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As Long As You Have Your Health?  
Subjective Well-being Trajectories In An Inflammatory Rheumatic Disease Sample

by  
Jennifer Voth

A Dissertation  
Submitted to the Faculty of Graduate Studies  
through the Department of Psychology  
in Partial Fulfillment of the Requirements for  
the Degree of Doctor of Philosophy at the  
University of Windsor

Windsor, Ontario, Canada

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As Long as You Have Your Health? Subjective Well-being Trajectories In An  
Inflammatory Rheumatic Disease Sample

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## AUTHOR'S DECLARATION OF ORIGINALITY

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## ABSTRACT

The purpose of this study was to explore different trajectories of subjective well-being (SWB) in a sample of people with rheumatic conditions using growth mixture modeling (GMM), and to identify demographic, disease-related, and psychosocial risk and protective factors associated with these response patterns. Four hundred and thirty two adults with rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), ankylosing spondylitis (AS), or gout were recruited online, and data were collected over the internet at six monthly intervals. Satisfaction with life (SWL; Diener, Emmons, Larson & Griffin, 1985) and positive and negative affect (PANAS; Watson, Clark, & Tellegen, 1988) were measured at each time point. Other measures included demographic information, disability, pain, disease activity, control beliefs, optimism, perceived social support, and other major life events. The majority of the sample were Caucasian (70.8%), married (60.7%), women (70%). The average age of respondents was 44.3 years and the mean time since diagnosis was 8.9 years. Four trajectory groups were uncovered representing resilient, low SWB, rapid recovery, and gradual recovery response patterns. Compared to the resilient group, the low SWB group experienced greater negative emotions and less positive emotions, and reported lower income, greater disability and disease activity, and less optimism and perceived control. The rapid recovery group were less optimistic, and reported greater disability, disease activity, and less perceived control initially. The gradual recovery group was less optimistic, had greater pain at Time 1 (T1), and less perceived control at Time 2 (T2). Low SWB and resilience were the most prevalent trajectory groups, whereas the two recovery groups were less represented. Experiencing greater positive emotions was associated with recovery in life satisfaction, whereas

negative emotions hindered life satisfaction growth. The combination of maintaining higher positive emotions and experiencing fewer negative emotions over time was critical for sustainable higher satisfaction with life. Disease fluctuations and optimism played important roles in achieving and maintaining well-being. Future research directions are discussed.

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## CHAPTER I

### **Introduction**

There are a wide variety of experiences that have the potential to radically alter the course of one's life trajectory. Life circumstances that bring about these lasting changes are known as *turning points* (Rutter, 1996). Turning points can happen through individual choice, such as when one decides to change careers, but can also result from circumstances that are outside of a person's control, such as being diagnosed with chronic illness or suffering a traumatic injury (deRoos-Cassini, Mancini, Rusch & Bonanno, 2010; King, Cathers, Brown & MacKinnon, 2003; Kralik et al., 2006; Rutter, 1996). Not everyone responds to stress in the same way: some people will succumb to incapacitating distress and depression (Alvarez & Hunt, 2005; Briere, 1992; Courtois, 2004; Mancini & Bonanno, 2009), whereas others will display resilience and have the ability to overcome significant life stress with seemingly little emotional strain (Bonanno, 2004).

Pollock (1986) proposed that individuals suffering from chronic illness face three crucial turning points: when the chronic illness is diagnosed, when symptoms increase (e.g., disability) and health deteriorates, and when the patient realizes it is up to them to learn how to manage the disease outside the presence of medical professionals. For years, health psychologists have laboured to understand why some people adapt rather well to these turning points, whereas others struggle (Stanton, Revenson, & Tennen, 2007). What researchers do know is that living with a chronic illness is an individual journey, one without a cure or, in many cases, without a completely effective treatment strategy.

Adapting under these circumstances is therefore a complex issue. Stanton et al. (2007) recommend tackling this issue with research that examines adaptation as it unfolds

over time and across multiple life domains (i.e., psychological, physical, social, and environmental), with the understanding that there is considerable variability in psychological adjustment to chronic disease. The aim of this study is to identify and examine heterogeneous trajectories of psychological functioning in individuals with inflammatory rheumatic diseases, some of the most prevalent chronic health conditions in Canada, the United States, and Europe. Specifically, this study will (a) describe the psychological functioning of people who have rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), ankylosing spondylitis (AS), or gout over the course of six months using multiple indices of adjustment; (b) identify a number of different trajectories of psychological functioning using growth mixture modeling (GMM), a relatively new and sophisticated statistical procedure recommended for this type of research (Muthén, 2004; Muthén & Muthén, 2000); and (c) identify and explore possible predictors of these trajectories in order to glean a more holistic understanding of psychological adjustment to inflammatory rheumatic diseases. The following paper describes the burden of chronic illness, attending particularly to rheumatic conditions; discusses adaptation and adjustment to chronic disease; reviews the literature on resilience and other trajectories of emotional well-being; and finally, identifies some factors that may promote or impede successful adjustment.

### **The Cost of Chronic Illness in Western society**

Chronic illness is a persistent health issue that is rarely completely cured and has the potential to produce profound changes in a person's life (de Ridder, Greenen, Kuijer, & van Middendorp, 2008). As one of the foremost global health issues (Mirolla, 2004; Weinert, Cudney, & Spring, 2008), chronic disease has been labelled an "invisible



epidemic,” responsible for 65% of all deaths in 2005 (<http://www.who.int/chp/en/>). In Canada, chronic illness currently affects the lives of approximately nine million people (Canadian Academy of Health Sciences, 2008) but will continue to rise in the coming decade (Perruccio, Power, & Badley, 2006). In the United States (US), over 130 million adults live with at least one chronic condition, which means that almost one out of every two people are managing chronic disease (Bodenheimer, Chen, & Bennett, 2009).

Rheumatic disease is among the most common chronic conditions in North America and the United Kingdom (UK), yet it receives less public health attention because it is considered a quality of life issue and is assumed to be an inevitable part of aging (Badley, 2008; Brady, Kruger, Helmick, Callahan, & Boutaugh, 2003). Nevertheless, rheumatic conditions are the leading cause of disability in Western society, currently affecting 16% of the Canadian population, 21.6% of Americans, and 19% of people in the UK (Canadian Academy of Health Sciences, 2008; Helmick et al., 2008; McCormick, Fleming, & Charlton, 1995). These prevalence rates are predicted to rise to between 21 to 26% in Canada by 2021 (Perruccio et al., 2006) and to 25% in the US by 2030 (Hootman & Helmick, 2006).

As it stands, chronic illness poses one of the largest challenges to the sustainability of a country’s health care system (Mirolla, 2004; Weinert et al., 2008). For instance, in Canada, patients with chronic disease use a large portion of health care resources, amounting to over 70% of hospital visits and over 50% of all visits to community nurses, family doctors, and specialists (Canadian Academy of Health Sciences, 2008). Chronic illness accounts for over 75% of the direct health care expenditures in the US (Thrall, 2005). Medical care costs for those with chronic illness

are more than 39 billion dollars per year in Canada (Mirolla, 2004) and currently over 1.5 trillion dollars in the US (Thrall, 2005). Rheumatic conditions, in particular, cost the UK economy £18 billion per year and the Canadian economy almost 15 billion dollars per year due to disability.

### **Rheumatic disease**

People living with rheumatic conditions, such as arthritis, experience more pain, activity restrictions, and long term disability than those suffering from any other chronic health issue (Health Canada, 2003). Rheumatic conditions are largely been considered diseases that affect the elderly. However, it is now known that at least 200,000 people in Canada between the ages of 25 and 34 are suffering from arthritis, and more than 8 million people with arthritis in the US are between the ages of 18 and 44 (Hootman & Helmick, 2006). In fact, three out of every five Canadians with rheumatic diseases are under the age of 65. In total, one in every six Canadians over the age of 15 is affected by some form of rheumatic disease, which demonstrates the urgent need to understand the burden of rheumatic conditions on individuals, their families, and on society as whole (Health Canada, 2003).

Rheumatic disease is a label for more than 100 different conditions (Arthritis Society of Canada, 2010), all of which have common symptoms of joint and musculoskeletal pain. These conditions are, nevertheless, vastly different, ranging from mild “tennis elbow” to the more severe and crippling rheumatoid arthritis (RA). The Arthritis Society of Canada has categorized the types of rheumatic conditions into two broader forms, degenerative and inflammatory, based on what they know about the features of each of the conditions. The degenerative forms of rheumatic disease, the most

common being osteoarthritis, are characterized by joint degeneration, where the cartilage that covers and protects the bone begins to wear away leaving the bone underneath to thicken and move less smoothly. Over time, pain in the joints becomes progressively worse. By contrast, in the inflammatory forms pain and stiffness tends to grow in quick succession, starting in one or few joints and spreading to more joints over a period of sometimes weeks to months. These are autoimmune diseases in which the immune system begins to attack the tissues lining the joints, releasing chemicals that cause swelling, pain, stiffness, and, eventually, damaging the cartilage and bone.

One reason for limiting the current study to a sample of adults with inflammatory rheumatic disease is that there is a paucity of research regarding the impact of these inflammatory conditions on quality of life (Badley, 2005). However, a recent national report published by Health Canada revealed that four of the five most common rheumatic conditions affecting Canadians are inflammatory (Health Canada, 2003). In particular, over one million Canadians currently suffer from gout, over 17,000 Canadians have systemic lupus erythematosus (SLE), and both RA and ankylosing spondylitis (AS) affect approximately 345,000 people. An estimated 100,000 new cases of rheumatic diseases occur each year and as many as half of these may be inflammatory forms. In the US, 3 million Americans reported having gout, over one million people suffer from RA, approximately 300,000 adults have AS, and as many as 322,000 individuals have SLE (Helmick et al., 2008). These conditions will be described in further detail in the coming sections. Despite the relative neglect of these chronic diseases in the psychological research literature, these conditions clearly have a huge physical and psychosocial impact on the population.

Furthermore, this group of rheumatic conditions can seriously affect a person within a relatively short period of time, as pain, inflammation, and swelling can spread from joint to joint within a few months. A recent study finds that erosive damage to the joints of people with RA occurs within the first two years, and 75% of total joint damage will take place within five years of onset (Lindqvist, Jonsson, Saxne, & Eberhardt, 2003). Similarly, preliminary findings suggested people with AS lose most of their functional ability in the first 10 years (Boonen & van der Linden, 2006). These findings are quite troubling in light of the fact that it can take years for these inflammatory diseases to be properly diagnosed (Khan, 2006). Given the earlier onset of complications arising from inflammatory rheumatic disease, it stands to reason that these individuals may present more variability in terms of psychological adjustment compared to those who have degenerative forms, which can take many years to progress.

### **The Four Major Types of Rheumatic Disease**

RA typically begins with pain and swelling in the small joints of the hands and feet, quickly spreading to other joints in a symmetrical pattern over the course of the disease (Arthritis Society of Canada, 2011). AS, the most frequently occurring subtype of a group of diseases called the spondyloarthropathies, develops early in adulthood and is characterized by chronic inflammation and stiffness of the pelvis, spine, and lower back, as well as restrictions in chest expansion (Davis, van der Heijde, Dougados & Woolley, 2005). SLE is the most common and severe type of lupus and involves inflammation of multiple organ systems, which can become severely damaged over time. The cause of lupus is unknown and symptoms of SLE vary widely, including fatigue, skin rashes, sensitivity to light, and arthritis of the hands, knees, shoulders, hips, feet, or jaw (Sharpe,

Denton, & Schrieber, 2004). On the other hand, gout is caused by crystallization of uric acid in the joints, skin, and tendons, which causes significant inflammation, pain, and stiffness in affected areas (Khanna et al., 2008). Attacks of gout are extremely painful and over time can cause permanent joint damage (Arthritis Society of Canada, 2011). Both AS and gout are associated with a variety of co-morbid conditions, such as osteoporosis, which further contribute to a loss in functional mobility (Boonen & van der Linden, 2006; Khanna et al., 2008). Furthermore, both AS and gout are far more likely to occur in men, whereas RA and SLE are more prevalent in women (Health Canada, 2003; Helmick et al., 2008).

Overall, RA and SLE are considered the most severe and crippling of these four types of conditions. In terms of disability, AS and RA patients report that the disease has a similar influence on their overall emotional functioning (Hyphantis et al., 2013; Khan, 2006), however, people with RA self-report worse physical functioning than their age-matched AS counterparts (Boonen & van der Linden, 2006). A recent study comparing disability in a sample of adults with gout and RA suggests that people with RA had substantially more disability than the adults with gout (van Groen, ten Klooster, Taal, van de Laar, & Glas, 2010). SLE can be a potentially fatal condition when there is permanent damage to vital organs such as the kidneys, lungs or heart; however, this is rare, especially with the advancement of aggressive treatment options. In general, people with RA experience more pain and stiffness, reducing their ability to perform some of the most basic tasks (Archenholtz, Burckhardt, & Segesten, 1999); however individuals with SLE suffer from more diverse symptoms, such as renal dysfunction, skin rashes, seizures,

and enlarged liver and lymph nodes due to the illness targeting major organs in the body (Philip, Lindner, & Lederman, 2009).

Despite some differences, all inflammatory rheumatic conditions share common features of pain, stiffness, and swelling of the joints, as well as, extreme fatigue, low grade fevers, weight loss, muscle pain, and numbness in the fingers and hands (Arthritis Society of Canada, 2011). The hallmark of inflammatory rheumatic disease, however, is the experience of pain and stiffness that ebbs and flows over a period of time (called a “disease flare” or “flare up”). Disease flares can occur without warning, involve intense pain, and can result in the loss of functional mobility (Smith & Wallston, 1992). However, when a flare remits, people with these inflammatory conditions are for the most part, symptom-free and are able to carry on a relatively normal life. This cycle of relapsing and remitting symptoms may have an interesting and significant influence over psychological functioning.

The severity of inflammatory rheumatic disease can vary greatly from person to person and there are several available treatment options that show some promise in terms of improving quality of life (Badley, 2005; Brady et al., 2003). Several different combinations of medications are effective in targeting inflammation and reducing pain and stiffness, although some of these drug therapies can cause unwanted side effects (Scott, Wolfe, & Huizinga, 2010). Other intervention strategies include physiotherapy, occupational therapy, education, a healthy diet, and exercise to increase joint mobility, strength, and fitness (Brady et al, 2003).

### **The Mental Health of People with Inflammatory Rheumatic Conditions**

Although the focus of modern medicine has increased the life span of those suffering from a chronic illness, Sidell (1997) lamented that the same amount of passion and attention has not been paid to the mental health of these populations. In fact, Badley (2005) stated that psychological distress resulting from inflammatory rheumatic conditions and disease management is generally overlooked in medical research. Instead, research interest tends to focus on investigating the range of physical symptoms accompanying these diseases, their progression over time, and whether different treatment strategies have shown success in alleviating pain and inflammation. However, in addition to the physical ramifications, individuals with inflammatory rheumatic disease are impacted psychologically (Chaney et al, 2006; Wright, Zautra & Going, 2008; Zautra, Johnson & Davis, 2005), and it is important to attend to these consequences in order to understand how to enhance the quality of life for people with these chronic conditions. To be sure, there has been some interest in the psychological functioning of people with RA and lupus (Chaney et al, 2004; Wright, et al., 2008; Philip et al., 2009; Zautra et al, 2005); however, there is a noticeable lack of research examining the psychological consequences of living with AS or gout (Karatay, Melikoglu, & Senel, 2004; van Groen et al., 2010), which is a gap that this research aims to address.

Furthermore, Smith and Zautra (2008) suggested that rheumatic patients present an interesting opportunity to examine psychological adaptation because of the cyclical nature of their disease progression. At times these individuals will experience unyielding pain, fatigue, and disability that can adversely impact psychological adjustment. That being said, there also are times when physical symptoms abate, during which people with

rheumatic disease have opportunities to engage in activities that may lead to a positive outlook on life.

Interestingly, some researchers argue that the quality of life of people with inflammatory rheumatic conditions may differ from healthy individuals only in the obvious ways that someone with any chronic illness would, with lower life satisfaction attributed to the state of one's physical health (Denton, Sharpe, & Schrieber, 2005). Our common understanding of what it means to have "good life quality" presumes good mental and physical health (Goode, 1994). Albrecht and Devlieger (1999) argued that, to outside observers, people who live with disability and chronic pain could not possibly be in possession of a good quality of life. Their claim is certainly supported by the popular adage "as long as you have your health," which seems to imply that a person cannot truly enjoy life unless he or she is in good physical health (Gana et al., 2013). However, recent research evidence demonstrates that general public opinion about the quality of life of all people with chronic illness may be misinformed, and that in reality, some rheumatic patients report satisfaction with emotional well-being on par with that of the general population (e.g., Germano, Misajon, & Cummins, 2001). These data have led to an interest in understanding why, and under what conditions, some people are able to achieve and maintain psychological well-being (de Ridder, Greenen, Kuijjer & van Middendrop, 2008; Quale & Schanke, 2010; Strand et al., 2006; Waaktaar, & Torgerson, 2010). However, in general, these questions have garnered only limited attention in research on chronic disease populations (Hamilton-West & Quine, 2009; Karoly & Ruelhman, 2006). Research endeavoring to understand the dynamic process of adapting



to a chronic illness is needed to inform intervention strategies aimed at helping chronically ill individuals to effectively manage their disease.

### **Adaptation**

When people are diagnosed with a chronic illness, they are confronted with a situation that challenges their previous ways of life (de Ridder et al., 2008). The question is: how do they adapt to these new circumstances? This remains the subject of a rather heated debate between health-care professionals (Stanton et al., 2007). Despite being one of the most vibrant and prolific research areas, the ability to reach a unified definition of adaptation to chronic illness has been strained by diverse philosophical perspectives, training, and research methodologies (Elliott, 2002; Livneh, 2001; Walker, Jackson, & Littlejohn, 2004). All things considered, most researchers would likely agree on a few important tenets: (a) adaptation is a series of individually experienced responses to stressful life events (in this case a chronic illness) that follow a dynamic, long-term, and often unpredictable course (Elliott, 2002; Larson & Hummel, 2009; Livneh, 2001); (b) it is necessary to study adjustment over time and across multiple life areas (Stanton et al., 2007); and (c) responses to stress are mostly internal, but the pace and direction of their trajectory is determined by contextual variables such as psychosocial, disease-related, and environmental factors (Livneh, 2001; Suurmeijer et al., 2001). Although defining adaptation according to outcome measures is commonly practiced, it is imperative to understand that these contextual variables provide the backdrop for the psychological responses and exercise a more sustained influence on the evolving process of adaptation (Bishop, 2005; Devins, 2010; Livneh, 2001; Rutter, 1987; Yi et al., 2008). The following discussions center on each of these tenets in turn, beginning with responses to chronic

illness, in which research on resilience is highlighted. Discussions then turn to specifying the outcome criteria by which adaptation would be considered successful and the importance of examining these responses over time. Finally, a number of possible contextual variables that may influence the pace and direction of these trajectories will be explored. Prior to discussing adaptation in-depth, it should be noted that the terms adaptation and adjustment are often used interchangeably in the literature (Larson & Hummel, 2009; Stanton & Revenson, 2007) and therefore, will be used here in a similar fashion.

### **Responses to Stress**

Most people will be exposed to at least one potentially traumatic event during their lifetime (Kessler et al., 1995); however, the manner in which these events are experienced, processed, and remembered differs among individuals (Erikson, 1995). Hans Selye (1936) posited that responses to stressful life events are not necessarily due to the specifics or the severity of the event per se, but how a person perceives that event and the meaning that he or she attributes to the experience (Erikson, 1995).

One of the primary areas of dissension among researchers who study adaptation is the nature of the anticipated psychological outcomes that follow an experience of adversity and the measures that are used to capture their meaning (Livneh, 2001). Broadly speaking, measuring responses to stressful life events has typically followed a pathogenesis model of mental health (Agaibi & Wilson, 2005; Bromley, 2005; Harvey & Delfabbro, 2004; Strumpfer, 1999; Reich, Zautra, & Hall, 2010). In other words, the emphasis has been on identifying and treating psychological dysfunction. The result is a considerable number of studies linking the experience of stress and trauma with poor

long term health outcomes, namely post-traumatic stress disorder (PTSD), affect dysregulation, anxiety, and depression (Alvarez & Hunt, 2005; Briere, 1992; Browne, & Finkelhor, 1986).

This same deficit-focused paradigm is used in rehabilitation psychology to explain the process of adaptation to chronic illness (Devins, 2010; Elliott, 2002). Findings suggest that people with chronic conditions, such as RA, not only experience pain and disability, but also fear and uncertainty about the future course of their disease and how that will impact their daily life (de Ridder et al., 2008; Siddell, 1997; Taylor, 1983; Walker et al., 2004). Much of the research examining the psychological consequences of inflammatory rheumatic disease focuses on identifying and understanding the root of depressive symptoms, which are well documented responses to RA, AS, and SLE (Dickens, McGowan, Clark-Carter, & Creed, 2002; Karatay, Melikoglu, & Senel, 2004; Martens et al., 2003; Pincus, Griffith, Pearce, & Isenberg, 1996; Schattner, Shahar, Lerman, & Shakra, 2010). Several longitudinal studies have demonstrated that depression in people with RA relates to a host of negative consequences over time, particularly, experiences of pain (Bartlett, Piedmont, Bilderback, Matsumoto, & Bathon, 2003; Smith & Wallston, 1992), disability (Hommel, Wagner, Chaney, & Mullins, 1998), loss of independence (Lutz & Archenholtz, 2007; Suurmeijer et al., 2001), and activity restrictions (Fitzpatrick, Newman, Archer, & Shipley, 1991; Neugebauer et al., 2003; Treharne, Lyons, Booth, & Kitas, 2007; Williamson, 1998). Other negative consequences associated with RA include, fatigue (Smith, Wallston, & Dwyer, 1995), negative illness attributions (Chaney, 2004; Keefe, Brown, Wallston, & Caldwell, 1989; Minnock, Fitzgerald, & Bresnihan, 2003; Neugebauer et al., 2003), the

use of avoidant coping strategies (Conner et al., 2006; Curtis et al., 2004; Smith, Wallston, Dwyer, & Dowdy, 1997; Evers, Kruijer, Geenen, Jacobs, & Bijlsma, 2003), and interpersonal distress (Bediako & Friend, 2004; Demange et al., 2004).

Though far fewer studies have examined depression in other forms of inflammatory rheumatic disease, findings tended to parallel those of RA patients. For example, Karatay et al. (2004) demonstrated that depressive symptoms are associated with disease duration, pain, and functional impairment in people with AS. Furthermore, Davis and colleagues (2005) found that a multinational sample of people with AS reported significantly higher scores on depression and anxiety than a sample of healthy American adults. For women with SLE, depression is a common complaint and is associated with disease activity resulting in sleep disturbances, skin rashes, abdominal and joint pain, and functional disability (Adams, Dammers, Saia, Brantley & Gaydos, 1994; Da Costa et al., 1999; Philip et al., 2009). Additionally, in a longitudinal study following 30 women with SLE, Schattner et al. (2010) found that depression is related to disruptions in valued activities caused by the illness and to concealing symptoms from significant others, possibly depriving the individual from helpful social support.

Other psychopathological responses to inflammatory rheumatic disease have also been reported. For example, activity restrictions resulting from RA, AS, and SLE are associated with higher negative affect and lower positive affect (Archenholtz et al., 1999; Blalock, Orlando, Mutran, DeVellis, & DeVellis, 1998; Bartlett et al., 2003; Curtis et al., 2004; Davis et al., 2005; Zautra et al., 1995). In people with RA, pain, fatigue and disability are linked to feelings of anxiety, hostility, higher levels of distress, lower self-esteem, and feeling less autonomous (McFarlane, Kalucy & Brooks, 1987; Suurmeijer et

al., 2001; Smith et al., 1995; Treharne et al., 2007). In addition, feeling stigmatized, changes in self-perceptions, lower vitality, and withdrawing from social situations are noted in people with AS (Boonen & van der Linden, 2006; Hamilton-West & Quine, 2009), whereas dissatisfaction in losing control of one's body is reported by people with SLE (Archenholtz et al., 1999).

The literature examining outcomes of poor adjustment to inflammatory rheumatic disease is both rich and compelling; yielding important knowledge that has been used for treating and preventing psychological distress (Weinert et al., 2008). However, claims that depression and related psychological issues are common responses to inflammatory rheumatic disease have recently been tempered, owing to new evidence suggesting that people with RA, AS and gout report similar overall quality of life and psychological functioning to those of their physically healthy counterparts (Arnold et al., 2004; Davis et al., 2005; Germano et al., 2001; Khanna et al., 2008; Poole, Cordova, Sibbitt, & Skipper, 2010). Although it is true that some people succumb to adversity (Dickens et al., 2002), there are many others that have shown the ability to successfully adapt to the stress of living with a chronic condition and display resilience (Brix et al., 2008; Bonanno, Moskowitz, Papa, & Folkman, 2005; Karoly & Ruhlman, 2006; Kendall, & Terry, 2008; Smith & Zautra, 2008; Taylor, 1983; Zautra et al., 2005). However, the collective reliance on an inherently negatively skewed framework has often neglected an individual's capacity for resilience and, in turn, has failed to capture these responses (Agaibi & Wilson, 2003; Bonanno, 2004; Kralik et al., 2006; Richardson, 2002; Zautra et al., 2010). Recent efforts to overcome these limitations have generated a scholarly shift

from focusing on negative responses to identifying and examining successful adaptation in the face of significant adversity.

### **Conceptual Definitions of Resilience**

When it became clear that examinations of adjustment held a one-sided view, Antonovsky (1990) strongly advised researchers to concentrate on identifying the origins of health, rather than on the origins of disease. He began a new paradigm in stress research, highlighting strengths rather than deficits. At the helm of this shift was the concept of resilience, which attempts to explain how people can face significant adversity yet successfully adjust (Bonanno, 2004; Masten, 2001; Newman, 2005; Zautra et al., 2010).

Human resilience is commonly referred to as an individual's ability to "bounce back" or quickly regain healthy functioning in the face of stress and adversity (Agaibi & Wilson, 2003; Bromley, 2005; Carver, 1998; Harvey & Delfabbro, 2004; Masten, 2001; Richardson, 2002; Zautra, 2009). The term *resilience* was first discussed in the 1960s, then called "*ego resiliency*," and was believed to be a rare personality trait that relates to adaptability and coping (Block & Turula, 1963). A second wave of resilience research emerged in the 1970s from investigations in developmental psychopathology. Interest was piqued by Werner and her colleagues (1984) after they discovered unexpected evidence that some children living in highly impoverished environments did not demonstrate lasting emotional damage, but rather grew up to be competent and caring adults. At first, their research was explained as an unusual phenomenon; concluding with the idea that these children must be invincible "superkids" (Johnson & Wiechelt, 2004; Masten, 2001). Although they believed resilient reactions to stress were uncommon, the

question still remained: what was it about these children that made them so special? This question inspired several researchers to explore what was by now termed “resilient” responses to stress (Garmezy, 1993; Masten, Best, & Garmezy, 1990; Rutter, 1987). What they uncovered, to their surprise, was that resilient children may not be so rare. In fact, Masten (2001) argued that resilience is not a remarkable attribute, but rather “ordinary magic” that can potentially transpire within any person.

However, identifying the reasons why some people do not succumb to stress has been hampered, owing in large part to conceptual ambiguity. Recent reviews have noted that there is no universal agreement on what constitutes resilience (Agaibi & Wilson, 2003). The most prominent definitions of resilience fall victim to circular arguments, defining resilience as an outcome and also as the process that contributes to that outcome (e.g., Bonanno, 2004). A review of the literature revealed three main camps of conceptual definitions. The first camp conceived of resilience as it was originally intended: a personality characteristic or set of fixed traits that moderate the negative effects of stress (Wagnild & Young, 1993). However, this definition has received criticism on the grounds that it implies that a person not in possession of a “resilient” trait would automatically be condemned to psychological dysfunction when confronted with a potentially traumatic event (Mancini & Bonanno, 2010; Luthar & Zigler, 1991). Given this criticism, researchers now recommend distinguishing *resiliency* when referring to a personality trait, from *resilience* when describing the ability to successfully adapt to stressful circumstances (Masten, 1994). The second camp of definitions came from studies on adult resilience. These researchers defined resilient individuals as people, in otherwise normal circumstances, who experience an isolated and potentially traumatic

event and continue to maintain a stable, healthy level of psychological functioning. Resilience was therefore examined from a categorical perspective. That is, investigators focused on classifying and comparing groups of people that share defining outcomes and then, in turn, attempted to identify factors that promote or impede these outcomes (Bonanno, 2004; Bonanno, Moskowitz, Papa, & Folkman, 2005; Brix et al., 2008). The third group of definitions emerged from developmental psychology terrain, wherein resilience was viewed as a dynamic process in which a person negotiated stressful events through the use of important contextual variables, called *protective mechanisms* (Rutter, 1987). Protective mechanisms refer to factors that help insulate individuals from the negative effects of stress and promote healthy, adaptive outcomes. Researchers who conceptually defined resilience as a process focused on uncovering the relational patterns among risk factors, protective mechanisms, and adaptive outcomes.

A cursory glance at these definitions reveals few differences between the adult and childhood literatures in terms of how researchers are defining resilience. For both sets of researchers, the end goal is the same: they are concerned with understanding and describing predictors and outcomes of healthy adaptation. Therefore, choosing to categorize “resilient” individuals based on outcome measures or to test a model of the resilience process required further inspection of the nature of the stressor, the research questions, and the population under study. For example, developmental psychologists are interested in studying multiple chronic stressors (e.g., poverty or neglect and abuse) that endure across a lifespan. Therefore, it made sense to view resilience as a process that unfolds and varies over time. Conversely, researchers who study resilience in adulthood have examined responses to acute, usually isolated events (e.g., loss of a loved one).



Defining resilience as an outcome of adaptation reflected individual responses to a specific event that is usually short in duration (Bonanno, 2004; Mancini & Bonanno, 2010). Although, the nature of the stressor currently under investigation is chronic and poses significant challenges to a person's present and future daily living, the primary objective of this study was to identify groups of adults with inflammatory rheumatic conditions that differ in terms of their levels of psychological functioning. For this reason, the current study conceptually defines resilience as a response to stress or, essentially, one outcome of the adaptation process, rather than a process in and of itself.

### **Operational Definitions of Resilience**

In the adult literature, there are two methods of identifying resilience: the absence of psychopathology or the presence of positive outcomes, such as positive emotions or having purpose in life. These two approaches are rarely combined. The vast majority of investigators favour the first option and suggest that low levels of depression or lack of PTSD symptoms are markers of resilience among various populations (Beasley, Thompson, & Davidson, 2003; Bleich et al., 2006; Bonanno, Galea, Bucciarelli, & Valhov, 2006; Coifman, Bonanno, & Rafaeli, 2007; Hoge, Austin & Pollack, 2007; Karoly & Ruehlman, 2006; King et al., 1998; Norton, Sacker, Young, & Done, 2011; Palmieri et al, 2008; Solomon and Berger, 2005; Tebes, Irish, Vasquez, & Perkins, 2004; Tucker et al., 2002). Although not as popular, there are some researchers who attempted to correct for the neglect of positive outcomes by using measures of well-being (Bradshaw, 2007; Souza et al., 2007) and positive emotions (Bradley & Davino, 2007; Dumont, Gervais, Fougereyrollas, & Bertrand, 2004; Hamilton, Zautra, & Reich, 2005; Smith & Zautra, 2008; Strand et al., 2006; Zautra et al., 2005).

Each of these methods for identifying healthy outcomes has notable limitations that speak to the broader gaps in the resilience literature. First, conceptual definitions of resilience inherently assume that people quickly restore or maintain healthy levels of functioning following adversity (Bonanno, 2004; Carver, 1998; Zautra, 2009). Few studies employ prospective designs, therefore proper measures of pre-trauma functioning are rarely collected. Lucas (2007) is one of the few studies to examine well-being before and after the onset of disability and found that this turning point significantly decreased life satisfaction and increased psychological distress. Interestingly, although some adjustment was demonstrated with respect to distress, no significant changes in life satisfaction were found after disability onset (Lucas, 2007).

