grandchildren even before she was diagnosed with multiple morbidities including AD.
To her, watching birds and squirrels play in her yard and having tea parties with her grandchildren (after restful naps) were activities that connected her to her former self. Continuing to choose stable activities from her past reminded her of her former life and abilities. As Kleiber et al. (2002) suggest, taking part in familiar leisure activities helps in the affirmation of identity and reinforces valued aspects of one’s (former) life.

The final component of Kleiber et al.’s (2002) leisure-coping strategy applied largely to June who noticed that her levels of self-awareness had heightened since the diagnoses of AD and Rheumatoid Arthritis. Based on this realization, she restructured her life goals (for example, focusing more on her children than family feuds), took up new activities (such as video-gaming) and strived to live more in the present than brood over the past or feel anxious about the future. By staying involved in the above behaviours, participants attempted to transcend AD and preserve the self, exercise choice and freedom and distance themselves from everyday stressors. Furthermore, as participants paced their lives around people, activities and circumstances that brought out the best in them, leisure became a helpful resource to spur optimism, look forward to the future, and engage in self-enhancement and personal transformation.

5.2.2 Meaning focused coping: Finding silver linings

The findings of this study signify a paradox of loss and gain. While AD dented the known and cherished, leisure attempted to remedy the damage to some extent. The participants’ juxtaposing experiences, at first, bewildered me. However, with time, I came to realize the criticality of leisure in letting participants move on with hope and positivity. Amid the myriad of stress, leisure added meaning and value to their lives, and helped arrest the diminishment of roles and responsibilities that were a part of their
identity. During data analysis, I also found myself become increasingly aware of my own thoughts and emotions. This ultimately helped me locate myself further in a study I am so intricately linked with. I have included an entry from my reflexive journal below because it demonstrates my initial attempts at understanding the intriguing world of AD from another’s perspective, in addition to showing the complex navigation between positive and negative emotions in chronic illness.

**February 28, 2015**

*I am going through the data and it looks like the participants have undergone a great deal of transformation, just like me. Their experiences swirl in my head, as I try to make sense of their words and the meaning behind them. There is an irony hidden in their story that intrigues me. Their voices were full of paradox – as if riding waves of happiness and sadness concurrently. I imagine life as a sand castle that stands whole, serene and beautiful on the beach. And then these huge waves occasionally come along and pound the castle down without much warning or ado. The grains of sand hit by the water get scattered by these periodic unforeseen events. Regardless, their fundamental beauty and characteristics don’t change. We are those grains of sand, blown around by the waves of human emotions from time to time. Yet fundamentally, deep down, we are resilient creatures, adapting and moulding to the circumstances we find ourselves in. Individuals with chronic illness are no different than individuals without chronic illness. However, painful spells of symptoms, medications and low self-esteem frequently strew us. We do bounce back, like any other, coming up for air with renewed strength and knowledge about the world within and around*
us. This makes me wonder if it really takes us humans some level of suffering to dig deeper and find ourselves beneath the surface of all this pain and confusion that occasionally accompanies life.

AD crumbles my foundations sporadically. Nevertheless, I somehow find my way back. I am unbelievably, in some bizarre way, grateful for AD. It helped me appreciate whatever I have today. It eggs me on to cherish the small joys of life and appreciate access to healthcare, food, residual health and friends and family. And yet I would lie if I said that I do not find myself anguished with the challenges of this disease. I do find it hard to be positive sometimes, especially when new neurological symptoms plague me. Nonetheless, I am grateful to have the chance experience this beautiful life and do what I love – teach and pursue knowledge of my choice. I am afraid when I think about my future. It looks cloudy and burdensome. And yet I am thankful for these hardships because they help me inch closer to the person I have always wanted to be – a person who loves and lives deeply and makes wiser choices. Thinking about the limited energy and perhaps even time that I have, I am beginning to live my life with greater freedom and peace, doing what my heart desires. Despite my challenges, I believe I can make a difference in people’s lives. I can be there for them, offer kind words, a shoulder to cry on, or share a joke. This makes me believe that perhaps even in the midst of futility, it is possible to find meaning and purpose. Perhaps it is possible for us to be that wildflower that sprouts rebelliously in a bed of gravel. And maybe helping others can fill some abysmal voids that gnaw at us, regardless of our backgrounds and personal circumstances.
As I engaged in reflexivity and continued analyzing the data from different angles, I realized that stressful situations generally do not evince positive undertones. When we consider coping, we assume that the process largely revolves around the regulation of distress (Folkman & Moskowitz, 2007). In chapter 2, I defined coping as a culmination of cognitive and behavioural responses to situations appraised as stressful (Lazarus & Folkman, 1988). For the purpose of this study, coping also refers to the various thoughts and behaviours people use to regulate emotions and address stressful situations (Folkman & Moskowitz, 2007). Folkman and Moskowitz (2007) state that while coping with stressful situations, it is possible that an individual can experience positive emotions because coping refers to the need to overcome or master a situation (such as wanting to make efforts to thrive as I state in my journal). This, in turn, implies something to look forward to (even if that means crossing hurdles to get to the sunny side of the fence). The hope of getting through a stressful situation can give birth to renewed vigor, strength, optimism and confidence, thus establishing positive tones to the process of surviving threatening circumstances (Folkman & Lazarus, 1985; Skinner & Brewer, 2002). Positive emotions are vital to successful coping (Genoe, 2013; Tugade, 2011). Catherine, Pamela, Richard and June used leisure-based engagements to cope with AD. They continued with former leisure habits as well as implemented new behaviours to enjoy life without jeopardizing their health. Working around leisure constraints and adjusting their pace around AD led to positive changes in their lives, which, in turn, led to the meaning-making, active engagements, and consequently, successful coping strategies.
The participants’ attempts to generate positive outcomes in their leisure contributed to positive emotions while coping with AD. Activities such as meeting friends, spending more time with loved ones, developing greater empathy for others, letting go of redundant things, appreciating life more deeply, and continuing to find sources of joy helped them deflect negative circumstances when they arose. The participants’ coping strategies mirror Lazarus and Folkman’s (1984) Cognitive Theory of Stress and Coping, which is an appraisal-based method of coping. This process indicates that when an individual experiences a stressor, such as a chronic illness, they appraise the stressor to determine its significance (Genoe, 2013). If an individual feels that a stressor needs attention because it is challenging or threatening, then they consider their options for coping (Folkman, 2008). If the person feels that a stressor or situation will not die out on its own and requires action on their behalf, they may then opt for problem and/or emotion focused coping strategies depending on what the situation demands (Genoe, 2013).

In problem focused coping, the individual evaluates the problem clearly, looks for possible solutions, weighs the pros and cons of every alternative, and eventually settles on a decision. Emotion focused coping sees an individual use tactics such as buffering, avoidance, minimization, distancing and positive transformations to cope with an undesirable event (Folkman, 2008; Lazarus & Folkman, 1984). Richard, Catherine, June and Pamela shared a number of problem focused coping strategies such as restructuring their homes, carrying notebooks to deal with cognitive clouding, engaging in religious and spiritual pursuits, helping others, and taking frequent breaks. Additionally, participants also embraced emotion focused coping strategies by investing their
sentiments into close relationships, developing empathy, reaching out to others, discussing their achievements and distress on virtual support groups, attempting to engage in hobbies to distract themselves from the pain (Hutchinson et al., 2003), and focusing on former and current abilities. Practicing the art of letting go, enjoying the present moment, living life to the fullest, focusing on meaning and purpose, and spending time in solitude were also identified as additional strategies.

