

Wellness in the Midst of Disease: A Narrative Analysis of
Growing Up with Rheumatic Conditions

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Dedication

To the strong, inspiring women
who participated in this project.
I'm a better person for knowing you
and I'm not scared anymore.

Abstract

Rheumatic diseases affect approximately 300,000 U.S. children and cause inflammation of cartilage, bones, connective tissues, and internal organs. More than half of these children may experience life-long disability, chronic pain, and potent medication side effects (David et al., 1994; Foster et al., 2003; Hersh, von Scheven, & Yelin, 2011). Due to recent advancements in the treatment of rheumatic conditions, little is known about the long-term physical or psychosocial outcomes of childhood-onset rheumatic conditions (Duffy, 2004). Thus, the primary aim of the present study was to use a developmental and ecological approach to capture rich descriptions of the physical and psychosocial development of young adults living with childhood-onset rheumatic diseases during the transition into adulthood. Purposeful sampling was used to recruit 12 young adults (ages 25-35) with childhood-onset rheumatic diseases from rheumatology clinics in the Twin Cities metro area and the Arthritis Foundation. Participants engaged in up to three one-hour long interviews; multiple interviews allowed for increased depth and reflection time. A semi-structured interview guide was used to probe about the experience of growing up with rheumatic diseases, current health status, and coping mechanisms. Interviews were audio-recorded, transcribed, and data were coded with the assistance of NVivo software (QSR, 2012). Thematic analysis highlighted commonalities across participant narratives and was guided by the narrative model described by Lieblich, Tuval-Mashiach, and Zilber (1998), as well as Erikson's construct of Vital Involvement (VI: Kivnick & Wells, 2014). Eight categories and 27 themes emerged from the data. Findings from this study have the potential to make significant theoretical and practical contributions to social work, rheumatology, and beyond.

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Chapter 1

Introduction

While the words 'rheumatic' and 'arthritis' often elicit images of elders, there are approximately 300,000 U.S. children living with rheumatic conditions (Arthritis Foundation [AF], 2015a). Autoimmune in nature, rheumatic diseases cause inflammation and destruction of cartilage, bones, connective tissues, and internal organs. Many children living with these conditions will acquire chronic pain and functional limitations despite sometimes taking up to 20 pills daily and receiving intravenous infusions (IV) of powerful immune-suppressant medications.

Each year, thousands of these children reach adulthood and face life-long disability, chronic pain, potent medication side effects, and decreasing quality of life (David et al., 1994; Duffy, 2004; Foster et al., 2003; Hersh, von Scheven, & Yelin, 2011). Many young adults presently living with rheumatic conditions will require at least one prosthetic joint replacement by their third decade of life and will acquire a long list of medical complications including cardiovascular disease, osteoporosis, gastrointestinal damage, uveitis (inflammation of the eye), cataracts, and amyloidosis (buildup of protein in tissues and organs; Hersh et al., 2011; Moorthy, Peterson, Hassett, & Lehman, 2010; Nigrovic & White, 2006).

Not surprisingly, these physical outcomes can have significant effects on young peoples' psychological and social functioning. Scholars have documented increased rates of depression and anxiety (David et al., 1994; Packham and Hall, 2002d) as well as decreased quality of life in young adults living with rheumatic conditions (Foster et al., 2003). With regards to social health, young adults with rheumatic diseases are

significantly more likely than their peers to be unemployed (Duffy, 2004; Gerhardt, et al., 2008; Packham & Hall, 2002c); have challenges with body image, sexual activity and intimate relationships (Packham & Hall, 2002b; de Avila Lima Souza, et al., 2009); and struggle to relate with important people in their lives (Ostlie et al., 2009).

While it is necessary and important to document such problems, lists of “burdens” (Moorthy et al., 2010) are not sufficient for understanding the holistic and integrated development of young people living with childhood-onset rheumatic conditions. Decades of research demonstrates fundamental connections between physical, emotional, and social aspects of health and disease (e.g., Abraido-Lanza & Revenson, 2006; Boehm, Peterson, Kivimaki, & Kubzansky, 2011; Coty & Wallston, 2008; Ferreira & Sherman, 2007; Manderscheid et al., 2010) and increasing evidence suggests that effective psychological coping more strongly predicts long-term outcomes than disease activity alone (Friedman & Ryff, 2012; Packham & Hall, 2002d). However, no studies could be located in the rheumatology literature identifying specific strategies or coping mechanisms that young people use to succeed in college, create productive and meaningful careers, or start families while living with these conditions. This significant gap in the rheumatology literature reflects an urgent need to understand how best to promote healthy development during the transition into adulthood and beyond (McDonagh, 2008; Nigrovic & White, 2006).

Furthermore, since most children living with rheumatic conditions will carry their diseases into adulthood (Hayward & Wallace, 2009; Hazel, Zhang, Duffy, & Campillo, 2010), it is important for pediatric- and adult-focused health care providers to understand the unique medical and psychosocial needs of this population. In recent years, there has been a surge of interest in improving the process of transitioning from pediatric to adult

health care for young people with chronic conditions (Nigrovic & White, 2006; McDonagh, 2008), resulting in a Healthy People 2020 (U.S. Department of Health and Human Services, 2013) objective focused on the improvement of transition services. However, there is a significant gap in the literature surrounding what it means to successfully transition into adulthood (Chira & Sandborg, 2004; Hazel et al., 2010). This gap poses challenges to creating clinical interventions that aim to support healthy development in young people.

These gaps in knowledge may be related to the fact that nearly all studies in the rheumatology literature utilize large surveys with closed-ended questions. Such uniformity in measurement ignores the important nuances derived from lived experience and precludes the discovery of innovative strategies that young people are using to cope with their diseases. In addition, despite numerous calls for “developmentally appropriate care” (e.g., McDonagh, 2008, White, 2008; Tucker & Cabral, 2007), there is a dearth of developmental theory in the rheumatology literature. Apart from one pilot study (Ostlie, Dale, & Moller, 2007), no other studies could be located that explicitly used theory to understand the emotional and social development of young people living with rheumatic conditions as they transitioned to adulthood.

Purpose statement and research questions

It is clear from the rheumatology and health care transition literatures that scholars and health care providers could benefit from the application of existing social science theories and conceptual frameworks to better understand the holistic development of young people as they transition to adulthood. Thus, the current study took a developmental and ecological approach to exploring the personal and environmental factors that both prevented and promoted healthy development among

young people growing up with rheumatic diseases. The following research questions guided the study:

- 1) What are the personal challenges and environmental barriers faced by young adults living with childhood-onset rheumatic diseases?
- 2) What are the personal strengths and environmental supports used by young people living with childhood-onset rheumatic diseases to promote health and wellness?
- 3). How do these challenges, barriers, strengths, and supports develop over time, from childhood and into adulthood?

Research approach

Qualitative methods were used to capture developmental changes over time and facilitate a reflective process as participants described and elaborated upon their own disease stories. More specifically, narrative methods uncovered complex internal processes, such as meaning-making and identity development, which are otherwise difficult to observe through traditional quantitative methods (Lieblich, Tuval-Mashiach, & Zilber, 1998). Further, Erik Erikson's theory of lifespan development (Erikson, Erikson, & Kivnick, 1986; Kivnick & Wells, 2014) was used to identify specific strategies and resources that promoted the physical and psychosocial health of this population.