Gathering information on pre-trauma functioning when studying an applied population is undeniably difficult. The best alternative appears to be collecting comparison group data in order to answer the question of whether, for instance, scores on depression in a particular sample are comparable to depression levels among well-functioning adults in the general population (Luthar & Zigler, 1991). However, for practical reasons such as time or resources, comparison data is not often used, barring a few exceptions (Armata & Baldwin, 2008; Bonanno et al., 2005; Tebes et al., 2004). Another approach, which is used quite frequently, is to choose measures with commonly used cut-off scores as a rationale for identifying resilience (Kinard, 1998). However, there are some studies in which cut-off values seemed to be arbitrarily chosen without offering a clear explanation as to why the chosen cut-offs describe resilience (e.g., Bonanno et al., 2006; Tremblay, Blanchard, Pelletier, & Vallerand, 2006; Wagnild & Young, 1993).

Another common pitfall is that researchers tend to ignore the fact that the absence of an undesirable outcome does not necessitate the presence of a desirable one (Almedom & Glandon, 2007; Kaplan, 1999; Litz, 2005) or, likewise, investigators assume that good outcomes mean the absence of distress (Harvey & Delfabbro, 2004). Luthar and Zigler (1991) warn that focusing exclusively, for example, on a child's behavioural competence does not allow for the possibility that they experience anxiety or depression. Some people exhibit few PTSD symptoms, yet are known to demonstrate considerable functional impairment (Litz, 2005). Furthermore, some protective mechanisms, such as perceived control and adaptive coping, are related to lower psychological distress but do not protect abuse survivors from sleep disturbances (Chambers & Belicki, 1998). "Global" resilience may in fact be rare, perhaps even impossible, because although a person may achieve resilience in one area of life, they may also display vulnerability in others (Harvey & Delfabbro, 2004; Vanderbilt-Adriance & Shaw, 2008). In other words, theories on resilience have so far failed to address whether it is important to consider the pervasive impact of stress on an individual's life as a whole. That is, beyond emotional well-being, how does stress disrupt an individual's employment, social relationships, physiology, and leisure activities? If it is important to identify the global effect of stress on a person's life, then the question is: where would one separate those who are resilient from those who are not?

Finally, Rigsby (1994) argued that all resilience research has assumed a culturally-specific view with respect to defining "normal functioning." The choice of outcome measures has invariably been heavily weighted towards indicators of success or failure that are valued in Western culture. This suggests that researchers should perhaps

be mindful that resilience may mean different things in different cultures and, by extension, in different populations. There are multiple pathways to resilience and, depending on circumstances; people may have divergent, yet equally successful ways of adapting to adversity (Harvey & Delfabbro, 2004).

Altogether these gaps in the resilience literature reflect powerful ways in which to enhance and further understand the nuances of stress responses, there remains little doubt that defining resilience is a more complex issue than merely a single measure of PTSD. Perhaps it is more prudent to measure resilience by combining multiple indicators, therefore developing a profile of successful adjustment. For example, pioneering work conducted by Rutter (1996) suggested that examining both cognitive and affective processes activated in response to turning points is important for determining whether resilience is achieved. Finally, outcome measures chosen based on the particular stress encountered (Luthar & Cicchetti, 2000; Vanderbilt-Adriance & Shaw, 2008) and that are highly valued by the population of interest (Zuibalde, Mold, & Eubank, 2009) are critical to gaining a true representation of successful adjustment.

### **The Model of Subjective Well-being (SWB)**

The reality facing people living with chronic illness is that they will probably never be cured. But this does not mean that they will ultimately be unhappy. Investigations into subjective well-being suggest that there are a range of responses to stressful life events, and most people are eager to find some happiness and satisfaction in their lives regardless of their circumstances (Diener, Suh, Lucas, & Smith, 1999). Subjective well-being emerged from a positive psychology framework and is a field that has grown considerably in the last 20 years as an important new direction in stress and

health research (Pavot & Diener, 2008). Diener and colleagues (1999; 2000) present a model of subjective well-being that is comprised of three components: positive affect, negative affect, and life quality. According to this model, people who experience mild to moderate positive emotions most of the time and less negative emotions tend to report higher quality of life and are overall happier people. The following sections demonstrate that these cognitive and affective processes, maintaining positive emotions, experiencing few negative emotions and quality of life, are arguably the most germane psychological indicators of adjustment to inflammatory rheumatic disease.

### **Maintaining Positive Emotions**

To date, there are few studies examining resilience in people with a chronic illness, including people with inflammatory rheumatic conditions. However, the studies that do exist find compelling evidence that successful adaptation may be the result of experiencing and maintaining positive affect during times of stress (Smith & Zautra, 2008; Strand et al., 2006; Ong, Bergeman, & Chow, 2010; Wright et al., 2008; Zautra et al., 1995; Zautra et al., 2005; Zautra, Smith, Affleck, & Tennen, 2001). For example, Silver (1982) found that people with spinal cord injuries were extremely unhappy immediately following their accident, but within a matter of eight weeks showed a downward trend in negative emotions and an upward trend in positive affect. In a qualitative study of 68 AS patients, some people reported that having AS made them feel stronger as a person, more proud of their current achievements, and capable of finding pleasure in life when symptoms were in remission (Hamilton-West & Quine, 2009). Likewise, women with SLE suggested that being in a good mood is an important contributor to a higher quality of life (Archenholtz et al., 1999).

As previously mentioned, experiencing chronic pain and fatigue due to rheumatic disease is commonly associated with depression over time (Bartlett et al., 2003; Dickens et al., 2002; Smith & Wallston, 1992). However, the accuracy of assessing depression in people with RA, AS, SLE and gout may be questioned on several accounts. For one, the hallmark physical symptoms of these conditions (e.g., fatigue, sleep disturbances) also describe some of the key symptoms of major depression (Bormann & Celiker, 1999; Iverson, 2002; Martens et al., 2003). Second, recent investigations documented that current depressive symptoms in RA patients appear to be attributed to pre-morbid depression rather than the result of having the disease itself (Conner et al., 2006). Denton et al. (2005) recently discovered that in a small sample of people with SLE, depression levels were generally mild, with few participants scoring in the range indicating clinical depression. In light of this evidence recent research has focused on a more immediate, and perhaps more relevant, affective consequence of arthritis: negative affect (Hamilton et al., 2005; Kratz, Davis, & Zautra, 2007; Ong et al., 2010; Zautra & Smith 2005).

In their dynamic model of affect, Zautra and colleagues (2001) proposed that stress (i.e., experiencing pain due to arthritis) tends to change the degree of independence between affective states, such that positive and negative affect become bipolar. Accordingly, experiencing pain leaves arthritis patients vulnerable to negative affect and with fewer opportunities to experience positive affect. However, these authors believed that if people with chronic pain could sustain higher levels of positive emotions during times of stress, it would follow that they experienced less negative affect and would therefore be more likely to preserve well-being. To further understand the role of positive emotions in relation to pain and negative affect, Zautra et al. (2005) collected weekly

registrations of pain and positive and negative affect from 124 women with osteoarthritis (OA) or fibromyalgia for 10 to 12 weeks. As expected, experiencing pain was concurrently and prospectively related to negative emotions. This relationship, however, was moderated by positive affect during the weeks when pain was reportedly high. In other words, those who reported higher positive affect had reduced negative affect during times of high stress. These findings have since been replicated with RA patients, newly diagnosed HIV patients, people with diabetes and a sample of older adults (Moskowitz, 2010; Moskowitz, Epel, & Acree, 2008; Ong et al., 2006; Strand et al., 2006).

The unique importance of positive affect also has been the focus of another well established health psychology theory: Fredrickson's (1998) "broaden-and-build" model of positive emotions. The broaden-and-build model posits that stress has a tendency to narrow one's attention, which is associated with negative affect. However, for some people, experiencing positive emotions during times of stress can momentarily broaden their modes of thinking. This in turn protects them from experiencing depression and gives them the opportunity to build a range of personal resources (e.g., self-esteem or positive social relationships) that are important for coping with stress. Thus, people with high positive affect have greater capacity to quickly recover psychologically and physiologically to stressful events (Tugade & Fredrickson, 2004). In particular, heightened positive affect was associated with lower depression in HIV positive men six months after losing their partners to AIDS (Bonanno et al., 2005). As well, these emotions were linked to positive social interactions and disease acceptance in women with OA and RA (Smith & Zautra, 2008), the use of adaptive coping strategies, and affect

regulation in women with RA (Hamilton et al., 2005), and extraversion and vitality in men and women with early knee OA (Wright et al., 2008).

Whereas the dynamic model of affect explores the interaction between positive and negative affective states, the broaden-and-build model by comparison focuses on the consequences of positive affect. At the same time, both theories firmly establish the importance of maintaining positive emotions during times of stress. These models strongly corroborates Diener and colleagues (1999; 2000) model of SWB claiming that experiencing pleasant emotions most of the time, while infrequently experiencing negative emotions, is a key ingredient of a happy life. Altogether, these findings suggest that experiencing more positive affect and less negative affect may distinguish those who adapt well to inflammatory rheumatic disease from those who do not.

### **Quality of Life**

Quality of life (QOL) is considered the most vital outcome in chronic illness research (Bishop, 2005; Devins, 2010; Kojima et al., 2009; Moons, Budts, & De Geest, 2006; Livneh, 2001) and an important goal in the management of inflammatory rheumatic disease (Marra et al., 2005; Zautra et al., 2008; Zubialde et al., 2009). For people living with chronic medical conditions, QOL is a term that broadly describes the impact of the disease on an individual's life as a whole (Brown, Brown, & Bayer 2004). It is a multi-faceted construct that demonstrates that chronic illness affects more than just a person's physical health; it can greatly disrupt other life domains such as social relationships and emotional well-being (Bishop, 2005; Borman & Celiker, 1999; Devins, 2010). Therefore, defining adaptation in the context of the QOL framework provides a more comprehensive



description of how individuals manage their illness than measuring depression alone (Borman & Celiker, 1999).

The World Health Organization defines QOL as the impact a chronic or acute disease has on physical functioning and people's perceptions of their position in life in relation to their goals, expectations, standards, and concerns (Vergrugge & Jette, 1994). Though many different operational definitions of QOL exist, one of the most widely cited conceptualizations of QOL is the framework proposed by Spilker (1990). Spilker's hierarchical model defines QOL as an individual's overall evaluation of satisfaction with life and general sense of personal well-being. In this model, QOL is referred to as a three-tiered construct that ranges from general evaluations of satisfaction to more specific evaluations. At the highest level, QOL is described as an overall rating of satisfaction with life. The second level outlines three main domains that comprise QOL: physical, psychological, and social functioning. The bottom level consists of the specific aspects that inform these three domains. For example, depression is one element of the psychological domain, whereas restrictions in daily activities are part of the physical domain. According to Spilker (1990), the variables at the lower level determine QOL at the top level. In other words, overall judgments of life satisfaction require the respondent to access their evaluations of satisfaction in several important life domains.

Overall life satisfaction and health-related quality of life (HRQOL) are commonly used as outcomes for individuals living with RA, AS, SLE, and gout (Blalock et al., 1998; Coty & Wallston, 2008; Neugebauer et al., 2003; Treharne et al., 2007). In most cases, research suggests that reductions in satisfaction and life quality are mainly associated with the physical consequences of inflammatory rheumatic disease (e.g., Davis

et al., 2005). For instance, lower satisfaction in adults with RA, AS, and SLE is linked to a variety of physical symptoms including: functional impairment, disruptions at work, or loss of employment due to disability, pain, joint swelling, and fatigue (Archenholtz et al., 1999; Bartlett et al., 2003; Boonen & van der Linden, 2006; Poole et al., 2010; Smith et al., 1995; Suurmeijer et al., 2001; Treharne et al., 2007). Though it is less documented, psychological, and social domains also play a role in perceptions of life satisfaction. Specifically, previous research suggests that negative affect (Blalock et al., 1998), unhelpful social support (Coty & Wallston, 2010), and loss of control (Archenholtz et al., 1999) lead to poorer quality of life for RA and SLE patients. On the other hand, engaging in active coping strategies and positive social support enhance satisfaction with life (Boonen & van der Linden, 2006; Treharne et al., 2007).

Life satisfaction ratings comprise the cognitive component of the subjective well-being (SWB) model and refer to a global evaluation of one's life quality (Pavot & Diener, 2008). However, similar to Spilker's model (1990), Pavot and Diener (2008) noted that these global evaluations are heavily dependent on satisfaction in specific life domains. For example, Arnold et al (2004) found that psychological and social domains (compared to physical domains) predicted overall quality of life ratings in people with RA. Likewise, Heller, Watson, and Ilies (2006) demonstrated that variation in life satisfaction in the general population can be associated with changes in life domains such as marital and job satisfaction. In particular, dissatisfaction in the physical domain is a major contributor to lower quality of life scores for people with RA, AS, SLE, and gout (Archenholtz et al., 1999; Davis et al., 2005; Khanna et al., 2008). The belief is that the more important the life domain is to the individual, the more influence it exerts on global

assessments of life satisfaction (Bishop, 2005; Luhmann, Hofmann, Eid, & Lucas, 2012; Pavot & Diener, 2008).

Bishop (2005) theorized that reductions in QOL depend on the value a person attributes to particular areas of life and consequently how deeply these areas are affected by the illness. However, Bishop posited that highly motivated people restore their QOL. Initial reductions in QOL in people who are newly diagnosed with a chronic condition are expected, but Bishop hypothesized that these individuals will then work to restore QOL by responding to significant disruptions in one area of life by discovering value in another, less disrupted area. Therefore, extending this theory to the current study, it could be argued that it is possible to be resilient in one area of life and not in others, yet still be satisfied overall. Bishop and colleagues have found evidence to support these claims in examinations of people with Multiple Sclerosis and other disabilities (Bishop, 2005; Bishop, Frain, & Tscopp, 2008).

Arguably this value change may be the reason why some people who suffer from inflammatory rheumatic disease report ratings of personal health, well-being, and life satisfaction that often contradict their objective health status (Albrecht & Dvelieger, 1999; Arnold et al., 2004; Davis et al., 2005; Khanna et al., 2008; Poole et al., 2010). For example, Bendtsen and Hornquist (1992) demonstrate that although RA patients were dissatisfied with their physical health, they rated their psychological, social, and economic situations and overall satisfaction with life as being “quite good.” Similar findings have been reported for people with SLE and gout (Archenholtz et al., 1999; Khanna et al., 2008). When compared to healthy controls, however, accounts of overall life satisfaction have been inconsistent. As expected, people with inflammatory rheumatic

disease generally reported lower overall satisfaction than healthy controls (Coty & Wallston, 2008; Davis et al., 2005); however, this is not always the case (Arnold et al., 2004; Khanna et al., 2008). Studies finding equivalent ratings of quality of life among chronically ill and healthy populations parallel the research on resilience, suggesting that some people have the ability to bounce back from life stress and continue to live happy, satisfying lives. Furthermore, the fact that some inflammatory rheumatic patients experience a similar life quality to healthy populations, whereas others do not, suggests that there may be different patterns of adjustment to inflammatory rheumatic disease that can be distinguished based on ratings of overall satisfaction with life.

### **An Updated Operational Definition of Resilience**

Based on the research reviewed, resilience will be defined as a profile of psychological adjustment that is characterized by experiencing moderate to high levels of life satisfaction, and maintaining frequent positive emotions, and fewer negative emotions. This profile of resilience parallels the happy individual defined by the model of SWB (Diener, 2000). Specifically, happy people report feeling pleasant emotions most of the time and infrequently experience negative emotions. This profile of affective well-being is associated with higher satisfaction with life (Schimmack, Diener, & Oishi, 2002). Life satisfaction is believed to be the most stable and enduring component of the SWB model (e.g., Busseri, Rose-Krasnor, Willoughby, & Chalmers, 2006; Gana et al., 2013; Luhmann et al., 2012), and also is assumed to be more strongly related to the physical health domain (Gana et al., 2013). Affective well-being, on the other hand, is more transient and based on emotional evaluations of recent events or activities

(Luhmann et al., 2012). According to Diener (2000), happy people are better equipped to quickly adapt to stressful life events.

### **Identifying Resilience**

Resilience in adulthood received new theoretical insight and direction in 2004 when George Bonanno presented an analysis of reactions to adverse events. By this point, it was well established that people respond to stress differently; however, Bonanno claimed that these responses were best described and studied as directions of change or trajectories. According to Bonanno, resilience is among four distinct trajectories or patterns of psychological functioning following an experience of a potentially traumatic event. In this model, resilience is akin to a homeostatic concept; wherein adults in otherwise normal circumstances are exposed to a potential trauma and are able to maintain a stable, healthy level of psychological functioning over time. Recovery is then differentiated from resilience in that it connotes a trajectory in which healthy functioning will temporarily give way to symptoms of distress for a period of time before gradually returning to pre-trauma level functioning. Delayed distress is characterized by a pattern that initially begins as resilience but gradually wanes to distress over time, whereas chronic distress indicates initial dysfunction that persists. Note that both resilience and recovery trajectories could technically be considered patterns of successful adaptation, as both trajectories demonstrate maintaining or returning to healthy levels of psychological functioning.

This trajectory model has largely been embraced by researchers, with recent empirical investigations replicating the presence of these four heterogeneous patterns of PTSD and depressive symptoms following an experience of bereavement (Bonanno et al.,

2005), terrorist attack (Bonanno et al., 2006; Bonanno, Rennieke, & Dekel, 2005), onset of cancer (Deshields, Tibbs, Fan, & Taylor, 2006), and spinal cord injury (Quale & Schanke, 2010). Resilience was found to be a common response to these traumatic events, describing 35%-65% of the samples.

However, the utility of these findings should be considered in light of the method used to classify the trajectories of psychological functioning. Identifying trajectories was achieved by using clinically relevant cut-off scores, an approach that is limited in that cut-off values are known to exaggerate small differences between participants, thereby creating variability that is not necessarily representative of the sample (Henselmans et al., 2010). Furthermore, the between group comparisons that result from such a practice can obscure our understanding of the nature and course of stress responses (Clay, Wood, Frank, Hagglund, & Johnson, 1995). At least part of the problem can be attributed to the wide spread use of statistical procedures that are based on the *a priori* classification of defined groups (e.g., analysis of variance models). These methods are unfortunately inadequate for uncovering higher order and nonlinear patterns of longitudinal change in profiles of functioning (Clay et al., 1995; Röcke & Lachman, 2008). More recent advances in statistical techniques, such as growth mixture modeling, do allow for the examination of more complex models which enable researchers to capture a variety of unknown and unobserved trajectories of change in a single sample that have different shapes, antecedents, and consequences (Muthén, 2001).

### **Growth Mixture Modeling (GMM)**

Briefly, growth mixture modeling (GMM) is a useful extension of latent growth modeling (LGM), which refers to a broad class of statistical techniques that model

individual development over time (Muthén, 2004; Muthén & Shedden, 1999). Traditional LGM procedures assume that all people are drawn from the same population and therefore, a single trajectory of change can adequately describe the entire population. However, as Bonanno (2004) observes, not everyone follows the same trajectory of adjustment after being exposed to stressful life events. GMM are relatively new techniques that relax the single population assumption and can test for the presence of smaller, homogeneous latent subpopulations or classes that follow their own distinct developmental trajectories (Muthén, 2004). This is accomplished by a categorical *latent class variable*, which identifies a number of different clusters of participants in the sample that are similar in their responses on measured repeated variables or growth trajectories (Lubke & Muthén, 2005; Nylund, Asparouhov, & Muthén, 2007). In other words, the latent class variable models heterogeneity within a sample (Lubke & Muthén, 2005). In a given solution, each person's probability of group membership in each of the latent classes and their scores on the growth parameters are estimated (Kreuter & Muthén, 2008), with the result being distinct groups of people that follow different trajectories or growth rates (Jung & Wickrama, 2008). Furthermore, the model can extend to permit group membership in the trajectory classes to vary as a function of different covariates (or predictors) and long-term outcomes (Asparouhov & Muthén, 2006).

In the current study, the goal is to find different trajectory classes that correspond to different patterns or pathways of adaptation over time based on profiles of three key outcome variables: positive affect, negative affect, and life satisfaction. GMM is the most appropriate procedure to investigate this objective in that it models both continuous

(growth parameters or processes) and categorical (the latent class variable) variables simultaneously, thus capturing a more complete understanding of the variety of ways individuals respond to managing a chronic illness.

### **Investigating the Trajectory Model**

There are presently six studies that have employed GMM to identify latent trajectories of psychological functioning in health-related samples. Generally speaking, these investigations have found support for the four trajectories outlined by Bonanno (2004). Specifically, Bonanno et al. (2008) recruited a sample of 765 survivors of severe acute respiratory syndrome (SARS) from a large hospital in Hong Kong and conducted interviews at 6, 12, and 18 months post-hospitalization. These authors used latent growth mixture modeling to identify trajectories based on a measure of psychological distress. The four latent classes that emerged from their study resembled the prototypical resilience, recovery, and delayed, and chronic distress trajectories. However, contrary to studies examining trajectories following an acute trauma (e.g., Bonanno, 2004; Bonanno et al., 2005; Pietrzak, Ness, Fried, Galea, & Norris, 2013), the most prevalent trajectory was not resilience, but chronic distress, which included 42 % of the sample. The resilient trajectory closely followed with 35 % whereas the recovery and delayed distress trajectories included the remaining 10 and 13 %, respectively.

Norton et al. (2011) is the first study to investigate trajectories of psychological functioning in a recently diagnosed RA sample. These authors recruited 784 participants who had been diagnosed with RA in the last 24 months and assessed their levels of depression each year for 10 years. A four trajectory model was extracted, with the most prevalent class (68%) exhibiting a “low” level of depression that reduced slightly over



the course of the study. In addition, these authors found evidence of recovery (9%), delayed onset of depressive symptoms (11%), and high-stable depression (12%) classes.

Hou, Law, Yin, and Fun (2010) also used growth mixture modeling to identify trajectories of psychological distress in a sample of 234 colorectal cancer patients in China at 12 weeks post-diagnosis, and then at 3 month, and 12 month follow-ups. These authors found that a resilient response trajectory was quite common for these individuals (65-67%). The prevalence of a delayed distress or recovery trajectory was similar (10-13 and 13-16%, respectively), whereas very few succumbed to chronic distress (7-9%).

Another study conducted by deRoon-Cassini et al. (2010) collected information on both PTSD and depression symptoms from 330 injured trauma survivors at four different time points and ran two separate growth mixture models. Both analyses revealed four groups which followed the theoretically relevant trajectories: resilience (59% for PTSD, 60% for depression), recovery (13% for PTSD, 14% for depression), delayed (6% for PTSD, 17% for depression), and chronic (22% for PTSD, 10% for depression). Post-hoc analyses were conducted to investigate overlap between the uncovered trajectories for each of the two outcome variables. These analyses revealed that there was 69.7% concordance rates among class membership of the two outcome measures, with most of the participants (57.7%) being classified as resilient on both PTSD and depression.

Finally, van Leeuwen, Hoekstra, van Koppenhagen, deGroot, and Post (2011) investigated life satisfaction of 206 spinal cord injured (SCI) patients during inpatient rehabilitation (admission, 3 months, and discharge) and at one year, two year, and five years post-discharge. Interestingly, this was the only study to examine patterns of life satisfaction as an outcome of psychological functioning to managing a chronic disease,

and also the only study using GMM to extract greater than four trajectory groups. van Leeuwen et al. (2011) found a five class solution best fit their data, represented by an intermediate-stable level of life satisfaction (30.6%), low-stable (27.2%), recovery (23.3%), high (16.5%), and declining (2.4%) patterns of adjustment.

Notably, the deRoos-Cassini et al. (2010) study was the only one to fully report decisions made in the model specification process, which included the fact that all slope (linear and quadratic) variances were fixed to zero in order to identify the model. Given that most studies investigating depression and PTSD symptoms over time identified a four trajectory class solution, it may be that slope variances were fixed to zero in all studies in order to replicate the four prototypical trajectory groups. However, this is difficult to know without proper reporting practices. Admittedly, GMM is a relatively new technique to many psychology researchers, and the technical details of this analysis are complicated. However, model specification decisions do have important implications for the number and meaning of the extracted trajectory groups (Muthén, 2004). For example, Muthén and Muthén (2000) found that fixing intercept and slope variances (i.e., a latent class growth analysis) resulted in extracting a greater number of trajectory classes to fit the data. This is not to say that fixing slope variances is a poor decision, particularly if the identified trajectory patterns have practical utility (i.e., predictive validity) in that they demonstrate different associations with important predictor variables. Rather, it is important for applied researchers to be aware that decisions made in the model specification process have implications for the interpretation of their final solutions and for cross-validating findings in other samples. Thus, it is important to fully report

decisions made during the analysis process, and a more thorough discussion surrounding model comparisons is warranted (Muthén, 2004; Morin et al., 2011).

For instance, there are several important points to note regarding van Leeuwen et al.'s (2011) findings. First, SCI patients represented in the intermediate and high life satisfaction trajectories followed approximately the same pattern of life satisfaction over time, differing only in their life satisfaction intercept. This finding is suggestive of the authors fixing all slope variances to zero in order to identify the model. However, again, these model specification decisions were not reported, which makes it difficult to interpret and replicate their findings. Moreover, these authors reported post-hoc analyses of between trajectory class differences on important predictor variables for each pairing of trajectory groups, except those involving the intermediate trajectory. This is surprising given that the intermediate trajectory was the most prevalent pattern of adjustment in their sample, and it would be useful to know whether it could be distinguished from the other patterns of life satisfaction based on its associations with predictors. Additionally, the declining pattern of life satisfaction included a very small proportion of participants ( $n=5$ ), which Nylund et al. (2007) would suggest interpreting with caution. Small class sizes may indicate the presence of influential outliers; however, data cleaning efforts were not reported.

### **Latent Class Growth Analysis**

A related procedure called latent class growth analysis (Jones, Nagin, & Roedar, 2001) has been used in two studies examining adjustment following a diagnosis of breast cancer. In particular, Helgeson, Snyder, and Seltman (2004) conducted a landmark study following 287 women with breast cancer from around the time of diagnosis through over

four years of follow-up. Notably, this is the only research to investigate trajectories of both psychological and physical functioning. These authors performed two separate latent class models, one using the composite score for mental distress and the other using the physical health composite from the same measure of health-related quality of life. Both models produced four distinct trajectories of psychological and physical functioning. However, these trajectories varied from the typical trajectories hypothesized by Bonanno (2004). Specifically, one trajectory revealed a pattern of low levels of psychological distress that persisted throughout the four year period; however, this level was much higher than average. This trajectory characterized 43% of their sample. Another trajectory described 18% of participants who had slightly lower distress levels than the previously described trajectory and visually had some slight minor ups and downs over four years. A third trajectory, which included 27% of women, revealed an interesting pattern where distress levels were high initially, but immediately and sharply declined during the first 1.5 years of the study. This improvement was maintained for intervening years, before distress increased somewhat in the final year. The last trajectory also was intriguing, as it showed an immediate, substantial increase in distress that improved moderately by the end of the study. This trajectory included 12% of the women.

Four trajectories were also found for physical functioning. Those with the highest physical functioning scores, which was the majority of respondents (55%), remained high and even slightly improved over the course of the study. A very small proportion of women (2%) showed worse physical functioning from the start, which then deteriorated over the four years. Another 20% of women began with an intermediate level of physical functioning that persisted over time. The final 23% of the sample showed a pattern of

intermediate physical functioning that immediately improved and sustained over time. Similar to deRoos-Cassini and colleagues' (2010), Helgeson et al. (2004) also investigated concordance rates among the four trajectories for psychological and physical functioning. Interestingly, these researchers found that although it was likely that those with less distress were also in better physical shape, women in the high physical functioning trajectory also were evenly distributed among all four of the mental health trajectories. In other words, they found that women classified in any of the psychological distress trajectories were fairly evenly represented in the high physical health trajectory, suggesting that there are other factors that are important determinants of psychological health following a breast cancer diagnosis that are independent of a woman's physical health status.

In an attempt to replicate Helgeson et al.'s (2004) findings, Henselmans et al. (2010) followed 171 breast cancer patients over a one year period. They collected follow-up data at several key turning points: (a) following surgery, (b) following adjuvant treatment (e.g., chemotherapy), (c) entering the survivorship phase, and (d) follow-up of survivorship phase, in order to capture a more complete picture of psychological adaptation to breast cancer. Using a measure of psychological distress, these investigators found that more than a third (36.3%) of women experienced no distress over the year. This was fairly evenly matched by 33.3% of women who demonstrated distress only during chemotherapy treatment. A smaller group of women (15.2%) experienced a delayed pattern of distress that only emerged after entering the survivorship phase, whereas the other 15.2% of women experienced chronic distress that persisted over the course of the study. Altogether, Henselman et al. found that the prevalence of being

resilient (no distress) was about even with the prevalence of either maintaining or becoming distressed throughout the study.

### **Expanding the Trajectory Model**

The above research provides substantial evidence for the presence of heterogeneous patterns of psychological functioning following stressful life events. However, this is merely the inception of a new area of inquiry, particularly in context of managing minor chronic disease-related stressors known to affect daily living. Therefore, the prevalence of resilience, the number of trajectories, and the specifics of those trajectories is largely unknown (Norris, Tracy, & Galea, 2009). A few investigations have put forth an effort to expand the number of trajectories beyond the four proposed by Bonanno (2004). For example, studies examining survivors of mass casualty threats (Hobfoll et al., 2009; Norris et al., 2009) and natural disasters (Norris et al., 2009; Pietrazak et al., 2013) have identified a resistance trajectory, which is reflective of stable healthy functioning over time. These researchers argue that resistance is a separate trajectory from that of resilience, which they define as an initial dip in functioning that quickly returns to normative levels. This distinction not only suggests that perhaps a more nuanced definition of successful adaptation is in order, but also recalls a familiar tension among resilience researchers. That is, Bonanno (2004) argues that resilience is characteristic of stability or maintaining equilibrium (i.e., having initial low or no psychopathological symptoms that sustain over time), whereas other researchers claim that resilience represents adaptability (Carver, 1998; Norris et al., 2009; Zautra, 2009). That is, resilience represents a two-fold concept: one part recovery, meaning how quickly a person is able to regain former healthy functioning (as opposed to maintaining it), and

one part sustainability or the capacity to endure and continue in the face of adversity (Zautra, 2009). Although this argument has not necessarily been explicitly stated, it has certainly been implied by others in the field (Agaibi & Wilson, 2003; Bromley, 2005; Carver, 1998; Harvey & Delfabbro, 2004; Masten, 2001; Richardson, 2002). Bonanno (2004) explained in his theoretical work that resilient individuals can experience disruptions in normal functioning that can last for a period of several weeks, an explanation which seems to blur the line between his definitions of resilience and recovery.

Further variation in the resilience and recovery trajectories has been uncovered in women dealing with a diagnosis of breast cancer. Recall Helgeson and colleagues' (2004) breast cancer survivor study, which essentially found two different resilient trajectories. One trajectory described levels of mental functioning that remained above average, but visually showed some minor ups and downs throughout the duration of the study. The other trajectory was characteristic of much higher levels of mental health that remained fairly consistent over time. Similarly, Deschild et al. (2004) found two versions of recovery in women who had recently completed radiation therapy treatment for breast cancer. One group of women was above cut-off values for depression by the three month follow-up, whereas it took another group of women six months following treatment to rebound to healthy (symptom-free) functioning.