The participants of this study explained that they experienced incessant stressors and struggled to maintain normalcy. To not lose themselves to AD any further, they attempted to engage in activities from their past or create new ones to keep their senses engaged. By staying involved in the lives of their children, lending a hand in household chores, spending time with family, and maintaining social connections over the Internet or in person, participants did their best to incorporate valued engagements in coping with AD. My research is unique because it highlights emotion and problem-focused coping strategies in AD. However, another interesting aspect that further distinguishes my research is the fact that participants drew on another appraisal-based coping strategy known as meaning focused coping (Folkman, 2008), an area of study that has not been explored within the context of any rare disease. Meaning focused coping is usually triggered when stressful situations remain unresolved, such as the presence of a chronic illness. In this method of coping, a 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 wellbeing during a difficult time (Park & Folkman, 1997; Folkman, 2008, p. 6).
Meaning focused coping involves five components. These include: benefit finding, benefit reminding, adaptive goal processes, reordering priorities, and infusing ordinary events with positive meaning (Folkman & Moskowitz, 2007; Folkman, 2008). Below, I discuss how the participants drew on meaning-focused coping to deal with a stressful and persistent life event such as AD.

The first component of Folkman’s (2008) meaning focused coping is benefit finding. Benefit finding refers to those elements of transformation that most humans undergo when they experience sickness, loss or some form of suffering, namely wisdom, maturity, patience, competence, appreciation of life, the importance of what truly holds meaning, and spirituality or a deeper connection with a higher power (Folkman, 2008). Pamela, Catherine, Richard and June believed in a higher power/religion that helped them accept and let go of changes (both internal and external) that they could no longer control. A connection with God and/or religion held relevance in their lives because it helped them accept that their lives had value even after a diagnosis, and resist that AD could strip them of their joy and happiness in entirety. This belief, in turn, generated positive emotions and appreciation of family, friends, residual health and feeling empathy towards others. The challenges caused by AD brought about a sense of humility and surrender that participants did not recollect having before the diagnosis. As time went by, they developed forgiveness, understanding and closeness in their interpersonal relationships due to the threats to their health. Their connection with their loved ones bestowed them with the ability to see beyond their own distress and become more empathetic towards others. In many ways, AD helped them become better people. These lived experiences confirm that positive transformations can result from traumatic events.
(Helgeson, Reynolds, & Tomich, 2006). The fact that participants believed that their life had meaning, purpose and quality was enough motivation for them to want to find the benefits of fighting back and channeling their energies into relationships, leisure activities and altruism. Thus, an individual believing that doing or not doing certain things will benefit them (such as choosing to resist the presence of AD or letting go of the negativity and embracing positive circumstances) is more important than whether or not the benefits are actual (Folkman, 2008).

The second element of meaning focused coping, benefit reminding, revolves around individuals’ efforts to remind themselves of the possible benefits that may surface from a stressful situation (Folkman, 2008). While reminding sounds very similar to benefit finding, benefit finding attempts to penetrate a distressful situation to find or locate meaning or advantage in it. Benefit reminding, on the other hand, includes the recollection of the value of positive circumstances that may already exist but may have been forgotten, overlooked or taken for granted. Richard, June, Catherine and Pamela habitually reminded themselves of the benefits that accompanied with AD – such as appreciating the little joys of life more deeply, prioritizing themselves and their health, having more family time, living life more fearlessly, and having the support of family and friends. While these factors seem ordinary, as humans, we frequently forget to value the endless beauty and subtle nuances that exist in our lives and help us move forward with hope, until something catastrophic comes along and shifts our attention back to our blessings. Even though participants were surrounded by positivity (e.g., the love of family and friends, residual physiological functioning, and the ability to plan for the future) preoccupation with the burdens of AD made them lose sight of their blessings
occasionally. It was during such times that their heightened self-awareness reminded them of the benefits that were awaiting them at any given time.

Individuals with chronic illness often feel out of control due to the spiraling turn of events following a diagnosis. Losing control may mean losing authority over money, home, roles and position, mobility, health, decisions, and in general life (Charmaz, 1991). Such trying circumstances call for regular adaptations that focus on renewing strength and priorities to ensure minimum wastage of precious energy and effort. The third element of meaning focused coping, adaptive goal processes, focuses on exactly this, as individuals going through stressful times choose to concentrate on objectives that hold meaning to them (Folkman, 2008). When faced with leisure barriers of chronic pain and fatigue, participants restructured their engagements, creating new activities and goals that not only held importance but also took into consideration their current abilities (Baltes & Baltes, 1990). Being attentive to their bodies and avoiding potential triggers that exacerbated AD helped participants value their wellbeing and negotiate barriers in leisure and life (Kralik et al. 2010). For example, when June could not garden anymore, she engaged in art such as painting, to take her mind off the pain. Painting not only helped her appreciate her talents but also helped her adapt around AD. Similarly, Richard rested regularly and took breaks from professional engagements to focus on priorities that consumed less energy and still provided meaning and joy (e.g., going for a drive with their children, spending time with grandchildren, or enjoying the company of friends) (Baltes & Carstensen, 1996; Lang, Rieckmann, & Baltes, 2002). Wrosch, Scheier, Miller, Schulz, and Carver (2003) advised that to maintain wellbeing, it is important that a person does not entirely give up on goals that no longer work. In the
above examples, June and Richard substituted unsuitable goals with new ones. Diverging from old habits and creating new ones helped participants maintain vitality, overall wellbeing, and a positive outlook towards life.

In addition to reorganization of goals, chronic illness can bring about the rearrangement of priorities in one’s life (Folkman, 2008). This is because chronic illness often influences the meaning of fulfillment in an individual’s life and his or her stance towards it (Charmaz, 1991). Due to the intrusive symptoms of AD, participants were regularly pre-empted from meeting their daily needs and expectations. These obtrusions included limited career goals, restricted family time, and inadequate social connections (Charmaz, 1991) among others. Measuring what is truly valued against the superfluous was discussed in our interviews. Participants mentioned that, keeping in mind their limited source of energy and expendable time, they were determined to use their resources towards bettering themselves, helping others, and basking in the sweetness of life rather than hold on to resentments, anger, hopelessness and emotional pain caused by AD and personal life events. As Catherine, Pamela, Richard and June tried to make sense of the daily stressors, they also engaged in periodic ruminations to re-evaluate their life choices and circumstances. This helped them focus on what truly mattered and let go of things that no longer served them. Richard explained that this, for the most part, held true when his spouse was not available for emotional/mental support and he was having a particularly rough day. Instead of wallowing in loneliness, he chose to surf the Internet to communicate with like-minded friends, meet with people from different walks of life in social gatherings, or spend time listening to music with his son. Similarly, Pamela overcame isolation by making e-cards and personalized art on her iPad for her caregivers
and loved ones, instead of pondering incessantly over the abandonment of her friends. Thus, reordering priorities and adopting a different perspective on life could help individuals with AD embrace change and prioritize their current lifestyle in accordance to their strengths.

The final component of Folkman’s (2008) meaning focused coping involves ordinary events and how they can contribute to coping and better health when infused with positive meaning. Examples of this fifth component predominantly came forth when participants spoke of their children and/or grandchildren. Pamela mentioned how blessed she felt when her grandchildren visited her and how their very presence brightened her day. Catherine loved listening to musicals and watching movies with her children during her free time. The fact that both women could cherish and spend time with their families made them feel loved and happy. June also enjoyed planning family dinners. The chance to put her organizational skills to use, as well as spend time with her family, brought meaning to her life. This, in turn, became the foundation on which she attempted to build an optimistic and creative life (Caldwell, 2005). Similarly, Richard enjoyed cooking on days he experienced less fatigue and pain and looked forward to sharing his culinary skills with family and friends.