Purposeful sampling was used to recruit 12 young adults (ages 25-35 years old) living with childhood-onset rheumatic diseases from rheumatology clinics in the Twin Cities metro area and the local Arthritis Foundation. Participants took part in up to three face-to-face interviews. A semi-structured interview guide was used to probe about developmental milestones (e.g., school, relationships) and dimensions of their past and

present rheumatic conditions (e.g., medications, health care providers). Participants reflected upon their disease experiences by answering questions such as: “What have been the most challenging parts of growing up with your disease?” and “How have you learned to cope with the stress of a childhood-onset chronic disease?” Interviews were digitally recorded, transcribed, and data were coded with the assistance of NVivo software (QSR, 2012). Thematic and hermeneutic analyses were used to identify commonalities across participant narratives, guided by the narrative model described by Lieblich et al., (1998), as well as Erikson’s principle of Vital Involvement (Kivnick & Wells, 2014).

Reflexivity also played a significant role in the research approach. Since qualitative methods rely upon the researcher as its primary tool or instrument, it is crucial for researchers to observe and reflect upon how their personal and professional experiences could influence the study, and vice versa (Probst & Berenson, 2014). My experience of growing up with a childhood-onset rheumatic disease and holding leadership positions in the local rheumatology community undoubtedly influenced my approach to this study. In particular, my own disease-related mental health struggles, challenges within the health care system, and extensive involvement with the Arthritis Foundation shaped my research questions, methods, and analysis.

Rationale and significance

This study makes significant theoretical and practical contributions to our understanding of what it is like to grow up with childhood-onset rheumatic diseases. The application of Erikson’s long-standing theory of psychosocial development fills a much-needed gap in the literature about the interactions between person, environment, and time. Specifically, these findings illuminate the strengths and supports of 12 young

people used to counteract the challenges presented by rheumatic diseases. Identifying such strategies will help scholars outline important developmental pathways that could be used to create interventions to improve the transition into adulthood for young people living with rheumatic conditions.

Definition of key terms

Key terms are used throughout this dissertation to indicate specific concepts in the context of childhood-onset rheumatic diseases and the aforementioned research questions. First, the term *health* refers to the holistic definition put forth by the World Health Organization (WHO; 2007, p. 1): “health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” Second, although disease and illness are commonly used interchangeably, within the context of the health sciences literature, the two terms have specific, distinct meanings. Disease refers to the observable structural or physiological changes that are targeted with medical interventions, while illness describes the psychological and social aspects of the disease experience. Thus, illness is more elusive and is often viewed as the holistic experience of disease that manifests differently in each person and is not necessarily pathological (Cassell, 2004; Parmalee, 1997). Therefore, throughout this dissertation, the terms disease and illness refer to particular aspects of the experience of growing up with rheumatic diseases. Further, disease and condition are used interchangeably here, as they often are in the health sciences literature.

Third, the terms rheumatic and arthritis are used to describe specific types of conditions and cannot be used interchangeably. Rheumatic is an umbrella term that includes over 100 types of conditions, including all types of arthritis (e.g., juvenile arthritis [JA], rheumatoid arthritis [RA], and osteoarthritis [OA]) as well as other

conditions such as lupus and fibromyalgia. Arthritis is also an umbrella term that refers to specific conditions that cause inflammation of the joints (AF, 2015). Because of the complicated classification of these conditions, rheumatic is used throughout this dissertation to describe the overarching category of diseases experienced by participants in this study, unless a more specific condition is noted. Also, it should be noted that diagnoses containing the term juvenile (e.g., juvenile rheumatoid arthritis) are distinct conditions (i.e., JRA is not RA diagnosed in children) and therefore retain their full diagnostic label into adulthood (AF, 2015a).

Chapter 2

Literature Review

Rheumatic Conditions

Rheumatic conditions are characterized as autoimmune, meaning the immune system malfunctions and attacks otherwise healthy tissues, bones, cartilage, and internal organs (Cassidy, Laxer, Petty, & Lindsley, 2011; Jordan & McDonagh, 2006). The effects of these immune deficiencies include chronic inflammation, pain, and loss of function. Although the causes of many rheumatic conditions are unknown, many have genetic components and are triggered by environmental events such as viruses or injuries (National Institute of Arthritis and Musculoskeletal and Skin Diseases [NIAM], 2009). There are over 100 types of rheumatic conditions (Arthritis Foundation, 2015a; Centers for Disease Control and Prevention [CDC], 2015), including osteoarthritis, rheumatoid arthritis, lupus, and gout (Helmick et al., 2008; Gabriel & Michaud, 2009).

One in five U.S. adults report having doctor-diagnosed rheumatic conditions and arthritis is the number one cause of disability (CDC, 2014). People of all ages and races develop rheumatic conditions, but some types are more common among certain groups of people. For example, rheumatoid arthritis occurs two to three times more frequently in women than men; nine out of 10 people with lupus are women; lupus is more likely to occur in African Americans and Hispanics than in Caucasians; nine out of 10 people with fibromyalgia are women; gout is more likely to occur in men than in pre-menopausal women (NIAM, 2009).

Rheumatic Conditions in Childhood

Despite the perception that arthritis is primarily a disease of old age, rheumatic conditions occur in children as young as six months old and are some of the most

common diseases of childhood (Arthritis Foundation, 2015a; Weiss & Ilowite, 2007). Approximately 300,000 U.S. children (roughly 12 per 100,000) live with some form of rheumatic disease (Cassidy et al., 2011; Gabriel & Michaud, 2009; Helmick et al., 2008). This is double the number of children living with juvenile diabetes and 10 times the number of children living with cystic fibrosis (Child and Adolescent Health Measurement Initiative [CAHMI], 2012).

Typically, rheumatic conditions are diagnosed in children 16 years and younger when a health care provider detects pain, swelling, heat, and limited movement in one or more joints for a minimum six consecutive weeks (Jordan & McDonagh, 2006; Weiss & Ilowite, 2007). As was mentioned above, there are over 100 types of rheumatic conditions and at least 80 of them have been documented in children (Arthritis Foundation, 2015a; Cassidy et al., 2011; Weiss & Ilowite, 2007). The most commonly diagnosed include: juvenile idiopathic arthritis (JIA; formerly known as juvenile rheumatoid arthritis or JRA); systemic lupus erythematosus (SLE); and juvenile dermatomyositis (Cassidy et al., 2011). Similar to adults, twice as many girls are affected by rheumatic conditions as boys (Cassidy et al., 2011).

There are no cures for childhood-onset rheumatic conditions, but there have been dramatic changes in their treatments in recent decades due to advances in medical knowledge and technologies. Increased understanding of the pathophysiology of rheumatic diseases has resulted in medical interventions designed to reduce inflammation and prevent joint destruction. The most recent breakthroughs are medications known as biologic disease-modifying anti-rheumatic drugs (a.k.a. “biologics”). Biologics target and block specific molecules in the immune system which are responsible for inflammatory responses. These medications aim to interrupt the body’s natural defense cascade, thus preventing inflammation that would otherwise

cause permanent damage to joints, bones, tissues, and organs (Gartlehner et al., 2008; Minden et al., 2012).

Such medical advances have significantly reduced mortality and morbidity, permanently altering the life course of this population. For example, just three decades ago many children and adults with childhood-onset rheumatic conditions spent their lives confined to wheelchairs, unable to work full-time or have children. Now, when children are diagnosed, they are encouraged to be as active as possible and are told that their conditions should not prevent them from living active, successful, and meaningful lives (Cassidy et al., 2011; Nigrovic & White, 2006). Yet, even with the introduction of biologic medications, there are a number of physical and psychosocial complications associated with the diagnosis of rheumatic conditions in childhood. Recent studies show that 30-60% of children living with JIA have joint damage and functional limitations, 90% have feet problems, 60% have gastrointestinal (GI) issues, 40% have decreased bone density, and 14% have eye inflammation that could lead to cataracts and blindness (Duffy, 2004; Moorthy et al., 2010).