Norris et al. (2009) expanded Bonanno's (2004) theory by outlining six potential trajectories of functioning that may be of interest to adaptation researchers. First, they proposed a scenario in which minimal disruption maintained over time is considered resistance rather than resilience. Being true to Bonanno's (2004) initial proposition, these

authors suggested that a resilience trajectory is characterized by an initial decrease in healthy functioning that quickly returns within a matter of weeks, whereas recovery is a gradual return to healthy functioning following a course of several months. Norris and colleagues (2009) considered these three trajectories different routes to good mental health. The delayed distress trajectory is characteristic of distress emerging after a considerable amount of time has passed, whereas the chronic distress trajectory describes an initial distress reaction that persists. The final trajectory is that of relapsing/remitting, where symptoms will display a cyclical course. Using PTSD symptoms as a marker of dysfunction, Norris et al. (2009) gathered data from samples of individuals who had been exposed to one of two disasters: a natural disaster in Mexico and the September 11<sup>th</sup> terrorist attack in New York City. Despite uncovering several variations in trajectories of functioning for both samples, they noted that only four trajectories were present in both studies: resistance, resilience, recovery, and chronic distress (Norris et al., 2009). Only the New York participants demonstrated a delayed reaction and neither Mexico nor New York samples showed a relapsing/remitting trajectory.

### **Summary of Findings**

Taken together, previous findings from trajectory studies demonstrate some important implications for the current study. First, the findings from Helgeson et al. (2004) and Deschild et al. (2004) with regards to trajectories of functioning following a diagnosis of breast cancer and from van Leeuwen et al. (2011) with respect to managing SCI, demonstrated that not all responses to stress follow the same prototypical trajectories of emotional functioning observed by Bonanno (2004). Rather, the context of the stressor is important. Unlike the loss of a loved one or an acute incident of trauma,



chronic illness is not a distinct and retrospective event, but instead an experience that comprises multiple stressors that exist in the past and as well as endure in the future (Hou et al., 2010). The on-going challenge in terms of managing inflammatory rheumatic conditions is characterized by periods of remission and symptom relapse (i.e., disease flares; Stanton et al., 2007; Zautra & Smith, 2008). Thus, capturing measures of psychological adjustment more frequently than one year time periods (e.g., Norton et al., 2011) may provide greater insight into managing and adjusting to disease symptom fluctuations.

Whereas Norris et al. (2009) found no evidence for a relapsing/remitting trajectory in their two studies; this trajectory may be among the patterns of adjustment to chronic rheumatic disease. As mentioned, only one study has examined distinct trajectories of psychological functioning in people recently diagnosed with RA (Norton et al., 2011), and it found evidence for the four patterns of psychological adjustment proposed by Bonanno (2004). The primary aim of this study is to use growth mixture modeling to examine trajectories of subjective well-being in a sample of adults managing the on-going challenges associated with RA, AS, SLE, and gout.

Second, psychological functioning in all but one (van Leeuwen et al., 2011) of the reviewed studies is defined by indicators of PTSD symptoms, psychological distress, or depression; thus resilience was mostly equated to the absence of psychopathology in all cases. Similar to van Leeuwen et al. (2011), the current study investigates patterns of adjustment based on evaluations of life satisfaction over the course of several months. However, to the investigator's knowledge, the present study is the first to extend trajectories of psychological adjustment to include a set or profile of indicators. In

particular, time-varying predictors of positive and negative emotions are added to the trajectory model in order to describe two important underlying mechanisms known to affect the sustainability of life satisfaction over time (e.g., Pavot & Diener, 2008; Zautra & Smith, 2008).

Finally, understanding the true nature of adaptation to stress can only truly be captured by using longitudinal research designs (Jackson, 2010; Menard, 2002). As several studies found, the absence of pathology at one time does not ensure that it was absent previously, nor will it be in the future (Norris et al., 2009). The adjustment process is characterized by differences in the rate and direction of change following disease-related stressors (Stanton et al., 2007), and although there may be communalities in adjustment among some people with chronic illness, there may be just as much variability between others (Larsen & Hummel, 2009). Schattner et al. (2010) described the noticeable lack of longitudinal research in the field of inflammatory rheumatic disease research, particularly with respect to those who have AS, SLE, and gout. The current investigation employed a prospective and longitudinal research design in which monthly registrations of mood states and life quality of persons managing RA, AS, SLE, and gout were collected. This within-person research design coupled with the advanced statistical technique of GMM offered a good fit for studying the temporally unfolding process of psychological adjustment.

### **Contextual Variables**

The sustainability of responses to stress depends on an array of contextual variables. Theoretically, successful adjustment can be viewed as a transactional process that is determined by a balance of risk and resilience factors (e.g., Egeland, Carlson, &

Sroufe, 1993; Rutter, 1987). These individual difference factors serve as protective (resilience) or risk (or vulnerability) factors of which directly and indirectly influence adjustment (Egeland et al., 1993; Hobfoll, 1989). These variables can include any number of demographic characteristics, disease-specific variables, environmental, personal, and social resources (Elliott, 2002). The following are risk and resilience factors known to be associated with adjustment to rheumatic disease.

### **Risk factors**

**Disease-specific.** The physical consequences of living with inflammatory rheumatic conditions have profound effects on quality of life (Rupp, Boshuizen, Jacobi, Dinant, & van den Bos, 2004). Rheumatic patients, in both qualitative and quantitative studies consistently report that pain, fatigue, and functional disability are the main burdens of inflammatory rheumatic disease and as such, have become the target of many disease management interventions (Gignac, Cott, & Badley, 2002; Gunther, Mur, Traweger, & Hawel, 1994; Minnock, Fitzgerald, & Bresnihan, 2003; Rupp et al., 2004; Strand et al., 2006; Suurmeijer et al., 2001).

Qualitative data confirm the influence of pain and fatigue on increased functional limitations, disability, and psychological adjustment to RA and AS (Hamilton-West & Quine, 2009; Lutz & Archenholtz, 2007). When asked how the disease affects their daily lives, newly diagnosed RA patients complain that the pain and fatigue they experience is so strong that it forces them to adjust how they perform the most basic of tasks (Lutz & Archenholtz, 2007). At times, these individuals are prevented from engaging in activities that they value because the pain and fatigue that accompany performing the task is “not worth the trouble.” Some participants expressed that giving up valued activities left them

feeling angry, helpless, and depressed. Pain, fatigue, and disability also impacted employment, relationships, and leisure activities for adults with AS (Hamilton-West & Quine, 2009) and induced sleep disturbances in SLE patients (Philip et al., 2009). The intensity of pain and fatigue, and the severity of disability can vary widely among individuals with inflammatory rheumatic conditions and people will differ in the extent that pain, fatigue, and disability gives rise to emotional distress (Conner et al., 2006; Smith & Zautra, 2008; Surrmeijer et al., 2001; Strand et al., 2006; Treharne et al., 2007).

**Major life events.** The study of resilience has gained considerable interest in recent years; however, investigations have primarily centered on refining definitions and assessing prevalence rates. Rarely have there been discussions of resilience in the adult literature that look beyond a single isolated traumatic event. It remains to be seen, therefore, whether the presence of successful adjustment among individuals is hindered by the occurrence of further stressful life events. Intuitively it would make sense that if one stressful event is a source of vulnerability in the life trajectory of an individual, then further stressors would also have the same effect. However, in an effort to ensure that a sample of participants are exposed to a similar level of stress, researchers have virtually ignored the fact that stress does not occur in a vacuum, and that individuals in higher income circumstances, for example, may not experience the same amount of stress relative to those living in lower income environments.

Arguably, to fully understand adaptation over time, it should be common practice to describe other major life events that may impede an individual's ability to bounce back from adversity. To this end, Vanderbilt-Adriance and Shaw (2008) sought to understand the utility of resilience in the context of chronic adversity among children exposed to

“high risk” environments (e.g., living in violent, low income neighbourhoods, enduring chronic and severe maltreatment). These authors reviewed 11 studies in which the amount of risk experienced among the samples was quantified and, despite variations in how risk and positive outcomes were defined, found evidence suggesting that higher risk children experience a lower incidence of positive outcomes compared to children in lower risk circumstances. Though preliminary, these results are hardly surprising. These findings demonstrate the importance of assessing other major life events, by examining the limitations inherent in the ability to generalize findings on resilience across different populations.

### **Protective Factors**

**Optimism.** Generally speaking, people who are optimistic believe that good things will happen to them, and it is this positive outlook on life that aids people in coping successfully with stressful life events (Carver, Sheier, & Sergerstrom, 2010). Research has shown unequivocally that optimism is among the most robust predictors of sustained emotional and physical adjustment to chronic illness (e.g., Brenner, Melamed, & Panush, 1994; Quale & Schanke, 2010; Fournier, de Ridder, & Bensing, 2002). For example, Brenner and his colleagues (1994) considered the role of optimism, helplessness, and perceived social support in psychological adjustment over time in a sample of people with RA and found only optimism to be predictive of greater positive adjustment over time. Furthermore, optimism, considered a stable personality trait, is related to a host of personal resources that help insulate an individual from the negative impact of stress, including the use of problem-based coping strategies (Folkman & Moskowitz, 2004),

experiencing greater positive affect (Vaughn, Frederickson, & Taylor, 2008), self-esteem (Yi et al., 2008), and perceptions of control (Fournier et al., 2002).

**Perceived control.** Although there are medical treatments available to relieve the physical symptoms of inflammatory rheumatic disease, the lack of focus on mental health outcomes in clinical research implies that it is up to the patient to manage their own mental health (Eitel, Hatchett, Friend, Griffin, & Wadhwa, 1995; Ramjeet, Smith, & Adams, 2008; Taylor, 1983). This appears to be particularly true for adults with AS and gout, as the attention on the mental health of these individuals has been eclipsed by research centering solely on alleviating the physical consequences of these conditions. However, substantive evidence collected from patients with other chronic conditions suggests that beliefs about personal control can facilitate successful adjustment to chronic illness (Helgeson, 1992; Taylor, 1983; Walker et al., 2004).

A diagnosis of a chronic illness can dramatically undermine one's sense of personal control (Williams & Koocher, 1998). For instance, Chaney et al (2004) reported that people with RA who blame themselves for their disease and other negative outcomes in their lives have lower perceived control and are at risk for depression. Women with SLE express dissatisfaction with the loss of control they now have over their bodies due to their illness (Archenholtz et al., 1999). Similarly, Taylor and colleagues (2000) found that a lower sense of personal control over the risk of disease progression was associated with the onset of HIV symptoms in a sample of 72 previously asymptomatic men. On the other hand, people who maintain beliefs about control over a threatening event, and over life in general, can achieve a quality of life that is equivalent to their prior levels of satisfaction (Helgeson, 1992; Livneh, Lott, & Antonak, 2004; Taylor, 1983; Taylor, Lichtman, &

Wood, 1984). Taylor et al. (1984) interviewed 78 women in various stages of breast cancer and were surprised to find that many of these women held the belief that they could personally control the cancer and keep it from returning. What is interesting is that no matter the woman's prognosis, holding these beliefs about personal control related to better adjustment overall, demonstrating that beliefs need not be based in fact for them to be effective (Taylor, 1983). Illusions of control can restore feelings of invulnerability, lower psychological distress, and protect the physical health of people with cancer (Brix et al., 2008; Helgeson et al., 2004; Henselman et al., 2010). In fact, Henselman et al. (2010) report that personal control is the only psychological resource to distinguish women following a resilient trajectory after a breast cancer diagnosis from women in the recovery and chronic distress trajectories.

The stress buffering effect of perceived control is not exclusive to cancer patients. For example, Helgeson (1992) found that perceiving personal control at the onset of heart disease is related to less distress and psychological adjustment for both men and women at 12 months following surgery. As well, possessing a sense of control is an integral part of differentiating patterns of psychosocial adaptation among students with various disabilities (Livneh et al., 2004). Kendall and Terry (2008) found that perceptions of control have a long term impact on emotional well-being in a sample of 90 adults hospitalized with traumatic brain injuries. In a qualitative study, Kralik et al. (2006) formed an email support group with 37 men and women with various chronic conditions in which participants expressed that creating a sense of personal control is an important part of rebuilding and moving forward with life following a chronic illness diagnosis. Another study following 171 people with RA over seven years found that perceptions of

control at Time 1 related to less negative affect and disease impact over time (Smith et al., 1995). Finally, perceived control is also associated with lower pain ratings in chronic pain patients (Karoly & Ruhlman, 2004) and less distress in people with diabetes (Yi et al., 2008). Thus, as can be seen, there is overwhelming evidence of the beneficial effects of perceived control.

**Social support.** Research examining adults with RA, AS, and SLE demonstrates that these individuals heavily rely on the support of family and friends in order to complete certain activities and to find emotional comfort, particularly during disease flare-ups (Fekete, Stephens, Mickelson, & Druley, 2007; Hamilton-West & Quine, 2009; Lutz & Archenholtz, 2007). These findings are consistent with theory suggesting that the use of social support is among the most important means by which people, particularly those with chronic illness, maintain health and well-being during times of stress (for review see Chronister, Johnson, & Berven, 2006). Thoits (1982) argued that social support is a coping resource, a kind of social “fund” from which a person can draw in order to manage stressful life events. However, the actual receipt of social support may not be a particularly positive experience, as people can be provided with support that they did not ask for or deem to be helpful (Thoits, 1982). What is more important is that the support be perceived as available, whether it is called upon or not (Thoits, 1982). For example, Fekete and colleagues (2007) reported that a woman’s perception of her partner’s emotional responsiveness to a lupus flare-up fully mediated the relationship between the partner’s actual support efforts and the woman’s psychological well-being.

Cohen (1988) defined social support as the perception or experience that one is loved and cared for, esteemed, and valued, and part of a social network of mutual



assistance and obligations. His stress-buffering model proposed that social support protects people from the potentially detrimental effects derived from stressful situations. Bonanno et al. (2008) found that perceptions of available social support are a key factor in distinguishing those who were resilient from those who experienced chronic distress after surviving SARS. Similarly, Helgeson et al. (2004) found that women with breast cancer were more likely to follow a chronic distress trajectory of psychological functioning when they had fewer available social resources. The women who indicated having more social resources at their disposal were more likely to not experience any distress over a four year period. Feeling satisfied with the support received from family and friends is a significant predictor of the resistant and resilience trajectories in a national sample of individuals under mass casualty threat in Israel (Hobfoll et al., 2009). More importantly, perceived social support is associated with higher life quality and emotional well-being in people with RA, AS, and SLE (Danoff-Burg & Revenson, 2005; Demange et al., 2004; Smith et al., 1997; Fekete et al., 2007; Fitzpatrick et al., 1991; Hamilton-West, & Quine, 2009; Minnock et al., 2003; Suurmeijer et al., 2001).

### **Rationale for the Present Study**

The goal of the present study was to explore the longitudinal course of subjective well-being in people with inflammatory rheumatic conditions. In particular, the current study aimed to (a) identify different trajectories of SWB that manifest in a sample of people managing RA, AS, SLE, and gout, (b) uncover the prevalence of resilience in the obtained sample, and (c) explore some possible predictors of trajectories of SWB. Based on the literature reviewed, some people with chronic illness can display resilience and are able to successfully overcome the daily challenges put forth by managing a chronic

disease. However, few studies have specifically examined resilience in chronic disease populations, and only one study has attempted to identify different trajectories or patterns of psychological functioning in a sample of persons with RA. Thus, the number and specific trajectories of psychological functioning that manifest in chronically ill individuals is largely unknown, as are the possible predictors of these trajectories. Studying trajectories of adjustment to long-term inflammatory rheumatic disease provides an interesting context to investigate distinctions among the ways in which people adjust to on-going stressors that affect daily living. The cyclical nature of the physical symptoms that characterize these diseases may provide the opportunity to expand the current taxonomy of trajectories of psychological functioning.

Overall, recent examinations of trajectories of psychological functioning have focused on outcomes of depression, PTSD, or psychological distress. Essentially, functioning well has been equated to the absence of psychopathology. Moreover, there is little discussion in this research area concerning whether PTSD or psychological distress are indeed outcomes that are most relevant to the risk encountered or to the populations under study. Though separate research areas, it is apparent that resilience and SWB share a common theoretical purpose and draw similar conclusions regarding adaptation. However, the outcomes associated with SWB are more clearly defined. Therefore, using the SWB framework as a method of defining resilience could bridge the gap between resilience theory and its operational definition by providing useful criteria for evaluating successful adjustment. Specifically, in this study, resilience is defined by the indicators of Diener's (1984) SWB model. Trajectories of life satisfaction will be examined first, and then extended to include time-varying influences of positive and negative affect to further

understand why some people adjust well to inflammatory rheumatic conditions and others do not.

Finally, answering research questions that involve understanding and measuring change can only be satisfactorily addressed with longitudinal research (Kalton, 1983; Menard, 2002). Specifically, Stanton et al. (2007) suggested that research using intensive, process-oriented designs that frequently track changes in adaptation as it unfolds over time can shed light into the context of dealing with a disease on an ongoing basis. These types of research designs, along with the use of statistical procedures that allow for sophisticated modeling of change over time between and within persons living with chronic illness, can make a significant contribution to our understanding of psychological adjustment in this population (Stanton et al., 2007; Tennen, Affleck, Armeli, & Carney, 2000). Accordingly, the present study collected six waves of repeated measures and tested these measures for distinct latent patterns of adjustment using GMM (Muthén & Shedden, 1999).

### **Research Questions and Expectations**

This is an exploratory investigation examining the different patterns SWB that can manifest from ongoing management of inflammatory rheumatic disease. To the investigator's knowledge, there are no studies that have investigated trajectories of psychological adjustment defined by indicators of life satisfaction, positive affect, and negative affect. Therefore, the ability to make specific hypotheses regarding the number and type of trajectories is difficult. The present investigation endeavoured to answer the following research questions:

1. What is the number and magnitude of trajectories of SWB in a sample of people with inflammatory rheumatic conditions? Specifically, it is expected that response patterns associated with resilience, recovery, delayed dissatisfaction, and chronic dissatisfaction will be identified.
2. What is the prevalence of resilience in the obtained sample? Based on previous research (Bonanno et al., 2010), it is expected that at least 30% of the sample will display resilience. Resilience will be operationally defined by associations among the three components of SWB (Diener, 1984): experiencing at least a moderate amount of positive emotions, fewer negative emotions, and high to moderate satisfaction with life.
3. Are the identified trajectories of SWB distinguished by demographic variables, disease activity, pain, fatigue, disability, optimism, perceived control, perceived social support, and experiences of other major life events? In particular, it is expected that participants in the resilient trajectory group will possess a greater number of protective factors (e.g., optimism, perceived control, perceived social support) and experience fewer risk factors (e.g., disease-specific stressors) compared to the other identified trajectory groups (Rutter, 1987).

## CHAPTER II

### **Method**

#### **Participants**

Individuals who were 18 years of age or older, had been diagnosed with RA, AS, SLE or gout in their lifetime, and could read and understand English were invited to participate in the current study. Participants were recruited using a variety of online sources: (a) study notices advertised on the Arthritis Society of Canada and Spondylitis Society of Canada websites and facebook pages, (b) online support group forums targeting individual's with inflammatory rheumatic disease, (c) support groups and facebook pages dedicated to health and well-being, (d) facebook and google advertisements targeting people with arthritis, and (e) study notices advertised in several Canadian newspapers (see Appendix A for a complete list of recruitment sources).

Participants were screened for a diagnosis of RA, AS, SLE or gout in the initial Time 1 (T1) assessment survey. As an incentive, participants were given the opportunity to win one of ten \$10 gift certificates for their participation in T1, one of four \$25 gift certificates for their continued participation in Time 2 (T2), Time 3 (T3), and Time 4(T4), and one of two \$50 gift certificates for their participation in the final two time points (Time 5 (T5) and Time 6 (T6)). Names were drawn at three separate times over the course of the study and winners were contacted via email and asked their preference in type of certificate.

#### **Procedure**

Ethics approval from the University of Windsor REB was attained prior to performing the current study (Appendix B). A copy of the study consent form is provided in Appendix C.

**Initial assessment survey.** Participants completed the initial assessment survey over the Internet using a secure Fluidsurveys website. Although completing the survey by mail was offered as an option, no participants chose this method of completing the initial survey. Participants were screened for their age, time since diagnosis, and a diagnosis of RA, AS, SLE and gout. Eligible participants completed the initial assessment survey which included self-report measures assessing demographics data, health status, disease severity, subjective well-being, perceived control, stressful life events, and quality of social support.

All participants were asked to provide informed consent prior to completing the survey and a PDF document detailing the University of Windsor REB ethics approval of this study was linked to the study website for interested participants. The consent form explained that although this was the first of a six wave study, participants were consenting to participate in the initial assessment only. However, participants were asked to provide contact information, which included their name and email address, so that they could be contacted in one month to participate in the online follow-up survey at T2. At T2, informed consent was obtained again, indicating that the participant was consenting to participate in all five of the online follow-up surveys.

**Monthly interviews.** Following the initial assessment survey, participants were contacted individually via email by the dissertation student or a trained research assistant for five consecutive months (T2-T6). The first follow-up e-mail reminded respondents

that they had participated in the initial assessment one month ago and asked if they were interested in participating in five monthly online follow-up surveys. Participants were informed that in the follow-up surveys, they would be asked questions about their health and well-being, which would take approximately 10 to 15 minutes of their time. For those interested in continuing to participate, a link to the online survey was provided. Before the beginning of each month thereafter, participants were contacted individually and provided with a link to the month's online follow-up survey. Three reminder emails were sent to each participant over a two week period in order to minimize attrition.

**Rationale for internet data collection.** It is important to discuss the rationale behind choosing an appropriate number of data collection waves, as well as the method of collecting these repeated measures. Research has established that collecting several rounds of data is essential for tracking change and for determining whether resilience is achieved and maintained over time (Kalton, 1983; Kinard, 1998). Additionally, choosing an optimal number of repeated measures is of large concern for techniques such as GMM (Preacher, Wichman, MacCallum, & Briggs, 2008). As such, this topic is discussed further in the statistical analysis section. As this was a student dissertation, practical considerations, such as time and cost, were also factors in this choice.

A major consideration was the ability to retain participants over multiple waves of data collection (Sullivan et al., 1996). Menard (2002) reported that studies have up to 40-50 percent data loss in at least one wave of data collection. Follow-up surveys were kept relatively short in order to minimize the time commitment needed from each participant and data were gathered over the Internet to reduce cost. Follow-up emails also provided a practical and cost effective strategy of readily communicating with respondents. Other

successful strategies for retaining respondents noted in the literature were used, including providing monetary incentives to compensate participation and giving interim reminders of upcoming follow-up assessments (Helgeson, Voss, & Terpening, 2002; Sullivan et al., 1996).

## **Materials**

**Screening questions.** Participants were included based on their age and their responses to three questions aimed at confirming a diagnosis of RA, AS, SLE or gout (see Appendix D for a complete list of measures)

**Age.** Participants were asked if they were over 18 years of age (*yes/no*). If yes, participants were asked to supply their age. Only those who were 18 years of age and older were included in this study.

**Diagnosis.** Participants were asked if they had received a diagnosis of RA, AS, SLE, or gout from a medical doctor, as well as the month and year they were diagnosed. If the participant had a diagnosis of more than one of the conditions of interest (RA, AS, SLE, or gout), he or she was asked to indicate which of these conditions most affected daily living. Finally, respondents were asked if they were taking any medications to alleviate their symptoms and, if yes, to list these medications. Participants were asked to report to what extent these medications had been successful in relieving their symptoms.

## **Initial Assessment Survey and Follow-up Interviews**

The follow-up interviews contained only a subset of the measures that are included in the initial assessment survey. The measures repeated at each of the follow-ups were the items expected to change over time. That is, measures of subjective well-being, pain, fatigue, disease-specific activity (e.g., flare-ups), quality of social support, and other



stressful events unrelated to the disease that may have occurred over the last month were asked at each follow-up timepoint. All measures are discussed below. For the follow-up assessments, each measure was randomly assigned a number between one and nine. To reduce carry-over effects, the order in which each measure appeared in the follow-up survey was determined by the researcher randomly selecting a number between one and nine using Microsoft Excel.

### **Demographic and Health Status Information**

Demographic characteristics and information regarding physical and mental health conditions were included in the initial assessment survey.

**Sociodemographics.** Self-reported demographics included sex, education level, ethnicity, income, and relationship status. Income was determined by the total household income before taxes for the previous year.

**Comorbid mental health conditions.** Participants were asked to list any diagnosed mental health conditions.

Table 1  
*Measures to be Completed at Each Time Point*

Measure	# of items	Initial assessment	Follow-up
		(Time 1)	(Time 2-6)
Screening questions	8	✓	
Demographics	7	✓	
Health status information	2	✓	
Pain management strategies	1	✓	
HAQ - DI	21	✓	
LOT-R	10	✓	

(continued)

Table 1  
*Measures to be Completed at Each Time Point*

Measure	# of items	Initial assessment	Follow-up
		(Time 1)	(Time 2-6)
Pain	1	✓	✓
Fatigue	5	✓	✓
Disease activity and symptom flares	7	✓	✓
PANAS	20	✓	✓
Satisfaction with life	5	✓	✓
WHOQOL-BREF	26	✓	✓
Personal control	3	✓	✓
Perceived social support	3	✓	✓
Major life events	1	✓	✓

*Note.* The Health Assessment Questionnaire-Disability Index (HAQ-DI) is from Fries, Spitz, Kraines, and Holman (1980); The Revised Life Orientation Test (LOT-R) is from Scheier, Carver, and Bridges (1994); The Positive and Negative Affect Schedule (PANAS) is from Watson, Clark, and Tellegen (1988); The World Health Organization Quality of Life assessment instrument (WHOQOL-BREF) is from Skevington, Lofty, and O'Connell (2004).

**Comorbid physical health conditions.** Participants were asked to list any other physical health conditions.

### **Subjective Well-being (SWB)**

Trajectories of psychological functioning were defined by measures of positive and negative affect and life satisfaction (Diener, 2000). As well, quality of life in four specific life domains was examined. These measures were included in the initial assessment and in follow-up surveys.

**Positive and negative affect.** The Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988) was used to assess the affective component

of subjective well-being. This survey consists of 10 positive emotions (interested, excited, strong, enthusiastic, proud, alert, inspired, determined, attentive, and active) and 10 negative emotions (distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery, and afraid). Participants were asked to rate the extent to which they felt these emotions in the last month on a 10-point scale with response options ranging from 1 (*not at all*) to 10 (*extremely*). Data on this measure have shown it to have strong psychometric properties among various populations (Watson, Clark, & Tellegen, 1988). In addition, Curtis et al. (2004) reported good reliability scores for both PANAS scales, exceeding .84 in a sample of RA patients. Cronbach's alpha levels for each measurement time point ranged from .91-.96 for positive affect and .91-.94 for negative affect.

**Satisfaction with life.** The cognitive component of subjective well-being was assessed with the Satisfaction with Life Scale (SWLS; Diener, Emmons, Larson, & Griffin, 1985). This 5-item measure evaluates an individual's global judgement of his or her life satisfaction. Sample items included "I am satisfied with my life" and "If I could live my life over, I would change almost nothing." Participants responded to each item using a 7-point scale, ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The possible range of scores was between 5 and 35, with 20 being the neutral point on the scale (Pavot & Diener, 2008). Scores between 5 and 9 indicate being highly dissatisfied with life, scores between 15 and 19 fall into the slightly dissatisfied range, 21 to 25 represent slightly satisfied, and scores between 31 and 35 indicate that the respondent is highly satisfied with life. In their review, Pavot and Diener (2008) reported updated normative data and sample characteristics from over 30 different studies using the SWLS. In particular, the SWLS has demonstrated good reliability in a sample of RA patients,  $\alpha =$

.81 (Smith et al., 1997). In the current investigation, Cronbach's alpha levels for each measurement time point ranged from .88-.92.

**Quality of life.** Satisfaction within specific life domains or areas was investigated using the short version of the World Health Organization Quality of Life assessment instrument (WHOQOL-BREF; Skevington, Lofty, & O'Connell, 2004). This generic quality of life instrument contains 26 items evaluating satisfaction in four life domains. The first two items are global indicators of overall life satisfaction and general health. The remaining 24 items are classified into four domains: the 7-item physical health domain ("To what extent do you feel physical pain prevents you from doing what you need to do"), the six-item psychological domain ("How much do you enjoy life?"), the 3-item social relationships domain ("How satisfied are you with your personal relationships") and the 8-item environment domain ("How satisfied are you with your access to health services?"). Each item is rated on a 10-point scale, ranging from 1 to 10. Domain scores were averaged and transformed to lie between 0 and 100, with higher scores reflecting better QOL. This measurement was considered a valid outcome measure for people with RA and demonstrates good re-test reliability, ranging from 0.72 to 0.92 in each of the four life domains, and reasonable internal consistency, with alpha coefficients ranging from 0.64-0.87 in a sample of RA patients (Taylor, Myers, Simpson, McPherson, & Weatherall, 2004). Cronbach's alpha levels for the four life domains at each time point ranged from .69-.87.

### **Contextual Variables**

The contextual variables expected to predict different patterns of psychological adjustment to inflammatory rheumatic disease include disease-related variables, psychosocial, and environmental factors.

### **Disease-related factors**

Specific information relating to inflammatory rheumatic disease management and disability was assessed during the initial assessment survey. Only the questions concerning pain, fatigue and symptom flare-ups were repeated at all follow-up interviews. How these variables were assessed is described below.

**Alternative pain management strategies.** The Arthritis Society of Canada (2010) has suggested a number of treatment strategies that can be used to help reduce pain, stiffness, and swelling in the joints when used in conjunction with medications. These options included exercise, relaxation techniques, physiotherapy, diet, heat and cold treatment, occupational therapy or other complementary or alternative therapies. Participants were asked to indicate what other pain management strategies they have used to manage their disease.

**Disability.** The Health Assessment Questionnaire-Disability Index (HAQ-DI; Fries, Spitz, Kraines, & Holman, 1980) was employed to assess the extent of physical disability and disease severity. This measure is well recognized as a standard outcome in clinical studies of rheumatic diseases (van Groen et al., 2010). The HAQ-DI is a 20-item self report survey that assessed the extent to which arthritis affects the performance of daily activities. Sample items include: “Are you able to get in and out of bed?” and “Are you able to climb up five steps?”. The scale measures functional impairment in eight categories of daily living, which included: walking, eating, rising, dressing and grooming,

reach, grip, activities, and hygiene. Participants responded to each statement using a 10-point scale, ranging from 1 (*without any difficulty*) to 10 (*unable to do*). The highest item score within the category was used as the score for the category. Scores for all categories were summed and averaged to compute a total score of physical disability. In the present study, the alpha value for the HAQ-DI at baseline was 0.90.

**Pain.** Arthritis pain was assessed at the initial assessment survey and at each of the five monthly follow-ups. A single item visual analog scale was used to assess pain by asking participants to “choose a number between 0 and 100 that best describes the average level of pain that you have experienced over this month, with 0 indicating *no pain* and 100 indicating *pain as bad as it can be*”. This visual analog scale has been established as valid and reliable measure of pain and is widely used in chronic illness research (Danoff-Burg & Revenson, 2004; Katz et al., 2007; Smith & Zautra, 2008; Zautra et al., 2005).

**Fatigue.** Participants completed the 5-item The Energy/Fatigue Scale (Lorig, Stewart, Ritter, Gonzalez, Laurent, & Lynch, 1996), assessing perceived levels of fatigue experienced within the past month. A sample item included “I feel full of pep.” Participants rated these items using a 10-point scale ranging from 1 (*none of the time*) to 10 (*all of the time*). The scale demonstrated good internal consistency reliability, with alpha coefficients of .89 and .85, respectively. Alpha levels for the current study suggested good reliability, ranging from 0.83-0.90.

**Disease activity and symptom exacerbations.** Participants rated the amount of disease activity they have experienced in the last month using seven questions developed for this study. Five of these items were adapted from previously established disease

activity indices for RA, AS, and SLE developed by the American College of Rheumatology. These questions asked the participant to consider their health in the past month and rate the extent to which their condition has been active, the amount of discomfort they have experienced from their physical symptoms and the severity and length of time they experienced morning stiffness and pain on a scale from 1 (*none*) to 10 (*extreme*). Participants provided a subjective rating of their symptom severity in the past month on a scale from 1 (not at all severe) to 10 (extremely severe). The final two items were adapted from a study conducted with SLE patients (Philip et al., 2009), in which respondents were asked if they experienced a flare-up in symptoms in the past month and if they experienced a remission of symptoms in the past month.