Personally, this coping strategy tugged at my heart the most. Until a year ago, I would find myself drowning in despair, emptiness and existential crises due to AD and a myriad of personal events that left me with chronic stress and anxiety. My apprehensions would naturally accelerate when I focused on these negative events and I found myself becoming incessantly depressive, negative, and listless. It was at this time that I read Mother Teresa’s quote, “Not all of us can do great things. But we can do small things
This simple, yet profound quote pulled me out of my melancholy. Consequently, I attempted to let go of my fears and embrace life more fully, infusing mindfulness, attention, relaxation and optimism in my daily activities. Taking small pauses and relishing the tasks at hand became more important than obsessing with results. The simple act of instilling purpose to my daily activities added to the richness of varied experiences in my life. I truly believe I needed to experience this epiphany to empathize and comprehend the nuances of the participants’ experiences. Therefore, when Catherine spoke about the beauty of watching her children and grandchildren grow into young and talented adults, or Pamela spoke about the serenity of watching birds quench their thirst from water bowls placed in her yard, I grasped the intensity of their emotion. I understood that while these events may seem ordinary, they hold positive meaning (Dean, 2012) and are a reflection of the thoughts and emotions that help participants cope with the metamorphic aspects of AD.

Positive emotions have been linked with health related outcomes such as better immunity, lower basal cortisol levels, and reduced inflammatory responses to stress (Fredrickson & Losada, 2005). Positive experiences can broaden the scope of attention, cognition, and action, to build intellectual, physical and social resources (Fredrickson, 1998). Positive emotions brought about by meaning-focus coping remain central to my study because they demonstrate the possibility of hope and overall positive wellbeing in the lives of people with AD.

5.3 Leisure and Identity

Questions related to identity have hounded me since a very young age. I would generally try and (still do) associate myself with things or people that/who reflect some
part of me. For example my interest in human science is probably what led me to study subjects such as psychology in junior college, criminal law in undergraduate studies, and leisure behaviours at this time. My interest in traveling solo and meeting unconventional people along the way is also largely a reflection of that part of me that is constantly ravenous to understand the world through the eyes of fellow humans who have been granted the same life as me and yet experience it differently. My fascination perhaps stems from the fact that through the prism of inquiry, I seek to understand myself, relate with others, and find a spot for myself in the world around me. Thus, my personal thoughtfulness dictates that the activities and behaviours we chose to engage in, or put our being into, reflect a large part of who we are. Chunk by chunk, we build our world, handpicking people, activities and circumstances that form the essence of our existence. This essence assigns us with a stable image, a personality that remains solid even amid the flux of life (Haggard & Williams, 1992). Similar to me, the participants I had the privilege of interviewing sought stability and consistency in their lives. The topic of identity is therefore, a very important and relevant theme in this study, because who we are not only forms a large part of our lives but can also become a driving force behind a meaningful life (Christiansen, 1999).

Whilst pouring through the interview data, it came to my attention that multiple statements referring to the participants’ past (specifically the words “I was” and the phrase “before AD”) ran liberally across the interview text. This revelation led me to ponder over issues related to identity in chronic illness. Identity can be defined in terms of personal and social identity. Hewitt (1991) defines personal identity as the consistencies and inconsistencies of one’s former self, as well as the resemblances and
variances in one’s personality when compared to others. Social identity, on the other hand, encompasses identification with a specific group (Kleiber, 1999). As discussed in Chapter 4, AD lacerates the identity of individuals living with this disease. Chronic illness can disrupt one’s life (Bury, 1982), give rise to existential problems (Charmaz, 2000) and limit one’s identity and self-belief (Barnett, 2005). Nonetheless, recovery from a chronic illness can become a reality if one takes stock of one’s weaknesses and strengths, actively works towards a positive identity, sets meaningful goals, and takes control over one’s life (Shepherd, Boardman, & Slade, 2008). Since leisure is known to generate positive emotions, reaffirm identity, aid in transformation, and enable people to look forward to life with renewed priorities and maintain a sense of continuity amid stressful transitions (Genoe, 2010; Kleiber, Brock, Lee, Dattilo, & Caldwell, 1995; Kleiber et al., 2002; Reynolds, 2003), the relationship between leisure and identity formation within the context of AD forms an important part of this study. I will begin this section by discussing the effect of AD on identity. I will then explore how leisure and its many elements were useful anchors in helping participants find meaning and fulfillment when their familiar worlds crumbled down after diagnosis. More specifically, I will discuss the role of leisure in overcoming the master status of AD, as well as the value of a relationship based approach in identity formation in AD.

5.3.1 The Effect of AD on Identity

The diagnosis of a chronic disease involves complex alterations in perception of self (Barbero, 1995; Barnett, 2005). This is usually because the condition becomes the focal point and the individual ponders over an uncertain future and negative self-image (Charmaz, 1991). Since diagnosis, Richard, Pamela, Catherine and June saw themselves
dualistically. Their found commonalities when they compared themselves with others battling AD (or other challenges), and yet, they saw themselves differently when they compared their current selves to the people they were before AD. This inconsistency resulted in a fluctuation of identity that was further aggravated by the incessant stressors of AD. Participants, thus, not only had to battle symptoms of AD that eroded their abilities day by day, but also had to face the challenge of accepting who they are at this time. AD was an unexpected, hostile occurrence that crept into their lives, bombarding them with a myriad of concerns and unanswered questions. It changed integral components of participants’ identities (i.e., things, people, and life events) that were the foundations of their daily life. The loss of identity was not abrupt, but a steady process that chaffed away at their capabilities and life without warning. For the reason that participants still strongly identified with the life that they had created for themselves before diagnosis, not knowing who they were since losing their well-established life resulted in confusion, loss of meaning, apprehension and hopelessness. These findings are consistent with previous literature regarding identity and chronic illness. For example, noting the devastating effects of chronic illness on the self, Lundmark and Branholm (1996) argue that several internal and external changes accompanying long term illness can cause fluctuations in self-belief and self-worth. These changes include loss of paid employment, reduction in social networks, intrusion of medical regimes into everyday life, reluctant abandonment of valued leisure pursuits, increased dependence on others, illness stigma, and overwhelming emotions such as anger, grief, anxiety and depression. With onset of chronic illness, individuals are thus compelled to reconsider how they live and who they are becoming (Charmaz, 1995).
Richard, Pamela, June and Catherine explained how AD had taken away their aptitude for caretaking, jobs, financial wellbeing, and social support. Living with AD meant accommodating present disruptions, negotiating current dreams and wishes, as well as revising future hopes and plans. Describing their physical appearance at length on several instances, they explained how much it, along with personality and abilities, had changed since the diagnosis. As I re-read participants’ quotes several times, I understood that the physical distortions caused by AD changed the way participants saw themselves. In some ways, Richard, Catherine, Pamela and June experienced a love-hate relationship with themselves since the diagnosis. From strong, independent individuals to living with changes in self-image and overall physiology, AD had not only shackled their bodies but also chained their minds into believing less of themselves. Comparisons between life before and after AD encompasses more than just body image – it includes adjustments in cognitive abilities, the freedom to travel or go out to eat, date, take walks, entertain and socialize, work and drive (Moss & Dyck, 2003). Living with impairments meant being forced to love a new self – a new body which did not perform daily tasks with as much litheness or look familiar in the mirror. Befriending this new self with more modest and undermined abilities affected the participants’ self-expectations (and consequently expectations of how others perceived them). Richard, Pamela, June and Catherine experienced significantly lowered cognition, self-esteem, and the quality of intimate relationships due to physical (visible and/or invisible) disabilities. This consequently led them to experience greater social isolation and damaged identities (Nosek, Hughes, Swedlund, Taylor, & Swank, 2003).
Illnesses may not only radically disrupt biography, but may also have consequences for identity when situations in personal, professional and social life are in disarray (Asbring, 2001). As AD progressed, the participants’ changes in physical and mental abilities led to severe struggles in maintaining responsibilities in their personal and professional lives. The stigma of living with an illness not only impacts self-perception but also social identity (Charmaz, 2000), causing loss of individuality and sense of control over familiar surroundings and situations. Furthermore, adjusting to and shifting perceptions about the self were impacted by symptomatic interferences from AD causing multiple assaults on identity. Individuals with chronic illness usually try to stall the disease(s) from impacting identity, seeking instead to outgrow the disruptions and devaluations that make them vulnerable (Charmaz, 2000). Amid these transformations, the responses of others also hold value, as an illness is not only an event experienced by the individual, but also closely intertwined by social and community involvements (McElroy & Jezewski, 2000).