Quality of life also appears to be negatively affected by childhood-onset rheumatic diseases and treatments. Although findings are contradictory (Ding, Hall, Jacobs, & David, 2008; LeBovidge, Lavigne, Donenberg, & Miller, 2003), many scholars report challenges with psychosocial health in children and adolescents living with rheumatic conditions (Moorthy et al., 2010; Nigrovic & White, 2006; Ostlie, Dale, & Moller, 2007). In their meta-analysis, LeBovidge et al. (2008) found children and adolescents with JIA had greater levels of internalizing symptoms (i.e., anxiety, depression, and social withdrawal) than their peers. Ding et al. (2008) showed parent reports of emotional and social problems in kids with JIA and an inverse correlation between child-reported disability and psychosocial health. Likewise, Ostlie and

colleagues demonstrated in two separate studies that children and adolescents with JIA struggled to feel connected to their peers; they worried about being perceived as "lazy and unreliable" (p. 448; Ostlie et al., 2007) and desperately wanted to feel normal (Ostlie, Johansson, & Moller, 2009).

Long-term outcomes.

Along with the evolution of our understanding and contemporaneous treatment of childhood-onset rheumatic conditions, long-term outcomes are also continuously changing. Advancements in treatments offer the promise of increased physical functioning and enhanced quality of life for adults in current and future generations (Ding et al., 2008; Moorthy et al.; Duffy, 2004). However, despite this hopeful vision, recent reports show that even with the use of biologic medications, at least 50 percent of young people living with childhood-onset rheumatic diseases will continue to face periods of active disease into adulthood (Hayward & Wallace, 2009; Hersh et al., 2011; Hazel et al., 2010; McDonagh, 2007).

Physical and functional outcomes.

Historically, the rheumatology community believed that childhood-onset rheumatic diseases would 'burn out' or reach a point when active joint inflammation and destruction would cease in adulthood. However, decades of research now confirms that this is not the case for many adults living with childhood-onset rheumatic diseases (Duffy, 2004; Foster et al., 2003; Minden et al., 2002; Nigrovic & White, 2006; Packham & Hall, 2002a). Studies following adults with childhood-onset rheumatic conditions for several decades show similar patterns with regards to the physical and functional long-term outcomes. In adults who continue to experience active disease, joint damage and functional limitations are common and many young adults endure moderate to severe daily pain (Foster et al., 2003; Minden et al., 2002; Moorthy et al., 2010; Packham &

Hall, 2002a). Additionally, several studies show an inverse relationship between disease duration and functional outcomes; the longer a person lives with active disease, the worse their functioning becomes (Foster et al., 2003; Packham & Hall, 2002a; Zak & Pedersen, 2000).

Moreover, most young adults acquire long lists of disease- and medication-related complications commonly referred to as comorbidities or sequelae (Gabriel & Michaud, 2009; Hersh et al., 2011; Moorthy, et al., 2010). Comorbidities are concerning because the more conditions a person has, the more likely it is that treatments can interfere with each other and cause greater disability and mortality (Gabriel & Michaud, 2009). The most frequently observed sequelae in young adults with childhood-onset rheumatic conditions are: inflammation of the eye (approximately 20-30%) growth disturbances in limb length and/or the temporomandibular joint (approximately 25-40%), and renal disease in half of young people with lupus (Hersh et al., 2011). Other, rarer sequelae include: cataracts (10%); amyloidosis (9%); cardiovascular disease (5%); and glaucoma (4%; Jordan & McDonagh, 2006; Minden et al., 2002; Packham & Hall, 2002a). Many children and young adults are also prescribed medications to treat and prevent sequelae. For example, Packham and Hall (2002a) report that 54% of young adults take medications for GI protection, 53% take iron supplementation for iron deficiency anemia and 25% take anti-osteoporosis medications. There is also evidence to suggest that living with a childhood-onset rheumatic disease is associated with a lower life expectancy (French, Mason, Nelson, O'Fallon, & Gabriel, 2001; Gabriel & Michaud, 2009; Hersh et al., 2011).

Not surprisingly, these physical challenges often take a toll on the daily functioning of young adults living with childhood-onset rheumatic conditions. Studies show that young adults with JIA have worse physical health than their peers and that

their likelihood of disability increases with age (Arkela-Kautiainen et al., 2005; Foster et al., 2003; Hersh et al., 2005; Zak & Pedersen, 2000). While many factors contribute to the diminished quality of day-to-day life, there is evidence to suggest that pain and fatigue are two of the most challenging aspects. Zak and Pedersen (2000) report that over half of their participants experienced chronic pain - even some who were in remission – and that pain scores were positively correlated with functional limitations. Packham and Hall (2002d) find that 93% of their participants were in pain; 32% felt they had good control over pain, 45% moderate control, and 23% poor control. Furthermore, Minden et al. (2012) show that 76% of patients with active disease reported fatigue and 25% reported moderate to severe fatigue.

Psychosocial outcomes.

Similarly to the aforementioned findings for children, childhood-onset rheumatic conditions can significantly affect the quality of the social and emotional health of young adults.

Psychological and emotional health.

As could be expected, scholars have also documented long-term psychological and emotional effects of rheumatic diseases in the lives of young adults. However, it should be noted, very few studies have examined the long-term psychological implications of childhood-onset rheumatic conditions (Duffy, 2004; Packham & Hall, 2002d) and there is contradictory evidence about whether adults with these conditions have elevated rates of psychopathology or mental health problems (Arkela-Kautiainen et al., 2005; Duffy, 2004; Gerhardt, et al., 2008).

Several studies document significant associations between physical symptoms and psychological health. Foster et al. (2003) showed young adults living with rheumatic conditions had significantly lower quality of life (physically, emotionally, and socially)

compared to their healthy peers. David et al. (1994) found 21% of participants had moderate to severe depression and that there was a positive, significant correlation between disability status and both depression and anxiety. Packham and Hall (2002d) found nearly 40% of young adults with JIA felt their emotional states had been negatively affected by their diseases and over 25% of participants thought their arthritis had severe, detrimental effects. Also, while Packham and Hall (2002d) did not see elevated rates of current depression, they did find that nearly a third of participants had elevated anxiety scores.

Ostlie et al.'s (2009) qualitative description of the psychological and emotional health of young adults living with JIA was consistent with these findings. They documented substantial anxiety in young adults about the negative impact of their diseases on major milestones such as pursuing a career and starting a family. Participants struggled to find emotional balance in the face of insecurity and unpredictability related to bodily limitations, interpersonal challenges, and confidence. Participants described feelings of grief over the sense that they had lost their childhoods due to their diseases and that they continuously struggled with the "incomprehensibility and unfairness" (p. 671) of their suffering. These "complicated emotional responses" oscillated between protest and acceptance and participants demonstrated a "desperation to attain and maintain a positive view of the self and the world" (p.373).

An important dynamic described in the literature is the effect of time on the psychological and social health of young adults living with childhood-onset rheumatic conditions. As was previously mentioned, there is strong evidence to suggest that duration of active disease is associated with decreasing physical health (Foster et al., 2003; Hersh et al., 2011; Nigrovic & White, 2006), but the evidence for psychological and social health is more subtle. While some studies show depression rates in young

people with rheumatic conditions as comparable to the general population (Hersh et al., 2011; Moorthy et al., 2010), others suggest a more complex picture of psychopathology over time. Packham and Hall (2002d) found more than 20% of participants experienced a significant depression in the past, which tended to be between the ages of 15 and 25. These findings, of an elevated occurrence of mental illness in adolescence and emerging adulthood, are consistent with findings from the general population (Galambos, Barker, & Krahn, 2006), but the rate of 20% is double that of adolescents and young adults in the general population who report episodes of depression (CAHMI, 2012; NIMH, 2012). Furthermore, Packham and Hall (2002d) noted that a lifetime diagnosis of depression was most common among people who were diagnosed between the ages of 6 and 12, whereas anxiety was most common in participants who were diagnosed after 12 years of age.