### **Psychosocial and Environmental Factors**

Psychological, social and environmental factors included optimism, perceived control, perceived social support, and other stressful life events that occur within the course of the study. How these constructs were measured is discussed below.

**Optimism.** Individual differences in optimism and pessimism were assessed using the revised Life Orientation Test (LOT-R; Scheier, Carver, & Bridges, 1994). The LOT-R consisted of 10 items asking respondents to rate their agreement with each item based on a Likert scale ranging from 1 (*I agree alot*) to 5 (*I disagree alot*). Sample items included “Overall, I expect more good things to happen to me than bad” and “In uncertain times, I usually expect the best”. Ratings are averaged for a total score, with lower scores reflecting greater optimism. The LOT-R has been used extensively to assess optimism in health-related samples, including diabetes patients (Yi et al., 2008), people with RA (Brenner et al., 1995), and people with spinal cord injuries (Quale & Schanke,

2010). In a sample of RA patients (Brenner et al., 1995), the LOT-R demonstrated an acceptable level of internal consistency ( $\alpha=.83$ ). Cronbach's alpha for the present study was .86.

**Perceived control.** Three items evaluated perceptions of control at the initial assessment. Participants were told that “some people believe that they can exert control over the course of their illness. They believe that a positive attitude will achieve these effects or that certain exercise changes can help.” Then they were asked to select a number from 1 to 10 that “best describes how much personal control you think you have over the day to day symptoms of your illness,” that “best describes how much personal control you think you have over the future course of your illness,” and that “best describes how much personal control you have over the emotions related to your illness.” Responses were averaged for a total score, with higher scores denoting greater levels of perceived control. These three items were adapted from previous studies with RA and other chronically ill populations (Conner et al., 2006; Helgeson, 1992; Helgeson et al., 2004). These items demonstrated adequate internal consistency, with alphas ranging from 0.75-0.78 over the six time points.

**Perceived social support.** This study measured perceived social support using three items developed by Stanton et al. (2000) to assess perceptions of receptivity of the social support network to participants' cancer diagnosis. These items were adapted to reflect the participant's inflammatory rheumatic disease diagnosis. Items include “I have people to talk to about my worries concerning [RA, AS, SLE, or gout],” “I feel free to express all my feelings about [RA, AS, SLE, or gout] to those close to me,” and “There are people I can count on whenever I want to talk about my experience with [RA, AS,



SLE, or gout].” Participants rated each item using a 10-point scale with options ranging from 1 (*strongly disagree*) to 10 (*strongly agree*). These items were then averaged for a total score, with higher scores denoting greater levels of perceived support. This scale demonstrated adequate internal consistency in a longitudinal study on adjustment to breast cancer, with coefficient alphas of .75 at Time 1 and .85 at Time 2 (Stanton et al., 2000). Reliability coefficients for the present study were higher, ranging from .91 to .94 across the six assessment periods.

**Major life events.** Participants were asked to indicate any other major life changes unrelated to inflammatory rheumatic disease that occurred in the last month. Participants were provided with a list of examples taken from the Social Readjustment Rating Scale (SRS; Holmes & Rahe, 1967) and then an open-ended option to list “other” events that occurred. The SRS instrument provided a list of life events in order to assess the frequency of life events experienced by the participant that require a significant change in the ongoing life pattern. The emphasis of this measure was on quality and quantity, rather than on the psychological meaning, emotion or social desirability of the event.

**Open-ended question.** At the end of each monthly assessment, participants were asked if they would like to add any further information regarding their experience managing arthritis in the past month.

### **Data Analysis Strategy**

**Preliminary analyses.** Chi-square and logistic regression analyses were conducted to determine if personal characteristics (demographics and disease-related and adjustment variables) differ among individuals who complete only a subset of

assessments and individuals who complete the entire study. Other preliminary analyses included bivariate correlations among all variables of interest and other descriptive tests to best describe the characteristics of the sample and the ongoing process of adaptation in people with inflammatory rheumatic disease. Between group comparisons were performed in order to assess differences among demographics, disease-related, and subjective well-being variables across the different forms of inflammatory rheumatic disease. All preliminary analyses were performed using SAS 9.3 (SAS Institute, Cary, NC).

**Main analyses.** The main analyses followed a two step process. In the first step, only the repeated measures of life satisfaction were examined using GMM in Mplus version 6.0 (L.K. Muthén & Muthén, 1998-2010). This is called the unconditional model because the model is fit without including covariates (Muthén, 2004). The unconditional model is comprised of a latent class variable, which is a categorical variable that classifies individuals into different trajectory “classes” or groupings based on differences in their life satisfaction growth over time (i.e., scores on the trajectory intercept and slopes; Muthén, 2001). In other words, each class or group of individuals vary around different mean growth parameters (trajectory intercept and slopes), representing unobserved “subpopulations” within the larger, heterogeneous sample. In addition, the shape of the trajectory is permitted to differ across classes (e.g., one trajectory may follow a linear pattern, whereas another may be best represented by a quadratic curve; Muthén, 2004; Preacher, Wichman, MacCallum, & Briggs, 2008).

As previously mentioned, resilience in the current sample is operationally defined by the predicted associations among life satisfaction and positive and negative affect.

Specifically, these relationships were modeled to reflect changes in life satisfaction being influenced by concurrent levels of positive and negative affect (Schimmack et al., 2002). As such, once the best fitting unconditional model has been identified, the second step involves extending this model by adding the monthly assessments of positive and negative affect scores as time-varying covariates to predict and adjust life satisfaction ratings over time. The purpose of including covariates in the model is to correctly specify the model, find the appropriate number and meaning of the classes, and to estimate the class size and membership (Muthén, 2001; Muthén & Shedden, 1999).

Growth mixture modeling is performed using maximum likelihood estimation with an expectation maximization (EM) algorithm, with missing data estimated under the assumption that they are missing at random (MAR; Muthén, 2001; Muthén & Shedden, 1999). MAR assumes that the probability of missing data on variable  $X$  is related to other measured variables in the analysis, but not related to the participant's true score on  $X$  (El-Masri & Fox-Wasylyshyn, 2005; Enders, 2010). Based on the recommendations of Nylund et al. (2007) and Tofighi and Enders (2007), the present investigation relied heavily on four fit indices to determine the most appropriate number of latent classes: (a) the bootstrap likelihood ratio test (BLRT), which empirically derives a distribution of differences between two competing models ( $k-1$  and  $k$  models) and estimates a  $p$ -value to determine whether the null model ( $k-1$ ) should be rejected in favour of the  $k$  model, (b) Bayesian Information Criterion (BIC) derived from competing models with one through six class solutions, with lowest value across the model solutions indicating the best fit, (c) the sample sized adjustment Bayesian Information Criterion (ssBIC), and (d) the Lo-Mendell likelihood ratio test (LMR; Lo, Mendell, & Rubin, 2001), a likelihood based

method for testing  $k-1$  number of trajectory group against  $k$  group. According to Nylund et al. (2007), BIC and BLRT are the most robust indices for detecting the correct number of classes in smaller samples when departures from normality within class are minor. Furthermore, the entropy indices and estimated posterior probabilities were checked to ensure quality and reliability of classification (Muthén & Shedden, 1999). Entropy values were consulted to examine how well participants were classified into trajectory groups. Entropy values closer to one represent good separation among the identified classes (Celeux & Sorometho, 1996). Posterior probabilities are the product of the latent class variable, which refer to a post-hoc probability of an individual being assigned to a particular class given class size, the estimated means for each class, and the individual's response pattern. Estimates of each individual's most likely class membership are based on results from the best fitting model (Muthén, 2001). Note that individuals may have several classes in which they are a "partial" member (Clark & Muthén, 2009).

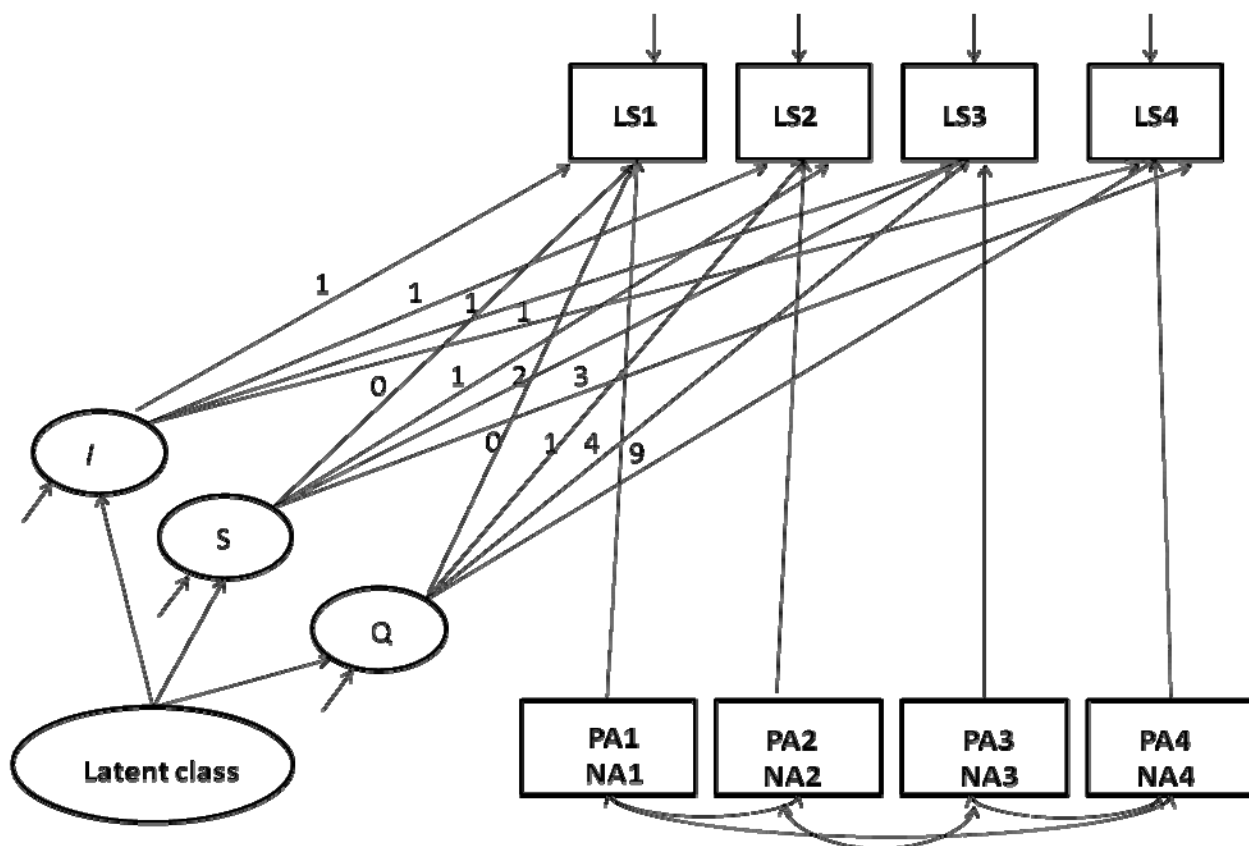
### **Model Identification**

Figure 1 visually depicts the growth mixture models examined in the current study. The growth factors, the intercept ( $i$ ), linear slope ( $s$ ), and quadratic slope ( $q$ ) are portrayed as circles, representing unobservable (or latent) continuous random effects that are estimated by life satisfaction scores measured repeatedly over time. Both linear and quadratic curve shapes were estimated in order to be consistent with previous literature examining trajectories of psychological functioning (e.g., Bonanno et al., 2008). The intercept and slope factors are allowed to vary across individuals, capturing individually varying growth trajectories on life satisfaction scores over time (Muthén, 2004). The intercept is defined by fixing all loadings at 1.0 and the values of the slope parameters

correspond to the amount of time between follow-up assessments. In this study, the values for the linear slope are equal to the sequential and evenly spaced monthly measurements (0, 1, 2, 3, 4, and 5). The path between the slope parameters and the first observed indicator is set to 0 such that the intercept represents the predicted value of life satisfaction at T1, and the slope represents the mean change in life satisfaction starting from T1. Finally, a categorical latent variable ( $c$ ) captures different classes or groups of people that differ based on their mean growth curve of life satisfaction (Muthén, 2004).

In this model, loadings for the life satisfaction indicators on the intercept and slopes, variances and covariances of the growth factors, and residual variances, were held constant across classes (called class invariant), while the means and variances of the intercept and slope factors were freely estimated within each class (called class-specific). However, the variance of the quadratic curve was constrained to zero for all models. This constraint was added for two reasons: first because it reduced model complexity and increased the likelihood of converging on a proper solution, and second because some methodologists have suggested that it tends to be difficult to estimate nonlinear variances even when effects are present (Morin et al., 2011; Tofighi & Enders, 2007).

Figure 1. Growth mixture model diagram



*Figure 1.* GMM model testing growth of life satisfaction in different trajectory groups, including time-varying positive and negative affect indicators. Circles denote latent variables for random intercepts, slope, and latent class variable, rectangles denote measured variables of life satisfaction (outcomes) and emotions (covariates). Time-varying covariates are specified as directly affecting outcome variables. I = intercept, S = linear slope, Q = quadratic curve shape, LS = life satisfaction, PA = positive affect, and NA = negative affect.

A series of growth mixture models were estimated from data available for 391 participants using robust full information maximum likelihood estimation (FIMLR) with an EM algorithm (Muthén, 2004; Shedden & Muthén, 1999). FIMLR handles missing data under the assumption that data are MAR, estimating missing values using all available data to yield unbiased standard error estimates. FIMLR has been widely accepted as a valid method for handling missing data (Enders, 2010). In addition, FIMLR can produce reliable standard error estimates under conditions of nonnormality (Muthén, 2004; Nylund et al., 2007), and is a highly efficient way to obtain parameter estimates and test statistics using all available data (Schafer & Graham, 2002).

In general, the important information to consider in a given GMM model is an individual's probability of class membership in each class, their scores on the growth factors, and measurements of classification quality (Muthén & Shedden, 1999). To identify the optimal number of trajectory classes that best represent the data, models between one and six classes were fit using Mplus. Because GMM and latent class analyses commonly suffer from non-convergence and improper solutions (Li & Hser, 2011; Lubke & Neale, 2006; Morin et al., 2011; Muthén, 2004), particularly in smaller sample size conditions (Nylund et al., 2007; Tofighi & Enders, 2007), 100 replications and random start values were generated for each model. Local or improper solutions and failures to converge were not included in model evaluation. Models with BLRT tests that may not be trustworthy as indicated by Mplus were re-run using a variety of random LRTSTARTS (likelihood ratio test) as recommended by Asparouhov and Muthén (2013). However, if BLRT tests were still untrustworthy after varying starting values, then this

test was not considered when evaluating model fit (Li & Hser, 2011; Tofighi & Enders, 2007).

Covariates were then added to the model sequentially, focusing carefully on changes in class trajectory structure and function. As shown in Figure 1, time-varying covariates are included in the model as directly predicting the concurrent score on the outcome variable (life satisfaction), thus indirectly affecting the trajectory intercept and slopes, which are defined by the repeated life satisfaction measurements, as well as individual classification in each of the latent classes or trajectory groups. In other words, time-varying covariates are interpreted in the same manner as regression coefficients in that they predict time-specific deviations in life satisfaction net of other included covariates (Bollen & Curran, 2006; Preacher et al., 2008). In the current investigation, the final model, which included time-varying positive and negative affect, examined the influence of emotions on initial status and growth in life satisfaction over time within trajectory groups (Kaplan, 2000). It should be noted that researchers have suggested that estimating direct influences between time-varying covariates and the outcome variables may result in trajectory groups that are radically different from the best fitting unconditional model (Morin et al., 2011; Petras & Masyn, 2010); however, no published research investigating trajectories of psychological functioning has included time-varying covariates. Therefore, the extent to which these covariates change the unconditional trajectory groups is currently unknown. Positive and negative affect indicators were centered around the grand-mean to facilitate interpretation and comparisons between models with and without covariates (Petras & Masyn, 2010).

### **Testing Invariance Assumptions**



Most of the published research employing GMM techniques relies on restrictive model parameters imposed as a default in the Mplus software (Morin et al., 2011). These defaults include freely estimating intercept and slope factors in each trajectory group (i.e., group specific means) but constraining the variance-covariance matrices and error variances to be equal across trajectory groups (invariance; L.K. Muthén & Muthén, 2010). Although these defaults are commonly used because of model convergence issues, there is evidence to suggest that these restrictions could result in over-extracting trajectory groups and biased parameter estimates (e.g., Bauer & Curran, 2003a). Many methodologists urge that testing the validity of these restrictions, known as invariance assumptions, is a critical step in identifying the model that is most representative of applied populations (Lubke & Neale, 2006; Morin et al., 2011; Petras & Masyn, 2010). Accordingly, the current analyses will compare both unconditional and conditional GMM models with a variety of model restrictions to verify the validity of invariance assumptions (Morin et al., 2011). Satorra-Bentler scaled chi-square difference tests were used to compare nested models (e.g., models with different constraints) within the same number of classes (Satorra, 2000).

## CHAPTER III

**Results****Sample Characteristics**

Demographic information is depicted in Table 2 for the overall sample and by arthritis group. The 432 participants who completed T1 were primarily female (70%), Caucasian (70.8%), and married (60.7%), with an average age of 44.3 years ( $SD=12.67$ , range=18-81 years) and possessing either some college (25.2%) or university level education (30.3%).

Table 2  
*Demographic Information for Overall Sample and by Rheumatic Group*

		Overall ( $N=432$ )	RA ( $n=108$ )	AS ( $n=191$ )	SLE ( $n=79$ )	Gout ( $n=54$ )
	Mean					
Age	(SD)	44.3(12.67)	45.2(12.03)	42.2(11.89)	41.7(12.2)	54.2(13.0)
	Median	44	45	43	43	55
	Range	18-81	18-68	19-69	19-65	31-81
	Sex					
( $n\%$ )	Female	302(70.0)	89(82.4)	134(70.16)	65(82.28)	14(25.93)
	Male	101(23.4)	11(10.2)	51(26.7)	5(6.33)	34(63.0)
	Missing	29(6.7)	8(7.4)	6(3.14)	9(11.39)	6(11.1)
	Ethnicity					
( $n\%$ )	Caucasian	306(70.8)	70(64.8)	151(79.1)	51(64.6)	34(63.0)
	Other	62 (14.4)	21(19.4)	20(10.5)	12(15.2)	9(16.7)
	Missing	64(14.8)	17(15.7)	20(10.5)	16(20.3)	11(20.4)

(continued)

Table 2  
*Demographic Information for Overall Sample and by Rheumatic Group*

	Overall (N=432)	RA (n=108)	AS (n=191)	SLE (n=79)	Gout (n=54)
Education (n%)					
some highschool	19(4.4)	4(3.7)	6(3.1)	8(10.1)	1(1.9)
highschool					
graduate	45(10.4)	11(10.2)	16(8.4)	6(7.6)	12(22.2)
some college or					
university	109(25.2)	23(21.3)	57(29.8)	19(24.1)	10(18.5)
college/university	131(30.3)	41(38.0)	64(33.5)	17(21.5)	9(16.7)
some					
graduate/professi					
onal school	33(7.6)	9(8.3)	14(7.3)	5(6.3)	5(9.3)
graduate/professi					
onal degree	65(15.0)	12(11.1)	28(14.7)	14(17.7)	11(20.4)
missing	30(6.9)	8(7.4)	6(3.1)	10(12.7)	6(11.1)
Marital status (n%)					
Married/cohabitat					
ing	262(60.7)	61(56.5)	130(68.1)	45(57.0)	26(48.2)
Single/separated/					
divorced	50(11.57)	15(13.9)	20(10.5)	8(10.1)	7(13.0)
never married	85(19.7)	23(21.3)	35(18.3)	15(19.0)	12(22.2)
widowed	4(0.9)	0	1(0.5)	1(1.3)	2(3.7)
missing	31(7.8)	9(8.3)	5(2.6)	10(12.7)	7(13.0)

(continued)

Table 2  
*Demographic Information for Overall Sample and by Rheumatic Group*

	Overall (N=432)	RA (n=108)	AS (n=191)	SLE (n=79)	Gout (n=54)
Mental health condition (n%)					
yes	158(36.6)	34(31.5)	85(44.5)	29(36.7)	10(18.5)
no	274(63.4)	74(68.5)	106(55.5)	50(63.3)	44(81.5)
Flares (n%)					
yes	348(80.6)	88(81.5)	159(83.3)	61(77.2)	40(74.1)
no	67(15.5)	15(13.9)	29(15.2)	12(15.2)	11(20.4)
missing	17(3.9)	5(4.6)	2(1.6)	6(7.6)	3(5.6)
Income (n%)					
under \$30,000	108(25.0)	24(22.3)	43(22.5)	21(26.5)	20(37.0)
\$30,000-\$44,999	46(10.7)	13(12.0)	24(12.6)	9(11.4)	0
\$45,000-59,999	41(9.5)	8(7.4)	22(11.5)	6(7.6)	5(9.3)
\$60,000-74,000	35(8.1)	7(6.5)	16(8.4)	8(10.1)	4(7.4)
\$75,000-89,999	23(5.3)	5(4.6)	12(6.3)	4(5.1)	2(3.7)
\$90,000-104,999	22(5.1)	4(3.7)	13(6.8)	4(5.1)	1(1.9)
\$105,000-\$119,999	16(3.7)	6(5.6)	9(4.7)	0	1(1.9)
\$120,000-134,000	11(2.6)	4(3.7)	6(3.1)	0	1(1.9)
over \$135,000	25(5.8)	2(1.9)	14(7.3)	5(6.3)	4(7.4)
Don't know	14(3.2)	7(6.5)	3(1.6)	2(2.5)	2(3.7)
prefer not to answer	44(10.2)	12(11.1)	19(10.0)	9(11.4)	4(7.4)
missing	47(10.9)	16(14.8)	10(5.2)	11(13.9)	10(18.5)

(continued)

Table 2  
*Demographic Information for Overall Sample and by Rheumatic Group*

	Overall (N=432)	RA (n=108)	AS (n=191)	SLE (n=79)	Gout (n=54)
Taking					
medications (n%)					
yes	391(90.5)	104(96.3)	172(90.1)	72(91.1)	43(79.6)
no	38(8.8)	2(3.7)	19(10.0)	5(6.3)	10(18.5)
missing	3(0.7)	0	0	2(2.5)	1(1.9)
Employment (n%)					
Full-time	135(31.3)	35(32.4)	66(34.6)	21(26.6)	13(24.1)
Part-time	76(17.6)	17(15.7)	39(20.4)	16(20.3)	4(7.4)
Not at all	139(32.2)	35(32.4)	63(33.0)	26(32.9)	15(27.8)
Retired	50(11.6)	12(11.1)	16(8.4)	6(7.6)	16(29.6)
missing	32(7.4)	9(8.3)	7(3.7)	10(12.7)	6(11.1)
Other					
physical(n%)					
yes	264(61.1)	57(52.8)	128(67.0)	51(64.6)	28(51.9)
no	168(38.9)	51(47.2)	63(33.0)	28(35.4)	26(48.2)
Remissions (n%)					
yes	148(34.3)	35(32.4)	61(31.9)	22(27.9)	30(55.6)
no	266(61.6)	68(63.0)	126(66.0)	51(64.6)	21(38.9)
missing	18(4.2)	5(4.6)	4(2.1)	6(7.6)	3(5.6)
Medication relief					
M (SD)	5.8(2.1)	6.1(2.05)	5.7(2.10)	5.7(1.93)	5.9(2.59)

(continued)

Table 2  
*Demographic Information for Overall Sample and by Rheumatic Group*

	Overall (N=432)	RA (n=108)	AS (n=191)	SLE (n=79)	Gout (n=54)
Years since diagnosis (n%)					
5 years of					
less	213(49.3)	52(48.2)	92(48.2)	43(54.4)	26(48.2)
6-10 years	91(21.1)	21(19.4)	48(25.1)	12(15.2)	10(18.5)
11-20 years	61(14.1)	21(19.4)	21(11.0)	12(15.2)	7(13.0)
21 +	56(13.0)	9(8.3)	29(15.2)	9(11.4)	9(16.7)
missing	11(2.6)	5(4.6)	1(0.5)	3(3.8)	3(3.7)
Length of morning stiffness (n%)					
0 hours	22(5.1)	1(0.9)	9(4.7)	3(3.8)	9(16.7)
0.5 hours	70(16.2)	22(20.4)	33(17.3)	9(11.4)	5(11.1)
1 hour	103(23.8)	22(20.4)	49(25.7)	19(24.1)	13(24.1)
1.5 hours	50(11.6)	8(7.4)	27(14.1)	11(14.0)	4(7.4)
2 or more					
hours	136(31.5)	41(38.0)	59(30.9)	22(27.9)	14(25.9)
missing	51(11.8)	14(13.0)	14(7.3)	15(19.0)	8(14.8)
First language(n%)					
English	383(88.7)	94(83.3)	178(93.0)	67(84.8)	43(79.6)
other	20(4.6)	6(5.6)	13	2	5
missing	29(6.7)	8(7.4)	5	10	6

(continued)

Table 2  
*Demographic Information for Overall Sample and by Rheumatic Group*

	Overall (N=432)	RA (n=108)	AS (n=191)	SLE (n=79)	Gout (n=54)
Major life event (n%)					
Starting new responsibilities at work	77(17.8)	14(13.0)	43(22.5)	15(19.0)	5(9.3)
Suffered a change in your physical health	145(33.6)	32(29.6)	52(27.2)	39(49.4)	22(40.7)
Change in health of a close family or friend	96(22.2)	23(21.3)	44(23.0)	16(20.3)	13(24.1)
A pregnancy	12(2.8)	1(0.9)	8(4.2)	2(2.5)	1(1.9)
Divorce or martial separation	10(2.3)	2(1.9)	5(2.6)	2(2.5)	1(1.9)
Death of a close family member or friend	43(10.0)	14(13.0)	18(9.4)	6(7.6)	5(9.3)
A personal injury	32(7.4)	6(5.6)	11(5.8)	6(7.6)	9(16.7)
An outstanding personal achievement	37(8.6)	11(10.2)	14(7.3)	11(13.90)	1(1.9)
Other	174(40.3)	38(35.2)	90(47.1)	26(32.9)	20(37.0)

*Note.* RA= rheumatoid arthritis; AS= ankylosing spondylitis; SLE= systematic lupus erythematosus, SD=standard deviation.

Nearly 200 ( $n=191$ ; 44.2%) individuals reported having AS, 108 (25.0%) had RA, 79 (18.3%) had gout and 54 (12.5%) had SLE. Thirty-five (8.1%) participants reported having more than one form of RA, AS, SLE or gout, with the majority having either a combination of RA and AS (45.7%) or RA and SLE (34.3%). The median time since diagnosis was 5 years ( $M=8.9$  years,  $SD=9.01$ , range=0-42 years), and over 90% ( $n=391$ ) of respondents reported taking medications to relieve associated symptoms of arthritis. Two thirds of participants ( $n=264$ ) self-reported having at least one co-morbid health

condition, including high blood pressure, diabetes, and other degenerative forms of arthritis (see Appendix F for complete list), and over one third ( $n=158$ ) self-reported at least one concurrent mental health condition, predominately major depression (65.8%) or anxiety disorders (57%).

Characteristics of disease-related, psychological, and social measures for the entire sample by time point are found in Table 3. Many participants (83.9%;  $n=348$ ) in the sample experienced at least one symptom flare-up in the month prior to participating, and the majority of respondents ( $n=266$ ; 64.2%) did not experience any periods of symptom remission. Notably, participants reported above average levels of discomfort, symptom severity, and stiffness resulting from their arthritis symptoms at each time point, however, corresponding pain levels appeared to decline over time. Stiffness or pain resulting from arthritis lasted a median of 1.5 hours after waking up in the morning.

Table 3  
*Means and Standard Deviations for Subjective Well-being, Disease-Related, and Psychosocial Variables for the Overall Sample by Time Point*

Variable	T1 ( $N=432$ )	T2 ( $n=273$ )	T3 ( $n=224$ )	T4 ( $n=194$ )	T5 ( $n=185$ )	T6 ( $n=152$ )
	$M (SD)$	$M (SD)$	$M (SD)$	$M (SD)$	$M (SD)$	$M (SD)$
SWL	17.5(7.5)	18.5(7.8)	19.7(7.7)	20.0(8.1)	19.9(7.8)	21.0(7.6)
PA	53.6(17.5)	55.3(18.6)	55.4(18.8)	57.7(19.1)	58.4(18.2)	60.4(18.9)
NA	48.4(20.3)	42.8(20.1)	41.3(20.0)	39.1(20.5)	39.3(20.6)	37.2(19.2)

(continued)



Table 3  
*Means and Standard Deviations for Subjective Well-being, Disease-Related, and Psychosocial Variables for the Overall Sample by Time Point*

Variable	T1 (N=432)	T2 (n=273)	T3 (n=224)	T4 (n=194)	T5 (n=185)	T6 (n=152)
<b>Disease related</b>						
Disability	1.0(0.6)					
Pain	58.7(26.5)	54.0(27.6)	54.5(26.2)	52.8(25.6)	51.2(26.9)	49.8(27.7)
Discomfort	7.2(2.0)	6.6(2.1)	6.6(2.1)	6.2(2.1)	6.3(2.3)	5.9(2.5)
Symptom Severity	6.6(2.1)	6.0(2.3)	5.9(2.2)	5.8(2.2)	5.8(2.3)	5.3(2.4)
Stiffness	6.7(2.4)	6.3(2.6)	6.2(2.5)	5.9(2.6)	6.1(2.6)	5.6(2.7)
Fatigue	4.4(0.8)	3.8(1.8)	3.9(1.8)	4.0(1.8)	4.2(1.9)	4.4(1.8)
<b>Psychosocial</b>						
Optimism	16.3(5.8)					
CB	5.0(2.1)	5.3(1.9)	5.3(1.9)	5.0(2.0)	5.3(1.9)	5.5(2.0)
PSS	5.6(2.9)	5.7(2.8)	5.6(2.9)	5.7(2.9)	5.9(2.9)	6.0(2.9)

*Note.* For all scales, higher scores represent more extreme responding in the variable being assessed, with the exception of optimism, in which lower scores connote a more positive outlook on life. SWB=subjective well-being, SWL=satisfaction with life, PA=positive affect, NA=negative affect, CB=control beliefs, PSS=perceived social support.

Over a third of respondents ( $n=165$ ) at baseline reported using some type of medical aid or mobility device to help them perform daily activities. Among the

participants using mobility devices, 65% reported using a cane, 16% a walker, 12% crutches, and 11% had wheelchairs. Other examples of mobility aids and devices used are illustrated in Appendix F. In addition to taking medication, many participants engaged in one or more alternative forms of pain management to relieve their daily symptoms. Heat and/or cold applied to joints (78%), exercise (73%), modifying diet (66%), and relaxation techniques were among the most common pain management strategies reported (see Appendix G for complete list).

### **Statistical Assumptions and Missing Data**

**Distributional assumptions.** The distributional assumptions associated with GMM differ considerably from those of conventional regression-based models. First, at least moderate nonnormality in the observed outcome variables (e.g., the dependent variables) is considered a sufficient condition for extracting trajectory groups, as this could reflect the presence of heterogeneous groups within a larger sample (Bauer & Curran, 2003a, 2003b). Second, within each trajectory group, outcome variables are assumed to be normally distributed conditional on covariates. Assessing the latter assumption is more appropriate following final model estimation; however, the first assumption can be examined by running a single class GMM to obtain univariate and multivariate skewness and kurtosis values based on Mardia's (1974) definition. In the present sample, significant univariate kurtosis values were associated with life satisfaction at each time point (range = -0.94 to -1.23,  $ps < .001$ ). However, neither multivariate skewness nor multivariate kurtosis values were significant ( $p = .27$ ,  $p = .74$ , respectively), demonstrating that life satisfaction scores were multivariate normal.