Several studies have demonstrated the role of leisure in sustaining and recreating identities in negative life events such as chronic illness (Genoe, 2009; Haggard & Williams, 1992; Kleiber et al., 2000). During troublesome times, the social/emotional support as well as the positive feelings stemming from doing leisure activities together with others can buffer the adverse effects of stress on physical and mental health (Iso-Ahola & Park, 1996). My findings demonstrate that AD threatened the identity of participants and stripped them of the known. Nevertheless, they also establish that holding on to important values and recreating the self were part of important coping mechanisms adopted by participants to deal with the detrimental effects of AD. The role
of leisure became abundantly clear in coping with stress and shaping identity in this study, specifically when participants displayed efforts to escape the master status and considered coping (and well as who they are) from a relationship-centered approach. Below, I explore how participants learnt to disengage from the domineering presence of AD from time to time. I then explore the significance of relationships in AD and discuss the importance of love, friendship, companionship, values, support, and community in identity formation and coping.

5.3.2 Overcoming the master status

“I am more than my scars”.

— Andrew Davidson, The Gargoyle

During my conversations with the participants, I noticed that our stories converged dramatically at several paths. However, the most significant similarity was the discussion on the relentless, overbearing presence of AD. Participants shared that living with a chronic illness is a daily battle, in which you are fighting hard to disallow the disease from leaving its mark in everything you do. Beginning from the first signs of illness to the blur of tests and medical appointments, chronic illness wrecks the mind and body with its forceful presence and aftermath (Garrino et al., 2015). I contemplated the weight of the participants’ words as I engaged in reflexivity over my own personal experiences with AD. I reflected on my own frustrating attempts to explain the effects of long-term illness to acquaintances and friends who on learning about AD, swiftly advise, “Don’t worry, everything will be fine”. The struggle to come to terms with the fact that AD is a lifelong condition – meaning it will not slip away from my life anytime soon, most possibly until my demise, periodically shakes the very foundations of my being. I
therefore empathized with the ordeals of participants, as it is not, by any means, an easy task to avoid the ever-present, ever-looming unpleasant company of AD, particularly when the symptoms interfere with everyday routine. Indeed the fact that AD is often considered first, and the individual second, does not make living with a chronic illness any less burdensome.

Charmaz (1995) observed that when an individual is diagnosed with a chronic illness, a label known as “master status” is assigned. What this really means is that upon diagnosis, the disease stands out before the individual. The participants of my study were branded with the master status of AD. Under the weight of this label, friends and family noted their illness first (based on changing appearance, abilities or behaviour), thereby threatening and damaging their uniqueness. Pamela’s revelation about her friends ignoring her because of her unusual physical appearance and interrupted communication skills indicate that it is her outer appearance and not her company that deters them from being friends with her. The fact that she is still the same person behind her changing exterior is something that is customarily overlooked by her social circle. This example evinces the identity crisis an individual may experience when experiencing a chronic illness or visible malfunctions in physical or mental faculties (Caddell & Clare, 2011).

As explained in Chapter 2, leisure can aid in identity formation and healthy aging (Hutchinson et al., 2008; Liechty et al., 2012). Leisure can also help individuals with comorbidities manage their chronic conditions by drawing on existing resources for continued involvement; setting leisure-based goals; using strategies to get more out of life; and living a life of meaning (Hutchinson & Nimrod, 2012; Kralik et al., 2010). Richard, Pamela, Catherine and June spent large amounts of time in the company of their
children and grandchildren. Since they could not engage in formerly enjoyed physical activities anymore (such as hiking, camping, traveling extensively or engaging in sports/swimming), they chose leisure engagements that did not require a great deal of their energy or cause them excessive pain and fatigue. The positive emotions emerging from close relationships as well as the joy of making the most of their existing abilities enabled them to see the self as much more than someone with AD. Taking the time to attend to their children, planning playtime with grandchildren, organizing family get-togethers, and advocating about AD helped participants look forward to things and plan for a hopeful future. Acting out roles in their personal and social lives helped them escape from the master status (Genoe, 2009) as these roles within their family and close relationships demonstrated that they had a lot to offer, despite their battle with AD.

Leisure also gave participants the space in which they could feel comfortable and at home (Dean, 2012; van Manen, 1997). Home was where Richard daydreamt of a positive future, Pamela listened to audio-books, Catherine helped her children with school projects, and June played videogames or simply lay on the couch reading a beloved book. June explained that painting and baking were also her favourite creative outlets (on pain and fatigue free days) because they reminded her of her talent to create. Creative artwork undertaken in chronic illness is typically an individual’s way of honoring personal strength, focusing on the positive and continuing life as the old self (Reynolds et al., 2008; Shaw & Wilkinson, 1996). Moss and Dyck (2003) note the significance of physical and social space in allowing an individual to get used to the many changes brought about by chronic illness. Richard, Pamela, Catherine and June appreciated the time and space that leisure provided them with to be themselves. It was
in this space that they could get lost in engagements of their choice without being judged or called upon on (Iwasaki et al., 2010). Pamela sitting by the large window in her house to appreciate nature is an example of the importance of personal space. She explained that the peace and solace helped her heal her body and mind from the constant bombardment of symptoms and let her be comfortable in her skin without worrying about how others saw her. Richard was the most socially active participant. Nevertheless, he still had a quiet space which he darkened and quietened down to keep the light and noise away. He explained that although socializing and preaching were important to him and offered him support and identity (Dupuis, 2008; Kelly, 1993) healing from the psychological and physical impact of AD was crucial to recovery and a positive state of mind. Being alone provided him with the space in which he did not have to act on carved out roles, but instead get the chance to vent his feelings and come to terms with his changing self.

While resisting the master status was not possible at all times, leisure did provide participants with the occasional opportunity to escape and create gaps in their daily life. This helped them pause, reflect, breathe, reorder priorities and strengthen themselves (Hutchinson & Nimrod, 2012). Reminiscing about their former selves and cherishing relationships and social support were also important leisure behaviours that supported their quest to live well with AD. Leisure was especially valuable because in their free time, participants often deliberated on their capabilities, which, in turn, led them to realize that they were uncomfortable being labelled with AD. The process of self-introspection experienced by participants blends well with Kralik et al.’s (2010) observations on the meaning of self-care in chronic illness. The authors note that
individuals living with chronic illness often discover themselves as they experience an illness. During these stages of reflection, they often become aware of the vision they wish to embrace for themselves and project onto others. On several instances Richard, Pamela, Catherine and June asserted that they did not want to be associated with the tag of AD, saying, “I may have AD but AD does not have me”. Thus, when participants focused on what they could do (or are comfortable with) instead of what they could not do, important spaces of satisfaction were created in their lives that gave birth to feelings of control, empowerment, identity construction and resistance to illness stereotypes/master status (Genoe, 2010; Green, 1998; Wearing, 1995).