Similarly, Ostlie et al. (2009) highlighted an element of time in their description of the “life-long process of adjustment” (p. 673) to childhood-onset rheumatic conditions, noting both negative and positive elements of adolescence and young adulthood. “Protest and denial” (p. 671) were common in adolescence and many participants talked about distancing themselves from their “diseased bodies” (671) through drug use, eating disorders, and aggressive behaviors. Over time, the participants discussed moving from a “here-and-now perspective in childhood” (p. 669) to a wider, more holistic viewpoint in young adulthood. Although adulthood brought with it more wisdom and maturity, it also intensified worries about the future.

Although the predominant theme from Ostlie et al.’s (2009) qualitative study - “Struggle and Adjustment to an Insecure Everyday Life and Unpredictable Life Course” – focused on challenges, they also described several benefits derived from life with a chronic, progressive disease. Over time, many young adults came to accept their health

status and recognize how their unique experiences prompted them to search for meaning in ways uncommon in their peers. Their increased self-reflection also resulted in what the authors referred to as “premature maturation” (p. 671), where they learned to focus on their strengths, reprioritize how they spent their time, and had more empathy for others.

Findings from these studies indicate that there are complex relationships between the physical, social, and emotional aspects of life for young adults living with childhood-onset rheumatic conditions. They also demonstrate that physical health is only one dimension of overall health and suggest that psychological and social health may be equally strong predictors of long-term well-being for children and young adults (David et al., 1994; Foster et al., 2003; Packham & Hall, 2002d).

Social health.

Reports of decreased quality of life may be related to the many challenges young adults experience with their social lives. Packham and Hall (2002b) show nearly a third of young adults with JIA felt their relationships had been negatively affected by their diseases and 57% reported reduced social activity due to their health. These findings are consistent with Ostlie et al.'s (2009) description of the interpersonal challenges faced by young adults living with JIA, who felt their social life was “restrained” (p. 670) and the fluctuations and invisibility of their disease negatively affected the “credibility” (p. 670) of their relationships.

With regards to intimate relationships, there is emerging evidence to suggest that rheumatic conditions negatively affect this area of life for many young adults; however, very few studies have examined this topic (Moorthy et al., 2010). Packham and Hall (2002b) showed 58% of sexually active participants reported challenges with sexual activity related to their diseases (e.g., pain, physical limitations) and de Avila Lima Souza

et al. (2009) showed joint pain was reported in 48% of young men with JIA during intercourse. Packham and Hall (2002b) also found that in participants who were not sexually active, 66% of them attributed this behavior to struggles with body image and 25% attributed their inactivity to not being perceived as “sexual beings” (p. 1442). On a related note, Ostlie, Johansson, & Moller (2009) documented that pregnancy was a major source of concern for young adult females and mothers with JIA worried about how their disease would affect their children.

In terms of educational and occupational outcomes, findings are inconclusive. Most scholars report academic achievement is comparable, if not better in young adults with rheumatic conditions than in their healthy peers, regardless of functional disability (Arkela-Kautiainen et al., 2005; Foster et al., 2003; Gerhardt, et al., 2008; Hersh et al., 2011; Packham & Hall, 2002c). However, findings on occupational outcomes are contradictory; young adults with rheumatic conditions appear to do well academically, but have been found to do worse occupationally when compared with their peers (Duffy, 2004; Gerhardt, et al., 2008), even though education is the strongest predictor of unemployment (Packham & Hall, 2002c). Several studies document unemployment rates that are 3-fold higher in young adults with rheumatic conditions compared to their healthy peers (Foster et al., 2003; Hersh et al., 2011; Packham & Hall, 2002c), with 88% of those with rheumatic conditions attributing their unemployment to their disease and 25% reporting discrimination in the workplace (Packham & Hall, 2002c). Complicating the picture even further, Gerhardt et al., (2008) found young adults with JIA were less likely than their peers to have jobs related to their future goals, while Packham and Hall (2002c) found young adults with JIA were more likely to report white-collar jobs than their peers. Although there is little understanding in the scientific literature about the underlying mechanisms of these contradictory findings (Gerhardt et al., 2008), Packham

and Hall (2002c) hypothesize that young people with rheumatic conditions may pursue higher education and white-collar jobs at higher rates than the general population because this type of work tends to rely more on cognitive abilities and less on physical bodies.

Ostlie et al.'s (2009) qualitative exploration of adult life with JIA described complex social experiences, cutting across settings. A key theme in their study was the challenge of being perceived as "normal" (p. 670) and the need for participants to constantly prove their normality and value to themselves and others. Young adults talked extensively about needing to manage and control the ways others viewed them and how this need strongly influenced their identity development. This mediating process began in childhood, but became more difficult in adulthood as their desire for normalcy conflicted with their need to feel believed and validated. Participants also discussed a strong desire to remain independent and to not be a burden to others. Lastly, on a positive note, all participants described feeling "enormous connectedness and freedom" (p.670) when they were with fellow patients.

Health Care for Young People with Childhood-Onset Rheumatic Conditions

Pediatric Care

Pediatric rheumatology is the sub-specialty of medicine that studies and cares for children with rheumatic conditions. The field only recently emerged in the U.S. during the 1960's, despite evidence of rheumatic diseases in children since 900 AD (Cassidy et al., 2011). Many children have benefited from the existence of the pediatric rheumatology sub-specialty; however, there has been a consistent shortage of providers across the U.S., continuing to the present day (Deal et al., 2007; Mayer, Mellins, & Sandborg, 2003). Currently, there are fewer than 300 trained pediatric rheumatologists in the U.S., making it impossible for all 300,000 children affected by rheumatic conditions to be seen

by the appropriate sub-specialists (Patwardhan, Henrickson, Laskosz, DuyenHong, & Spencer, 2014). Estimates show that only 3% of counties in the U.S. have a practicing pediatric rheumatologist and 13 states have no pediatric rheumatologists (Duke, 2007; Mayer et al., 2003).

An additional challenge is that most pediatric rheumatologists are located in large-city, academic settings where research and teaching consume most of their responsibilities (Mayer et al., 2003; Patwardhan et al., 2014); more than a quarter of pediatric rheumatologists do not list patient care as a primary responsibility (Mayer et al., 2003). This ongoing shortage means many families need to travel at least one hour to see their providers and some must fly to the nearest city or state (Duke, 2007; Patwardhan et al., 2014). For example, there are approximately 5,000 children living in the state of Minnesota with rheumatic conditions and there are currently fewer than 10 pediatric rheumatology sub-specialists, with all but one being located in the Twin Cities metro area (ACR, 2013).

In addition to medical sub-specialists, it is recommend that children with rheumatic diseases be cared for by multidisciplinary teams due to the complex nature of their conditions and treatment regimens (Ding et al., 2008; LeBovidege, et al., 2003). Children and their families typically receive care from a number of additional health care providers such as: nurses, physical and occupational therapists, social workers, psychologists, dentists, ophthalmologists, and orthopedists. In this type of care, generally referred to as family-centered (Nigrovic & White, 2006), it is common for the various providers to work in collaboration, with frequent communication and coordination between team members. Nurses and social workers often serve as care coordinators, either formally or informally, between team members, with patients and caregivers perceived as important members of the team.