Normality was also assessed by visually inspecting q-q residual and histogram plots, as well as by examining skewness and kurtosis values associated with each predictor variable. Overall satisfaction with physical health was skewed to the right at each time point, indicating that overall the sample reported lower satisfaction with their physical health. Perceptions of social support scores at each time point were moderately kurtotic (range= -1.0 to -1.3). These departures from normality were not considered severe; therefore data transformations were not undertaken.

#### **Detecting multivariate outliers and other regression based assumptions.**

Apart from distributional assumptions, all other statistical assumptions underlying basic regression models apply to GMM (Kreuter & Muthén, 2008). Data were screened for the presence of outliers, linearity, and homoscedasticity of residuals, and multicollinearity. Univariate and multivariate outliers at each time point were assessed using standardized z-scores and computed Mahalanobis Distance values. Z-scores greater than 2.58 and distance values significant at a  $p < .001$  level were considered outliers. A total of 18 univariate and 41 multivariate outliers were detected across the six time points. Kreuter and Muthén (2008) suggested that GMM analyses may have an advantage over other regression based models in that GMM estimates random effects (as opposed to fixed effects), and therefore may actually reduce the influence of outliers on the model parameters. Thus, instead of deleting multivariate outliers from the dataset outright, the GMM class solutions were analyzed with and without the presence of the outliers. The results of the GMM model comparisons demonstrated that models without covariates taken into account (unconditional models) did not change with the presence of outliers. However, when covariates were added to the models, the structure and meaning of the

trajectory classes changed dramatically, such that the reliability and stability of the class solution was called into question. Therefore, outliers were deleted from further analyses. The final sample sizes were the following:  $N=391$  for T1,  $N=239$  for T2,  $N=197$  for T3,  $N=171$  for T4,  $N=164$  for T5, and  $N=136$  for T6.

Linearity and homoscedasticity were assessed at each time point by examining the shape of residuals plotted as the differences between observed and predicted dependent variable scores. Scores were concentrated around the center of the plot, for the most part depicting a rectangular shape with no extreme scores. Based on visually inspecting the residual plots, linearity and homoscedasticity were assumed (Tabachnick & Fidell, 2001). Finally, correlation matrices were examined to assess problems with multicollinearity and singularity. No correlations exceeded 0.90 (Table 4) therefore no indication of multicollinearity and singularity was evident.

**Missing data between time points.** As with most longitudinal research, missing data were a pervasive issue for the current study. Complete data for all six time points was obtained for a mere 35% of the sample. Not surprisingly, the largest amount of attrition occurred between T1 ( $N=391$ ) and T2 ( $N=239$ ), with 38.9% dropout rate. Dropout rates were significantly lower following this initial dip, with overall rates of 17.6% from T2 to T3, 13.2% from T3 to T4, 4.1% from T4 to T5, and 17.1% from T5 to T6.

Patterns of missing data were assessed between time points by constructing five dichotomous variables (responder=1; non-responder=0) to distinguish missing data between T1-T6. Differences between responders and non-responders were tested using independent sample *t*-tests for continuous variables and chi-square analyses or Fisher's

exact tests for the binary and categorical variables. Differences between responders and non-responders from T1 to T2 were observed in terms of marital status, arthritis group, and education level. In particular, responders differed from non-responders in that they were more likely married (46.9%),  $\chi^2(3)=9.74, p=.021$ , whereas non-responders were more likely widowed (75%). Responders also tended to have AS (73.3%),  $\chi^2(2)=20.37, p=.001$ , and had achieved at least some college/university or higher (62.2%),  $\chi^2(5)=11.59, p=.041$ . Additionally, differences between the responder groups suggested that those with poorer physical health were more likely to drop out of the study. Specifically, responders at T2 reported significantly less morning stiffness or pain in the joints,  $M=6.5(2.38)$  vs.  $M=7.1(15.38)$ ,  $t(367)=2.48, p=.021$ , and responders at T5 reported lower pain levels  $M=68.3(12.38)$  vs.  $M=50.6(27.01)$ ,  $t(166)=2.02, p=.007$ , and greater personal control  $M=5.1(2.00)$  vs.  $M=4.0(2.1)$ ,  $t(169)=-2.60, p=.031$ , compared to non-responders. No other differences were observed in disease-related or psychosocial variables between responders and non-responders across the six study time points. Overall, the pattern of missingness between survey time points was monotone (Enders, 2010), such that when a participant dropped out of the study their follow-up data were missing or unobserved.

**Missing data within time points.** Missing responses on individual items within each time point (e.g., partial data were available for each participant) was also examined to uncover potential patterns. Three consistent patterns of missing items emerged across the six study time points. The first pattern showed that 26.2% of participants did not report their age at the initial assessment. In retrospect, it appears that the omission may have been caused by the physical location of the age item on the internet survey, as well

as the timing of when the age question was asked. Respondents were asked to supply their age during the initial screening phase in order to identify and exclude participants who were less than 18 years old. In particular, the screening item asked if the participants was over 18 years of age (*yes/ no*), and if participants answered “yes”, they were then asked to supply their age. Perhaps this personal question was asked too soon, and participants did not feel comfortable responding to the question before they knew what the rest of the study would entail. The amount of missing data was such that age could not be included as a covariate during estimation of the GMM models, however, age was used in subsequent between- trajectory group analyses.

The other two patterns of item missingness were associated with the QOL-BREF. Two items on this scale asked participants to rate their satisfaction with (a) their capacity to work and (b) their satisfaction with their sex life. The amount of missingness on these items was large, ranging from 23.7-38.2% across T1-T6. However, missing data on these items is not surprising given the nature of the questions. For instance, many participants indicated that they were not employed at T1. The QOL item relating to work capacity could have easily been interpreted as specific to work associated with employment. Furthermore, participants may not have felt comfortable responding to an item asking about their sex life. Because these items were included for descriptive purposes only (i.e., not intended to be included in the main analysis), they were omitted from all further analyses. Beyond those items already mentioned, the presence of missing data within each time point was random and not considered a serious issue. Percentages of missing item data ranged anywhere from 0 - 7.6% for individual survey items in T1 and 0 - 3.1% of individual survey items in T2-T6.

Missing data on key study variables were considered missing at random (MAR; Enders, 2010; Little & Rubin, 2002) because several demographic and disease-related variables could distinguish those who completed the study versus those who dropped out, and the missing data were not related to the variable itself. In short, missing values could be predicted by other variables within the dataset using maximum likelihood estimation.

### **The Impact of Data Loss**

Although data loss between time points was considerable, it was within the range of predicted response rates for longitudinal survey research designs (Mernard, 2002). That being said, however, significant loss of data could have detrimental effects on the reliability and validity of the main GMM analyses. Despite the use of a maximum likelihood estimation, which is considered a valid approach for handling missing values, the more information that is present for predicting missingness, the more reliable the resulting parameter estimates (Enders, 2010). To reduce the impact of missing data, the main analyses were conducted using only four data collection time points.

The choice to use four time points was based on previous research applying GMM to investigate psychological functioning following a potentially traumatic event. Previous studies have commonly included the examination of nonlinear growth patterns (e.g., quadratic curve shape) when estimating trajectories of psychological functioning (e.g., delayed distress, recovery; Bonanno, 2004; Norris et al., 2009; Norton et al., 2011). Therefore to compare present findings to previous research, a minimum of four data time points were required to examine quadratic curve shapes. The final two time points (T5 and T6) were used in a secondary analysis to investigate the criterion validity of the identified trajectory classes.

### **Correlations Among Variables of Interest**

Correlations among life satisfaction, positive and negative affect, control beliefs, optimism, and the inflammatory rheumatic condition disease-specific variables were significant in the expected directions within each study time point (Table 4-5). However, few variables of interest were associated with perceptions of social support. In fact, perceptions of social support were significantly negatively correlated with satisfaction with life at T1 and T3, and positively associated with symptom severity at T3 and T5, and discomfort and morning stiffness at T5 only. No associations among perceptions of social support and disease-related outcomes (i.e., pain, disability, disease activity, or fatigue) were observed.

### **Baseline between Group Comparisons**

No differences between rheumatic groups were found in terms of education levels, years since diagnosis, ethnic, marital, or income status; however, there were significant differences between arthritis groups in sex, age, self-reported mental health issues, and employment status. Specifically, the gout and AS groups consisted of more males, whereas participants with RA and SLE were more often female  $\chi^2(3)=66.25$ ,  $p<.001$  (see Table 2 for descriptive data). This difference is representative of prevalence rates by gender for each of these inflammatory rheumatic conditions. Otherwise, the gout group were older than the RA  $t(3)= 8.1$ ,  $p<.05$ , AS  $t(3)= 12.7$ ,  $p<.05$ , and SLE groups  $t(3)= 11.3$ ,  $p<.05$  and were also less likely to have a prior mental health condition  $\chi^2(3)=13.97$ ,  $p<.001$ . Finally, the SLE group were less likely to be employed relative to the other three arthritis groups  $\chi^2(9)=23.1$ ,  $p<.0024$ .



Table 4  
*Correlations Among Variables of Interest by T1*

	1	2	3	4	5	6	7	8	9	10	11
1. SWL											
2. PA	0.49**										
3. NA	-	-0.3**									
4. Disability	0.31**	-0.33**	0.35**								
5. Pain	0.31**	-0.26**	0.31**	0.45**							
6. Discomfort	0.27**	-0.29**	0.38**	0.50**	0.67**						
7. Severity	0.27**	-0.27**	0.30**	0.52**	0.62**	0.81**					
8. Stiffness	0.24**	-0.21**	0.33**	0.52**	0.59**	0.65**	0.67*				
9. Fatigue	0.22**	0.24**	-0.21**	-0.21**	-0.27**	-0.29**	-0.27*	-0.17*			
10. Optimism	-0.50*	-0.38**	-0.47**	0.13*	0.15*	0.17*	0.2**	0.12*	-0.12*		
11. CB	0.38*	0.42**	-0.22**	-0.21**	-0.23**	-0.23**	-0.24**	-0.26**	0.08	-0.32**	
12. PSS	-0.13*	0.01	0.13	0.03	0.06	0.05	0.03	0.1	-0.02	0.14	-0.04

*Note.* SWL=satisfaction with life, PA=positive affect, NA=negative affect, CB=control beliefs, PSS=perceived social support.

\* $p < 0.05$  \*\* $p < .01$  \*\*\* $p < .0001$ .

Table 5  
*Correlations Among Variables of Interest at T2-T6*

T2	1	2	3	4	5	6	7	8	9
1. SWL									
2. PA	0.55**								
3. NA	-0.43**	-0.39**							
4. Pain	-0.35**	-0.42**	0.34**						
5. Discomfort	-0.31**	-0.39**	0.43**	0.67**					
6. Severity	-0.26**	-0.27**	0.31**	0.64**	0.81**				
7. Stiffness	-0.22**	-0.23**	0.38**	0.64**	0.69**	0.68**			
8. Fatigue	0.40**	0.63**	-0.42**	-0.53**	-0.58**	-0.46**	-0.44**		
9. CB	0.42**	0.56**	-0.36**	-0.34**	-0.36**	-0.31**	-0.24**	0.52**	
10. PSS	0.05	0.03	0.05	0.03	0.02	0.07	0.09	0.01	0.03

(continued)

Table 5  
*Correlations among Variables of Interest at T2-T6*

T3	1	2	3	4	5	6	7	8	9
1. SWL									
2. PA	0.55**								
3. NA	-0.41**	-0.35**							
4. Pain	-0.15**	-0.20**	0.33**						
5. Discomfort	-0.14**	-0.19*	0.39**	0.76**					
6. Severity	-0.17*	-0.23**	0.38**	0.78**	0.84**				
7. Stiffness	-0.21**	-0.19*	0.38**	0.65**	0.67**	0.68**			
8. Fatigue	0.37**	0.62**	-0.43**	-0.39**	-0.39**	-0.38**	-0.36**		
9. CB	0.25**	0.41**	-0.21**	-0.36**	-0.37**	-0.35**	-0.27**	0.36**	
10. PSS	-0.14*	-0.01	0.04	0.09	0.12	0.15*	0.09	-0.08	-0.02

(continued)

Table 5  
*Correlations among Variables of Interest at T2-T6*

T4	1	2	3	4	5	6	7	8	9
1. SWL									
2. PA	0.57***								
3. NA	-0.49***	-0.47***							
4. Pain	-0.21**	-0.15*	0.27**						
5. Discomfort	-0.20**	-0.18*	0.29***	0.68***					
6. Severity	-0.29***	-0.22**	0.29***	0.68***	0.82***				
7. Stiffness	-0.17*	-0.13*	0.27**	0.54***	0.72***	0.74***			
8. Fatigue	0.33***	0.59***	-0.43***	-0.28**	-0.36***	-0.32***	-0.27**		
9. CB	0.28**	0.38***	-0.26**	-0.34**	-0.38***	-0.43***	-0.34***	0.26**	
10. PSS	0.05	-0.05	-0.01	-0.12	-0.07	-0.01	0.03	0.04	0.1

(continued)

Table 5  
*Correlations Among Variables of Interest at T2-T6*

T5	1	2	3	4	5	6	7	8	9
1. SWL									
2. PA	0.61***								
3. NA	-0.51***	-0.46***							
4. Pain	-0.24**	-0.34***	0.40***						
5. Discomfort	-0.26**	-0.33***	0.43***	0.76***					
6. Severity	-0.27**	-0.34***	0.42***	0.71***	0.89***				
7. Stiffness	-0.25**	-0.28**	0.39***	0.66***	0.76***	0.71***			
8. Fatigue	0.41***	0.67***	-0.47***	-0.48***	-0.52**	-0.57***	-0.41***		
9. CB	0.48***	0.57***	-0.43***	-0.46***	-0.40**	-0.40***	-0.44***	0.53***	
10. PSS	-0.09	-0.06	0.08	0.06	0.16*	0.15*	0.16*	-0.11	-0.06

(continued)

Table 5  
*Correlations among Variables of Interest at T2-T6*

T6	1	2	3	4	5	6	7	8	9
1. SWL									
2. PA	0.52***								
3. NA	-0.46***	-0.48***							
4. Pain	-0.35***	-0.39***	0.50***						
5. Discomfort	-0.33***	-0.41***	0.45***	0.79***					
6. Severity	-0.34***	-0.35***	0.43***	0.80***	0.86***				
7. Stiffness	-0.31***	-0.29**	0.45***	0.74***	0.74***	0.74***			
8. Fatigue	0.29**	0.58***	-0.53***	-0.63***	-0.60***	-0.57***	-0.49***		
9. CB	0.42***	0.53***	-0.44***	-0.40***	-0.48***	-0.43***	-0.41***	0.49***	
10. PSS	0.06	0.02	-0.08	0.09	0.15	0.12	0.13	-0.08	0.01

*Note.* SWL=satisfaction with life, PA=positive affect, NA=negative affect, CB=control beliefs, PSS=perceived social support.  
 \* $p < 0.05$  \*\* $p < .01$  \*\*\* $p < .0001$ .

Analysis of covariance was performed to test for rheumatic group differences on the disease-related and psychosocial adjustment variables. Age, sex, self-reported mental health condition (binary variable recoded as 1=*yes*, 0=*no*), and employment status were controlled for on all between group comparisons. Differences between arthritis groups emerged suggesting that those with gout had significantly less disability on average than those with RA,  $t(7) = -0.52, p < .05$ , whereas the RA group had significantly greater disability than participants with AS,  $t(7) = 0.27, p < 0.05$ . Participants with gout reported experiencing more remissions (59.1%) than participants with RA (33.3%), AS (33.8%), and SLE (29.7%),  $\chi^2(3) = 12.06, p < .001$ , however, no differences in terms of experiencing a recent symptom flare-up were observed. In terms of quality of life, the gout group had higher overall quality of life than people with RA,  $t(3) = 1.27, p < .05$ , AS,  $t(3) = 1.48, p < .05$ , and SLE,  $t(3) = 1.59, p < .05$ . Finally, those with gout were more satisfied with their lives compared to people with AS,  $t(3) = 4.1, p < .05$ . No other significant differences between inflammatory rheumatic groups were demonstrated. The between group findings supported the creation of two binary variables (gout=1 other=0 and RA=1, other=0) to be tested as potential predictors of the trajectories identified in the GMM analyses.

### **Main analyses: Growth mixture modeling**

**Step 1: Selecting the unconditional model.** Growth models between one and six classes without covariates (unconditional models) were examined to identify the best fit of the data. The important fit indices for evaluating each model are summarized in Table 5. The lowest BIC value and significant BLRT suggested the four class model provided the best fit of the data. However, an evaluation of the other fit indices suggested that the 2

or 6 class solutions may also provide optimal fit. In particular, the 6 class solution resulted in the lowest ssBIC value, whereas the significant LMR test suggested the 2o class model best captured the data. To compare these results, the functional form of the two, four, and six class solutions were inspected by plotting the estimated means of each class across the repeated measures of satisfaction with life (Figure 2).

Table 6

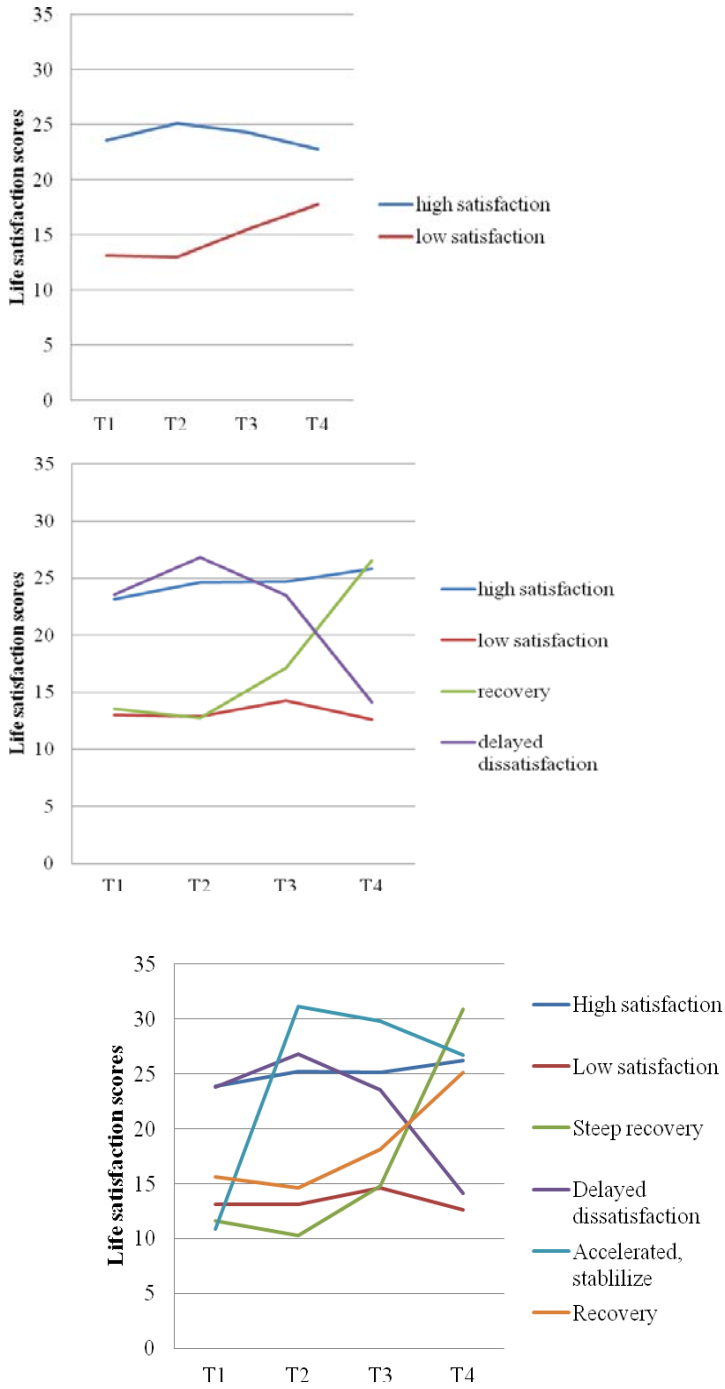
*Fit Indices for Unconditional Models with One to Six Classes*

Fit index	Growth mixture class solutions					
	1	2	3	4	5	6
-2LL	-3240.49	-3221.03	-3211.68	-3195.72	-3186.66	- 3180.20
BIC	6540.66	6525.63	6530.79	<b>6522.75</b>	6528.52	6539.47
ssBIC	6508.93	6481.21	6473.68	6452.94	6446.02	<b>6444.28</b>
LMR ( <i>p</i> -value)		<b>0.027</b>	0.189	0.124	0.083	0.121
BLRT ( <i>p</i> -value)		<0.001	<0.001	<0.001	untrustworthy	0.12
Entropy		0.64	0.63	0.57	0.58	0.62

*Note.* -2LL= Loglikelihood value; BIC=Bayesian Information Criterion; Adjusted BIC=Sample size adjusted bayesian information criterion; LMR=Lo-Mendell-Rubin likelihood ratio test; BLRT=Bootstrap likelihood ratio test. Bolded values reflect best fit according to fit criteria.



Figure 2. Two, four and six unconditional trajectory group models



*Figure 2.* These figures represent unconditional GMM models with two, four, and six trajectory groups. Mean life satisfaction scores are plotted by each of the four study time-points (T1, T2, T3, and T4). The two group model identified the high and low life satisfaction groups, whereas the four trajectory group model included the previously represented delayed onset and recovery patterns (Bonanno, 2004). The two additional groups uncovered in the six trajectory group model appear to represent only quantitative variations of the recovery trajectory rather than adding qualitatively different response patterns.

The additional classes uncovered in the six class solution contained only a small proportion of individuals from the overall sample ( $n=7$ ; 1.8% and  $n=2$ ; 0.5%). Recall that Nylund et al. (2007) recommended that class sizes under 5% should be interpreted with caution. Moreover, the six class model did not appear to add any unique information in terms of how individuals adjust to disease fluctuations over time in comparison to the four class solution. Relative to the four class model, the trajectory demonstrating a recovery pattern, which was characterized by lower scores initially with a steady increase over time, was split into three separate types of recovery patterns in the six class model, with the two new classes representing small proportions of individuals who either demonstrated accelerated or “steep” recovery over time or an initial accelerated recovery that leveled off after T2 (“accelerated, stabilized”). The two class model captured the more prevalent high and low dissatisfaction groups; however, these two trajectory groups were split in the four class model to include a recovery and a delayed dissatisfaction

response pattern, which have been identified previously (e.g., Bonanno et al, 2008; deRoon-Cassini et al., 2010; Norton et al., 2011).

The difference between the entropy values of the two, four, and six class models were nominal at 0.64, 0.57 and 0.62, respectively. These entropy values are moderate (Bauer & Curran, 2003a). Thus, consistent with hypothesis 1, the four latent class solution was selected as the most parsimonious and theoretically informative unconditional model for understanding different trajectories of life satisfaction exhibited by persons managing the daily stressors and chronic pain that accompanies inflammatory rheumatic disease.

### **The Final Unconditional Model**

Growth factor means and variances for the four trajectory group model are illustrated in Table 6. The first group, which was named “high satisfaction”, represented individuals with high, stable satisfaction with life over the four time points (33.1%). Intercept means and variances for this class were significant, indicating that although all individuals in this class started out with high life satisfaction, these initial scores varied significantly among the group. On the other hand, the slope means and variances for the high satisfaction class were not significant; demonstrating that life satisfaction scores for members of this group remained stable and did not change over the four study time points. The second class, called “recovery” (18.2%), was characterized by low life satisfaction scores that gradually increased at T3, recovering to a level of life satisfaction similar to the high satisfaction class at T4. Intercept and quadratic slope means and intercept variances were significant, suggesting that there was considerable variation among individuals in the recovery class in terms of their initial life satisfaction scores,

but that all members demonstrated approximately the same significant quadratic growth pattern over time.

Table 7

*Growth Factor Means and Variances for the Four Class Unconditional Model*

Class (%)	Intercept		Linear Slope		Quadratic Slope	
	<i>M</i>	<i>V</i>	<i>M</i>	<i>V</i>	<i>M</i>	<i>V</i>
<b>High</b>						
Satisfaction (33.1%)	23.2(0.99)**	11.7(3.48)*	1.4(1.19)	0.07(0.68)	-0.2(0.35)	-
Recovery (18.2%)	13.6(0.93)*	11.7(3.48)*	-3.5(1.08)*	0.07(0.68)	2.6(0.35)**	-
<b>Delayed</b>						
dissatisfac tion (9.1%)	23.6(3.09)**	11.7(3.48)*	6.5(3.59)	0.07(0.68)	-3.2(0.91)**	-
<b>Low</b>						
satisfaction (39.6%)	12.9 (0.62)**	11.7(3.48)*	0.4(0.84)	0.07(0.68)	-0.1(0.26)	-

*Note.* Standard errors are in parentheses. Intercept and linear slope variances were constrained equal across trajectory groups (a default assumption of GMM), quadratic variances were fixed to zero (-) to reduce model complexity and promote model convergence (Tofighi & Enders, 2007). *V*= variance estimates, \**p* =.001, \*\**p*<.001

The third and fourth classes represented two different patterns of poor adjustment over time. The third class, called “delayed dissatisfaction” (9.1%), started out with high life satisfaction at T1 and at T2, however, following T2, life satisfaction scores declined considerably. The final class was characterized by low, stable dissatisfaction scores over the course of the four study time points (39.6%; “low satisfaction”). In both classes the intercept means and variances were significant, suggesting that individuals varied with respect to their initial life satisfaction scores. The slope mean (but not variance) for the delayed dissatisfaction class demonstrated significant quadratic growth, showing that all individuals classified in the delayed dissatisfaction demonstrated the same trajectory of life satisfaction over the four month assessments. However, the slope mean and variance for the low satisfaction class were not significantly different from zero, again demonstrating that all individuals assigned to the low satisfaction class reported the same stable trajectory of low life satisfaction over time. Average posterior probabilities of class membership were high for each trajectory group, 0.89, 0.75, 0.95, 0.80, suggesting fairly good classification quality.

### **Assessing Normality Within Trajectory Groups**

Recall that life satisfaction scores within each trajectory group are assumed to be normally distributed. Histograms, skewness, and kurtosis values for each of the four trajectory groups identified in the final unconditional model were consulted to assess within class normality. Within class histograms and skewness values, which were below one at each time point, suggested that the assumption of within class normality was tenable. However, a moderate level of kurtosis (-1.210) was observed in life satisfaction at T4. Nylund and colleagues (2007) recommended relying more heavily on the BIC

when comparing models with differing numbers of groups, as this is the most robust index for detecting the true number of classes in smaller samples when departures from normality within class are minor.

### **Testing Invariance Assumptions in the Final Unconditional Model**

A four class model freely estimating class specific intercept, and linear and quadratic growth curves were compared to the class invariant model (i.e., when the growth factor variances assumed equal across classes) to assess model fit (Petras & Masyn, 2010). The Satorra-Bentler scaled chi-square difference test demonstrated that the class-specific model did not provide a superior fit of the data,  $\chi^2_{\text{diff}}(6) = 30.5, p = .10$ . However, the class specific four class model did reveal that linear and quadratic slope variances specific to each class did not significantly differ from zero, which is consistent with previous work (deRoos-Cassini et al., 2010). Freeing the linear slope parameter did not improve model fit,  $\chi^2_{\text{diff}}(2) = 0.27, p > .02$ , therefore, the linear and quadratic slope variances were fixed to zero when estimating the conditional models (models with covariates) in order to reduce model complexity and increase the likelihood of converging on a proper solution.

### **Step 2: Introducing Covariates (Conditional Models)**

Positive and negative affect were included in the model separately in order to investigate how positive and negative emotions impacted life satisfaction ratings separately. Invariance assumptions also were tested for each conditional model. However; all models in which the intercept was freely estimated within each trajectory group resulted in a model that did not converge on a proper solution. Accordingly, these models were not included in evaluating the best fitting conditional models. Results from

the best fitting positive affect conditional model (PA-only model) and negative affect conditional model (NA-only model) are illustrated in Table 7.

**PA-only model.** The model in which the influence of positive affect on life satisfaction was assumed to be constant across trajectory groups provided optimal fit of the data compared the model in which these direct effects were freely estimated within each class,  $\chi^2_{\text{diff}}(12)=17.54, p > .10$ . In other words, although the extent to which an individual experiences positive emotions can change at each monthly data collection, the estimated relationship between positive emotions and evaluations of life satisfaction is assumed to be the same across time and across trajectory groups (Raudenbush & Bryk, 2002). More specifically, and consistent with previous research, experiencing more positive emotions significantly predicted higher evaluations of life satisfaction at each corresponding time point,  $\beta_{\text{range}}=0.44- 0.29, ps<.001$ , which resulted in adjusting the intercept and slope factor means in each trajectory class compared to the unconditional model (Table 7; Davis et al., 2007; Hamilton et al., 2005; Zautra & Smith, 2008;). Adjusting for monthly positive affect scores demonstrated no changes to the structure and meaning of the original four trajectory classes.

As predicted in hypothesis 2, maintaining a greater amount of positive emotions characterized the high satisfaction class compared to the other three trajectory groups, whereas the low satisfaction group maintained the lowest life satisfaction scores (Figure 3). Both the recovery and delayed dissatisfaction trajectories frequently experienced positive emotions, though at some months more than others. A visual inspection of Figure 3 revealed that the recovery group experienced the highest level of positive emotions at T4, whereas the delayed dissatisfaction group experienced more positive

affect in the first two months of the study, and then declining levels of positive emotions were seen in the latter half of the study. Shifts in positive emotions were consistent with the respective growth in life satisfaction demonstrated by the recovery and delayed dissatisfaction groups.

**NA-only model.** Similar to the PA-only model, the model in which the time-varying indicators of negative affect were constrained equal across classes provided optimal fit of the data compared to the class-specific model,  $\chi^2_{\text{diff}}(12)=19.56, p=.075$ . Consistent with previous research (e.g., Luhmann, Hoffmann, Eid, & Lucas, 2012), experiencing more negative emotions significantly predicted lower evaluations of life satisfaction at each time point ( $\beta_{\text{range}} = -.49- -.29, ps < 0.001$ ), which adjusted the growth factor means in each trajectory class compared to the unconditional model (Table 7). However, unlike the influence of positive affect, including negative affect altered the form of the identified trajectory groups and the class distributions (Figure 4).

For example, the eventual decline in life satisfaction exhibited by the few individuals populating the delayed dissatisfaction group in the unconditional model (9.1%) now characterized over a third of the sample (31.1%) when life satisfaction ratings were adjusted for monthly negative affect scores. The opposite trend was observed for those in the stable high satisfaction trajectory in that significantly fewer individuals were assigned to this group (9.3%) compared to the equivalent group identified in the unconditional model (33.1%).



Table 8

*Means and Standard Error Estimates of Growth Parameters for the Unconditional and Conditional Models*

	Unconditional model			
	Low (39.6%)	High (33.1%)	Recovery (18.2%)	Delayed (9.1%)
Intercept	12.9(0.62)**	23.2(0.99)**	13.6(0.93)**	23.6(3.09)**
Linear slope	0.3(0.84)	1.4(1.89)	-3.5(1.08)*	6.4(3.59)
Quadratic slope	-0.1(0.26)	-0.2(0.35)	2.6(0.35)**	-3.2(0.91)**
	PA-only model			
	Low (43.5%)	High (31%)	Recovery (18.2%)	Delayed (7.3%)
Intercept	13.8(0.51)**	23.1(0.89)**	13.6(0.94)	24.2(1.87)**
Linear slope	0.9(0.88)	1.2(1.24)	-1.8(1.37)	4.3(2.32)
Quadratic slope	-0.3(0.31)	-0.1(0.39)	2.0(0.47)**	-2.5(0.68)**
	NA-only model			
	Low (31.1%)	High, reducing (31.3%)	Recovery (28.3%)	Stable, intermediate (9.1%)
Intercept	13.5(0.84)**	20.9(2.24)**	14.31(0.93)	23.1(0.89)
Linear slope	0.5(1.27)	3.3(3.1)	-1.3(1.19)	1.9(1.06)
Quadratic slope	0.4(0.47)	-0.7(1.01)	0.9 (0.37)*	-0.8(0.31)*

\*\* $p < .001$ . \* $p = .01$ .