Individuals with chronic illness may try to hide the diagnosis because they do not wish to be seen or treated differently due to their condition (Bury, 1982; Joachim & Acorn, 2000). While on some level, I expected my study to follow those lines, I was pleasantly surprised to note that Richard, Catherine, Pamela and June had no intention of hiding their illness. Indeed, they did not want to be seen or treated differently because of AD. Nonetheless, they cared enough to be vulnerable, even when their honesty came with a price of being misunderstood or labeled. The participants in this research wish to be heard and sharing their health status is a small price to pay for the awareness and potential interest their testimonies could garner.

5.3.3 Affirming identity through relationships

“To be fully seen by somebody, then, and be loved anyhow - this is a human offering that can border on miraculous”.

— Elizabeth Gilbert
Haggard and Williams (1992) state that humans ordinarily seek to relate with the world around them to maintain a sense of self-consistency. This self-consistency remains strong even when things around us are fragile. Genoe and Dupuis (2011) explore identity in dementia, a chronic illness where a loss of self-worth, self-respect, competency and change in relationships are experienced. They explain that considering the many assaults on identity brought about by dementia, including loss of capabilities, employment, purpose and autonomy, affirming identity becomes important to cope with threatening circumstances and maintain a sense of continuity in life. Chronically ill individuals often experience a changing sense of identity when things they took for granted begin to slip away. Between making sense of symptoms, reconstructing order, and attempting to take control of life (Charmaz, 2000), leisure can be beneficial. Leisure can help in the reaffirmation of identity in chronic illness because leisure engagements can result in positive emotions, meaning-making, love connections, and satisfying behaviours that can help persons with long term illness relate with the world around them (Genoe & Dupuis, 2011; Green, 1998; Reynolds, 2003).

Relationships played a significant role in affirming identity for Richard, Catherine, Pamela and June because the roles and responsibilities that close relationships brought, provided them with information about who they are, such as parent or grandparent. This self-belief also helped them portray the same image to others. By engaging in personal and social relationships, participants were able to maintain a sense of continuity from their pasts and look forward to the future with hope (Hutchinson et al., 2008). Choosing familiar relationships and leisure activities (such as reading together, spending time together, and cultivating hobbies together) helped Richard,
Catherine, Pamela and June regain some control over their lives and feel relatively unthreatened by the newness of constant adaptations called for by chronic illness (Reynolds & Prior, 2003).

Relationships have been known to bring identity and stability in stressful events (Kleiber et al., 2002). Like most stressful circumstances, AD brought a sense of self-awareness in participants that helped them reflect on their strengths, weaknesses and priorities. They realized that AD impacted their vitality, financial freedom and social support, however, there were some things that none of the participants were willing to let slip away, such as the love for their family and the desire to live a life genuine to them. Realizing this aspect of their identity helped participants cultivate their most loving and strongest traits and become fun-loving and caring parents, grandparents and community members. For example, in the absence of sufficient opportunities to play the role of doted husband, Richard extensively channelled his emotions into his children and grandchildren (Iwasaki et al., 2010). Bonding with his children and grandchildren secured him a strong role within the family, while affirming and strengthening his personal identity. Seeing that his children and grandchildren appreciated and valued him raised Richard’s self-esteem and helped him to see himself in a positive light. Genoe (2009) explains that being recognized for one’s abilities can lead to the acknowledgment of a person’s uniqueness. To know that they mattered to their loved ones helped participants acknowledge their uniqueness and appreciate themselves as an individual first, and not just someone with AD. Engaging in loving relationships reinstated their identity and gave them the confidence to reach out and offer support to others who were going through similarly trying circumstances (Nimrod & Kleiber, 2007). Richard added
that as an emotional person (a self-realization that stemmed from introspection during his free time), giving and receiving love in relationships were important coping mechanisms that allowed him to live well with AD.

This finding blends well with Ronning’s (2002) observation that even sharing positive emotions of a reciprocal nature can be beneficial to wellbeing. Instead of suppressing his feelings and subsequently letting negativity affect his health, Richard learned the art of open communication with people he cared about. Furthermore, having the freedom to choose his leisure activities such as learning new things (Castelli & Valley, 2007), interacting with others, listening to his son playing the drums or babysitting his grandchildren granted him a sense of control and self-affirmation because his leisure choices came together to reflect parts of his innate, loving nature. Similar to Richard who sought relationships with children and grandchildren, June, Catherine and Pamela were focused on continuing their roles as mothers. Being a good parent was extremely important to them because they believed setting strong examples was crucial to raising responsible children. Discussing their personal identities at home, all participants concluded that sustaining loving relationships with their families, essentially with their children and grandchildren, kept them going during the good times and the bad. Centering their leisure engagements on relationships helped participants see themselves in a positive light. Thus, the time and energy spent in leisure helped participants maintain and preserve valued parts of their identity (Genoe, 2009; Green 1998; Haggard & Williams, 1992). Spending time and investing energy into nurturing relationships, as well as sharing favourite leisure activities together was identified as the space where love, understanding, support, reciprocity, identity, resilience, hope,
positivity and happiness flourished (Adams et al., 2011; Hutchinson & Nimrod, 2012; Hutchinson et al., 2008).

In addition to personal roles and responsibilities, participants also had strong social roles and relationships to uphold. Coleman and Iso-Ahola (1993) noted that social contacts can buffer stress and serve as good coping resources. Social identities formed out of freedom and appreciation of talents can also grant individuals the autonomy and confidence they crave (Kleiber et al., 2010). Connecting with others in-person as well as maintaining social networks virtually through online chat forums, support groups and social networking sites contributed to identity formation in participants. Reaching out to others in need, sharing their empathy and offering support, sharing their knowledge about AD, as well as becoming advocates of AD validated the participants’ talents, skills and sense of self and helped reclaim a sense of order (Kralik et al., 2010). Although AD caused the participants to slow down in some aspects of their lives, their devotion and loyalty to their loved ones as well as social commitments remained unwavering, allowing them to give and receive affection and validation from others. Thus, engagements made out of personal space as well as leisure remained important as they offered avenues for self-reflection, connection with the positive, contentment, ego gratification, and a mind filled with constructive ideas (Kleiber & Hutchinson, 2010).

The participants’ accounts brought to light diverse factors that shaped their lived experiences of AD and leisure. Their common journeys resulted in emerging themes that addressed the research questions of this study. The participants’ narratives not only show the promising role of leisure in the management and prevention of acceleration of rare chronic illness, but also indicate that it is possible to find breathing space (meaning,
purpose and hope) amidst the clutches of chronic illness (Hutchinson et al., 2003; Kleiber et al., 2002; Genoe, 2013). Leisure can be a very useful resource in helping individuals with chronic illness fill occupational voids, distract from the illness, promote flow and spontaneity, provide channels to cope with grief, maintain positive identities, and engage in social networking (Reynolds & Prior, 2003). Leisure offered participants a versatile means to overcome the restrictions imposed by chronic illness on the self and lifestyle (Reynolds & Prior, 2003), and in many instances enriched their lives in ways that were not, before AD.

