

# **Living Well with Multiple Autoimmune Diseases: An Interpretive Description**

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University of Saskatchewan  
Saskatoon

By

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## **ABSTRACT**

Autoimmune diseases (ADs) are a classification of chronic of illnesses in which the immune system mistakes healthy cells for foreign invaders and attacks the body's own tissues or organs. They are unique in that the diagnosis of one AD makes the individual more susceptible to developing other ADs, and the symptoms of one AD, influence the disease activity of the others. Disease activity may also be influenced by a mind-body connection due to the relationship between stress and the immune system. The purpose of this study was to provide empirical evidence to generate new knowledge and expand our understanding of how individuals diagnosed with multiple ADs are living well. The methodology of interpretive description guided analysis. Five women with their ages ranging from early twenties to late seventies who were diagnosed with two or more ADs participated. The participants' experiences were illuminated through semi-structured interviews. Four major interconnected themes and 13 sub-themes emerged. They discussed their challenges and successes, their attitudes towards their illnesses, and how they managed living with multiple ADs. The knowledge of the importance of a holistic lens through which to view healthcare provides important insights for those working in physical or mental health settings.

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## **DEDICATION**

I wish to dedicate this thesis to my grandmothers, Gram and Nan. Your strength, optimism, and unconditional love will forever inspire me.

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## CHAPTER ONE: INTRODUCTION

In today's society people are leading busy, stressful lives and are often finding it difficult to juggle a career, family, household, friends, and finances. Adding another stressor to that list that negatively affects your sleep, daily functioning, use of time, and self-concept. A stressor that manifests these symptoms is chronic illness. Illness is often manageable with minimal impact for a week at a time, but when there is no cure and limited medical treatment options for the symptoms, individuals affected by chronic illness are faced with a multitude of social, emotional and physical challenges.

Envision living a busy life while making time for frequent doctors visits that may last all morning or afternoon depending on the wait time to see the professional; time periods of inactivity due to pain, inflamed joints or organs; canceling plans due to fear of embarrassment from external symptoms or fear of flare-ups; or missing work from lack of energy and then worrying about finances. All of these scenarios are realities for many people living with autoimmune diseases (ADs). ADs are a group of illnesses in which the immune system mistakes healthy cells for foreign invaders and in turn attack the body's own tissues or organs (Rose, 2002a). ADs are chronic, incurable, unpredictable, and challenge people with a unique range of symptoms and severity (Rose 2002a).

To date no underlying cause of ADs has been identified. For many ADs, research to discover a cure is still in the early stages (Abramovitz, 2011). More and more people than ever before are being diagnosed with ADs, making the lull in research problematic (Rose, 2002b). Until research and science have found a cure or effective treatments, it is important to identify how individuals are managing the challenges that accompany their diseases in order to enhance their well-being. Having to navigate the challenges of life

while diagnosed with a chronic illness can be a difficult hand to be dealt. Perhaps the key to being able to live well with these challenges lies in the way the individual approaches their illnesses.

### **Autoimmune Diseases and Other Chronic Illnesses**

ADs have some commonalities and differences from other classifications of chronic illness. ADs are unique in that they are strongly influenced by factors external to the individual such as environmental toxins, work, and, relationship stress (Hess, 2000). Although stress plays a role in many other chronic illnesses such as high blood pressure, it may affect individuals with ADs more severely than other people due to the relationship between the immune system and stress and the role the immune system plays in the pathophysiology in ADs. The positive correlation between stress and an adverse immune response has been sufficiently demonstrated (Stojanovich & Marisavljevich, 2008). This relationship proves difficult for people with ADs because stress may trigger the onset of symptoms. Yet living with a chronic AD can be extremely stressful in itself, and having a symptom exaggeration may contribute to more stress in that individual's life; thus creating a vicious cycle. Knowing that the individual has the agency to influence their disease progression through managing their stress and levels of inflammation in their bodies make ADs a group of illnesses well suited to psycho-social interventions.

ADs on average take more resources and time to gain an accurate diagnosis than most classifications of chronic illness (AARDA, 2012). Many individuals with ADs come in with a variety of symptoms that are difficult to make sense of and come and go sporadically, especially in that person has multiple ADs (American Autoimmune Related

Diseases Association [AARDA], 2012). Chrisler (2001) reports that practitioners are sometimes ill trained in the recognition and diagnosis of ADs so often individuals are labeled hypochondriacs in the process. This difficult diagnostic process, that may take years, also distinguishes ADs from other forms of chronic illness.

A final difference between ADs and other forms of chronic illness is that ADs attack all different parts of the body and are not focused on a single system. For example, the immune system attacks the brain in Multiple Sclerosis and the digestive system in Crohn's disease (AARDA, 2012). Although other illnesses affect a variety of areas as well, ADs have the ability to influence any system in the body once the individual has been exposed to them.

There is great comorbidity amongst ADs as having one AD increases that person's susceptibility for developing others (AARDA, 2012). Therefore, it is common for people to be living with 3, 4, or 5 different ADs. The greater likelihood of having to manage several different ADs and the fear of being diagnosed with other in the future is another concern for individuals living with ADs as opposed to other types of chronic illness.

### **Living with Multiple Versus a Single Autoimmune Disease**

The high rates of comorbidity among ADs create a series of unique challenges for people diagnosed with one or more AD. First, living with many chronic illnesses may require more time and energy to devote to healthcare needs. For example, the individual may have to be in contact with several different specialist doctors or have to travel for special treatment or care. In addition to working with multiple health professionals, multiple treatments may also be required (AARDA, 2012). The treatments may also be

time consuming, expensive, or the medication for one AD may negatively interact with the medication of another. Keeping track of the ways their medication or treatments interact with each other and communicating your health care plan to each specialist may be another source of stress for the individual (Abramovitz, 2011).

Another challenge associated with living with multiple ADs as opposed to just one is the symptoms of one AD typically influence the symptoms of another AD (Shomon); therefore, a flare-up of one AD may evoke the flare-up of the other ones. Managing stress and symptoms may become very important in multiple ADs so to not contribute to an increase in disease activity. In addition, with each new diagnosis the individual may have to learn about the disease and how to manage the new symptoms (AARDA, 2012).

### **Researcher Position**

I am not coming into this topic with an objective or unbiased perspective. I have a close personal relationship with chronic illness, which has led me to pursue this area of research. ADs are quite prevalent in my family. In my immediate family alone, three members are diagnosed with one or more. I was relatively healthy growing up, and experienced no major health upsets until I was 13 years of age. At that time I started getting several red spots on my torso. With time the spots covered more area and became uncomfortable. I was referred to a dermatologist who diagnosed me with psoriasis. So began my journey with treatments, medications, ointments and doctors. I was 14 years of age when the psoriasis went into remission and a host of new symptoms emerged. I experienced stomach cramps, weight loss, and fatigue. This time I was referred to a gastroenterologist, who diagnosed me with ulcerative colitis when I was 19 years of age.

During the time between my first two diagnoses, I was also experiencing mysterious pain in my joints that would come and go sporadically. I visited a series of specialists and underwent a bone scan, MRI and a series of x-rays with no definitive answers. When I was 22 years of age new symptoms started affecting my right eye. I noticed that it was tinted red but attributed it to the fact that I was tired. The red started to intensify and was accompanied by blurred vision, sensitivity to light, and pain. The optometrist referred me to an ophthalmologist when the symptoms worsened. I was eventually diagnosed with iritis. I was at eye appointment when a student resident asked me if I had any other ADs. When I mentioned psoriasis, she asked if I had ever experienced any joint pain. She told me that joint pain was common in people diagnosed with psoriasis and it was labeled psoriatic arthritis. My dermatologist later confirmed this diagnosis. Ten years after my first set of symptoms I was diagnosed with psoriasis, ulcerative colitis, iritis and psoriatic arthritis.

I have not always been calm in the face of my diagnoses. I took my first diagnosis the hardest. When the doctor labeled me with a disease, the reality that it would be with me my whole life was something that required time to accept. I was not as informed about the nature of ADs when I was younger so I did not expect to be diagnosed with any others; however, when I was diagnosed with them I welcomed the opportunity to put a name to the symptoms and was eager to start treatment. These illnesses have taught me the limits of my body and to not push those boundaries. This insight was a product of maturation and reflection. I had to realize that although I did not have control over the nature of my diseases, I did have control over how I perceived and responded to them. I have since sought out ways to manage my conditions along side managing my life.

My health management process consists of engaging in many different activities depending on what resources are available. I have identified a “repertoire” of positive resources I rely on to keep my spirits up and my stress levels low. I am most grateful to have access to a good support system of understanding people. I am also thankful for my calm disposition that has allowed me to put things into perspective and not become overwhelmed. In addition, I found it is very important to have a sense of humor.

When I’m feeling sick and frustrated I do not always maintain a positive attitude. This is why living well is a process that likely looks and feels different for each individual. For the purposes of this research, I was not as concerned about each individual day in the life of someone with multiple ADs, I was more interested in how their condition management process contributed to how they were living well with their illness, however they defined that. For myself I saw living well as a holistic concept that Ivancic (2012) appropriately articulated as a “concept that encompasses a person's physical, psychological, emotional, and spiritual components. Living well gives you the energy to engage with life in a meaningful and fulfilling way” (p.1).

### **Purpose of the Study**

My own experience, anecdotal experiences of others living with multiple ADs, and a lack of research on multiple ADs has led me to the rationale for this study. There are many aspects of living with ADs that can be challenging such as the process of diagnosis, frequently doctors visits, and navigating or working through the symptoms of each illness. Despite these challenges, many individuals diagnosed with multiple ADs are thriving. This has led me to wonder how people with multiple ADs are living well with their conditions. Several negative experiences accompany chronic illness, yet many

people have been able to see past them and focus on more positive aspects of their lives. This study sought to gain a deeper understanding of what living well with multiple ADs involves; specifically, what individuals are doing to live well and what their perspective on living well encompasses.

For individual ADs, there are many resources that address the symptoms as well as best treatment options; however, there is little research that investigates how individuals are navigating multiple ADs. The present study sought to identify and describe how people with multiple ADs were living well with their conditions. This study was consistent with the message generated by the positive health psychology movement. Positive psychology is the scientific study of health assets, and includes factors that produce longer life, lower morbidity, lower health care costs, better health prognosis, and higher quality of physical health (Seligman, 2008). Research has shown that factors such as life satisfaction, positive emotions, optimism, meaning, purpose, and social support predict good physical health (Peterson, 2010). This movement emphasizes a biopsychosocial approach to well-being and explains how positive psychological constructs relate to biological, subjective (i.e. psychological), and functional physical health outcomes (Seligman). Consequently, the goal of this study was to explore how individuals with multiple ADs were living well with their conditions according to their subjective definitions of well-being.

Interviews and observations were combined using the interpretive description approach articulated by Thorne, Kirkham, and O'Flynn-Magee (2004) in order to guide the perspectives and experiences of individuals living well with multiple ADs. Interpretive description is a non-categorical methodology aimed at moving qualitative

research relating to clinical practice beyond a level of description into the realm of interpretation (Thorne, et al., 2004). This approach acknowledges the researcher's theoretical and practical knowledge of the topic of study. This, combined with the emphasis of in-depth interpretive descriptions of applied health phenomena, make this method an appropriate choice for the study of living well with multiple ADs.

### **The Research Question**

This study was guided by the following primary research question: How were individuals diagnosed with multiple ADs living well with their conditions? Secondary questions included: How do they perceive living with multiple ADs? How have they managed their illnesses? A deeper understanding of the phenomenon of living well with multiple ADs was generated through personal accounts of people sharing their experiences with the researcher.

### **Significance of the Study**

The aim of this study was to explore the perspectives and experiences of individuals living well with multiple ADs in order to understand the challenges they face and how they manage their conditions to generate knowledge that can inform clinical practice. In-depth accounts of individuals living well with multiple ADs can be informative to others living with one or more AD. Little research on the experiences of navigating multiple ADs has been published leaving a gap in the literature. Individuals living with multiple diagnoses of ADs could benefit from these descriptive accounts of navigating health care to assist them in managing their own conditions.

In addition, health care professionals such as doctors, nurses, and counsellors could use this knowledge to inform future interventions and psychosocial suggestions for



their clients. ADs are accompanied by many challenges that individuals may need to be informed of in order to work through them. Healthcare professionals are in a position to assist these individuals by recommending ways of managing their conditions that supplement biomedical means. Finally, family members of individuals with ADs may also benefit from an increased understanding of their loved one's diagnoses and how they experience them. Familiarity with the experience and perspective of others in similar circumstances may provide knowledge and resources they can apply to the situation of their family member.

## **CHAPTER TWO: LITERATURE REVIEW**

The following section includes an overview of ADs, the theoretical framework in which the present study is situated, and empirical support demonstrating the effectiveness of positive internal and external resources on AD prognosis. Specifically, the physiological manifestation and consequences of ADs are discussed along with their prevalence and a brief overview of current treatments. The biopsychosocial framework is introduced as a lens through which to view the topic of living well with multiple ADs. Finally, condition management strategies are explored through a positive psychological approach to health.

### **Autoimmune Diseases**

ADs are the focus of the present study because they are a group of chronic illnesses that incorporate a variety of diseases and symptoms, yet they share important sequelae that impact negatively on quality of life. Chronic illness is any disorder that persists over a long period and affects physical, emotional, intellectual, vocational, social, or spiritual functioning (Mosby's Medical Dictionary, 2009). Research has emerged on the link between the effect of stress and emotions on the immune system, which suggests a relationship between ADs and psychological health (O'Leary, 1990). Although new information is still emerging and explanations are not clear, stress is acknowledged as a precipitating factor in all ADs (O'Leary). For this reason it is important to identify ways in which individuals are able effectively able to manage stress and their illnesses in order to reach a place of well-being.

There are approximately 80-100 diseases that affect the immune system in humans and fall under the classification of AD (Jackson Nakazawa, 2008). When

functioning well, the immune system protects the body while eliminating all unhealthy infections. It immediately recognizes invaders that have penetrated the body and attacks them, allowing for a quick recovery from viruses such as colds (Jackson Nakazawa). In ADs, the immune system is misguided and it attacks the very tissues it was designed to protect. The immune system fails to distinguish between the self and foreign substances, resulting in attacks on its own tissues and organs (Abramovitz, 2011).

**Prevalence.** Individually, each of the 80+ diseases is not extremely prevalent, but taken as a whole, ADs are the second leading cause of chronic illness and represent the fourth leading cause of disability in women (AARDA, 2012). Kerr (2008) reports:

In some cases, ADs are three times more common now than they were several decades ago. These changes are not due to increased recognition of these disorders or altered diagnostic criteria. Rather, more people are getting autoimmune disorders than ever before.

There is a significant lack of epidemiological studies on several ADs, which hinders the accuracy of estimating the prevalence of ADs as a group. The National Institutes of Health (NIH, 2005) estimates that approximately 23.5 million Americans have an AD. However this number reflects epidemiology studies of only 24 of the 80+ ADs. More specifically, according to NIH, 1 in 12 Americans and 1 in 9 women are diagnosed with one of these 80 disorders. The AARDA (2012) estimates that 50 million Americans have an AD based on NIH epidemiology studies and data from patient members of the National Coalition of Autoimmune Patient Groups. There are currently no estimates of the prevalence of multiple ADs for women and men alone or as a group.

The prevalence rates are staggering and on the rise, yet ADs have received relatively little attention by national research efforts. The AARDA (2012) reports that there is a need for collaboration across basic autoimmune research. By focusing on the

etiology of all ADs rather than singular ADs, the root causes will best be identified. Currently, palliation is the dominant practice and involves superficially treating the symptoms after the disease has already affected the person (AARDA). There is little attention given to basic autoimmune research even though it affects millions of people. By comparison, approximately only 9 million people or 1 in 20 Americans will have cancer and 22 million people or 1 in 14 will have heart disease in their life (AARDA).

The statistics reflect the fact that more people will develop an AD over cancer than either heart disease, yet the latter receive much more attention, research, and funding. Recently, the NIH, the major funding agency for biomedical research in the United States, has significantly expanded its funding efforts to allocate more resources to ADs. However, the 2003 \$591.2 million dollar budget for ADs is still only a fraction of the cost of the \$6.1 billion dollar budget for cancer and the \$2.4 billion dollar budget for heart and stroke related diseases research (AADRA). Despite the fact that ADs on average take 15 years off people's lives, the level of AD research funding is less than 2.2% of the NIH budget, while 10 and 6 times more money is allocated to other diseases that affect less people (Shomon, 2002).

Canada has yet to issue a report on the prevalence of ADs as a group either provincially or nationally. AARDA is the only organized body that is focused on this classification of illnesses as whole. However, some Canadian statistics on individual ADs have been published. For example, according to the Multiple Sclerosis Society of Canada (2012), Canadians have one of the highest rates of multiple sclerosis (MS) in the world. There are approximately 55,000- 75,000 people living with MS in Canada with Saskatchewan alone having 3,500 cases. Canada also has one of the highest incidences of

IBD (includes irritable bowel disease, Crohn's disease and ulcerative colitis) in the world. A report released in 2008 reported that 200,000 Canadians suffer from IBD (Crohn's and Colitis Foundation of Canada, 2012). In addition, in 2010 arthritis affected more than 4.2 million Canadians aged 15 years and older, which is 16% of the population (Public Health Agency of Canada, 2012). Arthritis is the second and third most common chronic condition reported by women and men, respectively (Public Health Agency of Canada). Finally, rates of celiac disease have almost doubled in western countries in the last 25 years leaving 330,000 Canadians with the disease (Canadian Digestive Health Information, 2011).

**Table 1**

## Percentage of Population Affected by Common Autoimmune Disorders

Autoimmune Disease	Percentage of Population
Rheumatoid Arthritis (RA)	0.92%, 1 in 108
Type 1 Diabetes Mellitus	0.12%, 1 in 800
Hashimoto's Thyroiditis	1.55%, 1 in 182
Systematic Lupus Erythematosus (SLE)	0.15%, 1 in 94
Multiple Sclerosis (MS)	0.14%, 1 in 700
Crohn's Disease	0.18%, 1 in 544
Sjogren's Syndrome	0.37%, 1 in 272
Pernicious Anemia	0.15%, 1 in 680
Grave's Disease	1.12%, 1 in 89
Celiac Disease	0.40%, 1 in 249
Glomerulonephritis	0.02%, 1 in 4,428
Scleroderma	0.11% 1 in 906
Myasthenia	1 in 20,000

Source: AARDA (2012)

**Physiology and Etiology.** The immune system now recognizes increasingly diverse infectious agents to which people are exposed (Kerr, 2008). This refinement comes with an increased risk of malfunctioning. The result has been an increased frequency immuno response to an unidentified trigger causing the body to attack itself and an AD to be born (Kerr).

The body's immune system is made up of a vast network of cells and organs throughout the body. This network is responsible for recognizing and ignoring all the cells and tissues within the body and attacking all invaders such as foreign cells, viruses, bacteria or fungi (Jackson Nakazawa, 2008). Under normal circumstances, the immune system's army of white blood cells helps protect the body against harmful substances

called antigens (e.g. bacteria, viruses and toxins) (NIH, 2005). In ADs, the immune system cannot tell the difference between healthy body tissues and antigens (NIH). This results in the immune system destroying healthy body tissues.

The etiology of ADs is largely unknown but many theories have been proposed. The most prominent theory on why AD rates are on the rise is related to people's increased exposure to environmental toxins (Abramovitz, 2011). Research on what contributes to immune system malfunction focuses on the chemicals in the air, water, soil, and consumer products such as pesticides, industrial chemicals, flame retardants in fabrics, plastics and even non-stick cookware (Jackson Nakazawa, 2008).

Researchers are also starting to identify the genes that predispose individuals to develop ADs and are studying how these genes initiate the disease process or exacerbate symptoms (NIH, 2005). There is an established genetic link wherein those with a family member diagnosed with an AD are 20% more susceptible to developing one themselves (AARDA, 2012). There are also ethnic, geographic region, and hot and cold exposure symptom and etiology variance in some ADs (Chrisler, 2001). Since women are more affected by ADs than men, with the majority being diagnosed in their reproductive years, some hypothesize a possible endocrinological connection to the etiology of ADs (Rose & Mackay, 1998). Stress has also been found to play a significant role in disease development and severity, which is also common in women of childbearing age when trying to juggle motherhood with her other roles.

## **Classification of Autoimmune Diseases**

ADs affect various parts of the body and elicits a range of symptoms and severity. There are two classifications of ADs, organ-specific and non-organ-specific. The organ specific type attacks various organs depending on the disease (e.g. Hashimoto's thyroiditis attacks the thyroid, insulin-dependent diabetes mellitus attacks the pancreas, pernicious anemia attacks the stomach, and Addison's disease attacks the adrenal glands; AARDA, 2012). In non-organ specific diseases, autoimmune activity is widely spread throughout the body (e.g., systemic lupus erythematosus (SLE), rheumatoid arthritis (RA), and dermatomyostis; AARDA). Certain ADs fall between the two types. It is not uncommon for people to experience both an organ-specific and non-organ-specific AD at the same time because once an individual has been diagnosed with one AD they are more prone to developing others (AARDA, 2012).

In organ-specific ADs there are many types that are grouped according to the part of the body they affect. Classifications include endocrine, hair, skin, eyes, gastrointestinal, joint, musculoskeletal, and neuromuscular conditions (Shomon, 2002). The classification of diseases is important for this study because participants were required to be diagnosed with two or more ADs that fall under two or more categories. This differentiation allowed for the exploration of how individuals live well with multiple ADs that affect different parts of the body, since management is likely to be different for each category. The above categories are the ones in which the participants were expected to have a condition (e.g. diagnosed with an AD that affects the joints and one that affects the skin). The most common diseases (see Table 1) all fall under different categories that determine how the organ or tissue under attack is being affected.