Figure 3. Monthly positive affect scores by trajectory group

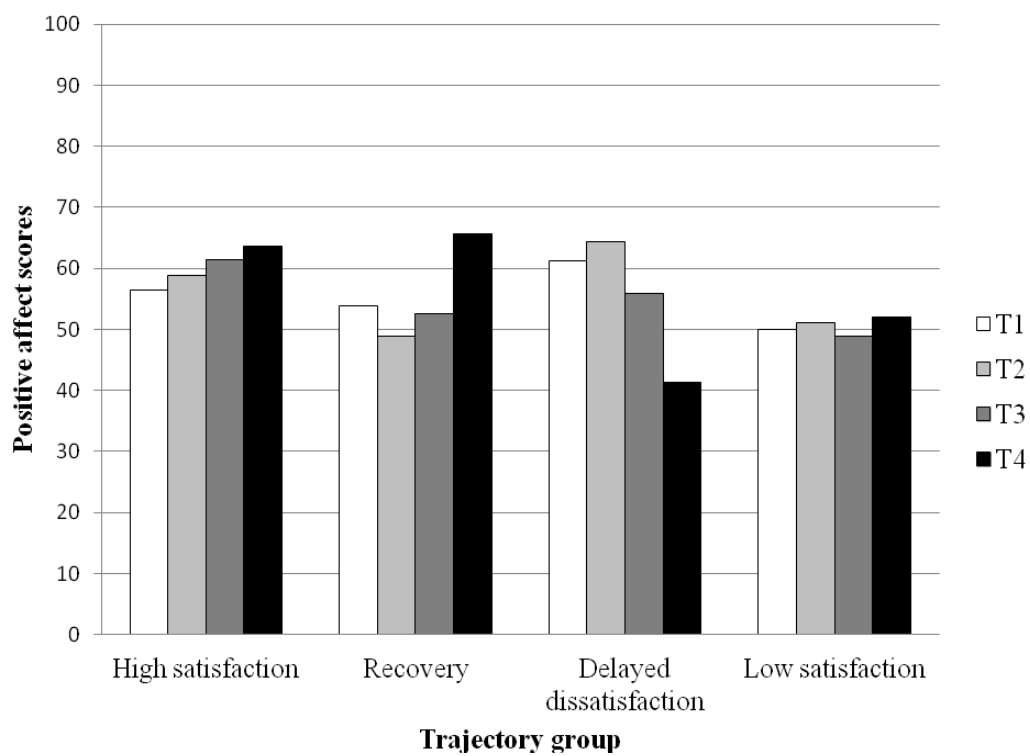
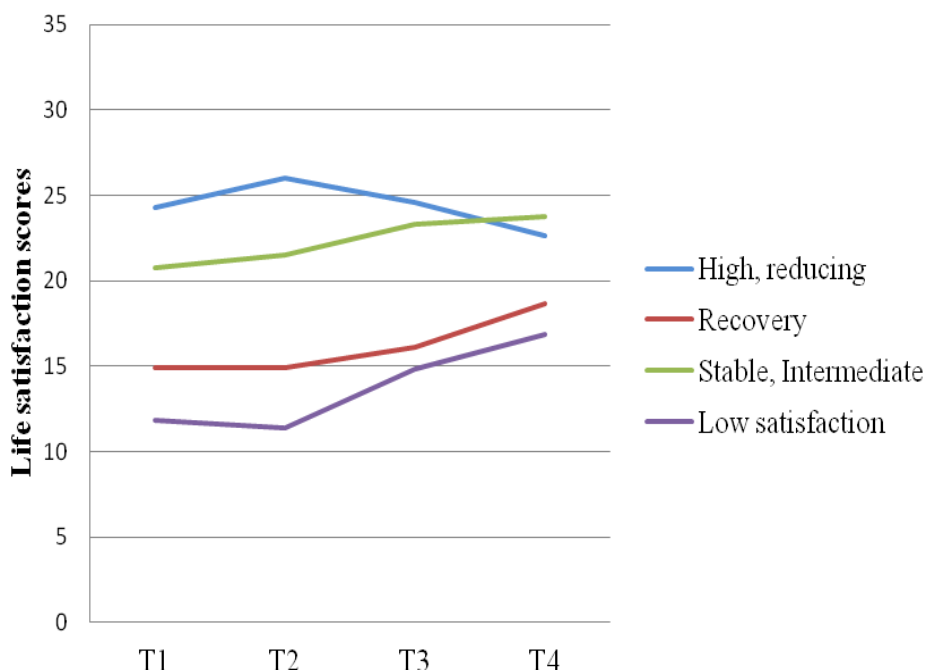


Figure 3. Monthly positive affect score are plotted by time point within each trajectory group.

Figure 4. Life satisfaction trajectories adjusted by monthly negative affect scores



*Figure 4.* This figure depicts the NA-only conditional model in which monthly scores on negative affect were directly predicting concurrent ratings of life satisfaction. Mean life satisfaction ratings are plotted by time point, and the four trajectory groups reflect a high, reducing pattern, a recovery pattern, a stable, intermediate life satisfaction pattern, and a low satisfaction pattern.

Furthermore, the negative growth demonstrated by the delayed dissatisfaction group was much more muted compared to the unconditional delayed dissatisfaction trajectory, demonstrating a response pattern marked by initially high life satisfaction that gradually reduced after T2 (Figure 4, “high, reducing”). Adjusting for concurrent negative affect resulted in overall lower monthly life satisfaction scores in the high satisfaction group such that the high group now represented a “stable, intermediate” level

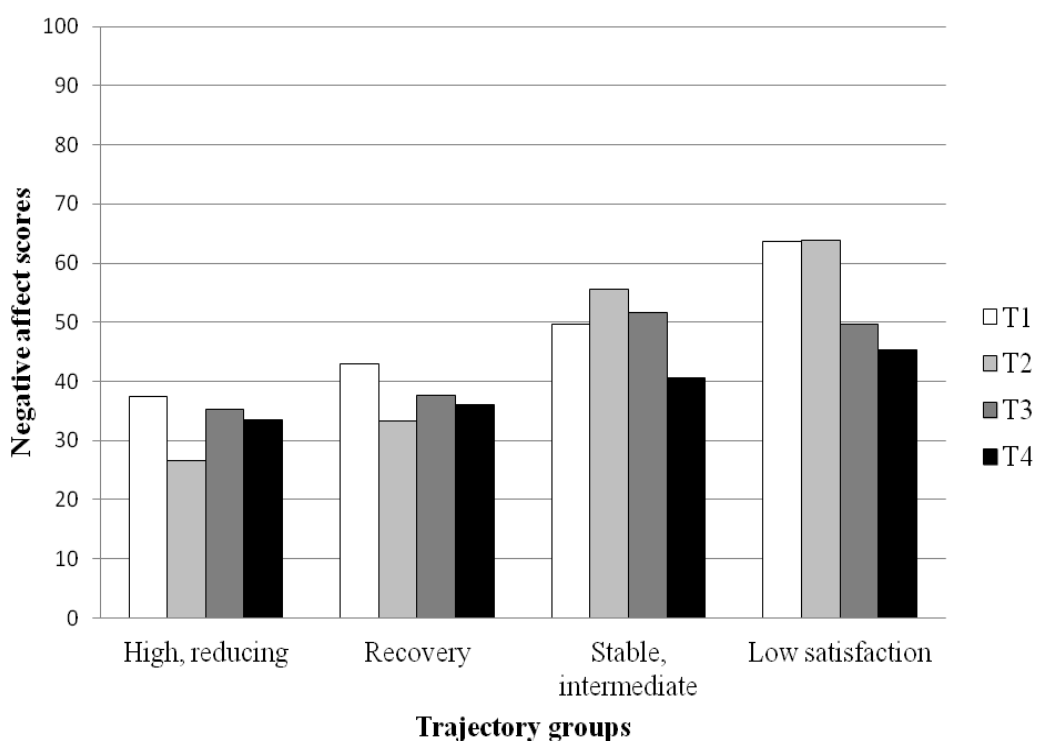
of life satisfaction similar to findings reported by van Leeuwen et al. (2011). The changes sustained by the delayed dissatisfaction and high satisfaction groups when concurrent negative affect was considered suggested that the new trajectory groups, that is, “high, reducing” and “stable, intermediate,” may represent a mixture of group members from the original delayed and high satisfaction groupings. Moreover, the gradual decline in life satisfaction represented by the “high, reducing” group, and downward adjustment of the mean initial (intercept) life satisfaction rating reported by the “stable, intermediate” group suggested that experiencing negative emotions decreased satisfaction with life.

The “recovery” trajectory demonstrated positive quadratic growth in life satisfaction over time, although similar to the high, reducing group, the estimated curve shape ( $M = 0.9$ ) was flatter compared to the growth exhibited in the unconditional recovery group ( $M = 2.6$ ), suggesting that the influence of negative affect slowed the potential growth in life satisfaction. Also similar to the high, reducing group, far more individuals were classified in this recovery trajectory than in the equivalent unconditional model group (28.3% vs. 18.2%, respectively). The higher proportion of recovered individuals is once more consistent with van Leeuwen et al. (2011), who found a similar proportion of recovered SCI patients (23.0%). Consistent with the unconditional model findings, the “low satisfaction” group did not display significant growth in life satisfaction over the four study time points; however, the conditional model low satisfaction group was comprised of slightly fewer individuals (31.1%) than the low satisfaction group in the unconditional model (39.6%).

Mean scores for negative affect by trajectory group are graphically displayed in Figure 7. In particular, consistent with hypothesis 2, people in the high, reducing

trajectory group reported experiencing fewer negative emotions compared to the low and intermediate trajectory groups. The recovery class also reported experiencing fewer negative feelings, although these individuals did experience negative emotions slightly more often than the high, reducing class. The low satisfaction and intermediate satisfaction trajectory groups experienced the highest amount of negative emotions over the course of the study. In particular, the low class reported high negative affect at the beginning of the study, which started to decline by T3 and T4.

Figure 5. Negative affect scores by trajectory group (NA-only model)



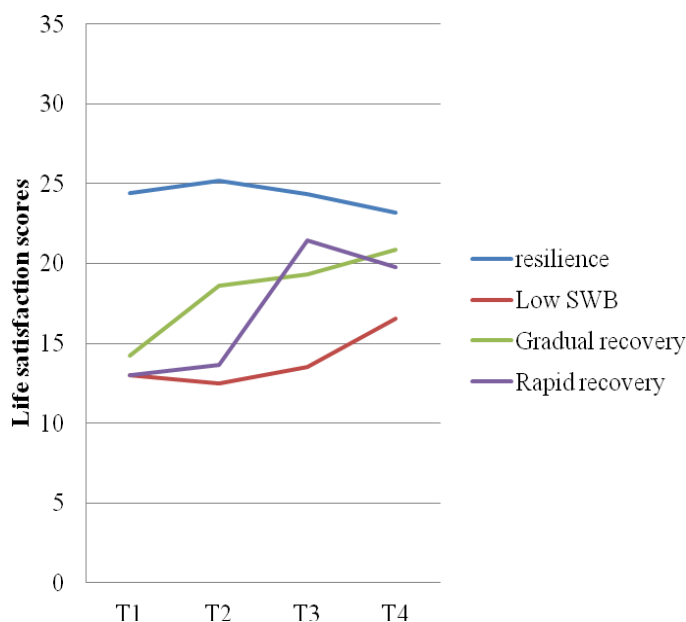
*Figure 5.* This graph represents average monthly negative affect scores at each time point within trajectory groups.

### Final Conditional Model

A final conditional model was run in which both monthly positive affect and negative affect indicators were included. The changes uncovered in the NA-only model suggested that a model in which both positive and negative affect were included would also likely result in altered trajectory groups compared to the unconditional model.

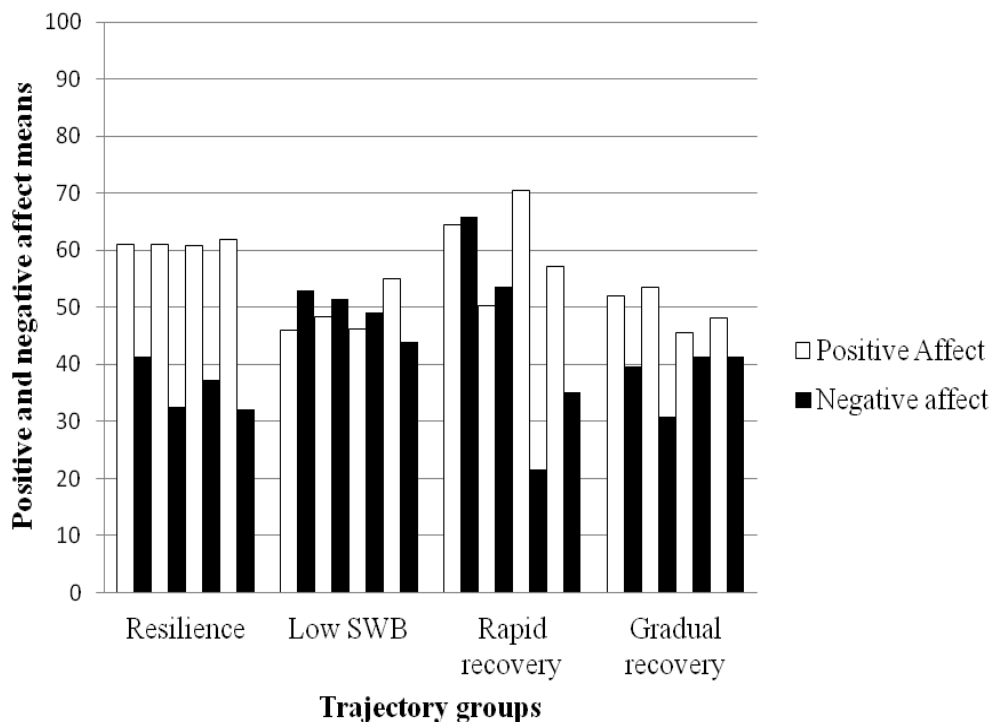
The model in which the relationships between emotions and life satisfaction were estimated within each trajectory group provided superior fit,  $\chi^2_{\text{diff}}(6)=24.08, p<.001$  compared to the model in which these relationships were assumed to be constant across trajectory classes. Correlations among the monthly indicators of positive and negative affect were also estimated. The final model is presented in Figure 5, descriptive information for positive and negative affect are illustrated in Figure 6, and model estimates are provided in Table 8.

Figure 6. The final trajectory model including positive and negative affect



*Figure 6.* This graph represents the final conditional model, in which life satisfaction ratings are adjusted for concurrent positive emotions and negative emotions at each time point. Direct effects between positive affect and life satisfaction scores and between negative affect and life satisfaction scores are freely estimated within each of the four trajectory groups.

Figure 7. Positive and negative affect means at each of the four time points by trajectory groups



*Figure 7.* This figure presents average positive and negative affect scores at each time point by final conditional trajectory groups. The white bars denote the four monthly positive affect scores, whereas the shaded bars denote monthly negative affect scores.



Table 9

*Means and Standard Errors of Growth Factors and Standardized Regression Estimates for Final Conditional Model*

Estimate	Low SWB (39.6%)	High SWB (33.1%)	Gradual recovery (18.2%)	Rapid recovery (9.1%)
Intercept (M)	14.4(0.77)***	23.1(0.62)***	15.0(3.56)***	13.8(1.24)***
Linear slope	-1.2(0.92)	0.9(1.19)	5.6(2.01)**	-2.1(1.73)
Quadratic slope	0.8(0.24)**	-0.5(0.39)	-0.8(0.67)	1.3(0.59)*
PA1 ON SWL1	0.33**	0.18	0.46	0.23
PA2 ON SWL2	0.33**	0.36***	0.9***	0.41
PA3 ON SWL3	0.25*	0.34**	0.77**	0.63***
PA4 ON SWL4	0.53***	0.50***	0.45**	0.57**
NA1 ON SWL1	-0.47***	-0.47***	0.25	-0.34
NA2 ON SWL2	-0.38***	-0.39**	0.10	0.32
NA3 ON SWL3	-0.34***	-0.42**	-0.13	-0.32*
NA4 ON SWL4	-0.24	-0.24	-0.46	-0.71***

*Note.* SWB = subjective well-being; PA=Positive Affect, NA=Negative Affect; SWL=Satisfaction with life. \*\*\* $p < .001$ , \*\* $p < .01$ , \* $p < .05$

The trajectory groups in the final model represented the joint effect of positive and negative emotions and growth in life satisfaction (Bollen & Curran, 2008). Stated differently, the model reflected the influence of the affective components of SWB on initial status and growth in life satisfaction over time. The latent class variable was then represented by these associations. In the present study, resilience was defined as maintaining high life satisfaction, experiencing highly frequent pleasant emotions, and

fewer negative emotions (the model of SWB; Diener, 1984). By this definition, and consistent with hypothesis 2, 37.5% of the sample demonstrated “resilience” to managing the on-going stressors of living with inflammatory rheumatic disease. A greater proportion of individuals in the current sample (42.8%) followed a “low SWB” trajectory which was characterized by low life satisfaction and experiencing greater negative than positive emotions. Interestingly, significant and positive quadratic growth was uncovered in the low SWB group when both positive and negative affect were included, corresponding to a slight improvement in well-being at the end of the four months. The improvement in life satisfaction in the low SWB group at T4 was in accordance with the descriptive information depicted in Figure 10, which showed that individuals in the low SWB group experienced greater positive emotions than negative emotions at T4. This positive growth pattern also corresponded with the NA-only model in which mean levels of negative affect decreased at T3 and T4 in the low satisfaction class.

Two different recovery trajectories emerged from the final conditional model. The first recovery group, called “gradual recovery” (11.3%), exhibited a trajectory pattern characterized by significant linear growth in life satisfaction, and experiencing more positive emotions than negative emotions at each time point (Figure 9). The second recovery group identified in the final model demonstrated a rapid recovery pattern (8.4%), which transpired between T2 and T3, but stabilized at T4. Descriptive information presented in Figure 10 showed that the rapid recovery group experienced more negative than positive emotions at T1 and T2, as well as less positive and more negative emotions at T4 compared to T3. These two types of recovery patterns, gradual and rapid, have been demonstrated previously (Deshields et al., 2006; Helgeson et al.,

2004). Though less prevalent than the high and low classes, the presence of differing recovery trajectories is consistent with research suggesting that psychological adjustment to inflammatory rheumatic disease is an ongoing and dynamic process (Stanton et al., 2007).

Results shown in Table 8 revealed that positive and negative affect were associated with life satisfaction ratings in the expected directions in both the resilient and low SWB groups. Interestingly, when gains in life satisfaction occurred in the low SWB, gradual recovery, and rapid recovery groups, only positive affect significantly predicted higher satisfaction ratings. In particular, negative affect was a strong predictor of life satisfaction at T1, T2, and T3 in the low SWB group; however, at T4, positive affect and not negative affect predicted life satisfaction, which corresponded with positive growth in life satisfaction at the end of the study period. Experiencing positive affect at T2, T3, and T4 predicted higher life satisfaction in the gradual recovery class, which was dominated by positive, linear growth over the course of the study, particularly at T2. Finally, the greatest improvement in life satisfaction in the rapid recovery trajectory occurred at T3, at which time only positive affect significantly predicted higher life satisfaction ratings. The significant influence of positive emotions was maintained at T4 in the rapid recovery group; however, negative affect was more strongly associated with life satisfaction at T4 in this group, which may have contributed not only to curbing the growth of life satisfaction, but also potentially slightly reducing it.

### **Class Membership Agreement**

Introducing covariates also had some impact on individual trajectory group membership. Table 9 presents the level of classification agreement between the

unconditional and conditional models based on an individual's most likely group membership. The resilient and low SWB groups proved to be the most stable, with 84.1% and 85.6% of participants assigned to the same class in the unconditional model. This is consistent with previous literature suggesting that life satisfaction ratings remain fairly stable over time (Gana et al., 2013). Many (45.8%) individuals classified in the gradual recovery trajectory were originally classified in the low satisfaction unconditional group, whereas 25% transitioned from the high satisfaction unconditional group to the gradual recovery conditional class when emotions were included in the model. The majority of participants in the rapid recovery group were classified in the low satisfaction class originally (63.6%), and several individuals moved to the rapid recovery group from the unconditional recovery group (27.7%).

Table 10

*Classification Agreement among Unconditional and Conditional Trajectory Classes**Based on Most Likely Class Membership*

Conditional model groups	Unconditional model trajectory groups				Total
	Recovery	Low satisfaction	High satisfaction	Delayed dissatisfaction	
Gradual Recovery	6	11	6	1	24
%	1.53	2.81	1.53	0.26	6.14
row%	25	45.83	25	4.17	
column%	18.75	5.7	4.08	5.26	
Low SWB	20	161	7	0	188
%	5.12	41.18	1.79	0	48.08
row%	10.64	85.64	3.72	0	
column%	62.5	83.42	4.76	0	

(continued)

Table 10  
*Classification Agreement among Unconditional and Conditional Trajectory Classes*

*Based on Most Likely Class Membership*

Conditional model groups	Unconditional model trajectory groups				Total
	Recovery	Low satisfaction	High satisfaction	Delayed dissatisfaction	
High SWB	0	7	132	18	157
%	0	1.79	33.76	4.6	40.15
row%	0	4.46	84.08	11.46	
column%	0	3.63	89.8	94.74	
Rapid Recovery	6	14	2	0	22
%	1.53	3.58	0.51	0	5.63
row%	27.27	63.64	9.09	0	
column%	18.75	7.25	1.36	0	
Total	32	193	147	19	391

### **Examining the Validity**

The current study conducted two validity checks to ensure the validity and practical utility of the four trajectory groups uncovered in the final model (Li & Hser, 2011; Muthén, 2004). First, the trajectory profiles were related to theoretically important predictor variables and distal outcomes. Second, the four group conditional model was compared to other conditional models with differing numbers of classes, much like the class enumeration process performed to fit the unconditional model (Li & Hser, 2011; Muthén, 2004; Tofighi & Enders, 2007) to examine whether the final four group model remained the best fitting model.

### **Criterion and Predictive Validity**

In the first check, the four trajectory profiles were validated by relating conditional group membership to risk and resilience resources, and T5 and T6 SWB

outcomes (Muthén, 2004). Typically, in previous research, secondary analyses investigating class differences are performed by saving a participant's most likely class membership based on posterior probabilities, and then applying a series of multinomial logistic regressions or ANOVAs to uncover group differences (e.g., Bonanno et al., 2008; deRoon-Cassini et al., 2010; Norton et al., 2011; van Leeuwen et al., 2011). However, an emerging area of literature suggested that this method can distort between group differences and produce biased standard errors when class membership is treated as a "fixed" or an observed variable (Asparouhouv & Muthén, 2007; Clark & Muthén, 2009, McIntosh, 2013). Instead, Clark and Muthén (2009) recommend conducting pseudo-class draws in which random draws from each individual's posterior probability distribution are made to establish class membership. Based on these draws, tests for equality of means are then calculated (Clark & Muthén, 2009). The AUXILIARY (e) function provided by Mplus performed pseudo-class Wald chi-square tests to examine whether other demographic, disease-related, psychological, or social contextual variables significantly differentiated trajectory groups in terms of mean differences (research question 3). However, one limitation of the auxiliary function in Mplus is that categorical variables can only be binary level data, thus follow-up chi-square tests to examine between group differences based on individuals' most likely class membership were performed to account for important predictor variables with more than two categories. Descriptive profiles for the four trajectory classes are presented in Table 13 and Table 14. Given the exploratory nature of the present investigation and the low sample sizes found in the recovery and declining SWB groups, no corrections to Type 1 error were applied. Therefore, the findings presented below should be interpreted with caution.

### SWB at T5 and T6

At T5, the resilient class displayed higher scores on life satisfaction ( $M= 24.7, SD = 0.78$ ) compared to the gradual recovery class ( $M= 21.4, SD= 1.52$ ), the rapid recovery class ( $M= 20.7, SD=1.71$ ) and low SWB group ( $M= 14.8, SD =0.80$ ). Significant differences between the gradual recovery and low SWB classes, as well as the rapid recovery and low SWB classes were observed with respect to life satisfaction. These patterns remained at T6, with the exception that no differences in life satisfaction were revealed between the gradual recovery and resilient groups.

Differences between the trajectory classes were observed for positive affect at T5 such that the resilient class reported experiencing more positive emotions ( $M=64.6, SD= 2.17$ ) relative to the low SWB group ( $M=51.9, SD = 2.14$ ). A trend toward significance ( $p=.068$ ) suggested that the rapid recovery class reported experiencing more positive emotions ( $M=62.9, SD = 5.56$ ) compared to the low SWB class. However, no differences in positive affect were observed between the gradual recovery class ( $M = 56.9, SD = 4.25$ ) and the other three trajectory groups at T5. Differences in positive affect at T6 were found between the resilient ( $M =65.5, SD = 2.27$ ) and gradual recovery groups ( $M =55.4, SD = 4.58$ ) as well as between the resilient and low SWB groups ( $M =52.3, SD =2.64$ ). No differences were observed between the rapid recovery class ( $M =64.6, SD = 7.64$ ) and the resilient class at T6.

Additionally, the resilient class experienced fewer negative emotions ( $M = 30.3, SD =2.03$ ) compared to the rapid recovery ( $M =44.24, SD = 6.73$ ) and low SWB groups ( $M =45.3, SD= 2.71$ ) at T5, whereas no differences between the resilient and gradual recovery class ( $M =35.8, SD =4.22$ ) were observed. Differences in negative affect were

found between the resilient ( $M=28.7$ ,  $SD=1.90$ ) and low SWB groups ( $45.7$ ,  $SD=2.86$ ) at T6. Differences in negative affect were not found between the resilient class and the gradual recovery class ( $M=35.4$ ,  $SD=4.20$ ) at T6, or between the rapid recovery ( $M=35.6$ ,  $SD=7.24$ ) and gradual recovery groups. A trend toward significance suggested that the gradual recovery group experienced fewer negative emotions at T5 and T6 compared to the low well-being group ( $p=0.065$  and  $p=0.058$ , respectively).

Table 11  
*Demographic Profiles by Trajectory Class*

Trajectory group	Gradual Recovery ( $n=24$ )	Low SWB ( $n=188$ )	Resilient ( $n=157$ )	Rapid Recovery ( $n=22$ )
Age				
Mean (SD)	43.4(2.87)	45.5(1.21)	44.0 (1.36)	44.3(2.98)
Arthritis type (%)				
RA	25%	27.60%	23.50%	22.70%
AS	58.30%	43.60%	42.40%	54.60%
SLE	16.70%	19.10%	19.10%	9.10%
Gout	0%	10.60%	15.30%	13.60%
Sex				
female (n%)	20(83.3)	131(73.6)	114(80.3)	13(68.4)
Ethnicity				
Caucasian	19(86.4)	133(82.1)	112(86.8)	15(79.0)
other	3(13.6)	29(17.9)	17(13.2)	4(21.1)
Education				
above median	17(70.8)	89(47.3)	87(55.4)	10(45.5)
below median	7(29.2)	88(46.8)	56(35.7)	9(40.9)
Marital status				
Married/cohabiting	17(70.8)	105(59.7)	100(70.4)	14(73.7)
Single/Separated/Divorced/Widowed	7(29.2)	71(40.3)	42(29.6)	5(26.3)

(continued)



Table 11  
*Demographic Profiles by Trajectory Class*

Trajectory group	Gradual Recovery (n=24)	Low SWB (n=188)	Resilient (n=157)	Rapid Recovery (n=22)
Co-morbid mental health issue				
yes	12(50.0)	78(41.5)	43(27.4)	10(45.4)
no	12(50.0)	110(58.5)	114(72.6)	12(54.6)
Income				
above median	13(54.2)	71(42.0)	76(56.3)	9(50.0)
below median	11(45.8)	98(58.0)	59(43.7)	9(50.0)
Flares				
yes	19(79.17)	160 (85.11)	116(73.89)	20(90.91)
no	5(20.83)	22(11.70)	32(20.38)	0
missing	0	6(3.19)	9(5.73)	2(9.09)
Employment				
Full-time	135(31.25)	35(32.4)	66(34.6)	21(26.6)
Not full-time	168(38.89)	51(47.2)	63(33.0)	28(35.4)
Remissions				
yes	9(37.5)	63(34.6)	58(39.2)	4(20.0)
no	15(62.5)	119(65.4)	90(60.8)	16(80.0)
Medication relief				
Mean(SE)	5.7(0.35)	5.5(0.18)	6.4(0.22)	5.4(0.38)
Years since diagnosis				
5 or less	10(43.5)	88(47.8)	86(56.2)	12(54.6)
more than 5	13(56.5)	96(52.2)	67(43.8)	10(45.4)
Mean(SD)	9.3(7.46)	9.4(9.3)	7.8(8.6)	6.8(5.7)
Reported at least 1 major life event				
T1	19(79.2)	137(72.9)	101(64.3)	16(72.7)
T2	16(72.73)	63(61.2)	52(53.1)	8(50.0)
T3	16(80.0)	47(59.5)	51(61.5)	10(66.7)
T4	8(47.1)	43(62.3)	44(61.1)	5(38.5)

### **Demographic Characteristics among Trajectory Groups**

No differences were found among the four classes in terms of age, sex, marital status, ethnicity, education, concurrent mental health condition or years since diagnosis. However, the descriptive statistics shown in Table 13 demonstrated that a greater proportion of people in the resilient and rapid recovery groups were married and more recently diagnosed. Respondents in the low SWB class reported lower income than the resilient class ( $p=.018$ ). Participants with RA, AS, SLE or gout were fairly evenly distributed among the four trajectory groups, although notably no individuals with Gout were classified in the gradual recovery class. For the most part, over 50% of participants in each class had experienced at least one other major life event during the study.

### **Psychosocial Characteristics**

Between group differences revealed that the resilient class was significantly more optimistic than the gradual recovery, rapid recovery, and low SWB groups. A trend toward significance indicated that individuals in the low SWB group were more likely to report a concurrent mental health disorder compared to the resilient class ( $p=0.059$ ). The resilient class also had greater beliefs about personal control compared to the low SWB group at all time points, the gradual recovery class at T2, and the rapid recovery group at T2 and T5. No differences in terms of perceptions about social support were observed.

### **Disease-Related Contextual Variables**

In terms of the disease-related risk factors several important patterns emerged. Overall, the resilient class reported less disability, less disease activity, and less pain compared to the low SWB group at T1, T2, and T3. The resilient class also reported less disability, less disease activity, and less fatigue compared to the rapid recovery class at

T1 and T2, and less pain than the gradual recovery class at T1. No differences in disease activity were reported at T4.

In particular, the resilient class reported lower pain at T1 relative to the other three trajectory classes, however these differences had attenuated between the resilient and gradual recovery class by T2, and only a trend toward significance was observed suggesting that the low SWB class had greater pain compared to the resilient class at T3 ( $p=0.06$ ). No differences between trajectory classes in terms of pain levels were observed at T4, although differences between the resilient and low SWB group did emerge again at T5. In addition, the resilient class reported less symptom discomfort and severity compared to the low SWB and rapid recovery classes at T1, and also relative to the low SWB group at T5. More participants in the rapid recovery group reported experiencing a disease flare 30 days prior to participation in the study compared to the resilient and gradual recovery groups. At T2, the low SWB and rapid recovery groups reported significantly greater fatigue relative to resilient individuals. However, at T3 individuals in the rapid recovery group reported a surge in energy compared to the other three trajectory classes. Finally, participants in the resilient trajectory group reported that their medications provided greater relief from disease symptoms compared to those in the low SWB and rapid recovery trajectory classes, whereas the gradual recovery trajectory class reported less symptom severity, discomfort, and stiffness at T5 relative to the low SWB class.