I chose to integrate a phenomenological exploration into the study of rare disease and leisure because I was keen to learn how, if at all, individuals with AD create pathways of meaning, purpose, fulfillment, acceptance, and healing through resources that are available to them. Suffering from AD opened my eyes to the many hindrances a chronic illness creates in daily life. I have, over time, become particularly aware of the multitude of adaptations this illness calls for such as purchasing water beds, physical aids, and compression garments in addition to rearranging homes and dealing with inadequate insurance coverage. This awareness coupled with my interest in investigating the lifeworld of individuals with AD helped me use a methodology that inquired into the intricacies associated with confronting an illness, negotiating with it, and eventually learning to live well it. I believe this research will add to our understanding of the relationship between rare chronic illnesses and leisure because phenomenology of illness offers valuable alternatives to the studies of diseases (McElroy & Jezewski, 2000). It provides us with insights into a person’s life, including their point of view, meaning-making process, subjectivity, and consciousness, thus expanding perspectives.
(Kaufmann, 1988) on chronic disease management strategies. This understanding can be used to create purpose and new priorities in illness. In addition to understanding an individual’s experience of health and illness, phenomenological studies also reveal the diverse transformations related to self-identity that can occur in illness, disability or trauma (McElroy & Jezewski, 2000). This can help us extend our compassion, sensitivity, energy and resources into making rare disease management more effective.

As a closing remark, I would like to add that leisure did not act as a cure or treatment to mediate the relationship between positivity and wellbeing in AD. However, it did support the participants’ quests to cope with everyday stressors, engage in self-management strategies to take responsibility over their lives to manage the progression of the illness (Kralik et al., 2010; Shannon & Bourque, 2006), and learn to live well with AD. Within the context of this study, leisure does not replace or undervalue the substantial contributions of the science and medical community. What it does do however, is give individuals with AD the opportunity to look forward to the future with hope, whilst awaiting clinical trials to address the root cause of this disease and potentially find plausible treatments to lessen their pain.

5.4 Practical Implications and Future Research

This thesis is my first official work on rare disease and leisure. As I come to the end of my study, I have become uncomfortably aware of the paucity of research on rare diseases as well research connecting leisure and rare disease. The lack of investigation not only impacts rare disease management and the potential of leisure in lending itself to different areas of health science, but also frustrates the efforts of researchers like me who are struggling to find adequate literature to support and understand their own research
from multiple perspectives. This study begins to bridge this gap in the sense that it presents subjective experiences of an illness that has never been explored in such depth before. It also adds to the richness of leisure-based literature by exploring the functionality of leisure within the context of an unexplored body of knowledge. Indeed, the findings are encouraging, but much remains to be done. In this section, I outline some recommendations for practice and potential future work. It is my hope that these considerations would be taken into account by leisure professionals and researchers, the medical community, government, and the rare disease population and their loved ones. Based on the findings of my research, I suggest the following implications for practice:

1) Rare chronic illnesses are on the rise and may not be as rare as previously thought (von der Schulenburg et al., 2014). Eventually, like other chronic illnesses, these conditions may also become burdensome on our healthcare system and taxpayers. Fortunately, information on chronic conditions is more easily accessible than ever before due to the Internet. It would be beneficial to undertake efforts to sustain substantial collaborations between healthcare practitioners and patients, and/or their families in order to implement knowledge required to manage rare diseases (Barbero, 1995).

2) The medical community must strive to offer greater sensitivity and compassion in their interactions with individuals seeking their care and support. Showing empathy can encourage fluid communication and thereby prevent silent suffering, which makes health worse. Adequate communication can also result in unearthing critical information that can aid in the customization of treatment plans and prevent misdiagnosis.
Having studied medical law, I am cognizant of issues related to negligence in healthcare. Furthermore, because my birth mother passed away due to the administration of faulty drugs, I take issues related to negligence very seriously. To avoid irresolute diagnosis and abrasive treatment decisions, patients should not be condemned for knowing more than their doctors. This phenomenon is very common in the orphan or rare disease community (Garrino et al., 2015) where patients are keen to share their knowledge with physicians. Like attorney-client privilege, the relationship between a doctor and their patient is delicate and confidential. It must therefore, be based on utmost trust and openness. Not all individuals have the financial means to seek multiple medical opinions across different geographic locations. If local doctors are not open to discussions, it could add to the emotional, physical and financial burdens of individuals, and leave crucial questions unanswered.

The government and national health institutes should actively participate in the emancipation of the orphan and rare disease community, especially in matters of diagnosis and insurance. Often, little known illnesses have no medical coverage, leaving individuals with these illnesses to pay enormous out of pocket expenses. Since this particular population is, more often than not, physically and financially stretched thin, going through the process of appeals and possible litigation to secure assistance can make life more complicated. Additionally, diagnosing rare chronic illnesses should not be so convoluted. To address this issue, sophisticated diagnostic tools and special diagnostic teams trained in rare disease management are needed.
5) Government and national health institutes should also divert funds towards rare chronic illness research and management. Additionally, they should consider partnering with hospitals and healthcare clinics to distribute mandatory pamphlets, set up workshops (for knowledge transfer between researchers, academicians and healthcare professionals), provide patient advocacy and empowerment training, and conduct information seminars for the community at large.

6) Leisure education will be beneficial for people living with rare chronic conditions. Since there is adequate literature to establish the role of leisure in coping with chronic illness, with support, people diagnosed with rare chronic conditions could learn about the value of leisure in distracting themselves from their symptoms and experiencing positive emotions, as well as sustaining or re-creating identity and maintaining connections with loved ones. Taking their physical, emotional, mental and spiritual wellbeing into account could help in the refreshment of the mind and buffer them from the constant shadow of medical procedures, symptoms, and side effects. Leisure education could also serve to support individuals in adapting pursuits to suit current capabilities and identifying the meaning attached to activities in order to find suitable replacements when necessary.

7) Based on the findings of this study that highlight several different self-management strategies adopted by participants, developing customized, strengths-based self-management programs in the community for individuals with (rare) chronic illness and their families would be helpful. Additionally, offering these programs free of cost or at subsidized rates would support the efforts of those living with rare disease to live well and successfully manage their health condition(s). Self-management
supports can consist of techniques and strategies brought forth by individuals with chronic illness as well as healthcare practitioners in the form of workshops and seminars integrated within clinical practice and community settings. To reduce healthcare costs and encourage a healthy nation, the provincial and federal government (in collaboration with medical and local communities) can create and fund self-management programs that cover a wide range of topics in chronic disease management such as techniques to deal with everyday stressors in (rare) chronic illness, communicating one’s needs effectively with family, friends and healthcare practitioners, learning about legal rights and equal access in healthcare, embracing balanced and affordable nutrition and gentle exercises to maintain overall wellbeing, and building confidence, self-esteem and meaningful leisure activities through interactive training with knowledgeable professionals.

In addition to the above practical implications of the findings, I highlight several key areas for future research below:

1. Of particular interest in this study is the importance of family and faith that clearly helped participants to defy many odds and portray astonishing spirit even in the midst of life challenging adversities. Further inquiry into these factors would help us understand how far the mysteries/challenges of both rare diseases and the coping properties of leisure stretch.

2. Further exploration of the value of leisure within the context of rare chronic illness from the perspectives of both the person living with the condition and their family members would lend insight into how family and spousal leisure are impacted by diagnosis and symptoms of rare chronic conditions. Such research
can help us understand the role of relationships in coping with rare disease stressors.

3. One potential limitation of my study was the inability to meet the participants in person and have the chance to connect with them and observe their body language and facial expressions. During communication, people often make use of their hands, arms and head to add greater emphasis on thoughts that resonate with them (Atkinson, 1984). This can help the interviewer make observatory notes during data collection and aid the data analysis process. In the future, it would be beneficial to undertake rare disease and leisure research in geographical areas that allow physical access to the rare disease community. By conducting in person interviews, subtle nuances that are otherwise not evident could be documented. This would add to the repertoire of rare disease and leisure literature and help us examine rare disease management and leisure studies from multiple angles.