Endocrine diseases include type 1 diabetes, in which the pancreas is attacked and too little insulin is produced; Grave's disease attacks the thyroid gland causing the body to produce an excessive amount of thyroid hormone, and in Hashimoto's thyroiditis the thyroid is destroyed by the immune system. Gastrointestinal diseases attack the digestive system and consist of Crohn's disease and ulcerative colitis. Connective tissue diseases include RA, which is when the immune system attacks the cartilage and membranes around joints and potentially the heart, lung, and eyes, SLE attacks connective tissues, scleroderma produces skin thickening and scar tissue in the skin, internal organs, and blood vessels, and Sjogren's syndrome attacks the exocrine glands, inhibiting the individual's ability to secrete saliva and tears. Neuromuscular diseases include myasthenia gravis, in which the muscles are attacked and gradually weaken, and MS, which, attacks the central nervous system and leads to tingling and numbness in the limbs. Vasculitis attacks blood vessels and hematologic AD attacks red blood vessels specifically (AARDA, 2012).

As with most illnesses, if an individual is diagnosed with an AD (e.g. celiac disease), it takes time and education to learn to adapt and manage the illness (Rose, 2002a). If this same person then receives a diagnosis of another AD that falls under a different category (e.g. RA), it could require additional learning and adjustment than if their second diagnosis had fallen under the same category (e.g. ulcerative colitis). In the above example, celiac disease and ulcerative colitis both affect the digestive system, so similar management strategies could be applied to live well with both. However, celiac disease and RA affect different parts of the body- the digestive system and the joints respectively. Therefore, different ways of managing both illnesses would need to be

implemented with the onset of RA since the symptoms differ from those of celiac disease (Piette & Kerr, 2006). Multiple ADs that affect different parts of the body require the individual to come up with new ways to cope with and adapt to their illnesses. Therefore, it is more difficult to manage multiple ADs as opposed to a single AD (Lowe & McBride-Henry, 2012).

**Multiple Autoimmune Diseases.** Recently researchers have begun to recognize how ADs tend to compound on one another. In other words, there is great comorbidity among ADs. Comorbidity differs from multimorbidity (the co-occurrence of medical conditions within a person) in that comorbidity refers to a medical condition existing simultaneously but independently with another condition in a person (Van den Akker, Buntink, Knotternus, 1996). Individuals diagnosed with one AD are more susceptible to developing others (Somers, Thomas, Smeeth & Hall, 2009). People with psoriasis, for example have a 62% increase risk for diabetes and approximately 30% of people with psoriasis develop psoriatic arthritis, which causes pain, swelling, and stiffness around the joints (Krueger, Koo, Lewohl, Menter, Stern & Rolstad, 2001; Solomon, Love, Canning & Scheeweiss, 2010). Gershwin et al. (2005) also found the prevalence of SLE, autoimmune thyroid disease, sjogren's syndrome, and polymyositis to be 6-20 times higher in cases of primary biliary cirrhosis than in controls. Unfortunately, few national epidemiology studies on the comorbidity of ADs in Canada or the United States have been attempted. However, Eaton, Rose, Kalaydijan, Pedersen & Mortensen (2007) conducted a study of the prevalence of the comorbidity of ADs in Denmark and found extensive comorbidity across 31 different diseases.

Living with multiple ADs presents many challenges for people trying to live well with their illnesses because often the symptom management plan or medication of one AD interferes with the treatment of the other (Piette & Kerr, 2006). Furthermore, if one AD is not properly managed, it can influence the flare up of another AD simultaneously; which only increases the stress and disability in that individual's life (AARDA, 2012). Often times individuals and clinicians alike can become overwhelmed by the need to address multiple co-morbid conditions in a manner that optimizes the well-being of the person. If all of these illnesses are not effectively treated, the individual may feel as if they are losing control over their illnesses, which decreases quality of life, lowers daily functioning, and increases mortality risk (Piette & Kerr). Many health systems tend to focus on specific individual disease management, while providing ineffective care for people with a variety of co-existing conditions that often need tailored symptom management since different diseases require different resources (Piette & Kerr). More research is required on how to address the challenges presented by this complexity in order to maximize clinical outcomes and quality of life (Eaton, Rose, Kalaydijan, Pedersen & Mortensen, 2007).

This is why effective management of multiple ADs is extremely important to living well, especially if the different diseases require different management and treatment strategies. Often medical treatments used to treat one AD exacerbate the symptoms of another, so having access to psychosocial resources that aid in symptom management and complement biomedical treatments may be beneficial. At this time, there is no research that indicates multiple ADs can be managed with positive psychosocial resources, suggesting the need to study this topic.

**Diagnosis.** People report extreme frustration with the AD diagnostic process (Amramovitz, 2011). People with ADs face a myriad of symptoms that are difficult to diagnose and often go through years of medical consultation before receiving a diagnosis (Chrisler, 2001). It is also very frustrating for people when their health care providers fail to believe anything is wrong with them since symptoms are often not physically noticeable, do not show up in many tests, and come and go sporadically. Rose (2002a) reports that many front-line practitioners are ill trained in how to diagnose these ADs. Hence many ADs are not recognized when the individual initially presents their complaints. The delay in diagnosis results in a delay of treatment, resulting in the physical and emotional deterioration of many peoples' conditions (Rose, 2002a).

On average, people with an AD visit six different doctors before attaining a correct diagnosis (AARDA, 2012). A recent survey conducted by AARDA (2012) discovered that 45% of people with an AD were labeled as hypochondriacs in the earlier stage of the diagnosis process. This finding may be in part explained by the fact that the majority of people with ADs are women (AARDA). This 75-80% of the women with autoimmune symptoms are dismissed in the medical field when presenting confusing symptoms (AARDA). This process leaves people feeling confused, frustrated, hurt, and labeled psychosomatic malingerers.

**Prognosis and Treatment.** ADs present many varied and inconsistent symptoms. Most often the course of the disease consists of periods of intense impairment and disability infused with periods of remission during which no symptoms are present (NIH, 2005). Some people go through a more gradual prognosis without punctuation. One characteristic feature of all ADs is their chronic and incurable nature. Although there are

treatments available, ADs have no cure and can result in a lifelong struggle since the person cannot predict when their symptoms will relapse or go into remission.

Effective medical treatments are only available for approximately 10% of the identified ADs (Abramovitz, 2011). For some people depending on their illnesses, such treatments are poorly tolerated and do not effectively manage symptoms (Olsen & Stein, 2004). ADs considerably impact a person's life and as with certain diseases, such as diabetes, treatment must begin as quickly as possible because the person's life is at risk. In other cases, such as RA, treatment can be less urgent. The AARDA (2012) states that there are two things one must consider when treating ADs: first, correcting any deficits from the result of the symptoms, and second, suppressing the activity of the immune system. ADs that require deficiency correction include diabetes with insulin injections, hemolytic anemias with blood transfusions, and Sjogren's syndrome with eye drops (Abramovitz). To suppress the immune system in illnesses like celiac disease or drug-induced lupus, disease triggers are removed (e.g., gluten or drugs). In others, immunosuppressant drugs or steroid creams are prescribed.

As a result of the progressive nature of many ADs, the severe symptoms, or no available medical treatments, people often rely on complimentary and alternative medicine (CAM) therapies (Taibi & Bourguignon, 2003). CAM as defined by the National Center for Complementary and Alternative Medicine (NCCAM), is "a broad range of healing philosophies, approaches, and therapies that mainstream Western medicine does not commonly use, accept, study, understand, or make available" (NCCAM, 2012). CAM is founded on the assumption that the mind is important for healing, which suggests emotional and spiritual aspects of physical health.

CAM posits that changes in attitude, lifestyles, and orientation toward self manifest abatement of disease. Estimates range from 28-90% of individuals with rheumatic conditions turn to alternative therapies, depending on the definition (Taibi & Bourguignon, 2003). In part because pharmacological and medical treatments are often expensive, ineffective, are sometime accompanied by dangerous side effects, and do not offer a cure, CAM treatments are relied on more from people with ADs than any other chronic illness population (Taibi & Bourguignon). CAM therapies can be used with conventional treatments and consist of special diets, herbal or vitamin supplements, massage, acupuncture, exercise, stress management, and therapy (Abramovitz, 2011; White, Lemkau & Clasen, 2001).

### **Psychosocial Influence**

The psychological influence on ADs is a very important feature of these illnesses because it allows individuals to manage multiple ADs with the help of positive psychological and social resources as a primary method or a means to supplement medical treatments.

**Stress Connection.** Psychosocial-based treatments are promising for the treatment of ADs since these disorders involve an attack on one's own body. The field of immunology has an abundance of research demonstrating the connection between the mind and body, specifically in ADs (O'Leary, 1990). One well demonstrated finding is that the presence of prolonged stress negatively influences the immune system (Selye, 1952). In fact, prolonged stress increases the risk for ADs (O'Leary; Selye, 1952; 1956; Stojanovich & Marisaylievich, 2008). For example, stressful events were linked to an increased chance of relapse in people with MS and highly stressful periods were found to

be related to the onset and worsening of RA (Buljevac et al., 2003; Gio-Fitman, 1996). In addition, individuals with posttraumatic stress disorder or who have been exposed to other traumatic stressors are more at risk for developing autoimmune conditions such as fibromyalgia, chronic fatigue syndrome, gastrointestinal disease, diabetes, and musculoskeletal disorders (O'Leary).

Negative emotional diagnostic experiences, the threat of physical symptoms, and the demands of everyday life can contribute to exacerbated feelings of stress in people with ADs. Stress can be imposed on people both externally and internally created by a mind-body connection. No matter the source, stress can overload the nervous system and dangerously elevate the level of stress hormones (Norton, 2001). Generally the production of stress hormones is supposed to stop as a self-protection mechanism; however, when people are continuously faced with stress provoking situations this mechanism goes awry and cannot shut off sufficiently (Norton, 2001). The stress response also decreases the ability of the immune system to fight off infection (Stojanovich & Marisaylievich, 2008).

Psychological distress has been shown to suppress the immune response through the activation of the hypothalamic-pituitary-adrenal (HPA) axis, which may result in exacerbation of symptoms (Ader, Cohen, & Felton, 1995). Inflammation, which is an important component of ADs, as well as immune challenges become physiological stressors that lead to the HPA axis activation (Kiecolt-Glaser et al., 2002b). Cytokines, the protein substances released by cells that serve as intercellular communicators that regulate the immune response to injury and infection, have been the focus of research in this area (Parham, 2000). Cytokines are seen as the messengers between the brain and

immune system (Maier, Watkins, & Fleshner, 1994).

Black (2003) suggests that the inflammatory response resides within the psychological stress response and the same neuropeptides, (molecules that communicate with each other), influence the body's reaction to both stress and inflammation. In addition, when cytokines are elicited by either stress or inflammation they may travel similar pathways to the brain in both processes (Black). There is evidence that negative psychological states such as anxiety and depression affect immune processes by increasing the production of pro-inflammatory cytokines (Kiecolt-Glaser et al., 2002a).

Dysregulation of the immune process is regularly seen in ADs and is correlated with psychological variables such as depression. Individuals with chronic physical health problems have a significantly increased risk for developing depression (Zeiss, Lewinsohn, Rhode, & Seeley, 1996). Berk, Wade, Kuschke, and O'Neill-Kerr (1997) found evidence of a relationship between depression and inflammation in individuals with ADs. Pain is another stressor experienced by individuals with ADs, which contributes to high levels of functional disability and greatly contributes to overall illness affliction (Turk & Melzack, 1992). In addition, pain is strongly related to negative affect and enhances stress-related hormones and immune dysfunction (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002b; Robinson & Riley, 1999). An abundance of physical and emotional energy is required when coping with pain, which may influence the management resources required of people living well with ADs. The relationship between the immune system and the mind as demonstrated by the previous examples illustrate that psychosocial-based interventions have the potential to positively influence the course of ADs.



**Psychological Importance.** Psychosocial factors are increasingly being recognized in the literature as playing an important role in the physiology of several diseases, yet practicing physicians and medical school curriculums often continue to overlook this mind and body connection. The connection between the mind and the immune system links the role of the mind to the physiology of ADs, implying the favorable role psychosocial-based management plays in living well with multiple ADs.

Individuals diagnosed with ADs live with disempowering diseases that are associated with many physical and emotional consequences. Apart from going through difficult diagnostic procedures, people with ADs suffer from a variety of symptoms that may come and go without warning, have a higher chance of developing other ADs, and endure debilitating pain (Chrisler, 2001). Some individuals with ADs have also reported feeling unsupported by friends and families. Their symptoms were interpreted “being in their heads” (Chrisler). As aforementioned, people with ADs are more susceptible to developing depression, which in turn worsens the disease response and creates negative psychological symptoms (Dantzer, O’Conor, Freund, Johnson & Kelley, 2008).

For all of these reasons it is important to study ADs and determine what people are doing to manage and live well with their illnesses. Specifically, individuals living with multiple AD are a population that merit attention because they face unique challenges in trying to manage multiple symptoms that affect different parts of their bodies. Researchers, therapists, health practitioners and educators alike need to consider the range of biological, social, and psychological variables that influence the development, severity and course of ADs.

## **Theoretical Foundation**

The theoretical foundation for the present study is the biopsychosocial model, which posits that physical health problems stem from an interplay of biological, social and psychological factors (Engel, 1977; Hoffman & Driscoll, 2000). This model is grounded in the assumption that the mind and body are inherently connected and this connection should be recognized and treated accordingly by medical and mental health professionals (Engel; Hoffman & Driscoll). This model is especially relevant when applied to ADs due to the role psychological processes play in the immune system and inflammatory response. Incorporating all aspects of mental and physical health into treatment may be the key to successfully treating individuals with ADs.

The mainstream medical model often does not address psychological or social concerns, and holds that biological/physiological processes are sufficient in the understanding, treatment, and prevention of illness (Engel, 1977). This model is biomedical, which is based in molecular biology and grounded in reductionism and mind-body dualism (Engel). Concentrating only on the biological processes does not incorporate the full span of influencing factors that affect ADs. One thing that draws people into the biomedical model is the promise of a “magic bullet” solution to health problems or a cure to their ailments (Suls, Luger & Martin, 2010). Such “cures” for example, are the discovery that insulin treats type 1 diabetes, and these treatments provide much support for this model. Within this mindset other aspects of the individual have been neglected as proponents “of the biomedical model, claim that it’s achievements more than justify the expectation that in time all major problems will succumb to further refinements in biomedical research” (Engel, p.536).

The biopsychosocial model provides a framework that incorporates the biological/physiological process as well as areas that have been previously neglected, such as mental and social health. Engel (1977) was the first person to introduce people to a new perspective on health and articulated the biopsychosocial model. He defined this model as “the idea that biological, psychological, and social processes are integrally and interactively involved in physical illness and health, medical diagnosis, medical treatment, and recovery” (Engel, 1980, p. 536). Engel sought to understand the influences on health on multiple levels of analysis, which is an appropriate context for understanding ADs (Suls, Luger & Martin, 2010).

The majority of the research on coping with a chronic illness is based on the biomedical, psychosocial, and biopsychosocial models of health (Walker, Jackson, & Littlejohn, 2004). In the present study it is important to understand the biomedical aspects of ADs but the focus of this study was on the important psychosocial factors that contribute to how well individuals are living with their diseases. The biopsychosocial model also incorporates environmental and cultural contributors to health that may influence how people are adjusting to ADs (Hoffman & Driscoll, 2000).

This model has previously been applied to populations with chronic illness and is consistently gaining popularity. For example, Nicassio and Smith (1995) have written about using the biopsychosocial perspective to enhance clinical work, assessment, and treatment for chronic illness. This model is also frequently applied to understanding chronic pain as the symptoms have biological, neurological, psychological, and social underpinnings (Gatchel et al., 2007). In terms of ADs, rheumatoid arthritis (RA) is the AD most often studied under the biopsychosocial perspective due to the discovery that

psychosocial factors are important for predicting disease activity and the high prevalence of RA in the population (Cohen & Herbert, 1996).

Commonly, the focus in the biomedical model is a diagnostic approach that works within a pathology perspective that focuses on illness. Hoffman and Driscoll (2000) expanded upon Engel's model and emphasized a strengths based approach that moves towards health and wellness and away from deficits and disease. This strength and empowerment perspective clearly differentiates from the medical model. It is also consistent with the goal of the present research as the positive psychological approach to health is the foundational assumption of this study.

The elements that make up the biopsychosocial model will each be addressed in turn. It is important to have a foundational understanding of the biological processes and physical effects of these diseases that contribute to how individuals experience them. A description of the dysregulated immune system and the resulting symptoms has been provided in the previous section. The upcoming section will discuss management techniques and introduce how positive psychological and social variables have been found to have a beneficial effect on physical health and mental well being.

### **Managing Chronic Illness**

When living with a chronic illness, it is essential that individuals find ways to help alleviate stress, pain, discomfort or other symptoms that may be equally important that accompany their illnesses (Chrisler, 2001). Effective symptom management will assist the individual with navigating difficult or painful periods. "Coping" is the most dominant term in the literature when referring to living with chronic illness. Coping may be an appropriate term for many people living with multiple ADs; however, the term

implies “dealing with” something negative. This study seeks to move beyond coping and explore the point at which individuals have overcome their initial coping stages and have reached a point of well-being. That being said, this section will first explore the coping literature to provide a foundation of support for the role psychosocial factors play in influencing health and disease.

Coping is defined as consciously using cognitive and behavioural strategies to manage situations in which there is a perceived discrepancy between stressful demands and available resources for meeting those demands (e.g., stress) (Aldwin et al., 2010). Coping is influenced by the demands and resources of the individual’s environment and personality dispositions such appraisal of stress and resources (Folkman & Moskowitz, 2004). Moo (1993a; 1993b) proposed a conceptual framework for understanding the coping process. Moo explains that factors within the individual (social supports or stressors), their personal systems (personality, temperament, and neurobiology), and demographic characteristics are all relatively stable. These three factors influence how one adapts to changes in life (e.g., living with disease) since they all affect health and well being through capacities such as cognitive appraisal and stress susceptibility.

There are many ways people cope. One of the main distinctions is between problem-focused coping, the ability to directly modify the stressor in order to minimize its impact, and emotion-focused which aims to soothe distress (Lazarus & Folkman, 1984). Problem-focused coping includes addressing the problem using a variety of problem solving strategies or directly altering the source of stress. Emotion-focused strategies include turning to others for support, maintaining a sense of humor, and cultivating optimism (Lazarus & Folkman). Another distinction is between approach

coping, attempts to deal with the situation, and avoidance coping, attempts to escape from the stressor. Avoidant coping is very effective as a short-term solution but becomes problematic if the stressor is never addressed or dealt with properly.

The concept of coping is very broad and extends into numerous related fields. Perhaps the best suited extension of the term is preventative or proactive coping (Aspinwall & Taylor, 1997), which instead of simply reacting to adversity, promotes good health and well-being. Numerous positive proactive coping and management strategies have been identified in the literature on chronic illness as contributing to a more favorable physical health prognosis, which results in being able to live well with chronic illness (Carr, 2011). Unfortunately, there is little existing research on the management strategies individuals with multiple ADs utilize. Due to the chronic and unpredictable nature of ADs, people diagnosed with multiple ADs may benefit both physically and mentally from positive symptom management. Research has identified that the reliance on internal and external supports may contribute to improved physical health and subjective well-being (Carr).

### **Positive Psychological Resources**

There are several positive resources that can be used for symptom management available to individuals with multiple ADs. The majority of these resources have sufficient empirical evidence to back up their effectiveness of alleviating disease symptoms. For example, self-efficacy (Bandura, 1977), optimism (De Ridder, Fournier & Bensing, 2004), hope (Rand & Cheaves, 2009), social support (Dickerson & Zoccola, 2009), and religion/spirituality (Ano & Vasconcelles, 2005) have all consistently been associated with improved physical health and psychological adjustment.

Due to the abundance of research on using positive psychological resources to cope with chronic illness, the present study explores whether similar positive resources are being utilized by people to manage living with multiple ADs. There is minimal research on the phenomenon of people living with multiple ADs, so focusing on how individuals are living well with multiple ADs will add to the literature by illuminating this common phenomenon. This would provide insight into the management strategies of individuals with this condition. Providing this information through a positive psychological lens will highlight some effective resources people hold within themselves to deal with their illnesses.

**Psychological Capital.** Human capital is generally recognized as the resources of an individual, including education, implicit knowledge, and experience. The positive psychology movement has urged researchers to further this concept in research and practice (see Seligman & Csikszentmihalyi, 2000) by focusing on “psychological capital” (Luthans & Youssef, 2004; Luthans, Youssef, & Avolio, 2007). Psychological capital focuses on both human capital (who you are) and what you strive to be developmentally (who you are becoming, your best self) (Luthans, Youssef et al., 2007, p. 20).

Psychological capital is formally defined as:

An individual’s positive psychological state of development that is characterized by: (1) having confidence (self-efficacy) to take on and put in the necessary effort to succeed at challenging tasks; (2) making a positive attribution (optimism) about succeeding now and in the future; (3) persevering toward goals and, when necessary, redirecting paths to goals (hope) in order to succeed; and (4) when beset by problems and adversity, sustaining and bouncing back and even beyond (resilience) to attain success. (Luthans, Youssef, & Avolio, 2007, p. 3).

Instead of the individual competing with others in the workplace, they can be seen as competing with the disease within themselves. To do so, individuals may rely on the

four resources outlined by Luthans, Youssef and Avioli (2007) in the psychological capital model. Self-efficacy, optimism, hope and resilience have all been linked to improved health and developmental outcomes when faced with a negative health prognosis (Maddux, 2009; Reich, Zautra, Stuart & Hall, 2010; Seligman, 1991; Snyder & Feldman, 2000).