As was previously described, the medical treatment for childhood-onset rheumatic conditions has changed dramatically over the past 30 years. In the past, providers began treatment with the least potent and toxic medications and gradually worked their way up to the most potent, if the patient's disease did not respond. Currently, the most potent medications are used first in an attempt to kick the disease into remission as soon as possible due to recent research revealing that childhood rheumatic conditions are most likely to go into remission during the first five years after diagnosis (Duffy, 2004).

Not only has the treatment approach changed, but the availability of medications has increased substantially. The 21st century ushered in a new phase of treatment for rheumatic and autoimmune conditions with the advent of the biologic disease-modifying anti-rheumatic drugs. Many scholars and providers expect to see lower levels of disability in the future due to the potential for the biologics to reduce inflammation and slow down the disease process (Duffy, 2004; Minden, et al., 2012; Moorthy et al., 2010). However, little is known about the efficacy or long-term effects (negative or positive) of these potent medications (Eleftheriou, Isenberg, Wedderburn, & Ioannou, 2014) and serious complications have been observed in adult populations such as: lymphoma, life-threatening infections, demyelinations, and liver damage (Gartlehner et al., 2008; Minden et al., 2012). Due to these concerns, few biologic medications have been formally approved for children by the US Food and Drug Administration and are therefore prescribed "off-label" (Gartlehner et al., 2008).

Health Care Transition and Adult Care

Each year, tens of thousands of children with rheumatic conditions reach adulthood and require services from adult-focused health care professionals who have little experience or training in the care of adults with childhood-onset conditions. Since

advances in treatments have resulted in longer lifespans and less functional impairment, most young adults with childhood-onset conditions will be able to participate in society in ways that were previously impossible (Cassidy et al., 2011; Nigrovic & White, 2006). Yet, as was previously described, most of these young adults will also continue to have disease activity and will, over time, acquire a long list of physical, emotional, and social complications (Duffy, 2004; Foster et al., 2003; Gerhardt et al., 2008; Packham & Hall, 2002a-d).

Consequently, there has been increasing attention paid to the process of moving from pediatric to adult-focused health care. Scholars and practitioners coined the terms 'health care transfer' and 'health care transition' to describe this process; health care transfer specifically describes the handing off process from pediatric to adult providers whereas health care transition refers to the broader developmental transition taking place as the patient moves from adolescence and into adulthood (Eleftheriou et al., 2014; McDonagh, 2008; White, McManus, McAllister, & Cooley, 2012). There are several concerns regarding these processes within rheumatology in particular.

First, there is evidence to suggest that some young adults 'fall through the cracks' because of the way the system is structured (Eleftheriou et al., 2014; Hersh et al., 2009; White, 2008). There are many elements of the health care system involved, but some commonly noted barriers to high quality transition services are: inadequate communication between pediatric and adult providers (Ostlie & Moller, 2007); lack of integration between electronic medical records (American Academy of Pediatrics [AAP], 2011); no clear understanding or agreement about the role of primary care providers in the transition process (Suris, Akre, & Rutishauser, 2009); no identified person to coordinate transition services (White et al., 2012); no reimbursement for transition services (White et al., 2012); insufficient amounts of time during clinic appointments to

discuss the multi-dimensional transition process (AAP, 2011); and lack of opportunities for adolescents to be seen alone, without their parents (Suris et al., 2009).

Additionally, rheumatology patients commonly describe a stark contrast between the cultures and/or approaches of pediatric and adult care (Eleftheriou et al., 2014; Suris et al., 2009). For example, adult practice tends to assume a more patient-centered approach, rather than the family-centered approach taken in pediatric rheumatology – meaning that adult providers typically expect their patients to take responsibility for their disease management and initiate daily tasks, such as making appointments and ordering prescriptions (White, 2006). Therefore, in order for the transition to go smoothly, adult rheumatology patients must be prepared to take over disease management from their parents and pediatric providers, who frequently help coordinate care through adolescence and into young adulthood (White, 2008).

Second, the culture clash mentioned above is thought to be due in large part to the fact that few adult providers have education or training in how to care for adolescents or adults with childhood-onset conditions (McDonagh, 2007; Suris et al., 2009; White, 2008). Although modern advances brought enormous benefits, the long-term outcomes and treatments of these conditions are still widely unknown. Subsequently, adult rheumatology providers must understand that the needs of young adults living childhood-onset conditions are likely different from those associated with adult-onset conditions (Nigrovic & White, 2006); many young people enter into adult rheumatology with a complex set of psychological, social, and vocational needs that adult providers are unequipped to handle (Foster et al., 2003; Ostlie et al., 2009).

Furthermore, nearly every article in the health care transition literature emphasizes the need for developmentally appropriate care for adolescents and young adult rheumatology patients (e.g., Bidwell, McDonough, & Bolt, 2009; AAP, 2011;

Eleftheriou et al., 2014; McDonagh, 2008; Suris et al., 2009). However, to provide such care, pediatric and adult providers must understand the unique needs of this population. Ostlie and Moller (2007) demonstrate that some young adult patients do not feel that they are understood. Rather, they feel like "objects on a conveyer belt" (p.448) because adult providers only see them as patients with a disease, rather than a whole person. These findings led Ostlie and Moller (2007) to conclude that providers must recognize that the primary focus of adolescence and young adulthood is identity formation; if they want young people to actively manage their diseases, providers need to balance the "power asymmetry" (p.451) by trying to understand the situation from the youth perspective.

Third, despite the urgent need and endless calls for high-quality care (e.g., McDonagh, 2008; White, 2008), the notion of health care transition is still in its infancy and the practice is usually "haphazard" (Nigrovic & White, 2006, p. 214). Most research focuses on identifying key elements or factors that should hypothetically be in place for a successful transition to occur (e.g., McDonagh, 2008; see Tables 1 and 2 below). These recommendations are primarily based upon observations from rheumatology providers; there is very little scientific evidence documenting specific patient, provider, or system characteristics that promote successful transition (Eleftheriou et al., 2014; Hazel et al., 2010).

Practice recommendations.

There is widespread agreement that neither young people with childhood-onset rheumatic conditions nor providers are prepared for or competent in managing the physical and psychosocial aspects of the transition to adulthood (Cooley & Sagerman, 2011; Eleftheriou et al., 2014; White, 2012). Consequently, many scholars offer recommendations for rheumatology providers and health care systems. Most believe

that the “window of opportunity” (p. 213) for increasing independence opens around 12 years of age and extends into the mid-20’s (Cooley & Sagerman, 2011; Nigrovic & White, 2006). Ideally, transition should be a gradual process of parents and providers relinquishing control and young people gaining it, with increasing levels of autonomy and competence. Ultimately, as Foster et al. (2003) summarize, the goal of transition is to produce an “independent adult living in society, with self-worth and self-esteem” (p. 774).

Similarly, Ostlie and Moller (2007) point out the aim of transition should be empowerment. They came to this conclusion after conducting focus groups separately with young adults living with childhood-onset rheumatic conditions and health care providers from a variety of disciplines (nursing, occupational and physical therapy, pediatric and adult rheumatology, education, and social work). The focus groups resulted in four recommendations for improving the transition process:

1. Formalizing the preparation for transfer and transition (i.e., working with each family and child to begin preparation from the time of diagnosis and gradually work towards the child taking over their own care).
2. Improvement in the patient-provider relationship (i.e., increasing the competence of providers working with adolescents, treating the whole person, and being more personal in adult-oriented services).
3. Improvement in patient care (i.e., providing more education on transition and adult life, pain management, coping with loss and grief).
4. Increased attention to education and vocation (i.e., career counseling and guidance, discussion about absence from school and work).