4. Research with larger number of participants must be undertaken to study leisure and meaning-focused coping within the context of other rare diseases. Additional models of coping could also be developed to focus specifically on symptom management and positive emotions in the rare disease populations.

5. In-depth explorations of lived space, lived body, lived time and lived other (van Manen, 1997) would be helpful to expand our understanding of the existential and leisure experiences of persons living with rare diseases. Further inquiry into the four dimensions of the lifeworld would contribute to our knowledge about the psychology of these illnesses and help us understand how persons living with rare
diseases experience the illnesses as the condition progresses. In the future, I would like to investigate this aspect and engage in data collection over longer periods of time (preferably for my PhD).

6. Keeping in mind the population size and geographical disparity of rare disease populations, additional exploration of leisure behaviours such as virtual socializing and networking in the lives of individuals with rare chronic illness would be beneficial. Studying the power of online social networks in developing healthy communities and potentially reducing healthcare costs as a result of knowledge transfer between members could contribute to our understanding of rare disease management as well as the role of leisure in enhancing QoL in rare chronic illness.

5.5 Conclusion

The primary objectives of this phenomenological research were to understand the daily lived experiences of individuals with AD and explore the role of leisure in their lives. Specifically, the study aimed to understand how individuals with AD experienced the illness and whether leisure helped them cope with everyday stressors in the absence of specific cure and treatment. The project was guided by research questions that resulted in a rich collection of data that was thematically analysed. Based on the stories shared by participants, it is clear that a) AD severely impacts daily life and leisure choices; and b) despite limitations, leisure can help individuals with AD create positive space in their life and allow them to live well.

The paradoxical revelations of this study showcase that participants value free time, yet struggle to do things because of everyday symptoms and stress. Furthermore,
they enjoy taking time off to relax and pursue engagements of their choice, but excessive free time becomes bothersome when awareness of nagging symptoms and negative life events arise. This study is unique because it focuses on both the positive and negative elements of one’s journey in AD. The insights gained from this study provide us with crucial knowledge about the challenges that plague an individual with chronic illness. This understanding not only allow us to comprehend the relationship between leisure and an orphan disease but also help us become aware of issues related to body image, invisible disabilities, identity, and hope in chronic illness. Life with AD is indeed complex, but leisure has a valuable role to play. The findings of this research are encouraging because they indicate that a long-term diagnosis does not necessarily mean a despairing future.
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I invite you to take part in a research study, which is being conducted as part of the Master’s thesis of the principal researcher, Urmi Mukherjee. Taking part in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about what you will be asked to do, and any risks, inconvenience, or discomfort you might experience. Participating in the study might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about this study with Urmi Mukherjee urmi.mukherjee@uregina.ca; 306. 216. 6307 or her supervisor Dr. Rebecca Genoe Rebecca.Genoe@uregina.ca; 306.585.4781.

The purpose of this study is to gain an understanding of how individuals with Adiposis Dolorosa (AD) experience the illness and cope with the symptoms of the disease without a cure or treatment. We want to find out about the role of leisure in coping with and self-managing AD. It is hoped that by doing so, we will be able to gain valuable information on rare chronic illness management, specifically AD, and the findings of the study will increase understanding of AD. By exploring the relationship between AD and leisure, the results of this study will also tell us about the relationship between rare chronic illness and leisure.

This study is designed to analyze your thoughts, feelings, and emotions, and involves a discussion and question and answer session regarding your daily experiences of living with AD. We will also discuss your leisure activities and their role in coping with, and self-managing AD. Interviews will be audio recorded and written out so that you can read what we have talked about. Audio recording will allow me to listen to the interview carefully both during and after the interview so that the information can be analyzed to the best of my ability. The questions are open-ended and flexible. I will be
taking notes during and after the interview to assist me in understanding what we have talked about.

You may participate in this study if:

- You are have been diagnosed with AD for at least one year
- Are able to communicate in English

In this study, you will be asked to:

- Take part in one telephone interview that will be approximately 60 minutes in length.
- You may choose to be interviewed through skype (audio only) if you prefer.
- The interview will take place on a day and time that is chosen by you. Once the interviews have been completed, the typed copy of what we have discussed will be returned to you for your review.

- You may add anything to the copy of the discussion, including comments and questions, or take anything out of the discussion.

- Follow up interviews that will be approximately 60 minutes in length will take place 3-4 weeks following the first interview. This will allow you to add any additional comments or insights that may have come up since the first interview.

There are some minor risks involved with participation in this study. There is a possibility of experiencing some apprehension, discomfort or emotional stress as personal experiences are discussed. There are also some possible benefits that may result from your participation in the study. Direct personal benefits include the opportunity to reflect on and share your experiences with others. Other benefits include contribution to knowledge, which will potentially lead to alterations in the way rare chronic illness, especially AD are perceived by the medical community.

I will protect your identity and the data you provide will be confidential. You will not be identified in any reports or publications. Your names will be changed in order to protect confidentiality in the final thesis and any publications that result. Any information in your copy of the discussion that identifies you will be removed. Discussions will be numbered to help protect your anonymity. The interviews will be stored in a secured location at the University of Regina for five years after the publication of the study. Only my supervisor and I will have access to the data. Direct
quotations from your discussion may be used, with your permission, in order to explain
the results of the study to others.

You will be provided with any new information which might affect your decision
to participate in this study, or continue ongoing participation in the study. Upon
completion of the study, you may request a copy of the findings if you would like to have
them.

If you feel, at any time you would like to withdraw from the research study, you
may do so freely and without consequence. You also have the option to remove your data
from the research study within one year from the time the thesis has been written, i.e.,
you will have time until June 30, 2015 to withdraw your data and cease absolute
involvement with this study. After this date, it is possible that some form of research
dissemination will have already occurred and the thesis may be completed, and it may
therefore not be possible to withdraw your data.

Once again, if you have any questions about the study, Urmi Mukherjee can be contacted
by telephone at 306-216-6307, or by email at urmi.mukherjee@uregina.ca. Dr. Rebecca
Genoe can also be contacted by telephone at 306.585.4781 or through email at
Rebecca.Genoe@uregina.ca.

Thank you in advance for your participation,

Urmi Mukherjee, MSc. candidate Rebecca Genoe, PhD
APPENDIX B

PARTICIPANT ORAL CONSENT FORM AND STUDY INFORMATION

Project Title: Coping with everyday stressors in Adiposis Dolorosa: Is there a role for leisure?
Researcher: Urmi Mukherjee, Graduate student – Msc. Thesis, Department of Kinesiology and Health Studies, University of Regina, 306.216.6307, urmi.mukherjee@uregina.ca
Supervisor: M. Rebecca Genoe, PhD, Department of Kinesiology and Health Studies, University of Regina, 306.585.4781, rebecca.genoe@uregina.ca

Invitation:
I invite you to take part in a research study, which is being conducted as part of the Master’s thesis of the principal researcher, Urmi Mukherjee. Taking part in this study is voluntary and you may withdraw from the study at any time.

Purpose of the study:
The study is described below. This description tells you about what you will be asked to do, and any risks, inconvenience, or discomfort you might experience. Participating in the study might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about this study with Urmi Mukherjee, who can be reached by email at urmi.mukherjee@uregina.ca or telephone at 306.216.6307 and/or her supervisor Dr. Rebecca Genoe, who can be reached by email at Rebecca.Genoe@uregina.ca or by telephone at 306.585.4781.