**Self-Efficacy.** Efficacy is a widely researched positive psychological construct that has received much theoretical and empirical support (e.g. Bandura, 1977, 2005, 2008). Research on self-efficacy in health related outcomes has been conducted for over twenty years (Holden, 1991). Self-efficacy is the belief in one's ability to accomplish a specific task (Bandura 1997). There are two principal ways in which self-efficacy affects health: (a) personal beliefs act on the biological systems that mediate health and illness and, (b) beliefs exercise control over habits that promote health and those that impair it (Bandura, 1997; Maier, Laudenslager & Ryan, 1985). When an individual believes they have the capacity to control events, the biological effects of stress are less prevalent. Similarly, if an individual with multiple ADs believes in their capacity to overcome and control their illness, the physical effects are less damaging.

Self-efficacy regulates an individual's behaviour through cognitive, motivational, emotional, and choice processes. For example, people with higher self-efficacy show increased cognitive resourcefulness, strategic flexibility, and effectiveness in managing environmental challenges (Bandura, 1997). They also tend to focus more on the benefits than the risks of a situation, visualize themselves succeeding, set challenging yet realistic goals, ascribe failure to uncontrollable factors, and are motivated to overcome obstacles (Bandura). In addition, people high in self-efficacy interpret demands as manageable,



worry less, and show less negative affect. They also tend to regulate their emotions by facilitating problem focused coping, elicit social support which acts as a stress buffer, and are more likely to use self-soothing techniques such as humor, relaxation, and exercise. All of these behaviours are immune enhancing which results in better physical health, increased resilience to stress, and increased psychological and social adjustment (Bandura, 1997; 2008; Madux, 2009).

Self-efficacy has also been found to have an impact on various biological processes that relate to improved physical health. These processes include immune system functioning, improved susceptibility to infection, neurotransmitters implicated in stress management, and endorphins responsible for numbing pain (Bandura, 1997; O’Leary & Brown, 1995). The various health benefits associated with elevated self-efficacy identified in the literature suggest that this construct is beneficial to managing and living well with multiple ADs. Stress and immunity play a larger role in ADs and the impact of self-efficacy on biological processes indicates its important role in well-being.

**Optimism.** Optimism is an overall general positive outcome expectation. The accepted definition in the literature is “optimists are people who expect good things to happen to them; pessimists are people who expect bad things to happen to them”. Subsequently, optimists “differ in how they approach problems and challenges and differ in the manner and success with which they cope with adversity” (Carver & Scheier, 2002, p. 231). In positive psychology there are two distinct conceptualizations of optimism. Seligman’s (1998) theoretical stream proposes an attributional framework (e.g., explanatory style). In this model, optimists form internal, stable, and global attributions of positive events and external, unstable, and specific attributions of negative events. In

contrast, Carver and Scheier (2002) rely on an expectancy perspective in which the underlying mechanism is the expectation that a desirable outcome will result from increased effort. Carver and Scheier explain that positive expectancy will motivate people to continue to bestow their efforts even when faced with adversity.

A strong association between optimism and physical health has been identified. For example, Rasmussen, Scheier and Greenhouse (2009) conducted a meta-analytic review on the association between optimism and physical health. Eighty-three studies were included that were divided into groups looking at the following: mortality, survival, cardiovascular outcomes, immune function, physiological markers, cancer outcomes, pregnancy outcomes, physical symptoms, and pain. Optimism was consistently found to be a significant predictor of health but the strength of the relationship was moderated by the nature of the outcome. In addition, optimism has shown to be a protective factor in that compared to pessimists, optimists with ADs report less pain (Affleck, Tennen, Zautra, Urrows, Abeles & Karoly, 2001), better immune function (De Ridder, Fournier & Bensing, 2004; Fournier, De Ridder & Bensing, 2002a; 2002b), and show fewer physical symptoms (Fournier, De Ridder & Bensing, 2002a). Furthermore, when diagnosed with an illness, optimists are more likely to engage in better health promoting behaviours such as taking vitamins, changing their eating habits, and exercising (Carver & Scheier, 2002).

Optimists are more likely to use effective coping strategies and regulate their personal states to achieve their goals (Carver, Scheier & Segerstrom, 2010). A meta-analysis that included 50 studies and 11,000 cases conducted by Solberg-Nes and Segerstrom (2006) examined the relationship between dispositional optimism and coping. Optimism was found to be positively associated with problem-focused coping strategies

designed to eliminate, manage, and reduce stressors and emotions. Conversely, optimism was negatively associated with avoidance coping strategies such as avoidance and withdrawal. When positive coping strategies cannot be accessed, optimists tend to use adaptive strategies, which focus on emotion such humor, acceptance, and positive re-framing, which contribute to feelings of well-being (Rasmussen, Wrosch, Scheier & Carver).

**Hope.** The construct of hope has been given considerable attention in positive psychology and merged as a therapeutic factor in the health care literature. For a thorough review of the different definitions of hope from diverse literatures see Elliott & Olver (2002). The most widely adapted view of hope comes from Snyder's (2002, p. 2) "empowering way of thinking". Snyder's hope theory is built off the assumption that people are generally goal orientated and behave in ways that allow them to accomplish their tasks. Snyder's conceptualization of hope involves two main components: agency (willpower) and pathways (Snyder, 2000). If there is agency thinking or willpower to behave in ways to accomplish goals, there is also pathway thinking, which is the ability to generate the routes that lead to the goals (Snyder, 2000, 2002). People who are high in hope tend to be more easily able to generate multiple pathways to accomplish their goals.

Hope is a valuable asset when managing chronic conditions like ADs because it instills a sense of optimism in facilitating treatment and maintaining a positive attitude. It is helpful resource for the newly diagnosed, people with recurrent disease or those in a terminal stage (Elliott & Olver, 2009; Rustoen & Wiklund, 2000). Rand and Cheaves (2009) conducted a review of hope and found that it was consistently associated with better judgment, physical health, psychological adjustment, and improved interpersonal

relationships. In another prospective study focusing on hope, optimism, and health; high hope scores were correlated with reduced frequency and severity of people's illnesses (Scioli et al. 1997). Individuals who are hopeful are more actively involved in their self-care and hold high levels of psychological adjustment because it allows them to rebuild their lives, deepen their relationships and construct new goals.

**Resilience.** No central definition of resilience exists, as there is still a debate about conceptualizing resilience as a personality trait or dynamic process (for an overview of the current conceptualizations see Davydov, Stewart, Ritchie & Chaudieu, 2010). For the present study, resilience “refers to a class of phenomena characterized by patterns of positive adaptation in the context of significant adversity or risk, which enables people to bounce back quickly and effectively from negative events” (Masten & Reed, 2002, p. 75). Resilience is the difference between those who have the capacity to regain physical and psychological well-being after an adverse event and those who remain devastated and unable to recover (Yi, Vitaliano, Smith, Yi, & Weinger, 2008).

Research has identified five main aspects of resilience: active coping strategies, positive emotionality, cognitive reappraisal, social support, and purpose of life (Reich, Zautra & Hall, 2010). Coping strategies including planning and problem solving, are linked to well being, the capacity to handles stress, trauma, and medical illness (Southwick, Vythilingam & Charney, 2005). Positive affect plays a key role in enhancing resilience (Ong, Bergeman, Bscanti & Wallace, 2006). Resilience is also dependent upon reappraising the situation in a better light, with use of humor or a positive outlook. Finally, social support and having a sense of purpose in life are also protective factors that buffer against negative events (Alim et al., 2008; Charuvastra & Cloitre, 2008). All

of these factors contribute to a resilient response, which may contribute to a sense of well-being.

Related concepts that can aid in managing multiple ADs include hardiness, benefit finding, and thriving. Hardiness is a dispositional characteristic that creates a sense of control over one's circumstances, allowing them to see the change as a positive and ascribe meaning to it (Kobasa, 1979). Benefit finding is similar in that it is the ability to make sense of the adversity by focusing on the positives and promoting self-growth (Weaver et al., 2008). Finally, thriving occurs when an individual returns to an even higher level of functioning than before the stressor occurred. The adverse event teaches new skills, knowledge, confidence, or improves social functioning (Carver, 1998). All of these concepts are what this study is seeking to identify and describe in individuals who see themselves living well with multiple ADs.

In addition to the four components that make up psychological capital, other resources have been identified that contribute to the promotion and maintenance of physical health. These elements include positive emotions, religion/spirituality, and social support. Each resource has demonstrated the capacity to aid in the recovery and the development of well-being.

**Positive Emotions.** Recently, the positive psychology movement has placed more significance on the benefits of displaying positive affect. It is now considered to be an important protective factor in health and well being. There is evidence that negative emotion (e.g., anger, anxiety, and depression) can lead to the development of disease, such as diabetes, and is associated with morbidity and mortality from a range of chronic illnesses such as cardiovascular disease, diabetes, and asthma (Barefoot, Brummet,

Helms, Mark, Siegler & Williams, 2000; Friedman & Booth-Kewley, 1987; Lustman, Frank & McGill, 1991). Since experiences that lead to positive emotions cause negative emotions to dissipate rapidly, it is important to focus on positive affect. In addition, there is an established relationship between positive affect and physiological changes that are linked to better immune functioning such as decreased susceptibility to infectious disease (Futterman, Kerney, Shapiro & Fahey, 1994).

Several theories have been proposed to explain the benefits of positive emotions. The broaden and build theory (Fredrickson, 2004; 2009) posits that many negative emotions narrow peoples momentary thought repertoires whereas positive emotions broaden them and lead to an opportunity to build up personal resources. These resources can be drawn upon for inevitable future threats. For example, when someone experiences joy, they may feel playful, creative, or ready to socialize. Their actions resulting from this feeling can strengthen social support, solve problems, or enhance creativity. This cycle ends with the individual experiencing increased personal growth or development (Fredrickson).

A meta-analysis of 225 cross-sectional, longitudinal and experimental studies conducted by Lyubomrisky, King, and Diener (2005) discovered that positive emotions lead to better adjustment in work, relationships, and health. They were also associated with more positive perceptions of health, sociability, likeability, altruism coping, conflict resolution, creativity and problem solving. Another finding came from Danner, Snowden and Friesen's (2001) Nun study that is one of the most widely cited studies on the topic. Nuns were required to write essays upon entering the religious order about their personal histories and hopes for the future. They were not aware the essays would be later read

and included in a study. One hundred and eighty essays were included in analysis. The findings indicated that the more happiness and positive emotions the nuns expressed in their essays in early adulthood were associated with their longevity. Ninety percent of the happiest quarter of nuns lived past 85 compared to only 34% of the quarter of nuns who expressed the least amount of happiness.

**Religion/Spirituality.** When health status is challenged or threatened, many turn to religion or spirituality. Many people rely on a religious or spiritual framework to facilitate recovery from an illness and find meaning after a highly stressful event like a symptom flare-up (Pargament, Smith, Koenig & Perez, 1998). The reviews on this subject found positive correlations between religiosity and mental health, spirituality, quality of life, positive religious coping and positive psychological adjustment (Ano & Vasconcelles, 2005; Hackney & Sander, 2003; Sawatsky, Ratner & Chiu, 2005).

Religion is appropriately applied to disease management because it satisfies the need to find meaning in life after a diagnosis, the need to exercise control over the environment and the self, and the need to form and maintain supportive relationships (Hood, Hill & Spilk, 2009). In examining the link between physical health and religion, research has examined four main dimensions: public participation/attendance, religious affiliation, private religious practices (e.g., prayer), and religious coping when ill (Crane, 2009). All dimensions are linked to improved health but attendance and religious coping have the strongest associations. For example, people who attended a religious service once a week showed less physical illness, a quicker recovery time and they lived longer than people who attended less than once a week (Koenig, McCullough & Larson, 2001).

There are four principal explanations why religion is found to be beneficial to people's health and other areas of their lives. First, having a belief system allows the individual to prescribe meaning to their lives while being hopeful and optimistic about the future. This helps people understand their place in the world, make sense of their difficulties, stressors, and losses, and be optimistic about an afterlife. Meaning also helps people cope better with stress. Second, religion is an avenue for social integration. When people attend religious services they become a part of a church community that provides social support. Social support in turn fulfills the universal needs of affiliation and belongingness. Third, religious practices such as meditation, singing, prayer, and rituals tend to produce positive emotions in people. Sensations of joy, compassion, kindness, or transcendence may be experienced from participation. Finally, religious people have been found to lead more physically and psychologically healthier lifestyles. For example, they tend to practice fidelity, altruism, balanced eating and drinking, family cohesion, and behave in virtuous ways with humility, forgiveness, gratitude, hard work, and compassion (Diener & Biswas-Diener, 2008; Myers, Eid & Larson, 2008).

**Social Support.** As aforementioned in the discussion on religion, social support is also linked to the development and maintenance of good physical health. The need for community is universal. A sense of belonging and being connected to others through shared values creates meaning and is shared by all. Buss (2007) proposes that evolution has hardwired humans to derive happiness and health from social support. Many studies report that social support is important to the successful adaptation to and living with chronic illness (Kralik, Van Loon & Visentin, 2006; Pentz, 2005).



Social support is the network of supportive relationships that surround the individual. Close relationships within family networks and wider social networks are related to greater well-being, health, longevity, and adjustment (Dickerson & Zoccola, 2009; Diener & Diener McGavran, 2008; Lucas & Dyrenforth, 2006; Taylor, 2007). When close family contact is maintained, feelings of social support are increased and the individual is happier. This promotes improved immune functioning and reactivity to stress (Dickerson & Zoccola).

The quality and quantity of an individual's social network influences the effectiveness of its supportive capacity. People with larger social networks and stronger bonds within the network tend to have better physical and mental health, fewer illnesses, less depression, recover more rapidly from illness, and have lower mortality rates (Dickerson & Zoccola, 2009; Taylor, 2007). Social support has also been found to be an important protective factor in stress related disorders (Charuvastra & Cloitre, 2008). When people are stressed, the strength of their social resources mediate how they perceive potentially threatening situations (Cohen & McKay, 1984).

Positive psychologist constructs such as self-efficacy, optimism, hope, resilience, positive emotions, spirituality, and social support have all been shown to improve well-being in individuals with chronic illnesses. People living with multiple ADs may find it beneficial to rely on these constructs in order to assist in managing their illnesses.

### **Summary**

This chapter outlined the biology and physiology of autoimmune diseases as well as some of the challenges individuals living with multiple ADs. It also commented on the importance of understanding these illnesses from a biopsychosocial perspective. The

biopsychosocial perspective encompasses all aspects of an individual's life contributing to their illness and well-being. Finally, evidence was provided for some positive psychological resources that have been shown to positively contribute when drawn on to manage multiple ADs. This chapter provided a rationale for researching multiple ADs because little is known about how one manages well with two or more ADs. It was suggested that using positive resources would be beneficial due to the strong link between stress and immunity.

## CHAPTER THREE: METHODOLOGY

The present study explored the perspectives and experiences of individuals living well with multiple ADs. The methodological orientation used in this study was interpretive description, which is an established approach to qualitative knowledge development in health settings (Thorne, 2008). Individuals diagnosed with two or more ADs who self-identified as living well participated in semi-structured interviews. During the interview process participants were invited to provide a brief personal history and describe how they have learned to manage their conditions. This chapter provides the rationale for using qualitative inquiry and describes the interpretive descriptive process, the procedures (participants, data generation, data analysis, and findings), trustworthiness of findings, and ethical considerations.

### **Paradigmatic Assumptions**

The research paradigm best suited for the present study is constructivism. Qualitative research commonly assumes social constructivist assumptions that posit that the entire research process, from deciding the research question to data collection and presentation of the findings, is a co-constructed interaction between the researcher and the researched (Thorne, Kirkham & MacDonald-Emes, 1997). In other words, constructivist philosophy acknowledges the existence of various levels of truth assertions and justification of knowledge, assuming that the knowledge is the product of how the knower constructs their own reality from his or her interactions, experiences, and perceptions (Hanley-Maxwell, Al Hano, & Skivington, 2007). The ontological and epistemological assumptions assume that knowledge is socially constructed by the person

who experiences the event creating multiple versions of the truth from the participants' to the researcher's (Hatch, 2002).

The purpose of this research was to explore how individuals with multiple ADs perceive they are living well; therefore, information on the perceptions of the participants' experiences and how they made sense of their situations was gathered. Receiving a direct account of the participants' experiences led to a deeper understanding of the phenomenon under study. My personal reality of how I construct my own situation and understand the participants' experiences was also present in the data. Through the process of analysis, a co-constructed understanding of the phenomenon, living well with multiple ADs, was identified and described.

### **Qualitative Research**

The present study used a qualitative approach to research to understand and describe how individuals diagnosed with multiple ADs are living well (Morse & Richards, 2002). Qualitative approaches to knowledge inquiry tend to highlight the complexities of the human experience in in-depth and rich ways from differing standpoints. For this reason, a qualitative approach was chosen as the means to highlight living well with multiple ADs.

In addition, qualitative research was chosen because it is an interpretive and naturalistic approach to everyday experiences and phenomenon (Denzin & Lincoln, 2005). Bogdan and Biklen (2007) highlight four primary features of qualitative research. Three of the four features are most relevant to the present study. First, the aim of qualitative research is to produce in-depth descriptive data, rather than reducing data to numbers. This allows qualitative researchers to thoroughly analyze the data by looking

for meaning, themes, and patterns (Bogdan & Biklen). Qualitative research is primarily concerned with meaning. The topic of interest or research question generally involves understanding, meaning, and significance while attempting to understand the participants' perspectives (Bogdan & Biklen).

### **Interpretive Description**

In the past decade, the need for a new approach to qualitative health research has emerged due to the limitations of traditional methodologies. Consequently, emergent methodologies have been proposed, designed to attend to the health and illness experiences of people that are embedded within a practical and applied focus health practitioners seek (Sandelowski, 2000). Interpretive description is one of these approaches (Thorne, 2008). Interpretive description was first introduced by Thorne, Kirkham and MacDonald-Emes (1997) and assumes that health and illness experiences are complex interactions within the individual as a biological, social, and emotional being. It goes further to assume that these interactions unfold within layered and shifting physical, social, and political worlds. The primary purpose of this methodology is to generate knowledge about health experiences to improve clinical practice (Thorne).

Interpretive description draws on methodological principals from other social science traditions including grounded theory, naturalistic inquiry, and ethnography. It differs from these approaches in its clear emphasis on the practice origins of the research problem and the practical implications of the findings (Thorne, Kirkham & MacDonald-Emes, 1997). The aim of this methodology is to design research studies in ways that will lead to the development of theoretically defensible conceptualizations of health

phenomenon that can shape clinical outcomes. Interpretive description was born out of the need for:

New knowledge pertaining to the subjective, experiential, tacit, and patterned aspects of human health experience- not so that we can advance theorizing, but so that we can have sufficient contextual understanding to guide future decisions that will apply “evidence” to the lives of real people (Thorne, 2008, p.35).

The descriptive nature of interpretive description consists of being open and exploratory, not narrow and focused. This brings the “phenomenon to the awareness of our colleagues, in creating an empirical basis from which new questions can be generated, and for taking note of the manifestations of the complex and messy world of human health and illness” (Thorne, 2008, p. 48). The goal of this study was to describe how individuals with multiple ADs are living well with their illnesses and to identify the voices and experiences of these individuals in the hopes of informing clinical practice.

Although this topic may be categorized as phenomenological since it seeks to gain insight into a deeply subjectivist issue, it does not strive to understand the pure essence of the phenomenon. Instead, this study “reflects quite a different attitude toward knowledge and knowing” (Thorne, 2008, p. 79). Specifically, interpretive description “reflects a commitment to knowing as: ‘empathizing’ or ‘understanding’ [more] than it is about knowing in the existential sense ... We seek patterns and themes within subjective human experience not so much as to grasp its essence as to understand what we are likely to encounter in future clinical practice and to have some meaningful sensitivity around it” (Thorne, p. 79). In order to minimize methodological ‘fuzziness’ often encountered by beginner qualitative researchers, Thorne (2008) suggests that it is best to adhere to a sound methodological guide. I chose interpretive description as a guide since it provides

an explicit theoretical and philosophical framework for the descriptive, interpretive and applied nature of the research question.

### **Role of the Researcher**

The role of the qualitative researcher is to be open to the research and interview process as it unfolds while being directly involved in it. Morse and Richards (2002) describe research as a process of reflection, flexibility, and decision-making. Qualitative data differs from quantitative because it is created between the researcher and participants, its existence does not precede collection. The subjectivity of the researcher and their value system must be acknowledged and articulated at the outset of the study and self-examination and reflection must be practiced throughout the research process (Morse and Richards, 2002). Another responsibility the researcher has is to develop rapport with the participants so both parties can constructively generate data together. Some of my values and pre-conceived notions of the phenomenon were outlined in the introduction in order to practice a reflexive evaluation of my biases that may be present in the research process.

Throughout the research process, I was continually aware of my biases and attempted to set aside all my previously held assumptions, expectations, and prejudices through the practice of bracketing (Van Manen, 1990). I was accepting and affirming to each participant and attempted to convey respect and understanding of how each person perceived their own illnesses and situation while opening myself up to new possibilities and outlooks.

## **Participant Selection**

Sample size remains a contested issue in qualitative health research. Sandelowski's view suggests that each sample should be small enough to "permit a deep analysis and large enough to give a new and richly textured understanding of the experience" (1995, p. 182). Thorne (2008) also suggests interpretive description research can be done with samples of any size but "the vast majority of studies within this approach are likely to be relatively small" (p. 94). Small sample sizes are supportable because phenomenological-based interviews tend to yield large amounts of rich data (Seidman, 2006). As a qualitative study, sample size was evaluated on an ongoing basis to identify when the participants' accounts started to overlap.