Other scholars make similar recommendations. Findings from several studies suggest vocational planning should be a major part of health care transition services (Foster et al., 2003; Packham & Hall, 2002c). In particular, Packham and Hall (2002b;

2002c) caution providers about the strong correlation between depression and unemployment and encourage providers to support the development of healthy coping strategies during the transition into adulthood. Additionally, Packham and Hall (2002b), along with many others (e.g., Bidwell et al., 2009; de Avila Lima Souza et al., 2009; Suris et al., 2009), emphasize the importance of providers talking to adolescents and young adults about sexual health (i.e., fertility, pregnancy, sexually transmitted infections, and contraception), especially given the teratogenic effects of some medications used to treat rheumatic conditions (Wallace, 1998) and the fact that most young adults are sexually active by the time they transfer to an adult provider (Bidwell et al., 2009).

In order to carry out these recommendations, most scholars agree providers and clinics should have established protocols for transition, good communication between pediatric and adult providers, and assigned roles for the coordination and management of transition services (McDonagh, 2008; Suris et al., 2009; White, 2008). Bidwell et al. (2009) also recommend longer appointment times for young adults, referrals to community resources, and using the HEADDSS assessment tool (Goldenring & Rosen, 2004) to evaluate the many aspects of young peoples' lives.

As part of the ongoing dialogue in the rheumatology community regarding health care transition, several prominent scholars developed checklists, which offer guidance to providers who would like to make changes in their practice settings. The two checklists below (Table 1 and 2) highlight widely accepted elements of health care transition.

Table 1

Content of transition policy for pediatric rheumatology (McDonagh, 2008)

Definition of transition
Overview of transitional care in rheumatology at host institution
Named team members who will coordinate the transition program
Age at main transition events

First discussion
Start of transition program
Transfer to adult service
Exceptions to stated timings
Target adult services (e.g., Rheumatology, Ophthalmology, Orthopedic, etc.)
Transition program elements
For young person
For parent/guardian
For pediatric rheumatology clinics
For adult rheumatology clinics
Will include
Individualized transition plan
Multidisciplinary team documentation process
Informational resources
Transfer process elements
Contact with adult services
Involvement with primary care
Medical summary and records transfer
Aftermath
Policy regarding contact with patients following transfer to adult services
Evaluation procedures
Audit
Regular review of policy
Participation of young people and their parents in evaluation and future development

Table 2

Checklist for transition: Core knowledge and skills for pediatric and adult practices caring for youth diagnosed with rheumatic disease (White, 2008)

Policy

1. Staff person coordinates transition activities
2. Office forms are developed to support transition processes
3. Coding is used to maximize reimbursement for transition services
4. Legal health care decision making is discussed prior to youth turning 18
5. Prior to age 18, youth sign assent forms for treatments, whenever possible
6. Practice transition policy including age when youth should be seen alone and/or youth should transfer care to an adult practice is posted for youth and families to see

Medical Home

1. Practice provides care coordination for youth
2. Practice creates an individualized health transition plan before age 14 and updates it regularly
3. Practice refers youth to specific adult medicine physicians for primary care
4. Practice recruits, provides support and confers with adult primary care and specialty providers post transfer if indicated

5. Practice actively assists youth to be able to describe their medical condition, health care team and medications succinctly

Family/Youth Involvement

1. Practice starts with formal transition planning with families/youth at least by the age of 11 or shortly after diagnosis is disease started after age 11
2. Practice provides educational packet or handouts on transition
3. Youth participate in shared care management and self-care
4. Practice assists families/youth to develop an emergency plan (health crisis or other environmental disasters)
5. Practice assists youth/family in creating a portable medical summary
6. Practice assists with planning for school and/or work accommodations if needed
7. Practice assists with medical documentation for program eligibility (SSI, College)
8. Practice refers family/youth to resources that support skill-building: mentoring, JA or other camps, national JA conference, recreation, activities of daily living, volunteer/part time paid work experiences

Health Care Insurance

1. Practice is knowledgeable about state mandated and other insurance benefits for youth after age 18
2. Practice provides medical documentation when needed to maintain benefits

Screening

1. Exams include routine screening for risk taking and prevention of secondary disabilities
2. Practice teaches youth lifelong preventative care, how to identify health baseline and report problems early; youth know wellness routines, diet/exercise, etc.

Gaps in the Literature

Several important gaps exist in the scientific literature related to young adults living with childhood-onset rheumatic diseases. First, there is a lack of information regarding the physical and psychosocial long-term outcomes. Due to the constant changes in medical treatments for this population, it will be necessary to do ongoing work in this area. In order to fully appreciate the long-term consequences of childhood-onset rheumatic diseases on individuals, families, and society, researchers must pursue more precise data regarding prevalence and disease mechanisms throughout adulthood. Currently, little is known about the numbers of adults living with these conditions or disease manifestations across the lifespan (Eleftheriou et al., 2014; Packham & Hall, 2002a-d). Additionally, there is an explicit call for more research examining the

psychosocial aspects of the transition into adulthood and the long term effects of growing up with rheumatic diseases. Several scholars point to the lack of research on topics such as depression and anxiety (LeBovidge et al., 2003; Ostlie & Dale, 2007; Packham & Hall, 2002d), coping (Ostlie et al., 2009), employment and vocational decisions (Gerhardt et al., 2008), and relationships and sexuality (Bidwell et al., 2009; Moorthy et al., 2010; Packham & Hall, 2002b).

Second, we need to more specifically examine the personal and environmental factors that may be protective against negative physical and psychosocial outcomes of childhood-onset rheumatic conditions. The inconsistent levels of psychopathology observed in this population may in part be due to the development of effective coping mechanisms and the presence of protective factors that buffer the impact of the many challenges faced by these young people. This hypothesis was put forth by a number of providers and scholars (e.g., Dahlquist, 2003; LeBovidge et al., 2003; Ostlie et al., 2009) and suggests that there may be undocumented pathways to resiliency underlying the observed physical and psychosocial outcomes.

Third, we must continue to identify the skills and resources young people need to transition from pediatric- to adult-centered health care (Eleftheriou et al., 2014; Stinson et al., 2008). Without this crucial information, many children with rheumatic diseases will grow up lacking adequate support from their health care providers and may acquire unnecessary impairments as a result. Likewise, it is essential that providers and scholars better understand what it means to have a successful transition; simply changing providers doesn't constitute a successful transition into adulthood (Eleftheriou et al., 2014). It is also worth noting that the topic of mental health is largely absent from the transition checklists (see Tables 1 and 2 above) and the transition literature. Despite empirical evidence that many young people struggle emotionally and socially while living

with rheumatic conditions, there is little discussion about how to provide support in these areas during the transition into adulthood. For example, there is little mention of the role of social work in the transition process even though most of the activities described in the checklists generally fall under the job responsibilities of medical social workers (e.g., planning for accommodations, community resources, applying for Social Security Disability Insurance, self-management skills, care coordination, screening for risk factors, etc.; Shanske, Arnold, Carvalho, & Rein, 2012; NASW, 2008).