The purpose of this study is to gain an understanding of the daily experiences of individuals with Adiposis Dolorosa (AD), and the different coping strategies they adopt to manage the condition. We want to find out whether or not leisure plays a role in coping with and managing AD. We hope that by doing so, valuable information that can
be used to understand the everyday challenges of individuals living with AD will be gained. This information may assist other individuals living with AD and their families to learn about coping and management of a chronic syndrome. Additionally, the relationship between rare chronic illness and leisure will be explored, and the findings will add to our understanding of rare chronic illness and leisure.

**Participant expectations, risks and benefits:**

- You will be asked to participate in an individual interview of about 60 minutes long.
- This interview will be conducted over the telephone, or using Skype (audio only), depending on your preference.
- I will ask about your thoughts, feelings, and emotions regarding AD, and discuss your leisure experiences, and what role leisure plays in your life.
- The interview will be audio recorded and written out so that you can read what has been talked about. Audio recording will allow the primary investigator (Urmi Mukherjee) to listen to the interview carefully both during and after the interview so that the information can be analyzed to the best of her ability.
- The questions are open-ended and flexible. Urmi will be taking notes during and after the interview to assist her in understanding what has been discussed.
- You may participate in this study if you have been diagnosed with AD for at least one year and have the ability to communicate in English.

There are some minor risks involved with participation in this study. There is a possibility of:

- Experiencing some apprehension, discomfort or emotional stress as personal experiences are discussed.

There are also some possible benefits that may result from your participation in the study.

- Direct personal benefits include the opportunity to reflect on and share your experiences with others.
- Other benefits include contribution to knowledge, which will potentially lead to alterations in the way rare chronic illness, especially AD are perceived by the medical community.
Follow up Interview:
Follow up interviews that will be approximately 60 minutes in length will take place 3-4 weeks following the first interview. The follow up interview will allow you to add any additional comments or insights that may have come up since the initial interview.

Confidentiality and Data Protection:
Every measure will be taken to protect the identity of the research participants, and confidentiality of the data will be maintained at all times. You will not be identified in any reports or publications. Names will be changed in order to protect confidentiality of the participants in the final thesis and any publications that result. Any information in your copy of the discussion that identifies you will be removed. Discussions will be numbered to help protect your confidentiality. The interviews will be stored in a secured location at the University of Regina for five years after the publication of the study. Only the primary investigator and her supervisor will have access to the data. Direct quotations from the interview discussion may be used, with your permission, in order to explain the results of the study to others. You will be provided with any new information which might affect your decision to participate in this study, or continue ongoing participation in the study. Upon completion of the study, you may request a copy of the findings if you would like to have them.

Right to Withdraw:

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Should you wish to withdraw please inform the researcher and/or her supervisor of your decision immediately. All data pertaining to you will be shredded and erased (including electronic or paper copies). Your participation will not be mentioned in any materials, and your privacy will be maintained.
- Please note that your right to withdrawal remains valid until the research has reached a stage where it might be impossible to withdraw from the study due to results being disseminated, data being pooled, the thesis being written, etc. Therefore, you may withdraw from the study any time before March 01, 2015 to withdraw your data and cease absolute involvement with this study. After this date, it is possible that some form
of research dissemination will have already occurred and it may not be possible to withdraw your data.

**Questions or Concerns:**
- Contact the researcher(s) using the information at the top of page 1.
- This project has been approved on ethical grounds by the University of Regina Research Ethics Board.
- Any questions regarding your rights as a participant may be addressed to the committee at (585-4775 or research.ethics@uregina.ca).

**Signed Consent:**
Please sign below and return a scanned copy to the researcher (Urmi) via email. Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urmi Mukherjee, Researcher</td>
<td>Signature</td>
<td>Date</td>
</tr>
</tbody>
</table>

*A copy of this consent will be left with you, and a copy will be taken by the researcher.*
APPENDIX C: ETHICS APPROVAL CERTIFICATE

University of Regina

Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR
Urmil Jhar Mukherjee
48 Centennial Street, Apt. 34
Regina, SK S4S 6A6

DEPARTMENT
Kinesiology and Health Studies

REB# 2014-172

SUPERVISOR
Dr. M. Rebecca Gence

FUNDER(S)
Unfunded

TITLE
Coping with everyday stressors in Adiposis Dolorosa: Is there a role for leisure?

APPROVAL OF
Recruitment Poster
Letter of Invitation
Consent Form
Interview Guide
Transcript Release Form

APPROVED ON
October 10, 2014

RENEWAL DATE
October 10, 2015

Full Board Meeting ☐
Delegated Review ☒

CERTIFICATION
The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion.
Please refer to the following website for further instructions: http://www.uregina.ca/research/REB/main.shtml

Dr. Larena Hoeber, Chair
University of Regina
Research Ethics Board

Office for Research, Innovation and Partnership
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775 Fax: (306) 585-4893
research.ethics@uregina.ca

Please send all correspondence to:
APPENDIX D: INTERVIEW GUIDE

Interview Guide

Project Title: Coping with everyday stressors in Adiposis Dolorosa: Is there a role for leisure?

I intend to explore the experience of Adiposis Dolorosa (AD). The purpose of this study is to understand how individuals with AD cope with and self-manage this illness. Additionally, I also intend to explore the leisure experiences of the participants and determine whether or not leisure plays a role in coping with and self-managing AD.

Please note: If at any time you feel you feel uncomfortable with the interview and wish to do discontinue, the recorder will be turned off and no further questions will be asked.

Interviewer: Urmi Mukherjee

Participant:

Date of interview:
Time of interview:
Place of interview: University of Regina

Preamble: Hi, my name is Urmi Mukherjee, and I am a graduate student in the Faculty of Kinesiology and Health Studies at the University of Regina. I have undertaken this study to understand the daily experiences of individuals living with Adiposis Dolorosa (AD) and the role of leisure in coping with and self-managing the disease. The focus of the interview is to get to know you and understand what life is like for someone experiencing AD.

Questions to get to know you:
1. Please tell me a bit about yourself?
   a. Your job, community role, friends, family, etc.
   b. Your current roles, involvement and activities.
2. Tell me about a typical day in your life.
3. What is central to your life right now? What keeps you going?
   a. How does it make you feel?
   b. Can you tell me a specific incident relating to what is central to your life now?

Questions for the study:
1. What is daily life like for you now that you are experiencing AD?
   a. How has your life changed since the diagnosis?
   b. Have your relationships changed?
   c. What are the challenges of living with AD?
   d. Can you share a challenge that you faced recently?

2. How do you cope with and self-manage this illness?
   a. Can you share an experience that may help others learn about your coping mechanisms?
   b. Tell me about an instance when you were able to adapt to the illness.

3. Please tell me about your leisure experiences.
   a. What do you like to do in your free time?
   b. What changes have you seen in your leisure experiences since the diagnosis?
   c. Are there any benefits to experiencing leisure?
   d. What challenges/barriers do you face while experiencing leisure? How do you address them?
   e. Is there any particular leisure activity you like to engage in? Why?
   f. What positive changes have you experienced?

4. How, if at all, does leisure help you to cope with AD?
   a. Can you tell me a specific example of how leisure helps you cope with your illness?
APPENDIX E: TRANSCRIPT RELEASE FORM

I, ______________________________________, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Urmi Mukherjee. I hereby authorize the release of this transcript to be used by Urmi Mukherjee in the manner described in the Consent Form. I have received a copy of this Data/Transcript Release Form for my own records.

_________________________________________  ___________________________
Name of Participant                          Date

_________________________________________
Signature of Participant                      Signature of Researcher