Participants were recruited using a purposeful sampling technique that included snowball sampling and combined criterion sampling (Van Den Hoonaard, 2012). Purposeful sampling is a foundational principal in interpretive description that ensures the researchers are guided towards people who have experienced the phenomenon of interest, in this case living well with multiple ADs (Thorne, Kirkham & MacDonald-Emes, 1997). These sampling techniques allowed initial participants or other members of the community to recommend those with multiple ADs to the study (Morse & Richards, 2002; Van Den Hoonaard, 2012). When recommendations were made, the individual doing the nominating was asked to refer the nominee to the advertisement for recruitment and instruct them to contact the researcher through those means. By adhering to the advertising protocol, the risk of coercion is minimized and less pressure is placed upon the potential participant. The criteria that each participant had to meet for this study included:



- Living well with multiple autoimmune diseases (i.e. see yourself as living well).
- Are of adult age (18 or older).
- Diagnosed with two or more autoimmune diseases that affect different parts of the body (i.e. endocrine, hair, skin, eyes, gastrointestinal, joint, musculoskeletal, and/or neuromuscular conditions).
- Not presently in a time of health crisis.
- Speak fluent English.
- Willing to speak openly about their experiences of living with multiple ADs.
- Able to commit approximately 3 hours of time to the interview and post-interview process.

The primary inclusion criterion was individuals who self-identified as living well with multiple ADs. This study was limited to individuals over the age of 18 based on the stage that younger people find themselves in their cognitive and emotional development. A requirement for participation was the ability to reflect upon experiences of living with multiple ADs, which required participants to have reached an appropriate level of understanding and the ability to articulate their experiences. Individuals younger than 18 years of age are often still attempting to integrate their experiences with their self-identity (Borgen & Amundson, 2012).

I also limited participation to individuals who are living with two or more ADs. There is much research that focuses on the treatment of individual ADs but little is known about how people manage multiple ADs. Another pre-requisite of participation was that a minimum of two of the their participant's ADs affected different parts of their body. There are several classifications of ADs that attack distinct parts of the body (i.e.

endocrine system, pain/fatigue, hair and skin, gastrointestinal, joint and muscle-related, and neuromuscular conditions, Shomon, 2002). Generally individuals with ADs that fall under the same category use the same management strategy for each illness. When faced with multiple ADs that affect different parts of the body, an additional challenge is presented in that managing a skin condition may not be the same as managing a joint condition, for example (Shomon, 2002).

This study also excluded participants who were presently experiencing a health crisis. Although it is important to recognize that each day brings new challenges when living with multiple ADs, I chose to focus on the overall picture of living well with illness and not significant physical or emotional issues. This criterion was not meant to exclude individuals who were entering the final stages of their illness. I believe those individuals may have provided great insight into their health because they would have likely had the opportunity to reflect on how to live well with their ADs; however the experiences of the final stages of life was not the focus of this study. Finally, since data generation was in the form of interviews, participants had to be willing to speak openly about their experiences and three hours was the maximum amount of time they needed to be willing to commit to the process.

Once Behavioural Research Ethics Committee approval (Appendix A) for this study was received, the recruitment process was started. Two methods of recruitment were utilized. First, an online invitation to participate was posted on the University of Saskatchewan Bulletin Board. Second, posters were displayed throughout the University of Saskatchewan campus and various places throughout the city of Saskatoon, Saskatchewan, specifically, health clinics and hospitals (see Appendices B and C). The

invitation to participate outlined the inclusion criteria, provided a brief explanation of the purpose of the study and the researcher's contact information.

### **Data Generation**

Recruitment strategies were used until 5 individuals who met the criteria outlined above agreed to participate. Ten individuals who were interested in participating contacted me. Of the ten volunteers, five people were chosen to participate based on order of response and inclusion criteria. The other individuals who identified themselves were asked to put their names on a waitlist in the event that: (a) the chosen participants did not complete the study for any reason or, (b) more participants were required. All five participants completed the interview. One individual's data was not included in the study because during the interview it was revealed that they did not fit the inclusion criteria as it was revealed she did not see herself as living well although it was discussed previously. I contacted a sixth potential participant from the waitlist, who completed the interview. Overall, ten individuals agreed to participate, six people were interviewed, and data from five participants who best met inclusion criteria were included. After five interviews were completed, no major new thematic concepts emerged.

Once participant contact was initiated either through telephone or email, I confirmed that they had met the participation criteria. During the initial conversation I provided the individual with more detail on the nature of the research project, their role and time commitment, that the research interview would be voice recorded, that participation was voluntary, and they reserved the right to withdraw at any time without penalty. When the individual agreed to participate, a time and location was determined in order for the interviews to be conducted. Before the commencement of any interviews,

informed consent was explained and obtained. A signature on the consent form (Appendix D) indicated each participant's willingness to engage in the study.

**Semi-Structured Interviews.** Semi-structured interviews are one of the most effective tools for generating data in an interpretive descriptive study (Thorne, 2008) and were chosen as the primary method of data collection in the present study. Interviews in interpretive description are intended “to elicit depth and clarification of threads within the account, and to foster elaboration, clarification, and even correction of your initial understandings and interpretations” (Thorne, p.129). In this study, semi-structured interviews yielded a rich set of data by allowing the participant to lead the conversation but concurrently leaving some control with the researcher. Each participant participated in one semi-structured interview that took the form of a guided conversation (see Appendix E for the interview guide).

Seidman (2006) outlined a 3-step technique for conducting in-depth phenomenologically based interviewing. The three phases of interviews consist of: (a) establishing the context around the participant's experience, (b) the participant reconstructs the details of their experience, and (c) the researcher encourages the participant to reflect on the meaning their experience holds (Seidman, 2006, p. 17). The meaning and understanding of an individual's experience was placed within a specific context and without this context, the listener can subscribe little meaning to the other's experience (Patton, 2002).

In order to attempt to gain a full understanding of the participants' experience this interview technique was followed with each participant. The interviews were also an opportunity to build rapport with each participant. Given that the focus of this study was

chronic illness, I recognized that the participants may have physical and time limitations; therefore, I merged Seidman's (2006) 3-steps into one interview instead of three.

Although I loosely adhered to an interview guide, the participants had the opportunity to direct the conversation and discuss their experiences in any way they deemed necessary.

Each interview was between 60-90 minutes in length (Seidman, 2006).

The emotional tone of the interviews varied with each participant. The participants were asked to reflect on the challenges of living with multiple ADs as well as the benefits. When recalling the challenges of their conditions, some participants had difficult emotions surface. In this case, we proceeded slowly, allowing the participant to reflect and process their emotions. Other participants did not experience difficult emotions and explained that they chose not to ruminate on the negative and felt it was a part of their experience that they didn't focus on.

Prior to conducting the interviews, a pilot run of the interview questions was completed in order to ensure the development of relevant questions (Seidman, 2006). Piloting the interview questions was accomplished by a review of the interview guide by colleagues. This informal review assisted with the improvement of the questions and contributed to an adequate data collection plan.

Once the interview guide was peer-reviewed and participants were recruited, a list of the possible areas for reflection and conversation were distributed to each participant. The topics included: life before initial diagnosis, description of and reaction to initial and later diagnoses, life after multiple AD diagnoses, how to live well with multiple ADs, learning experiences from living with multiple ADs, and advice for others in similar situations. When the participants' experiences resonated with my own I reminded myself

that every individual processes their situations differently, and asked open-ended questions so as to not skew the conversation one way or the other in order to minimize bias.

Following a minimum of two days after the topics were sent to the participants I contacted them to arrange a time and a location for the interview. All interviews took place in an interview room at the University of Saskatchewan. Each individual was given a \$50.00 honorarium as a token of appreciation and to off-set the expense of travel to and from the research interviews. In addition to semi-structured interviews, data was also generated from my observations and impressions throughout the research interview and incorporated into data analysis and interpretation.

**Observations, Field Notes and Journaling.** Observational data may augment research findings as they provide contextual cues that may otherwise be overlooked (Morse & Richards, 2002; Van Manen, 1990). Observational data in the present study was collected by the use of field notes. My observations captured both reflexive data (e.g. my own experiences, hunches, and acquired information) as well as descriptive data (e.g. information about the setting, the participant, and the interview process) (Creswell, 1998). The field notes also noted my biases when they emerged, worked out problems, clarified interpretations, and speculated about the process.

### **Data Analysis**

Conceptual themes were inductively derived from analysis among and between individual interviews (Thorne, Kirkham & MacDonald-Emes, 1997). My thematic analysis was guided by the analytic question: how are people with multiple ADs living

well. Data analysis is the process of applying meaning to the data of a study. According to Hatch (2002):

“Data analysis is a systematic search for meaning. It is a way to process qualitative data so that what has been learned can be communicated to others. Analysis means organizing and interrogating data in ways that allow researchers to see patterns, identify themes, discover relationships, develop explanations, make interpretations, mount critiques, or generate theories. It involves synthesis, evaluation, interpretation, categorization, hypothesizing, comparison, and pattern finding. It involves ... “mindwork”. (p. 148)

According to Hatch’s passage, data analysis is a process of asking questions about the data, as it is rich with information. In order to ask appropriate questions it is important to generate an analytic strategy to ensure proper analysis. In interpretive description, the intent is to discover relationships and patterns within the phenomenon and search for “underlying meaning that might further illuminate what is happening” (Thorne, 2008, p. 50). Data analysis took place simultaneously with data generation, which allowed me to see emergent themes or patterns and make any necessary adjustments (Thorne).

**Inductive Analysis.** Inductive logic approaches the data from a data-driven as opposed to hypothesis-driven standpoint (Thorne, 2008). According to Johnson and Christensen (2004), inductive analysis is “immersion in the details and specifics of the data to discover important patterns, themes, and interrelationships; begins by exploring, then confirming, guided by analytical principles” (p. 362). As such, themes and patterns were not imposed on the data but presented themselves throughout the analytic process. Bogdan and Biklen (2007) liken this process to puzzle “you are not putting together a puzzle whose picture you already know. You are constructing a picture that takes shape as you collect and examine the parts” (p. 6).

**Organizing the Data.** The data consisted of all the information generated by the researcher through observation, journaling, and semi-structured interviews. All information was organized in a chronological fashion (Patton, 1980) by first sorting through the information from the first participant, then the second participant and so on. The preparation of the data aided with analysis and interpretation (Patton).

**Analysis of Data.** Data analysis requires time to adequately reflect upon and examine the data. This allows the researcher to come to an understanding while prescribing appropriate meaning that honours the participants who shared their experiences. In accordance with the principles of interpretive description, I explored the thematic concepts and performed the interpretation through listening, observing, and taking notes (Thorne, 2008). In order to accomplish this, a step-by step process was recommended. The first step was to read and re-read the data until I felt sufficiently familiarized with it to be able to impart what it had to offer (Thorne). In the second step I performed thematic analysis in which the data was inspected for patterns and themes. The third step consisted of interpreting and describing patterns in a meaningful way.

In interpretive description, it is best to start with broad categories to “grasp what the underlying shared intent might be within that collection of intent” (Thorne, 2008, p. 144). The intention of the second step was to identify categories within the data by indexing, coding, and classifying the data according to the research question. Coding “forces you to look at each detail, each quote, to see what it adds to your understanding” (Rubin & Rubin, 1995, p. 251) of each category. Coding the pieces of data allowed me to later sort it into patterns, test those patterns for relationships, and conceptualize those relationships into findings (Thorne).



The third step was to assess those themes through the explanation of the data in a clear and meaningful way. This step involves a more ‘interpretive turn’ (Thorne, 2008) during which I considered what each piece of data might mean, both individually and in relation to each other. After identifying and exploring the commonalities and differences amongst and between the experiences of participants, as well as establishing patterns, four interconnected themes emerged. Each theme contains sub-themes designed to further describe and interpret the broader conceptualization. Finally, recommendations, implications, and conclusions were drawn from the interpreted data.

### **Establishing Trustworthiness**

Glesne (1999) posits that trustworthiness is achieved when the results of the research reflect as accurately as possible the meaning described by the participants. Trustworthiness is a deliberate process on the part of the researcher to take care in ensuring the thoroughness of data collection, analysis, and interpretation (Merriam, 1998; Denzin & Lincoln, 2005). Trustworthiness involves establishing credibility, transferability, dependability, and confirmability.

**Credibility.** Credibility can be seen as the substitute for internal validity (Denzin & Lincoln, 2005). According to Guba and Lincoln (1999), “Credibility is seen as a check on the isomorphism between the enquirer’s data and interpretations and the multiple realities in the minds of informants” (p. 147). The use of two sources of data collection and peer-review increases the credibility of the present study. Data was collected through the use of semi-structured interviews primarily but was supplemented by my observations and field notes taken throughout the interview process. Finally, this study was read and

edited by several individuals such as my thesis supervisor, Dr. Kinzel and committee members.

**Transferability.** The second category of trustworthiness is transferability, which is the degree to which the conclusions of this study can be applied or transferred to other situations or populations; it is the equivalent of external validity (Merriam, 1998).

Transferability in the present study was increased by the use of thick description, a detailed account of the data collection process and the data itself being within the appropriate context (Lincoln & Guba, 1985). To address thick description the complete set of data analysis documents will be kept on file and are available upon request for any readers who wish to formulate their own interpretations and make judgments regarding the transferability to other contexts.

**Dependability.** Dependability is the third category of trustworthiness and refers to the assessment of the quality of the integrated process of data collection, analysis and theory generation. In other words, dependability “is concerned with the stability of data overtime” (Guba & Lincoln, 1989, p. 242). Guba and Lincoln suggest that by stating the researcher’s position, using multiple methods of data collection and analysis, and describing in detail how the data was collected provides evidence of dependability.

Merriam (1998) also suggests the use of an audit trail. Dependability for the present study was evidenced through all these means. My position as a researcher was outlined in the introduction, I used two types of data collection, and an audit trail was performed in the later stages of analysis to ensure all data was accounted for (Lincoln & Guba, 1985). An audit trail informing the organization of the study, the data collection, data storage, data analysis, data synthesis, and interpretations and conclusions are all present in a researcher

journal.

**Confirmability.** Lastly, confirmability is a measure of how well the study's findings are supported by the data (Lincoln & Guba, 1985). It measures the accuracy of the data, rather than the objectivity of the researcher (Lincoln & Guba, 1994). Reflexivity is one way in which a researcher can increase confirmability. As aforementioned, I developed an audit trail and kept a journal in which I recorded observations and kept track of the data. In addition, I engaged in peer reviews as explained under credibility, as a way to discuss the data and analysis with colleagues (Thorne, 2008).

### **Ethical Considerations**

Prior to commencing data collection, approval was received from the University of Saskatchewan Behavioral Sciences Research Ethics Board. Participants were informed of their rights and their willingness to participate was demonstrated by signing an Informed Consent form. The nature of this study required interaction with human participants for the purpose of gathering information; therefore, appropriate ethical protocols were followed. When working with human participants two central issues need to be addressed; informed consent and the protection of participants from harm. Both guidelines attempt to ensure that:

- Informants enter research projects voluntarily, understanding the nature of the study, and the dangers and obligations that are involved.
- Informants are not exposed to risks that are greater than the gains they might derive (Bogdan & Biklen, 2007, p. 48).

I took special precautions to ensure that the above ethical guidelines were followed and that all participants were treated with dignity and respect. When the subject matter

discussed in the interviews evoked an emotional response, I ensured that the participant received appropriate support.

## CHAPTER FOUR: RESULTS

In chapter four the findings are presented following a brief description of the characteristics of the participants. In the participants overview, their individual health experiences are described followed by the conceptualizations of the complexities of living well with multiple ADs, which were grouped into four interrelated themes: the ups and downs of living with multiple ADs, mentally and emotionally conceptualizing living with multiple ADs, taking action to manage living with multiple ADs, and leaning on support systems to help live well. In order to assure confidentiality and anonymity, I selected participant pseudonyms and the names of family members and geographical locations were changed. Participants' quotations were also edited for confidentiality and ease of reading. For example, identifying contextual information was altered and repetitive filler words (e.g., uh, you know, hmm) were deleted and represented by ellipses. Added words that differ from the original quote were designated and represented by square parenthesis.

### **Participants**

**June.** June was a middle-aged mother of two adult daughters. She was living with three ADs. She was initially diagnosed with junior RA at age 7 which came after 4 years of being in and out of hospitals due to complaints of pain. Following the diagnosis of RA, June was subsequently diagnosed with ulcerative colitis and type 1 diabetes. ADs run in June's family and she has witnessed how these illnesses have influenced the lives of her mother and daughter. Despite managing numerous chronic illnesses, June drew strength from the people and activities that brought meaning to her life. Her goals consisted of

continuing to be active in sports, writing a novel to inspire young women, and completing her university degree.

**Elizabeth.** Elizabeth was in her early thirties and was also diagnosed at a young age. She was first introduced to ADs at age 10 when she was diagnosed with psoriasis. Living with psoriasis influenced Elizabeth's self-concept and interpersonal relationships because she was embarrassed by the visibility of the illness combined with the lack of awareness surrounding psoriasis. Her self-esteem suffered and she had a difficult time opening up to new people. At 21, she was diagnosed with Hashimoto's disease and hypothyroidism, and at 26, psoriatic arthritis. She had accepted the way her body worked and no longer lived in fear of new diagnoses. Living with multiple ADs helped mold her into the person she wanted to be. She had become her own health care advocate and strived to be a role model for others in similar situations.

**Casey.** Casey was a university student in her mid- twenties. Casey's journey with ADs also started in her youth. Her symptoms emerged at age 9. She started having trouble walking and running after previously being a healthy, active child. After undergoing a series of bone scans and numerous other tests, at age 12 she was diagnosed with RA. During that time, Casey experienced patches of hair loss and was diagnosed with alopecia areata and psoriasis shortly thereafter. Recently, her doctors identified early signs of lupus, but no official diagnosis had been made at the time of the interview. Casey had viewed her experiences of her illnesses as having a positive influence on how she approached life's challenges. She saw her physical symptoms as an advantage instead of a negative. Her outlook on life and health was very positive and insightful.

**Helen.** Helen was the most senior participant of the study. She was in her late 70's, was very physically and mentally active, and had a resilient spirit as evidenced by her motivation to stay active and live life to the fullest despite any setbacks. Helen's journey with ADs began at age 19 when she was diagnosed with psoriasis. She described it as having been a difficult illness to deal with due to its visibility, her age when she was initially afflicted, and the lack of awareness/tolerance during that time period of anything outside the norm. Twenty years later Helen was diagnosed with RA. Finally, in her late 60's, she was diagnosed with diverticulitis. Like Casey, Helen also had symptoms of lupus but no official diagnosis had been confirmed. Throughout her medical history Helen had remained optimistic and taken everything in stride. Helen had her hobbies, family, and faith to thank for getting her through her rough patches.

**Tina.** Tina was the youngest participant as she was just entering her 20's. She was a university student, who consistently maintained a positive attitude in the face of challenges. Tina was also living with psoriasis and was diagnosed at age 10. More recently she was diagnosed with Hashimoto's disease. These disorders were difficult at first for her to accept due to their visibility and uncontrollability. Tina reported that once an official diagnosis was made she felt relieved that a cause was identified and treatment was available. She also demonstrated a mature outlook on her situation indicating that it could always be worse so she was thankful for her health status. Tina relied on numerous ways of coping to manage her health and disorders.

## Findings

Each of the four main interconnected themes describe ways in which the participants were able to live well with multiple ADs and their journey of how they came to see themselves living well (see Table 2 for the list of thematic conceptualizations).

**Table 2**

Themes and Sub Themes

Theme	Sub-Theme	
The ups and downs of living with multiple ADs	-The impact of multiple AD diagnoses	-Emotional response to multiple diagnoses -Maintaining employment while maintaining health -Seeing yourself through others eye
	-Learning to find a balance	
	-Breaking the stress cycle	-Illness-Related Stress -General Life Stress -Relationship-Related Stress
Mentally and emotionally integrating multiple ADs with the self	-Navigating the treatment of multiple ADs	-Adjusting to a new routine and treatment regime -Experiencing treatment -Navigating the health care system
	-Accepting the diagnoses	
	-Gaining perspective on the situation	-Making the best of the situation -Living in the present
Taking action to manage living with multiple ADs	-Finding inner strength	-Building a positive self-concept -Willingness to be challenged
	-Self-advocating for quality health care	-Learning to be your own health expert



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		-Becoming a role model
	-Findings distractions to help maintain peace of mind	-Engaging in independent activities -Getting out and getting involved -Finding distraction through sport
	-Adapting to lifestyle transitions	-Eating healthy and exercising -Staying on top of symptom management -Having a sense of purpose
Leaning on support systems to live well	-Family as a foundational support -Friendships providing support -Finding support through spirituality	

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### **The Ups and Downs of Living with Multiple ADs**

One of the central themes that emerged from the data was the idea that living with multiple ADs was a journey of positive and negative experiences. The participants' negative experiences centered on having to adjust to living with multiple chronic conditions, while positive experiences emerged from finding effective ways to handle uncomfortable situations. This section speaks to the many challenges the participants had to overcome and were still learning to navigate. These include how they responded to their diagnoses, learning to balance their limitations with their health, identifying what caused the onset of symptoms, and learning the variances of treatment.

The ways the participants helped overcome their challenges is presented in more detail in the following sections. Although June, Elizabeth, Casey, Helen, and Tina all believed they were in a good place emotionally and physically at the time of

participation, they all described having challenges along the way. Amongst these challenges, the participants described the responses they perceived from others, how living well with multiple ADs required a balance between staying healthy and not pushing their physical limits, identifying a stress cycle and learning how to manage it, and navigating the health care system.

**The Impact of Multiple AD Diagnoses.** Several challenges were identified in the social, emotional and vocational/employment realms in response to being diagnosed with and living with multiple ADs. The findings that emerged were classified into the participants' views of how they perceived others viewed them, and their own self-perception following the onset of their symptoms.