Lastly, there is a dearth of developmental theory in the rheumatology and health care transition literatures. As was previously mentioned, 'developmental appropriateness' has come to be seen as an essential part of health care for children, adolescents, and young adults (AAP, 2011; Eleftheriou et al., 2014; McDonagh, 2008; White, 2008), however, only one study could be located that explicitly utilized developmental theory (i.e., Ostlie et al., 2009). Considering the vast research and practice experience of the scholars in these fields, it is likely that developmental theory has influenced the thinking behind much of this work, but losing sight of key concepts, such as identity development in adolescence, could be harmful to patients and the scholarly community.

Methodological Considerations

It is also important to consider how gaps in knowledge may be related to methodological issues. First, there are several concerns with the way researchers measure psychosocial functioning. The most commonly assessed outcomes in children are the frequency of internalizing and externalizing symptoms, measured by the Child Behavior Checklist (CBCL), which is a parent-report of behavior problems (LeBovidge et al., 2003). This measure could be problematic because researchers are relying on

parents to report a perception of their child's psychological health rather than receiving input from the kids and/or mental health providers.

In adolescents and young adults, psychosocial functioning is most commonly assessed with the Health Assessment Questionnaire, which is a measure of the day-to-day functioning and disability status of adults with rheumatic conditions (Wolfe, 2000). However, Foster et al. (2003) question whether the HAQ can accurately assess overall functioning in rheumatic diseases and Wolfe (2000) suggests that the biomedical model may be "inadequate" (p. 2760) for assessing psychosocial functioning. Packham and Hall (2002a) also comment that some of the psychosocial assessments used in rheumatology are "crude, poorly validated, and physician-centered" (p. 1428). Additionally, there are no published data in the rheumatology literature regarding the rates of diagnosed mental health conditions (in children, adolescents, or adults) or rates of prescribed psychotropic medications. Packham and Hall (2002d) also note that the numbers of young people with rheumatic conditions who are struggling emotionally is likely underestimated because of the common practice in medicine to prescribe psychotropic medications, which can mask the symptoms of mental illness.

Furthermore, common measures of psychosocial functioning do not account for internal strengths, protective factors, or resilience (LeBovidge et al., 2003). Only one study (Packham and Hall, 2002d) could be located that used standardized measures to assess anything other than problems or risk factors. Likewise, social health is usually assessed by educational and occupational variables, with scholars rarely taking into account any other type of support offered by family, friends, or communities.

Second, there is a need for greater specificity in study design and recruitment protocols (Arkela-Kautiainen et al., 2005; LeBovidge et al., 2003). There is a wide range in outcomes by type and severity of rheumatic conditions (Hersh et al., 2011; LeBovidge

et al., 2003). Some conditions (e.g., lupus) tend to have worse physical outcomes overall, whereas others (e.g., JIA) have a wider range of outcomes within the one condition. Such traits could be responsible for some inconsistencies in findings (e.g., occupation status, psychological health). Also, it is likely that the varied findings, regarding physical, social, and emotional outcomes, could be related to the enormous shifts in treatment over the past three decades; each age cohort may possess their own unique set of characteristics. These unique generational qualities will be important for researchers to keep in mind when it comes to documenting the life-long needs of adults living with childhood-onset conditions.

Third, there are very few studies employing qualitative methods (Hilderson et al., 2013). The fact that nearly all studies in the rheumatology and health care transition literature utilize large surveys with closed-ended questions, suggests that young adults living with childhood-onset rheumatic conditions have not been given the opportunity to share their lived experiences. Such uniformity in measurement precludes the discovery of innovative strategies young people use to cope with their health conditions and the ability to understand complex developmental pathways over time.

Finally, it is worthwhile noting that the vast majority of studies examining the psychosocial health and health care transition of young people with rheumatic conditions have been done in European and Scandinavian countries (e.g., Hazel et al., 2010; Eleftheriou et al., 2014; Foster et al., 2003; McDonagh et al., 2006; Minden et al., 2002; Tucker & Cabral, 2007). It is not clear to what degree location of research limits the generalizability of findings, but it is important to consider contextual differences. In the case of childhood-onset rheumatic conditions, there may be concerns related to differences in health care systems that may affect access to treatments and services. This is particularly relevant with rheumatic diseases, given that biologic medications

were approved significantly earlier in the European and Scandinavian countries compared with the U.S. (Arkela-Kautiainen et al., 2005).

Chapter 3

Theoretical Frameworks

It is clear from the rheumatology and health care transition literatures that there is a need to better understand and support the social and emotional development of young people growing up with rheumatic conditions. Over the course of my academic career, several theoretical frameworks have significantly influenced my thinking related to the relationship between health and disease, as well as my understanding of psychosocial health in the face of adversity. More specifically, this chapter highlights the following five frameworks: biopsychosocial medicine; Erikson's theory of life cycle development; resilience; well-being; and the social work perspective. When appropriate, these frameworks are discussed within the context of adolescence and young adulthood. The presentation of the frameworks is followed by an integration of their concepts and a discussion of their relevant contributions to scholars and practitioners who work to improve the lives of young people living with rheumatic diseases.

Biopsychosocial Medicine

The biopsychosocial perspective emerged in Western medicine as a response to the reductionist and compartmentalized biomedical model of health and disease. The biomedical model is rooted in the 17th century scientific revolution (Tarnas, 1991) and posits that all health conditions are caused by observable structural impairments in the human body (Engel, 1977; Weick, 1983). Subsequently, those who subscribe to this model believe cures or treatments for such impairments are simply repairs to the human machine (e.g., medications, surgical procedures). Within this paradigm, there is a strong emphasis on identifying, isolating, and fixing individual parts of the body; when the cause can be observed and identified it is a legitimate condition, and when it can't, there is an

assumption that the symptoms are not physical and hence its treatment is outside the purview of medicine (i.e., coming from the mind or some other intangible source). Due to the value placed upon observable and structural components, there is a strong chasm in the biomedical model between the body and the mind, with the body being viewed as more important and 'real' (Lowenberg & Davis, 1994; Frattaroli, 2001; Weick, 1983).

In the U.S., medical doctors and scholars began to challenge the biomedical model in the early part of the twentieth century in response to the "era of therapeutic nihilism" (p. 2; Shorter, 2005). As medical technology advanced and diseases did not abate, many began to question the effectiveness of the health care system and the biomedical model in particular (Cannon, 1952; Cassell, 2004; Shorter, 2005). This shift in thinking inspired the widely referenced WHO's 1948 definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2007, p. 1; Breslow, 1999; Diener, Suh, Lucas, & Smith, 1999; Jahoda, 1958; John & Wright, 2005).

In 1977, a physician named George Engel proposed the biopsychosocial model as an alternative to the biomedical model. He believed the medical model did not provide an appropriate foundation for the practice of medicine any longer and articulated three errors in biomedical thinking: 1) the separation of the body from mind and the privileging of the body over the mind; 2) the reduction of the person to their body and disease and in response the cold, technical practice of medicine; 3) the devaluation of the patient perspective in research and clinical encounters (Borrell-Carrio, Suchman, & Epstein, 2004). Engel (1977) believed individual physicians had always recognized the importance of the psychological and social aspects of disease, but the profession as a whole refused to acknowledge the significance of these areas of human functioning. While Engel was not the first person to espouse such ideas about medicine or health

care – many scholars and practitioners have made similar claims about Western medicine (e.g., Cabot, 1927; Cannon, 1952; Shorter, 2005) – it is widely accepted that Engel’s articulate presentation of these ideas struck a chord in the medical community that has lasted until the present day (Adler, 2009; Borrell-Carrio, Suchman, & Epstein, 2004; Shorter, 2005; Wade & Halligan, 2004).