Table 12  
*Means and Standard Errors for Time Invariant and Time-varying Psychological, Social,  
 and Disease-related Variables by Trajectory Class*

	Gradual recovery ( <i>n</i> =24)	Low SWB ( <i>n</i> =188)	Resilient ( <i>n</i> =157)	Rapid recovery ( <i>n</i> =22)
Time invariant				
Optimism	16.3(1.0)	18.1(0.5)	12.6(0.45)	19.0(1.14)
Disability	1.0(0.11)	1.1(0.05)	0.8(0.05)	1.1(0.12)
Time-varying				
Pain				
T1	62.3(4.49)	64.4(2.07)	52.2(2.47)	68.5(4.72)
T2	54.1(5.95)	61.1(2.52)	48.7(3.0)	59.9(5.4)
T3	56.7(6.0)	59.2(2.83)	48.4(2.94)	55.6(5.94)
T4	50.6(6.61)	56.2(3.15)	50.4(2.93)	44.6(7.59)
T5	44.9(6.46)	57.1(3.19)	44.1(3.31)	58.7(8.1)
T6	53.1(8.1)	55.5(3.76)	43.4(3.66)	6.3(0.72)
Discomfort				
T1	7.2(0.32)	7.5(0.15)	6.7(0.20)	7.5(0.37)
T2	6.7(0.40)	7.0(0.21)	6.3(0.25)	6.8(0.42)
T3	6.3(0.49)	6.9(.23)	6.1(0.25)	6.5(0.43)
T4	5.9(0.61)	6.6(0.24)	5.9(0.25)	5.8(0.6)
T5	5.6(0.54)	6.9(0.26)	5.8(0.3)	6.7(0.78)
T6	5.8(0.76)	6.6(0.32)	5.4(0.33)	5.8(0.82)
Symptom severity				
T1	6.4(0.36)	6.9(0.16)	6.1(0.20)	7.0(0.39)
T2	6.0(0.43)	6.3(0.22)	5.6(0.27)	6.3(0.48)
T3	5.8(0.52)	6.4(0.23)	5.5(0.24)	5.7(0.56)
T4	5.3(0.60)	6.2(0.25)	5.4(0.25)	5.2(0.66)
T5	5.0(0.58)	6.4(0.26)	5.2(0.31)	6.0(0.75)
T6	5.1(0.75)	6.2(0.31)	4.6(0.30)	5.4(0.85)
Stiffness				
T1	6.9(0.42)	7.2(0.19)	6.1(0.23)	7.0(0.46)
T2	5.9(0.57)	6.7(0.24)	6.0(0.28)	6.4(0.57)
T3	6.1(0.59)	6.7(0.26)	5.5(0.30)	6.8(0.61)
T4	5.5(0.70)	6.4(0.30)	5.5(0.31)	5.6(0.73)
T5	5.3(0.65)	6.8(0.30)	5.4(0.34)	6.3(0.76)
T6	5.0(0.80)	6.1(0.35)	5.0(0.35)	6.1(0.72)

(continued)

Table 12  
*Means and Standard Errors for Time Invariant and Time-varying Psychological, Social,  
 and Disease-related Variables by Trajectory Class*

	Gradual recovery (n=24)	Low SWB (n=188)	Resilient (n=157)	Rapid recovery (n=22)
<b>Fatigue</b>				
T1	4.5(0.60)	4.3(0.64)	4.6(0.80)	4.4(0.80)
T2	3.5(0.37)	3.4(0.18)	4.2(0.18)	3.2(0.38)
T3	3.1(0.40)	3.3(0.18)	4.2(0.21)	5.4(0.50)
T4	3.5(0.41)	3.9(0.24)	4.2(0.22)	4.0(0.47)
T5	4.1(0.46)	3.7(0.23)	4.5(0.24)	4.4(0.60)
T6	4.3(0.59)	4.2(2.26)	4.5(0.23)	5.0(0.68)
<b>Control</b>				
T1	4.9(0.39)	4.5(0.17)	5.5(0.18)	4.9(0.47)
T2	5.0(0.38)	4.7(0.19)	6.0(0.19)	5.0(0.42)
T3	5.2(0.42)	4.8(0.21)	5.5(.21)	5.2(0.53)
T4	5.1(0.46)	4.8(0.25)	5.4(0.24)	4.7(0.51)
T5	5.6(0.43)	5.0(0.25)	5.8(0.23)	4.6(0.51)
T6	5.4(0.57)	5.1(0.25)	5.9(0.27)	5.2(0.66)
<b>Perceived Support</b>				
T1	6.13(0.55)	5.8(0.25)	5.4(0.28)	6.2(0.6)
T2	6.0(0.67)	5.5(0.28)	6.2(0.31)	5.8(0.67)
T3	4.7(0.71)	5.9(0.33)	5.6(0.36)	5.5(0.79)
T4	6.1(0.72)	5.8(0.37)	5.6(0.37)	5.6(0.74)
T5	6.1(0.63)	6.2(0.35)	5.7(0.29)	6.3(0.76)
T6	6.7(0.67)	6.0(0.38)	5.9(0.42)	6.3(0.72)

SWB = subjective well-being.

### **Confirming the Validity of the Final Trajectory Groups**

The final step in confirming the validity of the final four group solution was to compare conditional models with differing numbers of classes to determine if the four trajectory group model remained the best fit of the data after time-varying positive and negative affect covariates were included. Muthén (2004) argued that researchers should not assume that class distributions or class membership will remain the same after

covariates have been added to the model. A recent simulation study conducted by Li and Hser (2011) confirmed this point, finding that models including covariates outperformed unconditional models in terms of uncovering the true number of trajectory classes. Specifically, Li and Hser (2011) found that the BIC and BLRT performed well in choosing the correct number of trajectory groups in conditional models when sample sizes were smaller (e.g.,  $N=400$ ). On the other hand, Tofigihi and Enders (2007) found the ssBIC to outperform the other fit indices when evaluating the best fitting conditional model.

Following the same process as evaluating unconditional models, GMM conditional models with one to six classes were assessed for optimal fit. Based on findings from the unconditional models, the model with two trajectory groups (e.g., high and low satisfaction scores) was of primary interest. The model with six classes was also of interest because the six class unconditional model provided a good level of fit. However, the six class solution did not converge, thus model evaluation and selection was performed with the two, three, and four class solutions only.

The model fit statistics led to conflicting findings regarding the optimal number of trajectory classes. The two class model had a lower BIC value than the four class model (22420.903 vs. 22551.254, respectively) which suggested better fit of the data. In addition, the LMR for the 2 class model demonstrated a trend toward significance,  $p=.055$ . However, the ssBIC value favoured the four group (22141.683) relative to the two group solution (22145.117), and the four group model demonstrated a significant BLRT,  $p<.0001$ . The two class model demonstrated high, decreasing (40%) and low,

increasing (60%) groups, which was similar to the two group unconditional model (Figure 4).

In these cases, Muthén (2004) suggests that choosing among competing models should ultimately be guided by prior theory, predictive validity, and the practical utility of the identified trajectory classes. The present findings demonstrated meaningful differences among the four trajectory group model with respect to important demographic, psychological, and disease-related risk and resilience factors. Additionally, the four group model was associated with the lowest ssBIC value, which was recommended by Tofigihi and Enders (2007), and a significant BLRT test, which was recommended by Li and Hser (2011). Finally, prior theory and research identifying similar trajectory groups provided further justification for the utility and validity of the four class trajectory model found in this study.

### **Summary of Main Findings**

The unconditional model findings supported the four trajectory class model consistently found in previous research investigating psychological functioning following stressful life events (e.g., Bonanno, 2004; Bonanno et al., 2008; Norton et al., 2011). The current findings lend further validating evidence of these prototypical adjustment trajectories following an adverse event. However, including monthly ratings of positive and negative affect changed the identified unconditional trajectory group substantially. Taking all three of the SWB components into account, the final four trajectory groups represented (a) a resilient response pattern in which participants maintained greater positive emotions, experienced fewer negative emotions, and a high, stable level of life satisfaction throughout of the study; (b) a low SWB response pattern which reflected high

negative emotions, low positive emotions, and a low life satisfaction that slightly increased at the end of the study; (c) a rapid recovery pattern characterized by initially low life satisfaction that significantly improved at T3, and stabilized at T4, and by greater positive emotions and less negative emotions at T3, which corresponded with the concurrent accelerated improvement observed in satisfaction with life; (d) a gradual recovery trajectory that was defined by a slow, linear increase in life satisfaction at each corresponding time point, with positive emotions significantly predicting higher life satisfaction at T2, T3, and T4. Finally, the results of the main analyses showed that when improvements in life satisfaction were observed in the low SWB, rapid recovery, and gradual recovery groups, positive emotions, but not negative emotions, significantly predicted higher satisfaction with life. The secondary analyses revealed that, in general, the resilient group was more optimistic, reported greater beliefs about control over managing disease symptoms, and were in better physical health than the other three trajectory groups.



## CHAPTER IV

### **Discussion**

The primary goals of this study were to explore heterogeneous patterns of subjective well-being in a sample of people with RA, SLE, AS, and gout, and to identify disease-related and psychosocial factors associated with these patterns. Overall, when life satisfaction ratings were examined in isolation, the differential patterns of emotional well-being uncovered in the current study were consistent with previous trajectory research (e.g., deRoos-Cassini et al., 2010; Norton et al., 2011). In particular, four unconditional life satisfaction trajectories were revealed, with the vast majority of participants being split between two opposing and stable response patterns. The most prevalent of these trajectories (39.6%) was characterized by individuals who reported low satisfaction with life that remained low throughout the study. However, a sizeable proportion of participants (33.1%) demonstrated a higher satisfaction pattern, reporting high to moderate life satisfaction from the start, which continued to remain high at each successive time point. In addition, some participants (18.1%) populated a trajectory class that featured initially low satisfaction ratings that increased appreciatively over time; however, others (9.1%) reported initially high satisfaction that gave way to dissatisfaction by the end of the study period.

These four life satisfaction trajectories nicely paralleled previous research conducted with newly diagnosed RA patients (Norton et al., 2011). Similarly, participants in Norton et al. (2011) study displayed response patterns relating to resilience (defined as little to no distress symptoms), recovery, delayed onset, and chronic psychological distress over a ten year period. Taken together, the present findings and those of Norton

and colleagues (2011) describe some of the nuances in psychological well-being that can manifest in people living with inflammatory rheumatic disease. However, as reviewed in the introduction of this paper, these patterns of emotional adjustment are not limited to inflammatory rheumatic disease patients. An emerging body of literature in which resilient, recovery, delayed onset, and chronic dysfunction patterns are described, presents a convincing argument that these phenotypic trajectories may in fact be common psychological responses to stress across a variety of contexts (Bonanno, 2004.).

Moreover, the four unconditional trajectory groups appear to emerge regardless of the outcome measurement used to define psychological adjustment. Recent trajectory investigations examining functioning after an experience of trauma or adversity have utilized measures of PTSD and depression to define adjustment. However, as noted previously, there are several reasons not to focus exclusively on defining successful adjustment as the absence of psychopathology (Almedom & Glandon, 2007; Hoge et al., 2007; Litz, 2005). The present study responded to these criticisms by examining life satisfaction, which may be an optimal measure of successful adjustment given the multifaceted nature of psychological adaptation to chronic disease (Bishop, 2010; Livneh, 2010; Stanton et al., 2007). That being said, however, quality of life, which in this case was measured by satisfaction ratings, and depression are highly interrelated (Livneh, 2010; Stanton et al., 2007), with life satisfaction considered a global evaluation of life quality that is influenced by particular life domains, including psychological health (Lucas et al., 1996; Luhmann et al., 2012). As evidenced by the current data replicating these four prototypical response trajectories, conceptually, the development of psychological adjustment may transcend objective outcome measures operationally

defining emotional functioning. However, future research replicating these trajectories using satisfaction ratings and other indices of adjustment in different life domains is warranted. Nevertheless, the results of this study contribute further evidence to the presence of individual variability in adjustment to inflammatory rheumatic disease.

### **Extending Existing Resilience Research**

Yet, the initial excitement associated with replicating previous work on trajectories of psychological functioning was damped when including the impact of important predictors in the model. The current research endeavoured to advance the existing body of literature by extending the unconditional life satisfaction model to incorporate associations among all three components of SWB to identify individuals who had a mixture comprised of higher global life satisfaction, greater positive affect, and the relative absence of negative affect (Diener, 1984). The inclusion of positive and negative affect was bolstered by previous research investigating resilience in people with arthritis (e.g., Hamilton et al., 2005; Zautra et al., 2005) in which several studies suggest that positive and negative emotions to operate as mechanisms that modify the relationship between disease-related stressors (e.g., pain) and psychological well-being (Connelly et al., 2007, Englbrecht, Kruchow, Araujo, Rech, & Schett, 2013; Robertson, Stanley, Cully, & Naik, 2012; Sturgeon & Zautra, 2010).

Thus far, all of the available literature investigating psychological adjustment trajectories has limited the examination of covariates to predictors of class membership only and therefore, has neglected to investigate possible underlying mechanisms that could directly affect the trajectory growth processes. As Nicassio (2011) observed, this can severely limit our understanding of why and how some individuals are able to sustain

well-being despite living with inflammatory rheumatic disease. Interestingly, though not surprisingly, the extracted trajectory groups were altered, sometimes dramatically, when they were adjusted for and influenced by concurrent positive and negative emotions.

These alterations in life satisfaction are not surprising from both an empirical and theoretical perspective. Methodological accounts from Muthén (2004), Petras and Masyn (2010), and Morin and colleagues (2011) all suggested that including time-varying covariates can result in substantive departures from the original unconditional model. These changes are generated not only because time-varying covariates influence class membership, but also because the direct effects specified between time-varying covariates and the outcome indicators allow the covariates to operate as indicators of the growth processes (e.g., the intercept and slopes; Petras & Masyn, 2010). Muthén (2004) argued that the unconditional model is perhaps only of interest for the purpose of examining varying growth development in different classes. In fact, when proper covariates are included, that is to say, covariates that are likely to directly affect the development of the trajectory growth, the results provide a greater understanding of the phenomenon of interest and a more reliable class solution, regardless of changes to the class distribution or individual classification (Muthén, 2004).

From a theoretical perspective, Rutter (1987) enumerated the role of vulnerability (or risk) and protective mechanisms in resilience, indicating that these two types of mechanisms are at work simultaneously, potentially changing or altering trajectories of adaptive outcomes, as well as creating individual transitions between trajectory groups. In the context of this theory, an individual classified in an adaptive trajectory can shift to a risk trajectory in response to an adverse event when the balance between vulnerability

and protection is disturbed. For example, an individual who would otherwise be resilient can become vulnerable to psychological dysfunction if he or she was to experience a swift cascade of stressful life events (i.e., job loss, death of family member, divorce). With respect to managing inflammatory rheumatic disease, experiencing chronic pain (a risk factor) can lead to increased negative affect (a vulnerability mechanism), which in turn can lead to lower quality of life. However, Fredrickson (1998) posited that ability to maintain positive emotions (a protective mechanism) in the face of on-going stress can guard against the harmful effects of negative emotions and enable a quick recovery and sustained psychological well-being. Numerous research studies have found support for these assertions in chronic disease samples (Hamilton et al., 2005; Kratz et al., 2007; Ong et al, 2006; Smith & Zautra, 2008).

### **The Protective Influence of Positive Emotions**

This study found confirming evidence for the adaptive benefits of experiencing and maintaining positive emotions while managing the on-going stressors associated with inflammatory rheumatic disease. Specifically, as predicted, positive emotions were higher on average (and negative affect was lower on average) in individuals who displayed resilience (37.5% of the sample). On the other hand, the opposite trend was observed in individuals who experienced low SWB (42.8% of the sample): experiencing greater negative affect and deficits in positive affect was associated with low satisfaction with life. Regardless of these differences, the occurrence of positive emotions was predictive of higher life satisfaction in both groups. Whereas individuals in the resilient class appeared to maintain a consistent level of positive affect throughout the study, participants classified in the low SWB group reported an increase in positive affect at T4

compared to their previous three months. Interestingly, accompanying this increase was the finding that positive emotions but not negative emotions were significantly associated with higher life satisfaction at T4, which likely enabled the positive growth in life satisfaction demonstrated by the low group.

Like the low SWB group, the same was true of the recovery classes: positive emotions, and not negative emotions, were predictive when substantial gains in satisfaction with life were observed in the gradual recovery (11.3%) and rapid recovery (8.4%) trajectories. In particular, positive affect was associated with improvements in life satisfaction at T2, T3, and T4 in the gradual recovery group, which corresponded with the demonstrated linear increase in life satisfaction. Similarly, in the rapid recovery group, positive affect was related to greater satisfaction with life at T3, which coincided with a noticeable surge in life satisfaction. Unfortunately, the improvement in life satisfaction in the rapid recovery group was short-lived. By T4, growth in life satisfaction was curtailed, and negative emotions were re-instated as strong predictors of lower life satisfaction.

The finding that positive emotions enhance outcomes of well-being has been well documented in previous resilience research, particularly in studies examining chronic pain populations (Kratz et al., 2007; Sturgeon & Zautra, 2010), but also interesting is the noticeable lack of relationship found between negative emotions and life satisfaction in the present study during times of life satisfaction recovery. Together these associations (or in the case of negative emotions, the lack thereof) played a key role in paving the way for improvements in well-being over the course of the study, highlighting some modifiable contributors to psychological adjustment to inflammatory rheumatic disease.

### **Resilient vs. Low SWB Group**

Greater insight into these four trajectory groups was provided by the secondary analyses examining differences in demographic, disease-related, and psychosocial characteristics. Specifically, individuals in the low SWB group reported lower income relative to the resilient group, which is consistent with previous work showing that financial difficulties are source of stress (e.g., Bonanno et al., 2007; Luhmann et al., 2012). In particular, Janke, Jones, Payne, and Son (2012) found that adults with arthritis who live in resource poor environments were less likely to actively seek opportunities to engage in leisure activities, which are associated with enhanced well-being and less depressive symptoms. These investigators argued that, by and large, resource poor individuals may need more services and support to assist them in disease management and adapting valued activities to suit their functional ability.

Additionally, a trend toward significance in the present study revealed that the low SWB group were more likely to report concomitant depression or anxiety compared to resilient individuals, which suggested that psychiatric diagnoses were risk factors for poor quality of life in this sample. Conner et al (2006) suggested that current depression symptoms may be more attributable to a pre-existing psychological disorder than to arthritis itself. Regardless, the prevalence of mood disorders in people with arthritis is double the prevalence reported in the general population (Geenen, Newman, Bossema, Vriezokolk, & Boelen, 2012), and co-morbid major depression and/or anxiety disorders has been strongly linked to lower physical and psychological health, unemployment, strained financial circumstances, and less rewarding social relationships (Gåfvels, Hägerström, Nordmark, & Wändell, 2012; Mok, Lok, & Cheung, 2012). In addition,

negative mood states have been connected with increased likelihood of disease symptom flares (Keefe, Lumley, Anderson, Lynch, & Carson, 2001). The current data underscore the importance of screening for clinical depression and anxiety as part of standard rheumatic disease practice in order to refer patients to appropriate psychological services (Geenen et al., 2012; Mok et al., 2012).

Compared to the resilient group, the low SWB group reported less relief from medications, less perceived control over daily disease symptoms, and greater disability, discomfort, symptom severity, stiffness, and pain at T1, less perceived control and greater pain and fatigue at T2, and greater stiffness, fatigue, and a trend toward significance suggesting less perceived pain at T3. No differences in disease activity were reported between the trajectory groups at T4, although the low SWB group did experience deterioration in terms of greater disease activity again at T5 and T6 compared to the resilient group. The increased inflammatory activity in these last two months corresponded with significantly lower life satisfaction ratings, fewer positive emotions, and greater negative emotions relative to the resilient group.

Altogether, these findings supported claims that remitting physical symptoms play a vital role in increasing well-being in people with arthritis (Schneider, Junghaenel, Keefe, Schwartz, Stone, & Broderick, 2012; Stanton et al., 2007). However, despite some recovery at T4, individuals in the low SWB class never reached a level of subjective well-being comparable to the resilient group at any point in the study. Consistent with findings reported by Egeland et al. (1993) and Vanderbilt-Adriance and Shaw (2008), the current data supported the idea that resilience may be more difficult to achieve, much less sustain, for participants who experienced the greatest amount of risk (i.e., lower income



and co-morbid depression and anxiety, in addition to greater pain and disability). In other words, people in the low SWB class had greater imbalances between protective and risk factors, which coalesced to make resilience less tenable for this group (Hobfoll, 1988; Rutter, 1987). Experiencing more positive emotions during periods of symptom remission provided some protection, but it only served to diminish the burden of disease-related stress on negative affect and life satisfaction, not eliminate it completely.

### **Resilient vs. the Rapid Recovery Group**

Likewise, fluctuating disease activity appeared to heavily influence the adjustment pattern demonstrated by individuals in the rapid recovery group. Interestingly, neither positive nor negative emotions were associated with satisfaction scores at the beginning of the study, yet were robust predictors at the recovery period at T3. The secondary analyses revealed that more individuals in the rapid recovery group were dealing with a symptom flare prior to participating in the study compared to the gradual recovery and resilient groups, and perceived less relief from their medications, greater disability, symptom severity, and pain at T1 relative to the resilient group. At T2, these individuals were more fatigued, a frequent complaint of arthritis patients (Benka et al., 2012), and felt they had less control over managing daily physical symptoms compared to resilient participants. However, circumstances brightened at T3: the rapid recovery group reported more energy than any of the other trajectory groups, and no differences in disease activity were observed compared to the resilient class. This corresponded with an upswing in experiencing positive emotions and significant growth in life satisfaction.

From a disease management perspective, findings from the low SWB and rapid recovery groups revealed that successfully controlling variability in disease symptoms is

critical to enhancing quality of life; however, given the enduring, progressive, and unpredictable nature of these conditions, it begs the question of how much control can one have, and, further, how long can it last? Consistent with past research findings (e.g., Hamilton et al., 2005), the current results offer some hope in that learning how to maintain positive emotions in the face of fluctuating inflammatory activity may mitigate dips in life satisfaction, effectively producing sustainable changes in life satisfaction.

Although this is not the first study to identify a rapid recovery pattern to managing chronic stress (Helgeson et al., 2004), it is the first study to uncover this trajectory using GMM. Similarly, Helgeson and her colleagues (2004) specifically examined emotional functioning trajectories in conjunction with disease-related variables and found that breast cancer patients classified in the rapid recovery class - who later went on to report increased distress at the end of their study - were more likely to have a lower level of receipt to chemotherapy and lower physical functioning compared to the no distress (i.e., resilient) group. Future research is needed to replicate this rapid recovery trajectory as a distinct trajectory with a unique set of antecedents and consequences. The current data implied that this profile of adjustment may be marked by greater variability in disease activity, which in turn created more variability in psychological adjustment. Following these individuals for a longer period of time may have uncovered that they were prone to a relapsing and remitting pattern of psychological adjustment dictated by disease symptom fluctuations.

### **Resilient vs. the Gradual Recovery Group**

Interestingly, unlike the rapid recovery and low SWB groups, no differences in disease activity were observed in the gradual recovery and resilient groups. In this case,

resilient individuals were distinguished from those who gradually recovered by a few important psychological features. First, negative emotions significantly predicted lower life satisfaction in the resilient class but not in the gradual recovery class. One explanation for this difference may stem from the recovery group engaging in explicit strategies. Emotion regulation refers to goal-oriented cognitive processes that influence the strength, duration, and type of emotion an individual experiences (Gyurak, Gross, & Etkin, 2011). One of the most common positive emotion regulation strategies is cognitive reappraisal, which is a well known coping strategy often associated with successful adjustment (Lazarus & Folkman, 1984). A series of studies conducted by Gross and John (2003) showed that people who apply cognitive reappraisal strategies experience more positive emotions and less negative affect. For some, cognitive reappraisals are a conscious, effortful process, in which coping with stressful situations is formed by intentionally changing the way that one views a stressor in order to reduce the impact of negative emotions. In some cases, experiencing more intense negative emotions can signal the need for employing coping behaviour, motivating individuals to take action to help alter their current emotional experience (Grønning, Lomundal, Koksvik, & Steinsbekk, 2011; Karademas, Tsalikou, & Tallarou, 2011). The steady increase in well-being over the course of the study lends support to the idea that the gradual recovery group may have successfully applied positive coping strategies to regulate negative emotions and better manage their chronic condition.

However, this is not to suggest that the resilient class did not successfully apply coping behaviour to manage inflammatory rheumatic disease. Rather, emotion regulation strategies may also be implicit or automatic responses to stress for some people (Gyurak

et al., 2011). Given the optimistic nature of the resilient group, perhaps engaging activities to increase positive emotions and accessing positive emotions reserves to reframe stressful situations is habitual. Therefore, they need not make a concerted effort to regulate negative emotions, but instead allow themselves to experience and in turn, be impacted by negative affect. Ong and Bergman (2004) argued that people who experience both positive and negative emotions during stress display greater affective complexity, a process that enables a person to gauge the quality of an emotional experience, which has implications for effectively sustaining psychological well-being. To date, research investigating the mechanisms of resilient outcomes in chronic disease populations is sparse; therefore future studies should aim to identify other promising sources of protection, such as coping behaviour and affective complexity, to mitigate the effects of disease-related risk over time.

Other key differences between the resilient and gradual recovery groups related to perceived control (at T2) and optimism. In particular, the resilient group differed from the gradual recovery group in that they were more optimistic and held greater beliefs about control over their disease symptoms at T2. Interestingly, unlike the low SWB and rapid recovery groups, there were no differences in disease activity observed between the gradual recovery and resilient classes, which suggests that perceptions of control and optimism may contribute to the sustainability of resilience, independent of disease-related factors. Control beliefs are well-known to facilitate successful psychological adjustment (Helgeson, 1992; Helgeson et al., 2004; Livneh et al., 2004), and optimism has also been strongly associated with good health outcomes (Brenner et al., 1994; Folkman & Moskowitz, 2004; Quale & Schanke, 2000; Yi et al., 2008). These results with respect to

the gradual recovery and resilient groups show the additive benefit of amassing more protective factors to combat against the detrimental effects of on-going stress (Hobfoll, 1988).

Although an optimistic outlook has many benefits, at the same time, it may also be a double edged sword. Binder and Coad (2013) cautioned that a positive outlook can lead to bias in terms of some chronically ill optimists overestimating their subjective physical health. Undervaluing disease symptom cues may cause some arthritis patients to over exert themselves, or simply dismiss important disease management activities, which can have long-term health consequences, particularly in the context of a progressive chronic condition associated with considerable functional impairment. Future studies examining objective measures of physical health may shed some light on whether resilient individuals are in fact in better physical shape or if they just perceive themselves to be.

### **The Prevalence of Resilience in the Obtained Sample**

Another aim of this study was to identify the prevalence of resilience in a sample of people with inflammatory rheumatic conditions. Previous studies investigating resilience have suggested that resilient outcomes are common responses to stressful life events (Bonanno, 2004; Bonanno, Westpal, & Mancini, 2010). For instance, Norton et al. (2011) found that 69% of recently diagnosed RA patients exhibit very few depression symptoms in the 10 years following diagnosis. In the present investigation, resilient outcomes were less prevalent, with 37.5% of the sample demonstrating higher life satisfaction, higher positive affect, and lower negative affect. Even so, having over one third of the sample display positive adjustment to the persistent and recurrent physical

symptoms associated with inflammatory rheumatic disease is a remarkable and hopeful finding. This study contributes to the emerging body of literature demonstrating that many people who live with a chronic disease can achieve a good quality of life. More encouraging is that an additional 19% of the sample recovered to a level of well-being suggestive of successful adjustment. As Norris et al. (2009) highlighted, there are multiple routes to positive adjustment of which resilience may only be one. Their conclusions spoke to resilience theory more generally, implying that resilience should perhaps not be viewed as one trajectory or one specific outcome of psychological adjustment, but rather a *process* that is representative of a set of trajectories associated with good outcomes in response to stress.

That being said, and despite the recent trend in conducting positive psychology research and investigating individual strength, a disproportionate focus on positive psychological adjustment is not the answer. In the current investigation, the low SWB profile was the most prevalent trajectory (42.8%). This finding is in sharp contrast to the recent review conducted by Bonanno and colleagues (2010) in which these authors argued that the proportion of people in a sample suffering from PTSD or other psychopathology rarely surpasses 30% even when the adversity is prolonged or severe.

There are several factors that may have contributed to this discrepancy. For instance, using life satisfaction as a measure of psychological adjustment likely contributed to differences in trajectory class proportions between this study and others in the field (e.g., Norton et al., 2011; Hou et al., 2009), given that global satisfaction ratings are in part determined by physical health (Gana et al, 2013). Another reason for this difference is that previous trajectory investigations have commonly collected data yearly,

as opposed to the more frequent, monthly registrations employed by the current analysis. Furthermore, the vast majority of these studies have focused on identifying responses to an acute episode of stress, typically in isolation, with little credence given to other intervening life events that can impose significant impact an individual's long-term adjustment (e.g., de Roon-Cassini et al., 2011).

As reviewed in the introduction, the cyclical nature of the physical symptoms that accompany inflammatory rheumatic disease and the affective consequences of these symptoms has implications for why some individuals are able to successfully adjust, whereas others do not (e.g., Zautra et al., 2005). Therefore, frequently measuring the chronic and pervasive stressors presented by inflammatory rheumatic disease was perhaps a more accurate representation of these individuals' lives, as they constantly seek balance between adjusting their routines and activities to disease fluctuations and living a "normal" life (Grønning et al., 2011). Arguably, differences in trajectory form, function, and proportions between the current study and other trajectory work can in large part be attributed to monthly data collection and examining responses to an on-going and chronic stressor. However, it can also be argued that these features are two of this study's biggest strengths, and precisely what contributed to furthering existing literature. That is, capturing frequent emotional and disease-related changes provided the opportunity to uncover unique and dynamic recovery patterns in the face of persistent stress.

### **Rheumatic Disease Group Differences**

Preliminary findings showed that individuals with gout were older, less likely to have a concurrent mental health condition, experienced more symptom remissions, and reported a higher quality of life compared to the RA, AS, and SLE respondents, which is

consistent with previous research (vanGroen et al., 2010). In addition, those with RA were more disabled than individuals with AS, and participants with SLE were less likely to be employed. However, when inflammatory rheumatic disease group differences were examined by trajectory group, no significant differences emerged. One explanation may be because the focus of the current study was on examining common disease features among these four conditions and, in particular, how this cycle of symptom fluctuations would impact individual trajectories of emotional adjustment. To parse differences among individuals with RA, AS, SLE and gout, future investigations may concentrate on collecting more detailed disease information, for example, affected joints or organs, age of onset, specific medications, as well as examining different domains of quality of life (e.g., social, vocational, physical).

Surprisingly, time since diagnosis did not reveal any significant differences between trajectory groups, despite the descriptive profiles showing that the resilient and rapid recovery groups were more recently diagnosed. Benka et al. (2012) found that disease activity and psychological distress become more closely associated with emotional functioning as arthritis progresses, which may suggest that by virtue of the progressive nature of arthritis, people who have lived with the condition longer may report a lower quality of life. However, much like an experience of trauma, a chronic illness diagnosis can evoke a significant amount of distress and uncertainty about the future (Gold, Marx, Solar-Baillo, & Sloan, 2005). Future research may benefit from purposeful sampling of individuals at various time points following diagnosis as well as at various stages in disease progression in order to further understand differences in emotional adjustment.



### **Application and Future Research Directions**

The findings from this study suggest that experiencing more positive emotions than negative emotions is essential for fostering recovery and achieving gains in life satisfaction. However, the challenge is maintaining more positive emotions and less negative emotions over time, as this appears to be a key ingredient for sustaining higher satisfaction with life (Fredrickson, 1998). Patient education programs and psychological interventions targeting increasing and preserving positive emotions and managing negative emotions, particularly during times of increased disease activity, may facilitate positive and sustainable shifts toward successfully managing persistent stress (Lyubomirsky, Sheldon, & Schkade, 2005). Future research should focus on frequently tracking changes in emotions and life satisfaction over longer periods of time and replicating these patterns in larger, more diverse samples.