*Emotional Response to Multiple Diagnoses.* A common struggle was identified following the participants' initial diagnoses. Several individuals experienced strong emotional responses. Although some participants had experienced the symptoms of their autoimmune conditions for a while prior to being officially diagnosed, having their conditions labeled as a life-long AD was initially difficult to grasp. For example, Elizabeth expressed the fear she felt over being diagnosed with an unpredictable illness:

Once you know you have [an AD] it's a lifelong battle ... you know you have to deal with it forever so I think that's the scariest part when you're young and being diagnosed with something... Being diagnosed with psoriasis I remember being terrified because it was my first experience going to a specialist doctor... It's terrifying, they're telling you you've got this now for the rest of our life ... They also can't tell you how it's going to progress so that's very scary.... I guess the uncertainty is the scariest thing for me and especially with it being that psoriasis and psoriatic arthritis are things that are just not talked about, they're not researched, there's no good role models out there that steps forward and say "Hey I have this horrible skin disfiguring disease!" You feel like no one understands and it also sometimes feels like people think you make it up.

Tina also experienced a range of negative emotions and stated her reaction to being diagnosed was: “Anger I guess, I was very upset and embarrassed. Angry, upset, and embarrassed.” She further explained that her symptoms were hard to make sense of at first:

It was difficult ... having psoriasis because suddenly it was my whole body was covered in guttate psoriasis... As a kid it was traumatic because why am I suddenly covered in red spots and why don't they go away? And it's not like chicken pox or something. It's not something anyone has heard of, it wasn't something normal to have.

Casey on the other hand did not view her diagnoses as a negative part of her life. She reported that they did not affect her or bring about any strong emotions. Casey did however, recall the effect it had on her parents which was difficult to watch because she did not want to see her parents struggling: “I think it was harder on my parents the initial diagnosis, the initial trying to figure out what I had, than it really was on me. It didn't really bother me much at all.”

***Maintaining Employment while Maintaining Health.*** For June and Elizabeth the strongest responses to their illnesses came from co-workers and authority figures in their places of work. Elizabeth had a difficult time being seen as a professional while tending to her health care needs. She emotionally expressed that she had to try to keep her personal life to herself in order to be taken seriously by her co-workers:

It's not like I want to walk around as this sickly person. I don't want people to feel sorry for me so I try to hide it. I don't tell everybody I meet that I've got these problems going on in my life. [My co-workers] saw me as a regular person then all of a sudden I'm taking days off at a time to deal with medical issues. It's always difficult opening up and telling someone new because I'm worried that it'll change their perception of me... My boss actually thought I was faking it for a long time.

June also recalled how her illnesses impacted her ability to work, which in turn impacted her career overall and her relationship with her co-workers. “It has affected my work and I haven’t been able to work a full-time job in a long time because I do not feel well enough... None of my co-workers understood why I had to miss work.”

***Seeing Yourself Through Others Eyes.*** In addition to the emotional and vocational responses these illnesses evoked, several participants recalled a social impact, which translated into how the participants viewed themselves. Elizabeth became quite emotional as she articulated: “The social impact I think is the hardest... You feel like no one understands you and it also sometimes feels like people think you make it up.” June echoed this thought:

[In response to being diagnosed] It was a relief to put a name to something because everybody always treats me like I’m a hypochondriac...the pain is not in my head, the pain is very real ... just because you don’t see it, doesn’t mean it’s not real.

Elizabeth, Helen, and Tina, who are all diagnosed with psoriasis, recalled attempting to cover-up their illness because they did not want other people to notice, or question them about it. Helen reflected on her experiences of psoriasis:

[When I was diagnosed] I was still young and I was still dating, and it’s disfiguring and it’s limiting... I wouldn’t wear some bathing suits. I had a big patch on my back so I’d have to choose specific clothes that would cover things up. It was embarrassing and I didn’t have all that much self-confidence anyways to say, so what. So it was definitely a whammy ... they also gave you smelly ointments, those tar ointments ... so that didn’t help.

Tina also shared her struggles when other people inquired about her plaques and how she tried to cover them up. Her classmates were always curious about what was on her body but she was hesitant and embarrassed to open up to people:

I definitely had a hard time with [psoriasis]. I didn’t like wearing shorts in gym class or swimming outside ... People would always ask me, other kids would ask

why do you have so many mosquito bites. I didn't ever want to tell them what I really had. It was really embarrassing.

Elizabeth had a similar experience with wanting to cover up the affected areas so nobody would notice them. She did not want anybody to know what she was living with so she restricted herself to certain clothes and activities:

It became a very limiting thing in my life, as you can imagine having a skin disorder that you don't want to be seen so you try to cover it as much as possible. I wore long sleeves, long pants, I wouldn't go to the swimming pool, and not to mention the fact that chlorine would sting and burn if you had any open wounds.

The visibility of this particular AD combined with the symptoms of the others made social relationships difficult for Elizabeth, Helen and Tina. Tina emotionally described that living with this illness changed the way she acted out of insecurity:

It changed the way I acted at school and with friends ... because I was always embarrassed about it. I always had to go [to the hospital for treatment] at lunch hour when I was in grade 6... and I was super tanned [from light therapy] and because it was mid winter and [my classmates] were all excited "You're super tanned, where have you been?" They thought I had gone somewhere tropical. I didn't want to tell anyone about it ... that had major effects on my social life and my social development maybe ... It probably contributed to the way I acted and then I got bullied more because I was acting all embarrassed, shy and vulnerable.

Elizabeth recalled a similar way of presenting herself in social situations and opening herself to new people due to insecurities surrounding the way she looked:

[My illnesses] made me less willing to meet people, it made me less outgoing. Psoriasis is the type of thing that it will hold you back because people don't understand and they think you're contagious, so that was major thing for me. I really found it kept me quiet a lot you know ... I just kind of hung back in the shadows. So that's been an ongoing challenge for me because even now that my psoriasis is clear you still have those long term effects mentally from dealing with that for so many years... I find it really difficult in social situations. I still find lots of times I have the tendency to try and cover up even though I have nothing to cover up visually anymore. I guess you're still trying to cover up those internal wounds that you've developed.

Being the most senior participant and experiencing living with her illnesses in a different time, Helen described the reaction to her illnesses as something the neighbors or her family did not understand and were not open minded about. She found their reactions to be very difficult because she felt alone with her ADs. She said: “Today’s society is, thank goodness, more knowledgeable and tolerant.” She went on to describe the reaction from her relatives:

Initially when I first came down with all this the only family I had then to relate to were the ones around [town] and they weren’t all that supportive. No that was difficult. Then I just had to go to my own resources and just say ok it’s just my children and me and I just left it go at that.

Helen had an optimistic view of society saying: “You have to trust people, they don’t notice it unless you make a big to do of it. They don’t care as long as they know you’re not contagious.”

Overall, the participants described a range of responses to being diagnosed including strong negative reactions upon their initial diagnosis. They had to process their emotions and make sense of their diagnoses. Another challenging experience to process was the response some perceived from their co-workers and members of their social networks. They described their perceptions of what others thought of them and how that influenced the way they approached their conditions, often attempting to cover them up. Although these experiences were difficult for the participants to navigate, they reported that experiencing them allowed each individual to gain a better understanding and acceptance of themselves, which contributed to them being able to live well.

**Learning to Find a Balance.** In addition to dealing with the social and emotional issues that accompanied their conditions, Elizabeth, Casey, and Helen described a balancing act of maintaining a healthy lifestyle and not pushing themselves to the point

where their bodies were in pain. Finding a healthy balance was considered one of the challenges of living with multiple ADs. A significant amount of thought and energy was required to discover what worked for their bodies and what did not work when managing individual conditions.

Several participants described having to go through their own, at times frustrating, trial and error process when attempting to maintain a balance between health and illness. Achieving this balance was an important part of living well for the participants. Most of them wanted to continue with the active lifestyles they had before they were diagnosed, yet were now limited so they had to find new ways to fulfill their desire to stay active.

Casey described this by stating, “[My parents] made sure I was the right balance of still being active but not pushing myself too far.” Casey described herself as a very active individual who was involved with many sports. She went on to talk about how she was able to maintain her level of physical activity while being conscious of her arthritis:

I try to go as far as I can without pushing myself. I think I’ve gotten to the point where I can run a bit. I’ll never be a runner, but I have played more sports. Being active and making sure to go as far as I can helps keep me healthy while not hurting myself.

Elizabeth also mentioned that she worked hard to find a healthy balance in her life. She said that her lifestyle had to change with her diagnoses because her body wasn’t capable of handling the same physical exertion that it used to:

The arthritis is limiting because I can’t be as physically active as I used to be. There’s this balance of having to stay active to maintain a healthy lifestyle but working around what works for you. I can’t ride a bike because it hurts my knees too much. So you have to try things out, try different things to see what works and what doesn’t work... Having arthritis, it’s one of those things where you have to keep in motion so you don’t lose motion... Always finding a balance in that and making sure you’re doing things that are good for you and good for your mind as well.

The participants acknowledged that participating in physical activities was not only good for the body but also the mind. Helen talked about the idea that being able to get out and be active is a blessing in itself. There are some days where the swelling of the joints was too much but Helen's motto was, "I'll do what I can. I'll walk a little bit. Keep exercising and that's it. That's all I can do."

Finding a balance between staying active and not overdoing it was a learning curve for Casey, Elizabeth, and Helen. There were no instructions on how far to push themselves and what their bodies would feel like the next day. Since each individual is unique, not even doctors always had the answers to what works best. Nobody could tell them how much was too much, or how little was not enough. Once they became more aware of how their bodies responded to physical activity, they were able to successfully participate in it, while recognizing their limits. This knowledge helped them live well with their conditions. Helen articulated:

It was difficult getting the point of knowing what works for you and finding the right balance for your body... But once you do it makes you feel good about you and what you are still able to do and it gives you something to work towards.

**Breaking the Stress Cycle.** June, Elizabeth, Casey and Tina all identified a cycle of stress that would contribute to flare-ups within their ADs, which would in turn cause more stress. They all recognized that when they were going through a stressful period in their lives, their symptoms worsened, which caused them even greater distress. Having the knowledge that stress impacted the course of their conditions was an important point of learning in their health journey. This knowledge allowed them to be more aware of themselves and what triggered a negative response. The participants were then better able to eliminate the stressful situation and cope well when they did get stressed out. Helen



stated, “Realizing stress affects you is very important because then you can do things to help yourself de-stress.”

The participants described several sources of stress that impacted their health. The stress associated with living with multiple ADs, the general stress that comes with the nuances of everyday life, and stressful relationships all affected their symptoms.

***Illness-Related Stress.*** Elizabeth described her frustrating experience of stress stemming from her illnesses when she said, “The more you get stressed out about your illness the worse it gets, yet you can’t help but get stressed out sometimes.” A lot of worry accompanied living with multiple ADs, which was a source of stress and in turn worsened the symptoms. Elizabeth described herself as a hyper vigilant worrier, always expecting to be diagnosed with something else:

There’s still a lot of worrying that goes with it. Every time you have an ache in your knee for a week you think oh no is it getting worse? What am I going to have to deal with now? I try not to be a hypochondriac even though sometimes I feel like I’m being one.

Elizabeth’s constant source of stress was thinking that she was always coming down with a new illness or new symptoms. Eventually she recognized that she couldn’t control any future diagnoses but she could control whether or not to focus on them. Recognizing that she was only stressing herself out more by focusing on the negative let her consciously shift her thoughts to more positive things.

***General Life Stress.*** Tina and Casey reported that the stress they felt in their daily lives contributed to a flare-up of their AD symptoms. They also had to learn how to manage the level of stress in their lives and practice self-awareness to recognize when they were becoming stressed. Tina said, “In order to avoid getting a psoriasis break-out I try not to get super stressed out about stuff and notice when I am stressed out.”

Similarly, Casey stated, “I learned being stressed out will onset my [conditions], so I just try to focus on the now and not let other stuff bother me.” She then described how the stress brought on by being a university student was something she needed to learn to manage in order to minimize her symptoms:

When I had flare-ups it was almost always school related because I hadn’t gone out to calm down for so long cause I had so much to do. I just realized I need to worry less and go out and have more of a life and I’ll do better in school because I’m more focused and energized and I won’t have as much inflammation.

Finding ways to manage their stress and identify when they needed to take time for themselves allowed each woman to better manage her conditions.

***Relationship-Related Stress.*** Stress was also a component related to a relationship in June’s case. She mentioned a previously abusive romantic relationship where the stress contributed negatively to her condition. That resulted in separating herself from her spouse, “After I left him I stopped having surgery [on my bowels]. The stress going on in my life from [my relationship] contributed to my colitis.” She also talked about having to end friendships with people who were not taking care of themselves because it took an emotional toll on her. Several of her friends were engaged in dangerous behaviours such as taking drugs, which June did not condone. This dissonance and knowledge of the harm her friends were causing themselves upset her, which influenced her disease activity:

I’m very selective with my friends now because I found a lot of them to be very toxic. My friends would cause a flare-up because of the toxicity of what they were doing to themselves [and this] would affect me. I cared about them too much to watch them do that to themselves, so I had to leave them to keep myself healthy.

Elizabeth also discussed the toll her illnesses had on her relationships. She stated that because she was shy and embarrassed by her psoriasis, she always hung back, never

wanted to be center of attention, and was always hesitant to meet new people, which caused social stress in her life.

How I dealt with people socially is I would become very quiet. If you don't stand out people don't notice you. If you're not a social butterfly you kind of blend in and people don't pay as much attention to what you look like. That's the approach I took.

No matter what form the stress in these participants' lives took, they all managed to identify the impact it was having on their health. After they discovered the effect of stress on their disease activity, they all tried to decrease the level of stress present in their lives.

**Navigating the Treatment of Multiple ADs.** The participants faced sorting out, securing, and accessing treatment, as well as navigating the health care system and their personalized treatment plans. Several of the participants described what it was like for them to be introduced to the world of health care.

*Adjusting to a New Routine and Treatment Regime.* Generally, the diagnoses of multiple ADs require an adjustment to daily routine. The participants' adjustments included adapting to new daily medication regimes, adjusting to the side effects of the medication, and finding time for frequent doctors visits. June, Elizabeth, Helen, and Tina all commented on the adjustments they had to make following their diagnoses.

One of the main adjustments for some participants was scheduling the time for required treatments, which were often time and energy consuming. June reflected that she had to go to the doctor once a month. Tina stated that while in treatment for psoriasis, she had to go to the hospital every second day for months at a time with each treatment session lasting approximately 30 minutes. Elizabeth remarked:

[You have to go] to a different city to see a doctor sometimes. [You go to the doctor] for tests and stuff as well because to track the arthritis you need x-rays and a lot of blood work on a regular basis. I missed a lot of work for medical reasons.

The actual treatment plans themselves at times also required a shift in routine and a time for adjustment. For example, Elizabeth said that when she was diagnosed with Hashimoto's disease, "I had to go on medication and take it everyday so that was kind of a big change for me." Several participants had to get used to taking medication as well as adjusting their schedules for numerous follow-up appointments.

***Experiencing Treatment.*** In addition to the shift in routine, the participants experienced their own unique side effects to their treatment and often turned to alternative sources of treatment when Western medicine's treatments were either unavailable or limiting. Helen recounted her experience of her various treatments indicating that it was a challenge adjusting to her treatment routine and procedures. She experienced various different treatments and medications throughout the course of her illnesses, "I would say for at least 10-15 years I was on medication [for arthritis]." She also found it challenging to deal with the side effects, "Every time you'd take one medication, two medications, then you'd have a reaction and I react to almost everything I take. It was hard to manage all of it."

Elizabeth also discovered a host of secondary challenges that stemmed from the medication she was prescribed for her psoriasis and arthritis:

[The medication] makes you very susceptible to infection. I had chronic tonsil infections to the point where I had to have a tonsillectomy just this year ... That's something that probably would have never happened had I not been on the medication but it just, it weakens your immune system so it puts you at risk for these types of things. And that changes your life as well because you end up becoming more careful. Sometimes it almost seems like you're hyper vigilant.

Helen and Tina were also diagnosed with psoriasis and underwent a treatment called 'light therapy' for their symptoms. Helen recounted a negative experience with her treatment:

I had a very bad flare-up of psoriasis and at the university [hospital] they put me under heat lamps and even after just one treatment I looked like somebody scorched me with a blow torch. So they did some tests and they found out I've got early lupus.

Tina recounted her experiences with light therapy saying she was embarrassed to have to undress in front of nurses so they could look at her skin. She stated, "I hated the treatment that they had, it wasn't fun."

When the treatment the doctors suggested did not work effectively, Helen turned to complementary medicine with positive results:

I was on everything including gold injections and they had to quit those because my kidneys were shutting down. But apparently it was enough to stabilize my arthritis ... I started doing physiotherapy and that helped a great deal and as the years went on I found out that massage therapy helped. So I got massage therapy if I started seizing up a lot just to keep the muscles limber. That helped better than medication.

Each participant's individual treatment plan was a new experience they had to navigate and adjust to. At times it took several attempts to find a successful treatment. New medications and treatments were always emerging so the participants worked hard to stay on top of their own health care.

***Navigating the Health Care System.*** Participants commented on the challenges of navigating the health care system and what it took on their part to receive quality health care. Elizabeth held strong views on the health care system and how it often took a little negotiating within the system to take care of her needs. She emphatically stated, "I hate battling the [health care] system here." Elizabeth went on to say how important it was to

have a good working relationship with the physician in order to get your health needs met and feel good about the process:

It's really important that you find a doctor that you feel listens to you, cares, and wants to help because I think a lot of them are really turned off and I find a lot of them really don't care that much... It's the best thing a person with a chronic illness can hope for is having a doctor who is very understanding and who wants to work with you. Having that kind of understanding from a doctor makes everything so much easier.

Elizabeth also discussed her perceived lack of support from some doctors and how difficult that was to process, "We look to our doctors for support on these [conditions] as well and help in understanding them and my doctors really have no answers." She experienced some up-hill battles with health care that she reported were difficult to overcome:

It was difficult because some of the doctors [in this city] were not very cooperative telling me that I wasn't religious enough in my treatment and that's why I was stricken with this so badly. You know all his other patients put the cream on and they're ok. I could've bathed in the cream everyday and it wouldn't have got better, that's just the way my body dealt with it.

Helen discussed how important it was to have access to quality health care and knowledgeable practitioners, "Get proper medical [care] ... people who really who know what they're doing, not fly by nights, ... but proper medical advice. That is so important."

The health care system was not always perfect for the participants and was a struggle to manage effectively. Identifying what the challenges were within the system and working around them helped Elizabeth and Helen receive better quality care and feel more comfortable with their doctors.

**Summary.** Whether it is adjusting to living with a chronic illness, experiencing negative reactions from others, finding a balance between health and wellness,

identifying and managing stress triggers, or trying to negotiate the health care system and quality of care, there are many challenges associated with living with multiple ADs. The following sections will describe in detail how the participants are living well with their conditions and are managing their overall health.

### **Mentally and Emotionally Integrating Multiple ADs with the Self**

This section speaks to the mental and emotional responses the participants had to process in order come to terms with the reality of living with multiple ADs. It begins to describe how the participants took strides towards overcoming their challenges and were able to come to a place where they considered themselves to be living well. This theme describes how the participants came to accept, conceptualize, mentally adapt to, and gain strength from their illnesses.

**Accepting the Diagnoses.** Upon receiving the news of their diagnoses, some participants identified that a necessary first step was to come to terms with the limitations of their bodies. According to the participants the sooner the individual comes to accept their diseases, the better off that person will be. They can then begin making strides towards investing their energy into a productive health care plan. Casey and Tina articulated how central acceptance of their health status was in order to live well with it.

After hearing the news of her diagnoses, Casey immediately accepted their reality and tried to make the best of the situation, “I handled the [news of getting diagnosed with alopecia] really well. Looking back I was never embarrassed about it. I never really covered it; I just let it run its course.” Although Casey was fearful of her future health prognosis, she did not let her fears get in the way of living life:

I just didn't give myself the option to think badly about [the situation]. These are the cards I've been dealt, this is how I'm going to have to live, and it's not going

to change. I think that's just being realistic... I just have to accept that everything's unpredictable and it could happen; it could not. It can be scary but I guess I just have to take it as it comes really.

Casey saw her condition as something that would inevitably change her life, but she did not associate that change with something negative. Instead she accepted her circumstances and put her energy into how to best manage her illnesses in the present. She chose to not focus on what her life would have been like had she not been given a diagnosis:

Try not to feel sorry for yourself and just accept this [illness] and what it is. You're going to have to find new ways to deal with it and new ways to adapt. That doesn't mean it's going to be a bad thing and that doesn't mean it necessarily is going to get worse. I just really like to focus on the now and deal with what comes when it comes.

Elizabeth also adopted an attitude of acceptance and realized that she did not have much control over her health prognosis so there was no use stressing over it. She instead learned to accept the limitations of her body and to deal with the associated challenges and limitations:

[My illnesses] are unique challenges and you have to learn to deal with each one differently. There is a different protocol to follow-up with and track [each one]. It's hard to understand the limits of your body. Because I'm young I feel like I shouldn't have limits yet I now have to accept that it does... [I] have a 'who cares' attitude a lot because what are you going to do about it anyways? ... It is what it is and there's nothing I can do to change it. It's what I'm stuck with, just how my body's reacting and that's all I've got. I just have to accept it.

Coming to terms with and accepting the reality of what their individual body's could and could not do helped Casey and Elizabeth process and understand their diagnoses. Acceptance assisted them with working through the array of negative emotions associated with the onset of their symptoms. It freed their thoughts and energy to focus on the next step in their journey.



**Gaining Perspective on the Situation.** This section addresses how the participants of this study made sense of, and came to terms with their illnesses. Realistically appraising their conditions permitted them to place their health in perspective and gain some understanding of their priorities, as to not let the small things bother them. Tina stated that living with multiple ADs made her realize that she had a lot to be grateful for when she compared her situation to others. She softly stated that going through this experience taught her to never judge other people because you do not know what they have going on in their lives. It opened up her eyes to challenges others were going through and how she should be thankful for all she had:

[Having these illnesses] makes me appreciate more. It gives me something to think back on when I see other people with challenges, then I'm like well no one is perfect, everyone's got something. I think of it often, how everybody may look normal or perfect, or you know look like they don't have any problems in their life and then you get to know them better and realize they have challenges or have this or ... their family has problems or something... I can look back and think to myself, I'm like them. I have my challenges, they have theirs, we can fumble along together... Now it's ok. I've grown used to it and realize that other people have bigger problems and it's not that big a deal. Even taking thyroid hormone for the rest of my life I'm like oh well, that's all right. I still have my legs and other things have happened in my life that made me realize that life is not easy so if you have small setbacks, and I consider these to be small now, it's not a big deal.

Casey expressed a similar view in that she saw her illnesses as something that could be much worse than it was, so she decided to focus her attention on being grateful for her opportunities as well:

I see how it can be so much worse, and even if it might potentially get worse... Everyone has problems whether it's health wise or other things. This just happens to be mine and I just have to deal with it and cope... I didn't view it as like woe me, I viewed it as like there are so many things that can go wrong, there are so many illnesses ... and I have something that's not really that bad. It hasn't affected me much. It's not mental health issues or anything so I view that has made me more grateful and thankful. There are a lot of things that could be worse

Tina and Casey took their experiences of their conditions and turned them into something positive. Casey's condition did not impact her self-esteem negatively, she stated that, "It was really just a discomfort thing versus anything else." Tina viewed her diagnoses as a reality that was a part of everyday life. The thought of living with multiple ADs no longer scared her after she was accustomed to them, "[Living with these conditions] doesn't really bother me very much. I just don't see it as a very big scary thing anymore like I used to at first." When the actual diagnosis was given she was relieved to start her treatment plan:

[When I was diagnosed] I kind of thought of it as a good thing because I got into rowing and when you have low thyroid you have less energy. I hadn't really noticed that much that I had less energy... but when I started taking the medication I noticed I had more energy so that was cool.

Elizabeth conceptualized her illness as something she preferred to not put too much thought into so as to not pay it more attention than necessary. It was difficult for Elizabeth to forget about her ADs because of the constant physical reminders, so when she had the opportunity to change her thoughts to more positive ones, she did:

For the most part I try not to think about it a lot. I don't want to rate everyday, I just want to live my life and enjoy it. When I have bad days, I just try to get up and go 'It's not going to kill me, I'm going to have to deal with it so let's move on'. There are people dealing with worse things ... I think I'm well prepared for dealing with these things. I've learned to just take everything as it comes.

***Making the Best of the Situation.*** The positive attitude shift that accompanied the perception of their situations allowed the participants to go on with their lives with an expanded view of their circumstances. Tina talked about her understanding of her situation, and having to come to terms with what life meant for her:

You need to learn how to cope. Having to accept failings of yourself, not really things that you do but when your body lets you down. It's not always easy but it's

something you have to do... It's not going to go away so you just got to handle it as best as possible.

Casey emphatically reflected a similar attitude towards her condition stating that situations arise in life that are not asked for. Since there was no choice but to live with them, it was important to adjust to those changes. She said, as with any challenge, you need to put hard work into in order to better get through it. Not complaining about it helped too:

I'm a hard worker... I have to work hard not to have flare-ups or inflammation, to be able to do things and to be determined ... life isn't easy and there are going to be things you don't like but you just have to deal with. I just see a task and I just have to do it, like I don't see an option of not doing it or even complaining about it.... It's going to affect your life and things are going to have to change, it doesn't have to be negative change, you're just going to have to find a way to adapt to it.

Helen also came to understand her condition and adapt to what it meant for her life. She approached it stating there are good days and bad days so let the bad days pass to make room for the good ones, "Today is good, if tomorrow isn't as good, it will be the next day... You always have to remember there are things to look forward to."

The mental adaptation process was made easier for Casey knowing that there were ways she could overcome her illness if necessary:

I know there are ways to help overcome it. Like my hair, knowing that it's just something superficial and that if I was to lose my hair I can [use] scarves, I can get a wig, I can do things. Knowing that there are options. If my arthritis does get worse and I have to stop running there are hip replacements... There will never be a cure or anything but knowing that there are ways to help [my illnesses], help me feel ok. I can keep living with this and if something happens there's a way to deal with it.

***Living in the Present.*** Living with the understanding that there was a possibility their conditions could deteriorate helped some participants embrace the present and cherish the opportunities they had because they recognized those opportunities may not

be available in the future. Elizabeth powerfully talked about being present and taking advantage of life by taking more chances and experiencing things she might not have been open to experiencing before:

Make sure you're doing things that are good for you and do good for your mind as well. I don't know what the future holds so I really try to enjoy life as much as I can and get out and do things that I don't know I'll be able to do in 20 years. I don't know what my life is going to look like when I'm retired so I try to get a lot of that great fun experience now and try to find a better balance. I see some people say "well I can do that in five years and I'll do this for now" and I say well I'm just going to do it now! ... It's made me take more chances than I otherwise would have. It makes me willing to try new things that I otherwise wouldn't have because I was always kind of shy and shut in from a lot of it. Now it's changed my attitude some in that if I'm going to experience things I have to put myself out there... I had to change my outlook on life and start doing more things for me.

Casey also found that focusing on the present helped her get through her challenges, "I don't focus on what might happen and just focus on [my] current condition and work on that because I think if you're too stressed out, that's not going to help. Just focus on the now."

Helen chose to live in the present and enjoy the time she had instead of complaining about what was not going well in her life:

I think as you get older, either you grovel and just let the days go by and complain or else just enjoy everyday because we only have today, but for somebody my age that's all there is.

Adjusting to the idea of managing multiple chronic conditions for the remainder of one's life can be a challenge to overcome. The participants in the present study turned their situations into a chance to learn more about themselves, appreciated what they had, and took more chances. Living with multiple ADs, although a struggle at times, gave the participants the opportunity to put things into perspective. Some even perceived their diagnoses as a positive outcome so they could begin treatment to improve their health.

Others chose not to focus their condition so they could enjoy life as best they could without ruminating on their limitations.

**Finding Inner Strength.** Learning to live well with multiple ADs required a period of mental adjustment. This adjustment period allowed them to get acquainted with the idea of managing multiple chronic illnesses and what that meant for their futures. It was beneficial to the participants to prepare themselves for what could lie ahead. The cognitive and emotional adjustment process helped create a new sense of reality so all setbacks and challenges did not come as a surprise.

**Willingness to be Challenged.** Each participant had a different way of demonstrating their strength and courage throughout their personal journey with multiple ADs. Casey indicated:

I was a really care free kid and I didn't let a lot faze me, I was like oh I have another thing! I didn't really see it as abnormal; I thought it was just something that was happening, something that I had to deal with.

When Elizabeth was experiencing challenges, she reported her thought process consisted of, "When I have a bad day I just go, you know what, if this is the worst it's going to be, bring it on. I can handle it, I can handle a lot." Helen dealt with her difficult days by thinking, "If it happens you deal with it and push it back and keep going. That's it!"

Helen demonstrated inner strength by her willingness to take an optimistic stance on her health and the blessings she had in her life:

As hard as it is try to be positive, everyday, try to have something at the end of the day to be thankful for. No matter how small or significant, even if you have to go out and hunt for it. Be positive, be thankful, and the rest sort of gets diluted.

*Building a Positive Self-Concept.* Having to live with these illnesses shaped some participants' self-image in a positive way. Casey and Tina both described how their experiences positively affected their self-concepts. Casey reported that her confidence improved because she embraced the special attention she attracted as a result of her physical differences:

I have physical problems that people can see that have made me more confident. When my alopecia was growing back I just cut it into a band and wore it in a little ponytail like a rhino, I definitely just went with it... It has just really shaped my confidence, being singled out when I was young made me much more confident today. It made me learn how to deal with a lot of things.

Tina also spoke about putting the physical and social realities of her ADs into perspective and how this made her feel more comfortable with herself:

I am now confident and comfortable with life. I feel like having gone through setbacks in life including having psoriasis when I was little has made me more comfortable in my own skin and more confident because I've gotten past it and I am more ok with other people's problems too and understanding what other people's problems are.

The participants in this study demonstrated a great deal of strength when working through their conditions. Although all of them experienced some setbacks along the way, they learned from their experiences and became more wise, capable, and empathetic due to their ADs. The participants recognized that it was easy to complain about the unfairness of a negative situation. What required strength and energy was re-framing their negative experiences into positive ones and not being hindered any more than necessary.

**Summary.** In order for the participants to process their illnesses they expressed that they needed to adopt a positive attitude. Being able to accept, adjust to, and makes sense of their conditions, helped them find the road to well-being. Accepting and

understanding the condition, and realizing how they felt about it was beneficial to the process of deciding how to manage it. This process has helped them come to live well with multiple ADs.

### **Taking Action to Manage Living with Multiple ADs**

This section is focused around the range of behaviours the participants engaged in, in order to help manage their ADs. Specifically, the participants discussed the importance of advocating for their own health care, engaging in activities that took the focus off their symptoms, and adapting to a lifestyle more conducive to maintaining a healthy mind and body. Each participant reflected on their personal plan which contributed to their sense of living well with multiple ADs.

**Self-Advocating for Quality Health Care.** Throughout the course of the interviews, the participants spoke of their challenges navigating the health care system. Some participants commented on the significance of keeping themselves informed about their medical conditions and approaching their treatment from a critical perspective. They spoke about the importance of educating themselves about their illnesses and their treatments, as well as informing others.

**Learning to be Your Own Expert.** A central component involved in advocating for quality health care and treatments required the participants to become their own experts in their illnesses and the uniqueness of their bodies. Helen and Elizabeth both commented on the importance of taking their health care into their own hands and not simply relying on what doctors were telling them. Elizabeth stated, “I’m concerned about my own health and I’m the only advocate I have in my own health, so it’s important to

keep yourself informed.” She recommended that individuals who are living with multiple ADs, or any chronic illness, should:

Be your own expert. Don't be afraid to get in over your head, don't be afraid to get your hands on a medical journal and read it. I feel like if I understand my disorder and I know what I'm up against, I have a better chance of beating it ... I think a lot of people get diagnosed with something and they're afraid. They just take what their doctor says. They don't go out and read on their own, they don't say they want a different doctor, I want a second opinion or I want to know more about this.

Helen also commented on taking her health into her own hands and taking responsibility for one's own treatment:

You have to be aware of your own health. I would probably put that number one. Be aware of your own health and try to maintain it as well as you can. Yes go to the doctor but they can only do so much. You have to be your own physician.

For Elizabeth, another part of being her own health expert was taking the time and energy to identify and maintain a health care team that worked with and supported her:

I work really hard making sure I find good people to keep on my team ... If I work really hard on that and follow-up on a regular basis, that's something. I see all my doctors twice a year whether I need to or not to follow up with things. You need to stay on top of your health. That's a big part of staying well.

***Becoming a Role Model.*** According to the participants, in addition to advocating for their health care needs, modeling healthy behaviour was also important. Modeling involved passing on knowledge of their experiences and advocating for others in similar situations. Elizabeth indicated that she tried to use her understanding of this process to educate other people with health care challenges. She said she did not want her experiences to be in vain; rather she wished to use them to act as a role model for others:

I really try to counsel other people that I see going through medical problems in that they need to push for it and you constantly have to ask questions and you can't take what your doctor says at face value. You need to do your own research... I have other people in my family that have other medical issues and I've learned to become a role model for them ... I've learned how to be



supportive of other people going through this stuff because that was something I never had. It's nice to feel I didn't have all this hardship and go through all this just for me. It's nice to know I can share it with somebody else and have them hopefully benefit from the mistakes that I made, the great learnings that I had or even help them by giving them that support person they can turn to.

The participants learned that if they were to receive the best health care available, they had to ask for it and make sure it happened because no one else was going to do it for them. They reported taking their health into their own hands, educating themselves about their conditions, and encouraging others to do the same brought them closer to being able to live well with their illnesses.

**Finding Distractions to Maintain a Peace of Mind.** Each participant had her own strategies for taking her mind off of her ADs. Whether it was physical activity, experiencing new situations or activities, or relaxing, all participants experienced some benefits from distracting themselves.

***Engaging in Independent Activities.*** Having activities that the participants could turn to on their own time, with or without inviting anyone else along was a reported comfort and means of escape. Several participants mentioned reading and watching movies or television programs as an effective distracter. June, for example said, that reading or watching movies helped put her in a better mood:

When I'm really depressed someone will take me to a movie and that always makes me feel better. I used to read a lot of books to make me feel better, now I watch a lot of movies. It's easy to loose yourself when you focus on things like that.

Tina also described how movies and books helped her when she was feeling overwhelmed with her conditions:

I read a lot in my spare time, and sometimes when I'm stressed out [I] watch TV, some junky thing online. That's good for giving my brain a break so I don't get stressed out ... It lets me concentrate on other things for a bit.

Helen discussed how reading had the ability to transport her away from her conditions for a while and give her peace of mind while she was caught up in someone else's story, "Keep on reading ... reading is extremely important because you can lose yourself. No matter how much you ache [or] feel down, just pick up a book and you're in another world."

Elizabeth said that it was essential to find an activity she could do for herself and by herself when she was experiencing a difficult day. She found comfort in quilting:

I think one of the most important things is finding something that I love that I can do on my own so that if I'm having a bad day, I don't need to rely on anyone else. I have something all on my own that I can immerse myself in to try and put [my conditions] on the back burner. Forget about it for a little bit, re-group and figure out how you're going to deal with it later. For me that's been quilting... and it's a nice quiet thing I can do at my own pace and I can go to my own space to do it. It's been really great for me to have that one thing that I really love that I can unplug from everything else that's going on and have something to do.

***Getting Out and Getting Involved.*** Getting out of the house and involved with new activities was also mentioned as a way to live well with multiple ADs. June said she tended to de-stress through traveling and experiencing new things, "[Travel] relaxes me ... It gives me good memories and it also relaxes me because of the new environments and the new experiences ... Especially when I travel with my family. It makes me happy to see them happy."

Helen said she liked to keep herself busy by committing her time to organizations within the community such as clubs, church, and creative classes, "Get involved in church or involved in bridge... sewing projects or art. I used to paint but any type of project like that helps."

***Finding Distraction Through Sport.*** Casey found participating in hockey allowed her to be released from her conditions for a short time allowing her to feel like she blended in with everyone else. By choosing hockey she was able to stay physically active in a sport she enjoyed, while not pushing herself too far:

The thing about hockey is I just blend in. I skate just as well as everyone else. I'm not sore after a game unless I fell or something. ...Jarring motions affect me but hockey is mostly gliding... Being able to play sports where I'm equal to everyone is really awesome... I have a helmet on so even when I have alopecia I'm all covered up. [I'm covered up] from my psoriasis too so I just blend in and I am totally normal. That activity just makes me forget. Physical activities remind me of what's happening and that I have a different situation than most people but hockey is something where I'm just the same as everyone else.

Having a distraction in the form of an activity helped the participants forget their conditions for a little while and concentrate on something that brought them joy. This strategy was consistently used in order for the participants to free their minds from the constant reminder of their conditions and be transported away from them.

***Adapting to Lifestyle Transitions.*** Taking action also required a change to the participants' lifestyle. Living with multiple ADs required some adjustment and commitment to new daily routines and learning to be flexible around what was no longer physically possible. Each participant discussed how they had to adjust the way they lived in order to properly manage their conditions, while maintaining their well-being. Eating well, exercising, staying on top of their treatment, and having something to work towards were all reported to be beneficial lifestyle changes.

***Eating Healthy and Exercising.*** In order to stay as healthy as possible, Tina, Casey, and June all commented on how they strove to exercise when they were able as well as paid attention to a nutritious diet. Tina indicated that to help manage her

conditions and to ward off other illnesses she relied on exercise and healthy eating as a preventative measure:

When I get stressed out I try to do things like yoga...I'm very physically active. I eat well because I think it's important not necessarily for anything to do with the thyroid or psoriasis but because I know that if you don't eat well, you can develop diseases of various kinds.

Casey viewed her ability to be physically active as a blessing, indicating that since her mobility had changed with her illness, she took her small accomplishments in stride and always worked to achieve more movement:

I can run and just knowing I can still do that is definitely something that I value. I've been working on getting more flexible. I haven't been able to sit cross-legged for almost my whole life and I feel like I'm getting to a point where I can almost kind of do that. I have to see small things ... and getting excited about them.

Physical activity also brought a sense of accomplishment to June. She was continually looking for new ways to get exercise and different sports to join because she knew it was beneficial for her well-being:

I'm trying to be more physically active because I know that helps me [feel] better. I try to play soccer, volleyball and do tae kwon do. I did a half marathon a couple of years ago. I'm always trying to challenge myself physically..

***Staying on Top of Symptom Management.*** In regards to maintaining symptom management, June, Elizabeth, and Helen all talked about how staying on top of their treatment by looking for new advances in medications or alternative treatment plans was an important part of living well with multiple ADs. Elizabeth relied on her prescription medication and stated that it was important to make sure the doctors were offering her the most effective treatment, “Stay on top of your medication, follow-up with your doctor, make sure it's the right medication because there are always advancements.”

In contrast, June said she was slowly trying to eliminate the medication she was prescribed in order to try more natural methods of treatment:

I just have to try and be as natural as possible. I'm going to try to get off the pills that I'm on. I don't want to become addicted to the medication or have to be dependent on it. I don't even like taking aspirin.

Helen also recommended pursuing alternative treatment plans that compliment Western medications. Throughout her journey with multiple ADs, she has tried several different types of alternative treatments with positive results:

Physiotherapy helped me a great deal and as the years went on I found out massage therapy helped too... [I also learned how to do] biofeedback to... control the pressure or the temperature in my veins. This helped me control my headaches. I found much better results with [alternative therapies] then with medication.

Helen was willing to try alternative treatments and medication for pain control. In spite of her traditional and westernized training as a registered nurse, Helen stepped out of her comfort zone in order to seek out treatments that worked for her. Being the most senior participant, the application of complimentary treatments required some risk since CAM therapies have only been formally introduced in recent years.

***Having a Sense of Purpose.*** In addition to distracting herself by getting involved with programs and activities in the community, Helen also talked about how helpful it was to have project or a goal to work towards everyday. Feeling like she could accomplish at least one thing a day contributed to her sense of purpose:

Have something to do every day. I think that's important. Have a project. If you don't, at least phone somebody for coffee, invite them in for coffee, or take the bus to the mall and if nothing else walk around it once. You have to have a goal. Everybody has to have a goal, no matter what it is. Having special projects to do is even better because that fills more time and space; it also keeps your brain active.

Keeping their bodies and their minds healthy by getting exercise, eating right, investing in treatment plans that were right for them, and keeping busy were all ways the participants identified as contributing to living well with multiple ADs.

**Summary.** Being active participants in their own health plans contributed to a sense of living well with multiple ADs. The participants stated that when they advocated for their health, conducted research, found ways to have fun, and set goals for themselves, they felt more in control of their treatment. This contributed to their sense of achievement. Concrete activities in the form of healthy distractions such as a hobby or sports outlet further lead to a sense of well-being.

### **Leaning on Support Systems to Live Well**

The significance of social support in the process of living well with multiple ADs was also identified. Seeking out social and spiritual support may also be seen as a type of activity the participants engaged in. However, due to the importance placed on it by the participants, it is addressed separately. The participants described the importance of social support as a diversion, a source of encouragement, an opportunity to laugh, and a chance to relinquish their worries to a higher power. The ability to accept the love and support from others made a positive impact on the mental and physical health of the participants. The women in the present study identified three main categories of support; family, friends, and spirituality, all of which sustained them in negotiating illness-related challenges.

**Family as a Foundational Support.** Having strong family foundations helped the participants feel less alone in their journey. The strength that came from the support of family members was articulated in every interview. June talked about the strength she

drew from her family. She emotionally described how much she valued her relationships with her daughters and sister, “ My daughters are my strength... My sister, she’s my family, she’s my rock ... I hold onto her for everything. I don’t know what I would do without them,” June went on to state that her family always helped her get through tough times and how it was essential being part of a family was for her own well-being, “I’m a person that has to have strong family foundations, I need that. I’m not a solitary person. I don’t think I could survive without having my family around me.”

Elizabeth explained how difficult it was to leave her family when she went to university because they had always been there to help her emotionally and physically with her ADs. She knew that by going to university she would be leaving this support behind. She managed by maintaining close contact with her family and expanding her social network. She also talked about the significant support her husband provided to her throughout her journey:

My mom had always been there to help me put on medication and reach the spots I couldn’t reach or scratch my head if I needed it scratched. [Leaving home] was really hard because I was leaving my biggest support system...I think a lot of it is having a really great support system. I’m so lucky that my husband is so supportive and behind me in everything that I do... He is kind of that constant motivation for me, which is really good. And my parents have always been really supportive. Having that kind of support behind you helps you live a better life. You know to have someone that you can open up to or cry your eyes out if you need to. Anytime that I have something small even come up now it’s good to let it out and share it with someone.

Casey looked to her parents as role models when the initial diagnosis was given. Her parents’ attitudes helped support her and normalize the experience. By not making a big deal out of it, their reactions allowed Casey to come to a place of acceptance:

I think [how I handled my illnesses] was a lot of how my parent’s handled it ...They were upset with what was going on but they never really showed it. So because my parents were really calm, handled it well, and didn’t act like it was

severe. [Because of their reactions] I never thought [my illness] was severe. So that definitely helped me handle it really well.

Casey's family also encouraged her and helped her go about her routine and daily activities whenever she could so it didn't feel like her condition was extremely disruptive to her life, "[My family] was great, they helped me through it all. They understood not to just let me sit around and let it get worse. They made me play in sports. They made sure I was still doing things I liked."

Helen also reflected on the influence her family had on her health and happiness. She said that without her family and their support, she would probably be leading a different life and would not get out and work on her health as much as she did. They were her motivation to stay healthy and happy:

I'm not an invalid by any means and I can still get around and I can still enjoy most everything and most of all it's because of my family. I think without my family, whatever my mobility and whatever I could do wouldn't be as great. That's the shining star and that's the goal to work towards. Otherwise I don't think I would bother with the sewing machine, I'd probably have my nose in a book, then find a bridge club somewhere and complain! ... [My family] is my main support. It's not so much the physical help, it's the emotional and mental support, and the love they give you. The rest you can cope with. If you know that you're accepted that's it.