In addition, interventions focusing on learned optimism and increasing confidence and control would be beneficial for helping people to function better with their illness. In particular, helping rheumatic patients to amass more protective factors would aid in buffering the negative impact of on-going stress and lead to the development of more resilient people. However, the factors associated with adjustment that were assessed in this exploratory study were not exhaustive of the factors relevant to better understanding adjustment to chronic health conditions; therefore, future studies should investigate other protective and risk mechanisms that are specific to managing inflammatory conditions.

Furthermore, this study is one of the first to investigate transitions between trajectory classes. As Rutter's (1987) theory predicted, when positive (protective factor) and negative affect (vulnerability or risk factor) were taken into account, individual

transitions between trajectory classes occurred. The majority of this movement was attributable to individuals in the gradual recovery and unconditional chronic dissatisfaction classes. Notably, when monthly positive and negative emotions were added to the model, many people shifted from the chronic dissatisfaction class to one of the other three profiles indicative of successful adjustment. On the other hand, some individuals who were originally in the unconditional recovery group moved to the trajectory associated with low SWB. Examining class transitions between unconditional and conditional GMM models has considerable practical utility. This type of analysis isolate important mechanisms that underlie recovery (Sturgeon & Zautra, 2010), which can inform factors that hinder or help a specific group's adjustment and contribute to the development of targeted and hopefully, more effective intervention strategies. In general, testing the dynamic process of psychological adjustment using GMM provides a new research direction for further understanding the psychological health of people with chronic disease, and the development of a comprehensive theory of psychological adjustment.

Identifying reasons why some individuals are resilient to chronic stress is important for identifying sources of positive emotional, cognitive, and behavioural change that can aid in recovery. At the same time, another useful application of GMM is the ability to specifically identify people who struggle in the face of adversity and are at risk for developing depression and other forms of psychological dysfunction. Isolating groups of individuals based on relevant psychological adjustment outcomes and predictor variables can form the basis for developing screening tools to distinguish particular at-

risk groups. These screening tools can act as a form of triage, effectively targeting and recruiting people for tailored intervention strategies based on individual support needs.

### **Limitations**

The current study had several limiting factors. First, the proportion of missing data in the present analysis was considerable, which is a common concern of longitudinal research designs. Missing data can have potentially detrimental effects on the validity of statistical analyses (Enders, 2010). However, the issue of missing data was tested and handled extensively in the current investigation, and, in this case, values were found to be missing at random (MAR; Little & Rubin, 2002), which is considered to be a relatively benign pattern of missingness (Enders, 2010).

A related issue was the relatively small sample size obtained in the present study. Because GMM is a new technique, there were no published recommendations concerning optimal sample sizes needed for identifying a reliable model and accurate parameter estimates (Muthén, 2001; Preacher et al., 2008). Muthén (2001) suggested that sizes as low as 300 may be acceptable, but warns that power is likely to be attenuated in these circumstances, particularly when examining the influence of covariates in the between group analyses. Notably, the sample sizes reported in the resilience literature have varied widely, ranging anywhere from 171 to 1267 participants. Nevertheless, caution needs to be applied when interpreting these exploratory results and should be viewed solely as hypothesis generating.

The majority of the sample was Caucasian and female, which places significant limitations on the generalizability of these findings. Furthermore, data were collected via the internet, which potentially biases the sample toward people living in more affluent

circumstances. However, online data collection may also be seen as a potential strength. In particular, Krantz and Dalal (2000) reported that online studies may recruit larger and more heterogeneous samples than those recruited from the community, which is in line with the objectives of this study. In addition, the quality of online data is considered as good as traditional community-based recruitment (Gosling et al., 2004).

This research may have suffered from carry-over effects due to collecting data using the same participants and the same measures repeatedly for six months. The presentation of assessment measures was randomly assigned at each data collection in an attempt to minimize carry-over influence, and it was felt that the strengths of using a longitudinal research design outweighed this limitation.

Furthermore, continuing to participate in the study could have accounted for the recovery in life satisfaction observed in the gradual recovery, rapid recovery, and low SWB groups, as this allowed participants the opportunity to continually focus on their emotions and the ways in which they effectively manage their disease. Finally, the underwhelming influence of perceived social support on satisfaction with life was surprising in light of consistent reports on the adaptive benefits of social support in chronic illness populations (e.g., Benka et al., 2012; Bonanno et al., 2008; Robertson et al., 2012; Taylor et al., 1994). An inspection of items assessed by the perceived social support scale used in this study demonstrated that the items were disproportionately focused on emotional forms of support. Although having a supportive environment to share and discuss one's feelings and concerns with friends, family, and health care professional absolutely critical for people with inflammatory rheumatic disease (Benka et al., 2012), however, the measure used in this study was perhaps not sensitive enough to

capture variability in emotional support. Moreover, instrumental forms of support may also be highly relevant for arthritis patients, particularly given that the disease is associated with severe functional impairments that can limit the performance of daily activities. Unfortunately, instrumental forms of support were not assessed in the current study.

### **Conclusions**

“As long as you have your health” is an old adage that implies that a person cannot truly be happy or enjoy a high quality of life without good physical health. Findings from this exploratory study provided evidence that “good” health may not be a necessary condition of a satisfied life. In fact, consistent with previous work, the current investigation found evidence of significant variability in psychological functioning in sample of people with inflammatory forms of arthritis, and support for the idea that successful adjustment is a common response among adults with inflammatory rheumatic disease. These data echo previous research (e.g., Zautra et al., 2005; Sturgeon & Zautra, 2010) in suggesting that a paradigm shift in the way we approach the study of psychological adjustment to arthritis and other chronic conditions is in order. Not everyone responds to chronic pain and functional limitations with negative affect and compromised well-being. Many individuals in this study were able to maintain or find opportunities to increase positive emotions to achieve greater satisfaction with life. This study joins a host of research demonstrating that accruing protective psychological resources can help people with rheumatic diseases recover from disease flares and promote sustainable satisfaction with life. Building in patient education focusing on the

acquisition and maintenance of protective resources to existing disease management strategies may help to promote successful self-management of disease-related stressors.

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## APPENDIX A

**List of Recruitment Sources**Internet support groups and websites:

About health.com  
Arthritis support – ivillage.com  
Spondylitis Society of Canada  
American Spondylitis Association  
Yahoo RA support group  
Yahoo Lupus support group  
Life with Lupus support group  
Psychological research on the net Facebook group (psych.hanover.edu)  
Craig's list  
Kijiji Advertisements  
Gout-pal.com  
Kickas.org  
the Lupus Site  
Arthritis Society of Canada  
Arthritis Society of Canada facebook group

Print and online newspaper advertisements:

The Metro: Toronto, Vancouver, Calgary  
The Calgary Herald Classifieds  
Northern news

Advertisements for purchase:

Facebook  
Google Ads

APPENDIX B  
**Ethics Approval Letter**

Today's Date: April 02, 2012

Principal Investigator: Ms. Jennifer Voth

REB Number: 29844

Research Project Title: REB# 12-012: Adapting to inflammatory arthritis: Identifying trajectories of change

Clearance Date: March 21, 2012

Project End Date: May 01, 2013

Milestones:

Renewal Due-2013/05/01(Pending)

Renewal Due-2013/02/15(Pending)

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This is to inform you that the University of Windsor Research Ethics Board (REB), which is organized and operated according to the Tri-Council Policy Statement and the University of Windsor Guidelines for Research Involving Human Subjects, has granted approval to your research project on the date noted above. This approval is valid only until the Project End Date.

A Progress Report or Final Report is due by the date noted above. The REB may ask for monitoring information at some time during the project's approval period.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the REB. Minor change(s) in ongoing studies will be considered when submitted on the Request to Revise form.

Investigators must also report promptly to the REB:

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

Forms for submissions, notifications, or changes are available on the REB website:

[www.uwindsor.ca/reb](http://www.uwindsor.ca/reb). If your data is going to be used for another project, it is necessary to submit another application to the REB. We wish you every success in your research.

Pierre Boulos, Ph.D.

Chair, Research Ethics Board

301 Assumption University

University of Windsor



## APPENDIX C

**Study consent forms for T1 and follow-up surveys**

## LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH

Electronic version

T1: Initial assessment survey

Title of Study: Living with inflammatory rheumatic disease

You are asked to participate in a research study conducted by Jennifer Voth, a doctoral student from the Department of Psychology at the University of Windsor. The results of this study will contribute to a doctoral dissertation.

If you have any questions or concerns about the research, please feel to contact the Faculty Supervisor for this project, Dr. Dennis Jackson (Faculty Supervisor) at (519) 253-3000, ext. 2229 or [djackson@uwindsor.ca](mailto:djackson@uwindsor.ca) or Jennifer Voth at (519) 253-3000, ext. 4886, or [vothj@uwindsor.ca](mailto:vothj@uwindsor.ca).

## PURPOSE OF THE STUDY

The purpose of this study is to examine the experience of living with Rheumatoid Arthritis (RA), Ankylosing Spondylitis (AS), Systemic Lupus Erythematosus (SLE), or Gout over the course of six months and to identify some factors that may contribute to your adjustment to the illness. This is the first of a six-part study and by participating in this study you may be eligible to be invited to participate in the short (10 minute) online follow-up surveys in approximately one month.

## PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- Complete a screening questionnaire. If you are 18 years of age or older and have been diagnosed with RA, AS, SLE or Gout, you will satisfy the study criteria and will be directed to complete the survey package.

- Complete an electronic survey package on Fluid Surveys, a web-based survey service that is supported by the University of Windsor, that will include background questions about you and your health condition, your quality of life, mood, self-perceptions, energy levels, life events, and your satisfaction with the support that you receive from your family and friends.
- Provide contact information. This information will only be used to invite you to participate in the follow-up online surveys and to contact you should you win one of the incentive draws. Please note: agreeing to participate in this study does not mean that you are committed to participate in the follow-up surveys.

This survey will take approximately 30 minutes to complete and you may complete the survey at a location of your choice. If you need to take a break, you may save your responses and resume completing this survey at any time.

The completed survey will be sent to the researcher with your IP address as the other identifying information attached to your survey. If you prefer to complete a paper copy of this survey, please contact Jennifer Voth at [vothj@uwindsor.ca](mailto:vothj@uwindsor.ca) or (519) 253-3000, ext. 4886.

#### POTENTIAL RISKS AND DISCOMFORTS

Some people who have severe pain due to arthritis may experience some physical discomfort while attempting to complete lengthy questionnaires. However, this survey has been kept short and includes only the essential questions relating to the purpose of this study. Should you feel any pain or discomfort, please click the “save and continue later” button located on the webpage. You will be provided with a website that you can bookmark in order to resume answering the survey questions at a later time.

In addition, some people may experience mild discomfort when asked to focus on their current levels of pain or quality of life. Your responses to these questions will be kept confidential and any report of the study findings will reflect group averages and will not have any information about specific individuals.

#### POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

By completing questionnaires about your health and quality of life, you may become more aware of some areas in your life that give you the most satisfaction and some areas

that could be improved. This may motivate you to examine how you could improve the areas in which you are least satisfied and/or invest more in the areas that give you the most pleasure. Both of these options could improve your health and well-being.

Adjusting to living with an inflammatory form of arthritis is not well understood. The findings of this study will highlight the importance of looking at adjustment as a process that unfolds over time and that may be dependent on current illness characteristics (e.g., current levels of pain or fatigue). The results of this study may find that many people with arthritis are able to achieve and sustain a quality of life that is comparable to people who do not have a chronic condition, and may identify a number of factors that are important contributors to life quality.

#### PAYMENT FOR PARTICIPATION

You are eligible to win one of ten gift cards from your choice of either Amazon, Starbucks or Walmart. The amount of these gift cards will be \$10 USD, or the equivalent depending on your country of residence, and should you win, it will be mailed to you (either by postal or electronic mail) after we have received your completed survey and performed the draw. Please note that agreeing to participate in this study implies completing at least 80% of the questions in the survey. Participants who submit a blank or substantially incomplete survey will not be included in the draw.

#### CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. At the end of the survey will be asked to give some personal information in the form of your name and email address. All survey data will remain anonymous and will only be directly identified by your participant number, therefore, your responses on the questionnaires will not be directly associated with your name. The contact information that you provide will be kept separate from your survey and used only for the purposes of sending you the gift card should you win the draw, contacting you for the follow-up online surveys, and for linking this survey with the future follow-up surveys (should you decide to participate later). Once the study is over, your personal information will be deleted from our files. Survey data will be stored in a secure location that is accessible only to the researchers directly involved with this study. In addition, any files containing personal information will be stored in a secure place. If a report of the findings is sent to a scientific journal then all information will be presented in a way that protects your confidentiality and will reflect only group information. Following the guidelines of the Canadian and American

Psychological Associations, data will be retained for a period of 10 years, after which time it will be disposed of in a secure manner.

## PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. If you wish to be entered into the incentive draw, please skip ahead to the contact information form and provide an email address so that an electronic gift card may be mailed to you in the event that you win. The investigator may withdraw you from this research if circumstances arise which warrant doing so. You also have the option to remove your data from the study should you decide to do so. Please note that individuals who complete a substantial portion of the survey questions (at least 80%) will be invited to participate in the follow-up surveys.

## FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

Once the research is complete, a brief report describing the study's findings will be made available for those interested. The report will be available on the study website (<http://uwindsor.fluidsurveys.com/s/inflammatory-arthritis/>) by May, 2013.

## SUBSEQUENT USE OF DATA

This data will be used in subsequent studies.

## RIGHTS OF RESEARCH SUBJECTS

If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: [ethics@uwindsor.ca](mailto:ethics@uwindsor.ca)

## SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Jennifer Voth, M.A.  
Department of Psychology  
University of Windsor

It is recommended that you print out a copy of this letter of information for your records.

Pass it on: Feel free to send this study's webpage to other people you know who might be interested in completing the survey.

Do you wish to continue? To acknowledge that you have read and understood this information and would like to continue with the survey, please click on "I agree".

I agree



## LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Living with inflammatory rheumatic disease

You are asked to participate in a research study conducted by Jennifer Voth, a doctoral student from the Department of Psychology at the University of Windsor. The results of this study will contribute to a doctoral dissertation.

If you have any questions or concerns about the research, please feel to contact the Faculty Supervisor for this project, Dr. Dennis Jackson (Faculty Supervisor) at (519) 253-3000, ext. 2229 or [djackson@uwindsor.ca](mailto:djackson@uwindsor.ca) or Jennifer Voth at (519) 253-3000 ext. 4886 or [vothj@uwindsor.ca](mailto:vothj@uwindsor.ca).

### PURPOSE OF THE STUDY

The purpose of this study is to examine the experience of living with Rheumatoid Arthritis (RA), Ankylosing Spondylitis (AS), Systemic Lupus Erythematosus (SLE), or Gout over the course of six months and to identify some factors that may contribute to your adjustment to the illness. This is the [second, third, fourth, fifth or sixth] part of a six-part study.

## PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

You will be asked to participate in five monthly online surveys that will take approximately 10 minutes to complete. A link to the survey will be sent your email address once a month for five months. In these surveys, you will be asked questions about levels of pain and fatigue in the past month, as well as your emotions, quality of life, perceptions of control, social support and other major life events.

## POTENTIAL RISKS AND DISCOMFORTS

Some people may experience mild discomfort when asked about their health and/or asked to focus on their current levels of pain or quality of life. Your responses to these questions will be kept confidential and any report of the study findings will reflect group averages and will not have any information about specific information.

## POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

By completing this survey, you may become more aware of some areas in your life that have provided you with satisfaction this month and some areas that could be improved in the future. You may also become more aware of certain factors that contribute to your life quality, which may help you to identify and deal with triggers in the future. Also, this may motivate you to examine ways in which you could improve the areas in which you are least satisfied and/or invest more in the areas that give you the most pleasure. Both of these options could improve your health and well-being.

Adjusting to living with an inflammatory form of arthritis is not well understood. The findings of this study will highlight the importance of looking at adjustment as a process that unfolds over time and that may be dependent on current illness characteristics (e.g., current levels of pain or fatigue). The results of this study may find that many people with arthritis are able to achieve and sustain a quality of life that is comparable to people who do not have a chronic condition, and may identify a number of factors that are important contributors to life quality.

## PAYMENT FOR PARTICIPATION

You are eligible to win one of [four (for Time 2 & 3); two (for Time 4, 5, & 6)] gift cards from your choice of either Amazon, Starbucks or Walmart. The amount of these gift cards will be [\$25 USD (for Time 2 & 3) or \$50 USD (for Time 4, 5 & 6)], or the

equivalent depending on your country of residence, and, should you win, it will be mailed to you (either by postal or electronic mail) after we have received your completed survey and performed the draw. Please note that agreeing to participate in this study implies completing at least 80% of the questions in the interview. Participants who do not answer a substantial portion of the interview questions will not be included in the draw.

#### CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. For research purposes, the information shared in this survey will be kept completely confidential. Individual responses and personal identities will be available only to the researchers directly involved in this study. All surveys only be directly identified by your participant number, therefore, your responses on the questionnaires will not be directly associated with your name. Your contact information that you provide will be kept separate from your responses and used only for the purposes of sending you the participation incentive should you win the draw and for linking this survey to the other time points of this study.

#### PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. You also have the option to remove your data from the study should you decide to do so.

#### FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

Once the research is complete, a brief report describing the study's findings will be made available for those interested. The report will be available on the study website (<http://uwindsor.fluidsurveys.com/s/inflammatory-arthritis/>) by May, 2013.

#### SUBSEQUENT USE OF DATA

This data will be used in subsequent studies.

#### RIGHTS OF RESEARCH SUBJECTS

If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: [ethics@uwindsor.ca](mailto:ethics@uwindsor.ca)

#### SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

Jennifer Voth  
Department of Psychology  
University of Windsor

**It is recommended that you print out a copy of this letter of information for your records.**

**Pass it on:** Feel free to send this study's webpage to other people you know who might be interested in completing the survey.

**Do you wish to continue?** To acknowledge that you have read and understood this information and would like to continue with the survey, please click "yes".



## APPENDIX D

**Screening Questions and Survey Package**

Are you over 18 years of age?

Yes

No

Please indicate your age: \_\_\_\_\_

Has your medical doctor diagnosed you with either Rheumatoid Arthritis (RA), Ankylosing Spondylitis (AS), Systemic Lupus Erythematosus (SLE) or Gout?

Yes

No

If yes, please list your diagnosis: \_\_\_\_\_

When were you first diagnosed with *X* (RA, AS, SLE or Gout) (month, year)?

\_\_\_\_\_

Some people experience the symptoms of their illness long before they are ever diagnosed with their condition. What was your experience? How long had you been experiencing symptoms before being diagnosed?

\_\_\_\_\_

Are you taking medications to relieve your symptoms?

Yes

No

Please list any medications that you are currently taking for your illness:

---

To what extent have these medications been successful in relieving your symptoms?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all

Extremely

Sex:  Female  Male  Other

What is your highest level of education?

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> some high school     | <input type="checkbox"/> some college or university  | <input type="checkbox"/> some graduate/professional school |
| <input type="checkbox"/> high school graduate | <input type="checkbox"/> college/university graduate | <input type="checkbox"/> Graduate/professional degree      |

Are you currently employed?

- full-time  part-time  not at all  retired

What is your first language? \_\_\_\_\_

What ethnic background do you most identify with? (For example: Caucasian, French Canadian, Italian, East Indian, etc.):

\_\_\_\_\_

What is your relationship status? (please check the one that applies best to you)

- |  |  |
|--|--|
| <input type="checkbox"/> married/living with an intimate other | <input type="checkbox"/> never married |
| <input type="checkbox"/> separated/divorced                    | <input type="checkbox"/> widowed       |

What was your household income last year (before taxes)? (please check the one that applies best to you)

- |  |   |
|--|---|
| <input type="checkbox"/> Under \$14,999      | <input type="checkbox"/> \$75,000 - \$89,999  |
| <input type="checkbox"/> \$15,000 - \$29,999 | <input type="checkbox"/> \$90,000 - \$104,999 |

- |  |  |
|--|--|
| <input type="checkbox"/> \$30,000 - \$44,999 | <input type="checkbox"/> \$105,000 - \$119,999 |
| <input type="checkbox"/> \$45,000 - \$59,999 | <input type="checkbox"/> \$120,000 - \$134,999 |
| <input type="checkbox"/> \$60,000 - \$74,999 | <input type="checkbox"/> Over \$135,000        |

Have you been diagnosed with any psychiatric or mental health conditions? (e.g., clinical depression, anxiety, panic attacks, etc.)

- No
- Yes

If yes, please list  
all: \_\_\_\_\_

Do you have any other physical health problems besides RA, AS, SLE or Gout? (e.g., diabetes, insomnia, digestive issues, asthma etc.)

- No
- Yes

If yes, please list  
all: \_\_\_\_\_

### Positive Affect & Negative Affect Scale

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Please indicate the extent to which you felt this way in the last month. Use the following scale to record your answers.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
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**Not at all**

**Extremely**

	interested		guilty		irritable		determined
	distressed		scared		alert		attentive
	excited		hostile		ashamed		jittery
	upset		enthusiastic		inspired		active
	strong		Proud		nervous		afraid

### Satisfaction with life scale

Below are five statements with which you may agree or disagree. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

1	2	3	4	5	6	7
Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree

In most ways my life is close to my ideal.	1 2 3 4 5 6 7
The conditions of my life are excellent.	1 2 3 4 5 6 7
I am satisfied with my life.	1 2 3 4 5 6 7
So far I have gotten the important things I want in life.	1 2 3 4 5 6 7
If I could live my life over, I would change almost nothing.	1 2 3 4 5 6 7

### World Health Organization Quality of Life Scale – BREF

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you. Use the scales provided to record your answers.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>Very Poor</b>					<b>Very Good</b>				

1.	How would you rate your quality of life
2.	How satisfied are you with your health

The following questions ask about how much you have experienced certain things in the last month. Use the scale provided to record your answer.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>Not at all</b>		<b>Moderately</b>				<b>Extremely</b>			

3.	To what extent do you feel that physical pain prevents you from doing what you need to do?
4.	How much do you need any medical treatment to function in your daily life?
5.	How much do you enjoy life?
6.	To what extent do you feel your life to be meaningful?
7.	How well are you able to concentrate?
8.	How safe do you feel in your daily life?
9.	How healthy is your physical environment?

The following questions ask about how completely you experience or were able to do certain things in the last month. Use the scale below

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>Very Poor</b>					<b>Very Good</b>				

10.	Do you have enough energy for everyday life?
11.	Are you able to accept your bodily appearance?
12.	Have you enough money to meet your needs?
13.	How available to you is the information that you need in your day-to-day life?
14.	To what extent do you have the opportunity for leisure activities?

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>Very Poor</b>					<b>Very Good</b>				

15.	How well are you able to get around?
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The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last month. Use the scale below to record your answers.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>Very Poor</b>					<b>Very Good</b>				

16.	How satisfied are you with your sleep?
17.	How satisfied are you with your ability to perform your daily living activities?
18.	How satisfied are you with your capacity for work?
19.	How satisfied are you with yourself?
20.	How satisfied are you with your personal relationships?
21.	How satisfied are you with your sex life?
22.	How satisfied are you with the support you get from your friend?
23.	How satisfied are you with the conditions of your living place?
24.	How satisfied are you with your access to health services?
25.	How satisfied are you with your transport?

The following question refers to how often you have felt or experienced certain things in the last month. Use the scale below to record your answers.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>Never</b>					<b>Always</b>				

26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?
-----	--

### Alternative pain management strategies

There are many treatment options that can help to decrease the pain and stiffness in your joints from having [RA, AS, SLE or gout]. Please indicate other ways that you have tried to manage your disease (*please check all that apply*).

<b>Treatment Option</b>	✓	<b>Treatment Option</b>	✓
Physiotherapy		Psychiatrist	
Relaxation techniques (e.g., listening to music, positive imagery, etc.)		Chiropractor	
Physical activity		Massage therapy	
Heat and cold applied to joints		Naturopathy	
Diet		Homeopathy	
Occupational therapy		Acupuncture	
Counsellor or Psychologist		Other alternative medicine practitioner: (e.g., Reflexologist, Iridologist, etc.) (please specify):	

### Health Assessment Questionnaire – Disability Index

We are interested in learning how your illness affects your ability to functioning in daily activities. Please check the response which best describes your usual abilities **OVER THE PAST MONTH**:

Are you able to:

1 Without ANY difficulty	2 With SOME difficulty	3 With MUCH difficulty	4 UNABLE to do
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Dress yourself, including tying shoelaces and doing buttons?	1	2	3	4
Shampoo your hair?	1	2	3	4
Stand up from a straight chair?	1	2	3	4
Get in and out of bed?	1	2	3	4
Lift a full cup or glass to your mouth?	1	2	3	4
Open a new milk carton?	1	2	3	4
Cut your meat or other hard foods?	1	2	3	4
Walk outdoors on flat ground?	1	2	3	4
Climb up five steps?	1	2	3	4
Wash and dry your body?	1	2	3	4
Take a tub bath?	1	2	3	4
Get on and off the toilet?	1	2	3	4
Reach and get down a 5-pound object from just over your head?	1	2	3	4
Bend down and pick up clothing from the floor?	1	2	3	4
Open car doors?	1	2	3	4
Open jars which have previously been opened?	1	2	3	4
Turn faucets off and on?	1	2	3	4
Run errands and shop?	1	2	3	4
Get in and out of a car?	1	2	3	4
Do chores such as vacuuming or yard work?	1	2	3	4

Please check any AIDS or DEVICES that you usually use for any of these activities:

- Cane
  Wheelchair  
 Walker
  Other: \_\_\_\_\_  
 Crutches

**Pain**

Please choose a number between 0 and 100 that best describes the average level of pain that you have experienced over this month, with 0 indicating “*no pain*” and 100 indicating “*pain as bad as it can be*”

**Energy/Fatigue Scale**

These questions are about how you feel and how things have been with you during the **past month**. For each question, please **choose number between 1 and 10** for each question that comes closest to the way you have been feeling.

Did you feel worn out?	
Did you have a lot of energy?	
Did you feel tired?	
Did you have enough energy to do the things you wanted to do?	
Did you feel full of pep?	

### Disease Activity and Symptom Flares

The following questions ask you to consider your health **IN THE LAST MONTH**. Please read the questions below and use the scale provided to rate the extent to which your illness has affected you in the last month.

The symptoms of [RA, AS, SLE or gout] can vary from times when your joints feel good to times when your joints are more sore, stiff and swollen. These “flares” seem to happen for no reason at all and can occur at any time.

Have you experienced any flares in the last month?  Yes  No

Have you experienced a remission in your symptoms in the last month?

Yes  No

How you would describe the overall level of discomfort resulting from your symptoms (e.g., joint pain, headaches, skin rash, and fatigue)?

<b>1</b> <b>None</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b> <b>Extreme</b>
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How you would rate the overall severity of your physical symptoms?

<b>1</b> <b>Not at all severe</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b> <b>Extremely severe</b>
--------------------------------------	----------	----------	----------	----------	----------	----------	----------	----------	--------------------------------------

How would you describe your overall morning stiffness or pain you have had from the time that you wake up?

<b>1</b> <b>None</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b> <b>Extreme</b>
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How long does the morning stiffness or pain last after you wake up?

<b>0 hrs</b>	<b>0.5 hrs</b>	<b>1 hr</b>	<b>1.5 hrs</b>	<b>2 hrs or more</b>
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### Personal Control

Some people believe that they can exert control over the course of their illness. They believe that a positive attitude will achieve these effects or that certain exercise changes can help. Please select a number from **1 (no control) to 10 (complete control)** that best describes how much control you think you have over your condition.

The day to day symptoms of your illness	1 2 3 4 5 6 7 8 9 10
The future course of your illness	1 2 3 4 5 6 7 8 9 10
The emotions related to your illness	1 2 3 4 5 6 7 8 9 10

### Perceived Social Support

The following questions ask you about your social network. Please respond to each item by choosing a number between 1 (strongly agree) and 10 (strongly disagree).

I have people to talk to about my worries concerning illness.	1 2 3 4 5 6 7 8 9 10
I feel free to express all my feelings about illness to those close to me.	1 2 3 4 5 6 7 8 9 10
There are people I can count on whenever I want to talk about my experience with illness.	1 2 3 4 5 6 7 8 9 10

### Major Life Events

Experiencing change is an inevitable part of life. Sometimes these changes can be a negative experience such as a marital separation or being fired at work. However, change may also be a positive event such as paying off a loan or getting a promotion at work. Think back to what has happened to you in the last month. Have you experienced any major changes in your life lately? (*please check all that apply*)

Major life event	✓
Starting different responsibilities at work	
Change in the health of a close family member or friend	
Suffered a change in your physical health	
A pregnancy	
Divorce or marital separation	
Death of a close family member or friend	
A personal injury	
An outstanding personal achievement	
Other ( <i>please list all</i> )	
Other	
Other	

## APPENDIX E

**List of Mobility Aids**

<b>Mobility Aid or Device</b>	<b>Frequency</b>
No Device Used	12
Scooter	6
Specific Type of Cane Use	5
Jar/Bottle Opener	5
Shower Bench	5
Reacher/Picking-up device	5
Braces (knee, ankle, etc.)	5
Assistance of family member or friend	4
Grab Bar for Shower	4
Raised Toilet Seat	3
Seat or Back Cushion	3
Wrist or Hand Splint	3
Rolling walker with seat	2
Shoulder Sling	2
Nordic Walking Pole	1
Hang onto furniture, wall, etc.	1
Shoe Horn	1
Special Knife	1
Drain Pull Plugs	1
Electric Can Opener	1
Lever Taps	1
Crocks	1
Vibrator	1
Electrically-Operated Chair	1
Handle of Car to Exit Vehicle	1
Ramp	1
Cart	1
Hearing Aids	1
Heating Pads/Thermacare	1
Glasses or Contacts	1
Spinal Stimulator	1
Special Shoes	1



## APPENDIX F

**Other Pain Management Strategies**

<b>Alternative Pain Management Strategies</b>	<b>Frequency</b>
Yoga	6
Hydrotherapy	6
Swimming	5
Hypnotherapy	4
Supplements	4
Meditation	4
Ultrasound Therapy	3
TENS Unit	2
Rest	2
Trigger joint injections	2
Antibiotics	2
Probiotics	2
Assistance from Family or Friends	2
Laser Treatment	2
Physical Therapy	2
Doctor of Osteopathy	2
Dry Needling	1
EFT Tapping	1
Sex	1
MSM	1
Nutritional Response Testing	1
Enbrel	1
Fasting	1
Anti-inflammatories (circum, omegs-3)	1
Rehab	1
Diet	1
Aromatherapy	1
Network Spinal Analysis	1
Other Climates	1
Pacing themselves	1
Personal Research	1
Pain Patches	1
Sculpting in Clay	1
Art Class	1
Acupuncture	1

Herbs	1
Reiki	1
Active Response Technique	1
Pain Management Doctor	1
Drinking Water	1
Reading	1
Prayer	1
Anesthetic Creams	1
Humor	1
Stretching	1
Inversion Therapy	1
Osteopathic Manipulation Medications	1
Muscle Relaxers	1
Elevation	1
Support Braces	1
Baths	1
Pilates	1
Spiritual Healing	1
Warming Treatments	1
Weight Loss	1
Plant Medications	1
Indomethicin	1
Positive Outlook	1
HD Vibrator	1
Hot Tub	1
Steam Room	1
Epidural	1

## VITA AUCTORIS

Jennifer Voth was born in 1981 in Grimsby, Ontario, Canada. She graduated from Grimsby Secondary School in 2000. She obtained a Bachelor of Arts degree (with Honors) in Psychology from the University of Western Ontario in 2004, and in 2007, she earned her Master of Arts degree in Applied Social Psychology from the University of Windsor. She hopes to graduate from the University of Windsor with a doctorate in Applied Social Psychology in 2013.