Finding commonalities between members of the family who are also experiencing health complications was found to be an additional support. Going through similar health related struggles as some family members allowed Tina to forge a deeper bond with her family and for her to contribute to a shared sense of support, "My family [supports me] with this because my mom and my sister both have low thyroid and my brother is asthmatic. There's other stuff in my family too so we all understand and support each other."



The mental, emotional and physical support that came from the participants' families helped them manage their conditions because they felt loved, cared for and strengthened by the comfort of their families.

**Friendships Providing Support.** Expanding their social network to include friends also played a big role in the narratives of Casey, Tina, and Elizabeth. They indicated that friends could be considered an extension of one's family due to the important role their presence and support played.

Having a group of friends who provide a safety net who understand the limitations associated with having multiple ADs was invaluable for the participants. Their understanding made it possible to continue spending time with friends and participate in activities that did not cause 'flare-ups'. Casey explained, "[My friends] would always made sure that if my hip was flared-up they'd do something I could be involved in, they were really supportive."

Elizabeth noted the significance of being surrounded by the support of a good group of friends: "I've learned to have a core group of people you can open up to and share with them. Them having a good attitude about [my illnesses] as well makes it easier." Tina also touched on the significance of having good friends in her life. For her, they were a welcome distraction when she needed cheering up or when she wanted to focus on something other than her condition, "Meeting up with friends, doing stuff with friends, talking to people, and being social is definitely important to me... I find that being with friends helps me relax and forget about what is going on in my life."

Having friends who are understanding and non-judgmental was an additional source support for the participants. It also beneficial to have their friends help take their minds off their conditions.

**Finding Support Through Spirituality.** Spirituality is unique to each individual including the participants of this study. The person holding the spiritual beliefs usually assigns their own meaning to them, as is the case of both Helen and June. Both incorporated their own spirituality into their healing journey.

Each woman held a different set of beliefs. June's spiritual beliefs incorporated forgiveness and being sure to tell her family she was sorry when she made a mistake. June learned to let go of the negativity within her; a lesson she learned from observing her mother:

[My mom] could never admit that she was wrong. The very first thing I ever said to my kids was sorry and she never said sorry to me once. I think by saying sorry I reduced my inflammations and she could never say that. I think that's why her pain [from arthritis] was so high. Saying sorry helped me feel better all around.

June also stated, "The moment I forgave [my mom] was night and day [with regard to my health]." Letting go of past negative experiences and allowing herself to move forward, released a lot of stress for June. She felt more at peace with herself, which in turn translated to an improvement in her symptoms.

Helen's experiences of relying upon her beliefs also helped lessen her stress because she felt that she was handing her health-related worries over to a high power. Releasing her struggles to a higher power gave her peace of mind. She no longer had to spend time worrying because the problem was now being taken care of by someone/something else:

You don't have to be quote religious, some people are they and get something out of that, I don't. But you have to have a deep faith and when things get to be too much, give it to a higher power. You can't handle it but you know it will be taken care of.

Whatever form the participants' spiritual beliefs and practices, they were able to translate those feelings into a calmer peace of mind, which in turn aided the management of their ADs.

Finding strength in friends, family and spirituality helped the participants feel supported in managing and understanding their conditions. No matter the form, each participant gained something of value from her support system.

## CHAPTER FIVE: DISSCUSION

This interpretive descriptive study which, followed the interpretive method outlined by Thorne, Kirkham, and MacDonald-Emes (1997), was conducted in order to grasp an in-depth understanding of how individuals diagnosed with multiple ADs are living well. Special attention was given to the biological, psychological, and social aspects of health. This study was one of the first to illuminate the phenomenon of living with multiple ADs. Previous research has concentrated on the experiences of those living with specific individual ADs (see Leverone & Epstein, 2010; Olsson, Lexell, & Soderberg, 2008; and Venning, Elliott, Wilson, & Kettler, 2008), yet in-depth accounts of those diagnosed with multiple ADs have not been examined. A deeper understanding of how individuals diagnosed with multiple ADs are living well has enhanced the literature by describing how the physical and emotional challenges and successes of the participants have positively influenced their state of well-being.

Unique challenges were presented that were associated with managing multiple ADs as opposed to one AD. One big challenge was learning to manage and process their fears around being diagnosed with other ADs in the future, and the limits they could be associated with. There was much worry associated with what the future held for the participants. Having multiple ADs also required more organization and energy because there were more aspects of treatment and follow-up to manage than when the participants only had one AD to manage. The participants also put more energy into learning about each of their illnesses and how they interact with each other. They also had to work harder to advocate for their healthcare because they interacted with more healthcare professionals in different settings than when they were only diagnosed with one AD.

Finding a supportive healthcare team in multiple settings also required more energy. Finally, the individuals were more motivated to keep stress levels to a minimum so to not exacerbate the symptoms of one or all their ADs.

Four interconnected thematic conceptualizations emerged from the individual interviews: the ups and downs of living with multiple ADs, mentally and emotionally conceptualizing their illnesses, taking action to help manage their ADs, and leaning on support systems to help them live well with multiple ADs. Some of these findings have been consistent with studies exploring specific ADs, such as the importance of social support. A deeper understanding of how the participants were able to live well with multiple ADs emerged which included the importance of maintaining a positive attitude, learning from past challenges, and taking control of one's personal health care. Overall, for the participants of the present study, the capacity to reach a place of well-being, despite having to negotiate the terms of their illnesses, came from a holistic understanding of health care.

This chapter reviews and summarizes the main findings of the study, and extends the findings to existing literature in the areas of nursing, chronic illness, and positive psychology. Practical implications for health professionals, the strengths and limitations of the present study, and areas for future research are discussed.

### **Integration of Findings into Existing Literature**

The path to well-being was described as a journey by the participants in the present study. They discussed the impact their illnesses initially had on their lives, the insight they gained into their bodies regarding how ADs affected them physically, and how to navigate their own treatment in order to ensure they had access to good health

care. Although, the participants in this study all considered themselves to be living well, individuals who find positive meaning in their illnesses are not immune to significant distress (Calhoun & Tedeschi, 2006). In order to get to a place of acceptance with their health conditions, the participants had to experience some negative situations in the process and learn how to overcome them. It is common for individuals with chronic illness to experience concerns such as physical limitations, pain, or fear of uncertainty about the future (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992; Newman, Fitzpartick, Revenson, Skevington & Williams, 1996). Each participant struggled with their own challenges, and recognized that achieving a sense of well-being was an ongoing going complexity of emotion, learning, and understanding.

Previous research characterizes living with chronic illness as a phased process in which the individual follows a predictable trajectory with possible regression along the way (Thorne & Paterson, 1998). The assumption of this model is that an end goal exists if the individual makes it through all the stages. Thorne and Paterson's (1998) study suggests that the Shifting Perspectives model of chronic illness (Paterson, 2001) is more appropriate for how individuals experience living with multiple ADs. The Shifting Perspectives model developed by Paterson states that living with chronic illness is depicted as an "ongoing, continually shifting process in which people experience a complex dialectic between themselves and their world" (p. 23).

Paterson (2001) states that people with chronic illness perceive their "wellness" by comparing their experiences to what is known and understood about illnesses and vice versa. The perspectives that are created help determine how the individual responds to the disease, themselves, caregivers, and situations that are affected by the illness, such as

employment). Depending on the individual's perception of the situation, either wellness or illness takes precedent in their "world". This perception may change with personal and social context changes, so illness may be in the foreground or in the background.

The Shifting Perspectives model of chronic illness is reflected in the experiences of the participants in this study. Their journeys with their ADs were not linear and although they perceived themselves to be living well, they had times, days, or even weeks where their health-related challenges brought illness to the foreground of the worlds, and pushed wellness back. This model acknowledges that it is ok to take time to process the challenges associated with chronic illness. It does not minimize the difficult aspects of chronic illness and understands that although people may experience growth and find meaning, the trying times also need to be acknowledged.

Living with multiple ADs impacted the participants emotionally, socially, and career-wise. They discussed how afraid they were when the reality of their health situations hit them, and how they felt obligated to explain themselves to their co-workers. Feelings of discomfort became prevalent in the workplace when fellow employees started to notice that some of the participants were frequently missing work, while seemingly healthy. The participants also spoke of the importance of staying active but not causing a flare-up in their symptoms by overdoing it. Being self-aware and finding balance was something they discovered was necessary to maintain good health. The relationship between the amount of stress in the participants' lives and the subsequent consequences on their ADs was also discussed. Without exception, keeping stress levels to a minimum was a high priority for everyone. Gaining access to proper treatment, adjusting to medical

regimes, and navigating the nuances of the health care system were recurring stressors identified by the participants.

The participants described their reactions and perceptions of others reactions as a difficult experience requiring processing following initial diagnoses. They processed distinct emotions throughout their personal health journeys. These included embarrassment, anger, social isolation, and fear of what the future held. These feelings were often accompanied by low-self confidence and low self-esteem. This finding was consistent with the results of Westbrook and Viney (1982), who identified patterns of psychological reactions of people to the onset of chronic illness. Westbrook and Viney compared patients during hospitalization at the onset of their chronic illness (N=126) to non-patients (N=54). Patients who were interviewed had a variety of different conditions including disorders of the circulatory system, respiratory system, genito-urinary system, nervous system, digestive system, musculoskeletal system, as well as skin, endocrine, nutritional and metabolic disorders. Multivariate analysis of variance revealed increased levels of anxiety, depression, feelings of helplessness, loss of sociability, and anger were generated by the frustration of living with chronic illness compared to controls. Similarly, the participants of the current study experienced withdrawal from social relationships, frustration, anger, and anxiety about the future was stronger following their initial diagnoses. They had learned to manage their emotions at the time of the study but they reported these negative emotions continued to resurface during challenging times.

Westbrook and Viney (1982) also found that the different reactions to the onset of illness, whether sudden or gradual, had more of an influence on the participants' reactions to it than did lifestyle variables (e.g. relationship status, children, leisure



activities, work satisfaction) or gender (Westbrook & Viney). For example, people with gradual disease onset describe feelings of uncertainty, which were replaced by feelings of relief when a diagnosis was made. The sample of the present study consisted entirely of women experiencing different circumstances; nevertheless, the findings from Westbrook and Viney indicate that most populations react similarly. These results are consistent with other past findings (see Abram, 1972; Rodda, Miller, & Bruhn, 1971; Worden & Sobel, 1978).

The burden of watching loved ones react sadly to their diagnosis, and perceived judgments from co-workers was also experienced by the participants in this study. When a child is diagnosed with a chronic physical or mental condition, the parents often assume the role of grieving to mourn the life they had hoped for their child (Tresca 2012). The participants described watching family and parent's reactions to their diagnoses as being hard on them because the participants knew their families were struggling with their own set of emotions. The participants found that they also had to in part give up the picture of their lives they had previously painted and adjust to their new circumstances.

In terms of the vocational impact ADs had on the participants' lives, some stated that their employment status was hindered by their symptoms by impairing their ability to complete their work. This phenomenon is quite common amongst individuals with ADs. For example, in people with RA, individuals leaving work due to disability rates vary between 25-50% after 10 years of disease and increase to 90% in people with longer disease duration (Jantti, Aho, Kaarela & Kautiainen, 1999; Meenan, Yelin, Nevitt & Epstein, 1981).

The participants also described experiencing negative judgments from others at their place of employment. This occurred after missing work for medical appointments or disease related reasons. Due to the sometimes invisibility of their illnesses, the participants appeared to be seemingly healthy to their co-workers, creating misunderstanding. The perceived stigma felt from living with multiple chronic illnesses can have many adverse consequences on the individual's well-being (Goffman, 1986). People living with chronic illness report experiencing social rejection (Chapple, 2004), poor health care quality (Sayles, Ryan, Silver, & Sarkisian, 2007), and workplace termination (West, Dye, & McMahon, 2006). For example, people living with chronic illnesses may perceive social rejection from friends and family, discrimination from work colleagues, and poor attitudes from health care professionals. The participants of the present study also reported they perceived social rejection, discrimination from coworkers, and poor health care quality, all of which negatively impacted their feelings of well-being.

Whether real or imagined, the presence of stigma and intense emotions are often felt by individuals who live with chronic illness. The participants of the current study were not spared these experiences. Although these adverse feelings can be mediated by a host of individual factors including stress, social support, and quality of care (Earnshaw, Quinn, & Park, 2011), the initial diagnosis and the self-consciousness surrounding living with multiple ADs was an experience each of the participants had to work through.

Achieving balance is an important component of achieving mental and physical health. The participants in this study identified their balancing act of maintaining a healthy body through physical activity, while not aggravating the symptoms of the ADs.

Identifying the boundaries between their bodies and their illnesses was another reported challenge. This was a trial and error process for each individual. The concept of balance has been an integral part of the wellness literature. It is centered on the idea that when the mind, body, and spirit are all considered and cared for, the individual will achieve a state of well-being (Yun-Hee et al., 2010) in spite of their diagnoses. The challenge of keeping stresses to a minimum influenced the participants' ability to maintain overall life balance.

The connection between stressful events and increased levels of AD activity has been discussed in the literature (Kiecolt-Glaser et al., 2002b). One's response to stress suppresses the immune system, resulting in symptom flare-ups, a stressor in and of itself. People with diseases that are influenced by stress levels, such as multiple ADs (e.g. RA, Crohn's disease, Scleroderma, etc.) may find it necessary to take meditation courses, change jobs, or practice daily relaxation exercises in order to lower their stress levels (Yun-Hee et al., 2010). The participants in the current study after much thought and energy were cognizant of this connection. They actively sought out ways to reduce the levels of stress in their lives.

Navigating the health care system and their individual treatment was yet another challenge experienced by the participants. Heszen-Klemens and Lapinska (1984) reported health care satisfaction is related to well-being. People diagnosed with a chronic illness who are less satisfied with their healthcare may suffer poor related outcomes such as minimal adherence to treatment regimes (Heszen-Klemens & Lapinska). When individuals with chronic illnesses anticipate stigmatization from their healthcare providers, they are less open about their symptoms and illness-related concerns (Heszen-Klemens &

Lapinska), potentially interfering with treatment. If a lack of physician-patient rapport is established, individuals tend to divulge less information, which can impede the ability of healthcare providers to offer satisfactory care. The difficult diagnostic process and the fact that there are not many effective treatments currently available, make ADs a class of illnesses requiring open communication and a good relationship with the health care team (Abramovitz, 2011). The participant's in this study stressed the importance of finding the right health care team to work with. They discussed how much more comfortable and happy they were with their treatment plans when they identified caring health professionals. This finding could be noteworthy for physicians and people with multiple ADs to be aware of when making health care decisions.

The manner in which the participants integrated their illnesses into their self-concept was also identified as a means to living well with them. The path towards living well with multiple ADs involved learning to accept their diagnoses and shift their perspectives in order to ascribe meaning to their circumstances. The participants did not allow themselves to focus their energy on thinking of their situations negatively. Rather they came to accept the reality of their bodies' limitations and appreciated how much they were still capable of. They put their situations into perspective in order to better understand them. The participants also revealed it had taken some time to mentally adapt to the notion of living with multiple ADs for the rest of their lives. Some participants came to terms with their illnesses by accepting that they were not going to be cured so the only option they had was to find strategies to manage as best they could. Although, this paradigm shift in attitude was challenging and took time, the participants described it as a necessary process. It put them on the right track to be able reach a place of well-being.

Chronic illnesses such as ADs carry important psychological and social consequences that require significant psychological adjustment and adaptation in multiple life domains (Stanton, Revenson, & Tennen, 2007). The literature on chronic illness promotes acceptance as an adaptive, positive outcome in the adjustment process. Behaviours associated with denial commonly lead to poorer illnesses management and higher levels of distress (Carver, et. al, 1993; Karlsen & Bru, 2002; Revenson & Felton, 1989). Increasingly researchers are considering positive indicators of adjustment to chronic illness such as demonstration of optimistic attitude and retaining purpose in life (Stanton, Collins & Sworowski, 2001). Stanton, et al. (2001), identified five conceptualizations of adjustment to chronic illness. They include mastery of disease-related adaptive tasks, preservation of functional status, perceived quality of life in several domains, absence of psychological disorder, and low negative affect. The participants in the present study added to this list by identifying mental and emotional aspects of adjustment.

A similar framework described by Luthans (2000a) was also evidenced through the participants' interviews in terms of adjusting to, and managing their illnesses. The participants described psychological capital, which was described by Luthans, as a means to live well with multiple ADs. Psychological capital consists of four elements; the belief in your ability to navigate a challenge (self-efficacy), presenting an optimistic attitude surrounding those abilities (optimism), persevering to reach set goals (hope), and bouncing back when met with adversity (resilience), (Luthans, Youssef & Avolio, 2007).

One of the initial tasks the participants underwent on the path to living well with multiple ADs involved accepting the limitations of their bodies and coming to terms with

what it meant to live with chronic conditions. Following this realization, the participants were able to find the confidence in themselves to process and manage their conditions. This confidence is also known as self-efficacy and is presented in the health-related literature as a concept that promotes well-being (Madux, 2009). Self-efficacy is one of the main components of psychological capital (Luthans, Youssef & Avolio, 2007). Individuals high in this trait tend to interpret demands as more manageable. They use effective stress buffering techniques such as eliciting social support, humor, relaxation, and exercise, which all enhance immune function (Madux).

Disease-related self-efficacy expectancies also predict adjustment. Longitudinal studies revealed the predictive utility of self-efficacy in adjustment to rheumatic diseases and joint replacement surgery (see Culos-Reed & Brawley, 2003; Engel et al., 2004). The participants described the process of adapting to their illnesses as shifting their perspective towards a more positive view of themselves and their situations. This allowed them to accept their diagnosis and start finding ways to work towards well-being.

Many of the participants chose not to see their experiences negatively, and although they experienced difficult challenges, maintained an optimistic perspective about their health. Optimism is another concept of psychological capital. Some participants described that they took more risks and lived in the present because they did not know what the future held. Others stated that they gained a broader understanding of the struggles people face and their experiences have made them more empathetic and compassionate. Their illnesses also reminded them not take things in life for granted and appreciate what was really important to them such as family, friendships, and health.

Dispositional optimism (Carver & Scheier, 2002) has been the most frequently examined personality attribute in relation to disease-related adjustment. Those with dispositional optimism use humor, acceptance, and are able to positively re-frame their situations (Rasmussen, Wrosch, Scheier & Carver, 2006; Wrosch & Scheier, 2003). The participants in this study consistently practiced re-framing. The reality was that they could do nothing to change their illnesses, so they chose to see them in a more positive light. Maintaining an optimistic perspective allows individuals with chronic illnesses to believe things will work out for them, so fighting for their health becomes a worthy cause (Carver & Scheier, 2002). Approaching their situations optimistically enhanced the ability of the participants of this study to live in the present and enjoy their lives, but also gave them the knowledge that whatever challenges the future would bring, they could handle them.

The participants spoke about determining their situations as worthy of ensuing coping efforts, and were motivated to persist despite encountering setbacks. This determination is a cognitive appraisal and fits the third component of Luthans (2000a) psychological capital. They saw future challenges with a “bring it on” attitude because they believed they could handle future adversity well after successfully overcoming many challenges. Snyder’s (2002, p. 2) view of hope is defined as an “empowering way thinking”, which is consistent with the attitudes of the participants in the present study. Adopting a hopeful attitude authorizes individuals to better adapt to challenges and cope well with adversity, while maintaining a positive dialogue focused on success (Snyder, 2000).

The participants' ability to thrive and ascribe positive meaning to their situations after being diagnosed with multiple ADs is indicative of their capacity for resilience, the final component of psychological capital (Luthans 2000a). Greene (2002) stated that resilience involves balancing levels of stress and coping. Resilient people show greater flexibility when using coping strategies to match external demands in order to deal with stress (Waugh, Thompson & Gotlib, 2011). This in turn is associated with improved mental and physical health and reductions of stress levels in people diagnosed with ADs (Fournier, DeRidder & Bensing, 2002). The participants in this study invariably experienced much adversity and stress; however, they overcame their challenges by accessing a variety of management strategies. Their use of different symptom management strategies may have enhanced their ability to cope with the demands of their situations and evidence a resilient disposition.

The participants described ways of taking action that assisted them in reaching a place of well-being with their ADs. They discussed the significance of being an advocate for their own health, informing themselves about their illnesses, researching the advancements in treatments, and persevering in their efforts to meet with the appropriate health care professionals. The participants also busied themselves with activities of their choosing to help take their minds off their illnesses. These distraction techniques consisted of being able to focus on a hobby at home, getting involved with the community, and being active in sports. Choices were also made to improve their lifestyles in compliance with the needs of their physical health. These included being as physically active as possible, adhering to a healthy diet, staying on top of treatment regimes, and keeping busy enough to maintain a sense of accomplishment. These results



are similar to those of Moos and Schaefer (1984), who discovered that managing pain and symptoms, negotiating the health care environment, and maintaining satisfactory relationships with medical professionals are important tasks that aid the individual's adaptation to their illnesses.

The choices the participants made helped them practice self-management. Self-management is a concept found in the literature on coping with behavioral interventions to promote health behaviors (Newman, Steed & Mulligan, 2004). Self-management is defined as activities a person undertakes to keep their illness under control, minimize its effects on physical health and daily functioning, and cope with both the psychological consequences of the illness and the symptoms (Clark, Becker, Janz, Lorig, Rakowski & Anderson, 1991). The research on self-management of chronic illness suggests qualities such as perseverance and discipline, the ability to accept imperfection and ambiguity, the ability to reframe adversity into opportunity; confidence in one's own ability to sustain spiritual or emotional self; and sufficient economic and social resources to enact decisions one makes are able to effectively manage their illnesses (Thorne, Paterson, & Russell, 2003). For participants diagnosed with HIV/AIDS, MS, or diabetes, self-care decision-making reflected the outcome of a conscious decision to gain control of their disease management and subsequent efforts to assume that control (Thorne, Paterson, & Russell).

Reducing pain and coping effectively through self-management skills were reported by the participants in increase well-being. Similarly, a study conducted by Bishop, Frain and Tschopp (2008) on self-management in people with MS found a positive correlation between self-management and perceived control. Increases in self-

management promoted improved quality of life and enhanced control. Self-management also contributes to keeping current with information about the illness, self-advocacy, and participating in treatment decisions (Newman, Steed & Mulligan, 2004); strategies that were identified in the current study. Through the practice of self-management, the participants felt as though they had gained some control over their health prognosis, which in turn resulted in a decreased stress response, and increased well-being.

Self-advocacy was an issue raised by the participants and identified as a key strategy in maintaining control in their own health. Although it required the participants to invest time to inform themselves about the nature of their conditions and practice becoming assertive, they all found it to be a beneficial and health improving practice. Andersen (2009) states that people with ADs can become experts in their own health by being in touch with their own bodies, being knowledgeable about their diseases, and initiating research. Armed with these insights, they can then advocate for a specific treatment plan or have the knowledge to know what may not work in their specific situations. This helps ensure the individual's interests are being represented within the health care system and that the decisions made are the best for this person. Becoming an expert also increases the confidence of the individual by perceiving more control over their health status, which helps lower stress levels (Andersen).

Advocating for proper treatment and health care is an essential element of living well with chronic illness (Schaefer, 2005). Self-advocacy involves being assertive with health care practitioners to insure one's questions are answered and needs are being met (Andersen, 2009). People who incorporate self-advocacy in their health care regime instead of approaching it with compliance are more likely to improve their experiences

within the health care system while feeling confident in the treatment they receive (Schaefer). The participants in this study echoed these findings. Some stated that advocating for their health and putting forth the effort to work with a good health care team is essential to effective treatment and feelings of living well.

The participants addressed the importance of having a support network when they were struggling with health challenges. Each individual highlighted the role their friends, family, and/or spiritual support system played in how they were able to live well with their conditions. Some participants talked about how their families were their rocks and the family's presence sustained them. In addition, others mentioned the importance of spirituality as a tool to relieve stress and burdens.

Social support has long been identified as a positive resource from which those with chronic illness have drawn upon (Charuvastra & Cloitre, 2008). The participants in this study all identified family and friends as a basis of support, comfort, and belonging throughout their time with multiple ADs. By nature, humans are social beings and the need to belong and be connected to others through a sense of community is universal (Charuvastra & Cloitre). This need is enhanced during trying times, such as periods of strong disease activity (Charuvastra & Cloitre), as demonstrated by the participants in this study.

Every participant in this study described how the support from their family and friends helped them be able to live well. The literature provides many examples of how social support contributes to the maintenance of chronic illness management (Berdsla, 1989; Kralik, Van Loon & Visentin, 2006; Pentz, 2005). When surrounded by supportive networks, the individual experiences more positive emotions, which helps improve

immune functioning and leads to fewer health symptoms (Dickerson & Zoccola, 2009). Social support has also been found to be a buffer against stress related disorders such as several ADs.

Charuvastra and Cloitre (2008) reviewed the literature on interpersonal traumas, social support, and the risk for PTSD. They integrated the findings into research from developmental psychopathology, attachment theory, and social neuroscience theories. What they concluded was that human social experience has a central role in the way an individual responds to setbacks. They stated that the role of social bonds in the assessment of threat and the management of fear responses, contributes to how the individual will experience stress. This has an obvious influence on health. Higher levels of social support will help protect against the development of ADs and facilitate coping (Charuvastra & Cloitre 2008). This is consistent with the findings of the current study. Overall, the participants stated that they had access to positive support networks, which they used both as a comfort and a way to help manage their illnesses.

The participants also discussed the beneficial influence of spirituality as a support. Spirituality differs from religiosity in that spirituality is a broader domain that may include religiosity, but religiosity is not necessarily an element of spirituality (Estanek, 2006). The relationships between spirituality, adjustment to chronic illness, quality of life, and mental health has shown that holding spiritual beliefs and practices increases well-being (Ano & Vasconcelles, 2005; Hackney & Sander, 2003; Sawatsky, Ratner & Chiu, 2005). This positive relationship is noteworthy in terms of ADs due to their connection to the mind and the immune system. In this study the participants reported

that the support and comfort they were able to find in their spiritual beliefs helped them influence their stress levels, which better enabled them to manage their illnesses.

Bartlett, Piedmont, Bilderback, Mastsumoto and Bathon (2003) looked at the role spirituality played in the health of people with RA. They discovered that a positive relationship exists because spirituality is one factor that enables the individual to overcome adversity, apply effective coping strategies, and attribute meaning to the situation. Landis (1996) found that in people with diabetes mellitus, existential well-being, a component of spiritual well-being, mediated the relationship between negative feelings of uncertainty and psychosocial well-being. These findings suggest spiritual beliefs may buffer the effects of factors that challenge well-being in people living with chronic illness. A conceptual framework proposed by Hiatt (1986) attempts to explain the importance of incorporating spirituality into a health model with a biopsychosocialspiritual paradigm. Hiatt's model combines Engel's (1977) biopsychosocial model with spirituality to reflect the role of the mind, body and spirit of multidimensional individuals. This model could be applied to the situations of people living with multiple ADs who identify spirituality as a meaningful support.

### **Psychosocial Application of the Findings**

The shared meaning that arose from the findings in this study suggests the importance of distributing this information on a holistic approach to health management to health professionals such as nurses, physicians, counsellors, and psychologists. This could increase their awareness about the phenomenon of living with multiple ADs and subsequently to assist these individual's live fuller lives. The participants in this study spoke of the importance of identifying a caring, supportive, and knowledgeable team of

health care professionals with which to work. If nurses and physicians viewed their clients from a broader, holistic lens encompassing the biological, as well as the social and psychological aspects of their clients, approaches to treatment could better target each individual. Incorporating such specifics in the treatment plan would increase the level of perceived control over their illnesses. They would have a greater repertoire of tools to help them navigate the challenges they might face. This can ultimately decrease stress levels and influence the level of disease activity. If nurses and physicians are able to incorporate more inclusive practices, their clients may be better able to reach a place of well-being while living with multiple ADs.

The findings from the present study can be transferred to professional counselling services as well. The focus of this study investigated how the participants were able to reach a place of well being while living with multiple ADs. It is appropriate to explore the notion of implications for counselling with reference to a framework situated in the positive psychology domain. Corcoran's (2005) Strength-and-Skills-Building Model is one of the frameworks that focuses on strengths as opposed to pathology. It is described as an eclectic approach that looks at both individual strengths and areas that can be improved upon using people's strengths and skills. This theory rests upon the assumption that people have the agency and skills within themselves to change.

The Strength-and-Skills-Building Model (Corcoran, 2005) draws from solution-focused, motivational interviewing, and cognitive-behavioral theory ethical frameworks. The practitioner's role is to build on the individual's resources while identifying personal limitations; thus utilizing existing strengths in order to motivate the individual to make changes. Popular techniques used in therapy include: normalizing the clients concerns by

de-pathologizing them, reframing the situation by introducing new ways of looking at the issue, and using coping questions by validating the client's challenges. Focusing on the strengths they have used to overcome past problems is also incorporated. Living with multiple ADs can be isolating if the phenomenon is not frequently recognized or discussed. Normalizing the individual's experiences and fears, and letting them know that others share similar struggles, which can be therapeutic. The present study found that reframing the situation by looking at it through a positive lens of acceptance helped the participants to be able to live better. Acknowledging challenges while at the same time recognizing personal strengths also contributed to the participants' well-being.

### **Strengths of the Present Study**

The current study extends the literature in several important ways. First, this study highlights an area of interest that has been given little attention in the literature. Minimal importance has been placed on researching the phenomenon of living with multiple ADs. This is the first study to seek an understanding of how individuals diagnosed with multiple ADs are living well. The majority of the research in this area has focused on people diagnosed with a single AD. This study addresses this gap in the research by presenting this phenomenon as a relevant and significant topic that warrants attention by researchers.

Second, the current study demonstrates the benefits of conducting an in-depth exploration into the phenomenon of living well with multiple ADs by relying on personal accounts. Presently, there is little research involving qualitative descriptions of people living with multiple ADs. Presenting the findings through personal narratives that allow

for a more comprehensive understanding the participants' experiences will hopefully generate more research and applied interest in this area.

Lastly, the research process benefited the participants. Although the purpose of this study was not to be therapeutic or beneficial to the participants, the experience of discussing their situations, concerns, and strengths proved to be favorable. The opportunity to reflect on their personal journeys' with their illnesses allowed them to see the progress and growth they had made. This study also proved to be a platform for the participants to share their stories and offer advice and guidance to others in similar situations. Some expressed gratitude that such a study as this could potentially benefit themselves and others.

### **Limitations of the Present Study**

The findings of this study cannot be transferred to all individuals living well with multiple ADs; however, important information on the topic was generated which met the analysis' interpretive descriptive aim. The sample size limits the transferability of the findings beyond the group of participants; however, the findings may still be applied in practice to many health care settings. Although an effort was made to recruit a heterogeneous sample by advertising throughout the community, only women responded and met the criteria for participation. This was not surprising considering most ADs disproportionately affect women compared to men (NIH, 2005). On average, women are three times more likely to be diagnosed with an AD than are men (Abramovitz, 2011) and account for nearly 80% of the 23.5 million Americans with these diseases (Dale, Davis & Faustman, 2006). Furthermore, ADs fall within the top ten leading causes of death in



American women under 65 (Walsh & Rau, 2000) and are the fourth largest cause of disability in women (U.S. Department of Health and Human Services, 2000).

Although women are more greatly affected by ADs compared to men, the sample recruited represents only the views of women and does not reflect male experiences of living well with multiple ADs. There is evidence to suggest that men and women respond differently to stress and illness; therefore, women may experience unique ways of managing their ADs. Men and women report different reactions to stress, both physically and mentally (American Psychological Association [APA], 2013). They attempt to manage stress in markedly different ways. Findings suggest that women are more likely to report physical symptoms associated with stress, tend to make better connections with other, and at times, these connections are important to their stress management strategies (APA). For example, women are more likely than men to report they read to manage stress (57% vs. 34%) and women utilize more stress management activities that connect them with other people, such as socializing with friends or family (54% vs. 39%) and going to religious services (27% vs. 18%) (APA).

In addition to the differences in how men and women handle stress, gender also plays a role in adjustment to chronic illness. For example, women tend to voice depression, pain, and disability in rheumatoid conditions more often than men (Katz & Criswell, 1996; Stommel, Kurtz, Kurtz, Given & Given, 2004). Stereotypical gender roles play a role in how women with complaints of chronic illness are perceived (Chrisler, 2001). Often they are criticized for being overly emotional, complaining excessively, imagining their symptoms, and having a low tolerance for pain (Chrisler). Following these misconceptions, women may have had to adapt unique ways of coping

with illnesses because historically they were not taken seriously. Therefore, it is likely that the ways in which men and women come to live well with and manage their conditions differ. Evidence of these differences comes from a qualitative study exploring how Asian women cope with breast cancer (Sagoo, 2010). Four main themes emerged from Sagoo's analysis: the importance of spirituality, family and friends, the benefits of a positive attitude, preserving their identities, and re-aligning their values. The women of the present study identified several of the same patterns on managing their illnesses. This suggests a pattern in the way in which women manage chronic illness.

Interpretive description differs from other qualitative methods in that the aim of analysis is neither thick description (ethnography), theory development (grounded theory) or exploration of the meaning of an experience (ethnography). It therefore, cannot satisfy those requirements. However, the present analysis was successful at investigating a clinical phenomenon, that of living well with multiple ADs, for the purpose of identifying themes and patterns within participants' accounts. It also generated an interpretive description capable of informing clinical understanding (Thorne, 2008). Interpretive description also acknowledges that not all patterns relevant to individuals living well with multiple ADs can be uncovered. In order to incorporate as many patterns as possible, outliers in the data were included in the analysis and interpreted based on how they best contributed (Thorne). This study does not claim that new variations in the topic cannot emerge, but did in fact produce findings with clinical relevance.

### **Implications for Future Research**

Many of the participants in this study shared the same or similar ADs, such as psoriasis, RA, and digestive disorders. These types and combinations of ADs may have

evoked a similar way of managing them. To extend this study, future research could focus on different types or combinations of ADs in order to determine if individuals with MS, diabetes, or lupus for example, have developed different strategies in order to live well and manage their conditions.

Another area of future research may be to examine the different experiences of living well between individuals with visible versus invisible ADs. Different types of ADs can be classified into ‘invisible’ illnesses in which all of the symptoms are internal (e.g. celiac disease), ‘visible’ illnesses in which the symptoms are physically present externally (e.g. psoriasis), and both visible and invisible (e.g. MS). The present study contained both invisible and visible ADs (e.g. diverticulitis and alopecia areata). Responses to invisible and visible ADs by those living with each type may be very different (Joachim & Acorn, 2000). They both have been found to evoke a stigma response from others; visible illnesses evoked reactions because of the physical symptoms, and invisible illnesses cause potential stigma when the individual is considered a hypochondriac (Joachim & Acorn). In addition, management strategies for each type may differ.

A further avenue to extend this research would consist of a longitudinal research study designed to track the participants’ experiences throughout their journeys of living with multiple ADs. An issue for extended investigation would be the following queries: during times of health crisis, uncertainty, or other challenges, do individuals continue to practice similar methods of symptom management and do they consistently maintain similar positive frames of mind? When individuals have reached the final stages of their

lives, do they still feel as though they have lived well with their conditions? How does the presence of death influence peoples' thoughts or behaviours around their illnesses?

## **Conclusion**

Living well with multiple ADs is an important issues given the diagnosis of two or more ADs is increasing in prevalence (Shomon, 2002). Understanding and describing the experiences of individuals living well with multiple ADs is critical in educating professionals on how to provide the most effective treatment for this unique class of illnesses. This interpretive descriptive (Thorne, 2008) study illuminated the phenomenon of how individuals diagnosed with multiple ADs are living well and managing their conditions. This study was one of first to attempt to gain a deeper understanding of the experiences of living well with multiple ADs. Consistent with the biopsychosocial model of health care (Engel, 1977), an interplay of biological, social, and psychological factors which influenced the participants' health and well-being were identified. The insights of incorporating a holistic perspective of health care including stress management strategies, provides important discoveries into the phenomenon of living well with multiple ADs. Thesis findings in the context of the larger body of available chronic illness and well-being literature help create a deeper understanding of health care, treatment, and mental health. It is my hope that physical and mental health professionals will be better informed after disseminating a conceptual description on how individuals with multiple ADs are living well.

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Appendix A  
Ethics Approval

## Appendix B

### Poster

#### Are you Living Well with Multiple Autoimmune Disorders?

I am a University of Saskatchewan graduate student working towards a Masters of School and Counseling Psychology degree under the supervision of Dr. Audrey Kinzel. I am looking for participants that meet the following criteria to engage in a research study about the experiences of living well with multiple autoimmune diseases. The title of the study is Living Well with Multiple Autoimmune Diseases: An Interpretive Description.

I am inviting people who meet the following criteria to be a part of my study:

- Living well with multiple autoimmune diseases (i.e. see yourself as living well)
- Are of adult age (18 or older)
- Diagnosed with two or more autoimmune diseases that affect different parts of the body (i.e. endocrine, hair, skin, eyes, gastrointestinal, joint, musculoskeletal, and/or neuromuscular conditions)
- Not presently in a time of health crisis
- Speak fluent English
- Willing to speak about their experiences of living with multiple autoimmune diseases
- Able to commit approximately 3 hours of time to the interview and post-interview process.

Please express your interest by contacting Emma Cey

Email: [emma.cey@usask.ca](mailto:emma.cey@usask.ca)

Phone: (306) 966-8861

Autoimmune Disorders Ph: (306) 966-8861 Emma Cey
Autoimmune Disorders Ph: (306) 966-8861 Emma Cey
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## Appendix C

### PAWS Bulletin Advertisement

#### Are you Living Well with Multiple Autoimmune Disorders?

I am a University of Saskatchewan graduate student working toward a masters of school and counseling psychology degree under the supervision of Dr. Audrey Kinzel. I am looking for participants that meet the following criteria to engage in a research study about the experiences of living well with multiple autoimmune diseases. The title of the study is Living Well with Multiple Autoimmune Diseases: An Interpretive Description.

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- Not presently in a time of health crisis
- Speak fluent English
- Willing to speak about their experiences of living with multiple autoimmune diseases
- Able to commit approximately 3 hours of time to the interview and post-interview process.

Please express your interest by contacting Emma Cey

Email: [emma.cey@usask.ca](mailto:emma.cey@usask.ca)

Phone: (306) 966-8861

## Appendix D

### Consent Form

My name is Emma Cey. I am presently completing a thesis for partial fulfillment of the requirements for a Master's degree in School and Counselling Psychology in the Department of Educational Psychology and Special Education at the University of Saskatchewan. I am interested in learning about how people diagnosed with multiple autoimmune diseases are living well. The title of the study I intend to do is Living Well with Multiple Autoimmune Diseases: An Interpretive Description. This study was funded by the Social Sciences and Humanities Research Council of Canada. Please read this form carefully, and feel free to ask any additional questions you might have.

The purpose of this study is to explore what individuals living with multiple autoimmune diseases are doing in order to live well with their illnesses. My hope is to gain an understanding of how individuals are positively managing their conditions. All information will be from the perspective of the individuals that have been impacted by this phenomenon. While much has been written on the topic of positive health management strategies on individual autoimmune diseases, little research has looked at people's experiences of being diagnosed with and overcoming the challenges of multiple autoimmune disorders.

In order to gather the information required for this study, I will be conducting up to two audio-taped interviews with each participant, each interview lasting approximately 60-90 minutes. Interviews will be conducted in-person at a mutually agreed upon location.

This is to certify that I, \_\_\_\_\_ have been informed about, and agree to the following:

1. I have been advised about the nature and purpose of the study.
2. My participation in the study is voluntary. I may withdraw at anytime for any reason without penalty.
3. Any information shared with Emma Cey will be held in confidence. Quotations and/or summaries of what I say will appear in the final thesis and may be published in an article or presented to a larger audience in the future. My confidentiality will be protected through the use of pseudonyms and all identifying information will be excluded.
4. The interviews will be audio-taped and then transcribed. Although each session is recorded, I have the option to ask to have the recorder turned off or to leave parts out as I see fit. Audio-tapes, transcriptions, and any notes will be safeguarded and stored at the University of Saskatchewan, and will be destroyed after the required 5 year time period has passed.
5. In order to minimize any discomfort I have been encouraged to answer only the questions I am comfortable with and know that I may request a break at any time.
6. Interviews will be conducted at times and locations that are mutually convenient for the researcher and myself.

7. In the event that I should need to speak to someone about my thoughts and feelings resulting from the interviews, the researcher will work with me to access appropriate professional assistance
8. I will have public access to the completed study in the University of Saskatchewan library. I may also request verbal debriefing and feedback on my interview dialogue or final draft of the project by contacting the researchers.
9. If I have any questions or concerns about my participation in this research, I may contact the following individuals:

Research Supervisor:           Dr. Audrey Kinzel  
  Phone number: (306) 966-8861

Researcher:                         Emma Cey  
  Phone Number: (306) 270-1104

This study has been approved by the University of Saskatchewan Advisory Committee on Ethics in Behavioral Sciences Research on July 23<sup>rd</sup>, 2012. Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services toll free at 1-888-966-2975 or [ethics.office@usask.ca](mailto:ethics.office@usask.ca).

My signature indicates that I have read and understood the content of this form. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I consent to participate in the research project. A copy of this Consent Form has been provided for my records.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

## Appendix E

### Interview Guide

#### Introductory Comments

- Thank the participant for accepting to participate in the research.
- Provide an overview of the purpose of the research.
- Remind interviewee of length of the interview session.
- Begin informed consent process by assuring participant of confidentiality of all responses and participant's right to refuse to answer any questions they feel uncomfortable with. The allow participant to ask any questions about their concerns before proceeding to interview questions.
- Get written consent letter signed and request permission to record interview and inform them that they may request stopping the recording at any time.

#### Initial Interview Questions (60-90 minutes)

1. Please tell me a bit about yourself before you were diagnosed with any autoimmune diseases.
  - What did you do?
  - What did you enjoy?
  - What were your goals?
  - What were your challenges?
2. How was your health during that time?
3. Can you tell me about your diagnosis?
  - What are you diagnosed with?
  - When were you diagnosed
4. How did you react to being diagnosed with autoimmune diseases?
  - How did you react to the first disease?
5. Tell me a bit about yourself after you were diagnosed with multiple autoimmune diseases.
  - What do you do?
  - What do you enjoy?
  - What are your goals?
  - What are your challenges?
6. How has being diagnosed with multiple autoimmune diseases impacted your life, if at all?
  - How has it impacted your relationships? Friends? Family? Work?
7. What is it like for you living with multiple autoimmune diseases?
  - How do you see yourself now?
  - How do you see your illnesses?
8. What do you do to live well with your condition?
  - Why do you consider yourself to be "living well"?
  - Provide me with some examples of how you live well.
  - What are your experiences of living well?
  - What is your attitude/approach to living well?
  - Is there anything you've tried that did not work well? If so, what was it?

9. What activities or experiences are essential to maintain in order for you to feel like you are living well?
10. What supports you/ lifts you up/ helps you when you face difficult challenges as a result of living with these illnesses?
11. How has, if at all, living with multiple autoimmune diseases brought any new meaning to your life?
12. What have you learned as a result of being diagnosed with and adapting to your condition?
13. Do you have any advice/suggestions/words of wisdom for other people who have multiple autoimmune diseases?