In recent years, support for the biopsychosocial model has strengthened due to growing doubts about the ability of biomedical interventions to adequately treat complex, chronic diseases (Alonso, 2004; Shorter, 2005; Wade & Halligan, 2004) and decades of empirical evidence documenting the undeniable connection between the mind and the body (Boehm et al., 2011; Friedman & Ryff, 2012; Manderscheid et al., 2010; Miyamoto et al., 2013; Rozanski & Kubzansky, 2005). In response, there are a number of recent practice- and research-oriented movements in health care that build upon the biopsychosocial model such as: patient-centered care (Mead & Bower, 2000); social determinants of health (Marmot, 2006); narrative medicine (Charon, 2001); interprofessional education (WHO, 2010); and integrative medicine (Snyderman & Weil, 2002). Scholars and practitioners are also working to integrate the biopsychosocial model into medical education. For example, Table 3 shows Borrell-Carrio et al.’s (2004) adaptation of Engel’s basic principles of the biopsychosocial model and Novack et al.’s (2007) framework for teaching medical students about the “domains of psychosomatic medicine” (p. 390), which they consider to be the building blocks of a biopsychosocial approach to health care. These elements of the biopsychosocial model illustrate the expansion of medicine’s approach to health and show considerable overlaps with other health professions such as social work, psychology, and nursing.

Table 3

Building blocks of the biopsychosocial approach to health care

Principles of Biopsychosocial-Oriented Care (Borrell-Carrio et al., 2004; p. 579)	
	Calibrating the physician
	Creating trust
	Cultivating curiosity
	Recognizing bias
	Educating the emotions
	Using informed intuition
	Communicating clinical evidence
Domains of Psychosomatic Medicine (Novack et al., 2007; p. 390)	
	Psychological/biological
	Developmental psychobiology
	Genetic basis of behavior/environmental influences on gene expression
	Psychophysiology (e.g., psychoneuroimmunology)
	Stress/allostasis
	Psychobiology of specific disease processes
	Psychological/behavioral
	Health behaviors and attitudes
	Behavior change
	Psychodynamics
	Coping
	Somatization
	Personality styles and disorders
	Developmental psychology
	Social/biological
	Biological consequences of social isolation, poverty, SES, etc.
	Protective effects of social support, social capital, religiosity, etc.
	Social/behavioral
	Social determinants of health and health practices
	Health disparities
	Effects of physician-patient communication
	Biopsychosocial
	Acute and chronic illness
	Illness behavior
	Pain and suffering
	Mood and addictive disorders

Despite its tentative history, the biopsychosocial model's hold appears to be strengthening over time and recent developments in health care policy (e.g., the Mental Health Parity Act and Affordable Care Act) may be exactly what are needed to appropriately encourage adaptation to the medical model. Furthermore, the

biopsychosocial model could serve as a tool for facilitating conceptual and practical connections between the various health-related disciplines represented in the model.

Erikson's Theory of Life Cycle Development

Erik Erikson's theory of psychosocial development offers one of the most comprehensive accounts of how people grow and remain "psychologically alive" (Erikson, 1980, p. 52) across the life span (Douvan, 1997; Hill & Burrow, 2012; Kivnick & Wells, 2014). Erikson is best known for his description of eight stages of psychosocial development, which initially appeared in his ground-breaking book *Childhood & Society* (1950), and was adapted in his last two books *The Life Cycle Completed* (1982) and *Vital Involvement in Old Age* (1986).

In an attempt to answer the question "how does a healthy personality grow or accrue from the successive stages of increasing capacity to master life's outer and inner dangers – with some vital enthusiasm to spare?" (Erikson, 1980, p. 53), Erikson divided the life span into eight stages, each associated with a corresponding psychosocial theme (see Figure 1). Each theme represents an ongoing tension between a syntonic (positive) and dystonic (negative) aspect of selfhood. Over time, individuals move through the loosely-based chronological stages and work (both consciously and unconsciously) on finding a healthy balance between the syntonic and dystonic qualities.

PSYCHOSOCIAL STAGES OF LIFE

Old Age							Integrity vs. Despair. WISDOM
Adulthood						Generativity vs. Self- absorption. CARE	
Young Adulthood					Intimacy vs. Isolation. LOVE		
Adolescence				Identity vs. Confusion. FIDELITY			
School Age			Industry vs. Inferiority. COMPETENCE				
Play Age		Initiative vs. Guilt. PURPOSE					
Early Childhood	Autonomy vs. Shame, Doubt. WILL						
Infancy	Basic Trust vs. Basic Mistrust. HOPE						

Figure 1. Erikson's psychosocial chart, as the stages came to be identified by the 1970's and 1980's (Erikson et al., 1986).

Adolescence and Young Adulthood

Erikson (1950) described adolescence and young adulthood as sensitive periods for identity development due to the newly developed capacity for abstract thinking and the occurrence of new life experiences (e.g., driving, dating, working, and college). During this time, young people use the psychosocial skills they've acquired up until that point (i.e., trust, autonomy, initiative, industry) to explore, and ultimately create, a coherent sense of self. They do this through thinking about and experiencing themselves trying on various identities in areas such as vocation/occupation, religion, politics, gender, and sexual orientation. As they put themselves in new situations and observe how it feels, they attempt to integrate the various aspects of themselves into one consistent, meaningful self. When young people struggle throughout this process, as they often do, Erikson (1982) described them as experiencing "identity confusion" (p. 72).

Erikson's conceptualization of identity development made an unparalleled contribution to our current understanding of adolescence by laying the foundation from which prominent scholars have emerged (e.g., James Marcia, Dan McAdams, and Jeffery Arnett). Marcia (1966; 1993), who is widely considered to be an expert on adolescent development (Berger, 2011; Meeus, Iedema, Helsen, & Vollebergh, 1999), expanded Erikson's conceptualization to include four identity statuses (i.e., identity achievement, moratorium, foreclosure, and identity diffusion) that describe patterns in the ways young people cope with the process of forming an identity. Marcia (1966) also developed and tested a widely used measure for assessing these four identity statuses. McAdams (1988; 2006) builds upon Erikson's work by describing the identity formation process as a story or narrative-making endeavor that begins in adolescence and continues throughout adult life. He calls the product of this process narrative identity,

which is a "psychosocial construction" (McAdams & Cox, 2010, p. 169) the self co-creates with its surrounding environment.

The central psychosocial theme in young adulthood is the balancing of intimacy and isolation. Erikson (1950) described this stage as a time when a young adult is "eager and willing to fuse his identity with that of others" (p. 263). The capacity for intimacy relies heavily upon the young person's ability to establish a healthy sense of identity, as well as opportunities for connection in his or her environment. Arnett (2004) builds upon and adapts Erikson's notions of prolonged adolescence and psychosocial moratorium by proposing a new life stage in response to recent cultural shifts in the U.S. His controversial theory (cf. Hendry & Kloep, 2007) suggests the rising age of first marriage and parenthood represents the development of a new, distinct time of life called emerging adulthood. This new stage is characterized by five main features: 1) identity exploration; 2) instability; 3) self-focus; 4) feeling in-between; 5) unparalleled possibility. Arnett (2004) notes that Erikson's notion of identity development primarily occurred in adolescence and he believes, based upon empirical findings, that identity development may now be more focal post-adolescence in today's society compared with Erikson's observations in the 1950's.

Principles of Psychosocial Development

In addition to the stages and themes, there are three key principles weaving throughout the life span and connecting Erikson's eight stages (Kivnick & Wells, 2014). The first - Dynamic Balance of Opposites - emphasizes the importance of both positive (syntonic) and negative (dystonic) experiences in healthy psychosocial development. It is through the psychological work of balancing the two inevitable aspects of the self, represented by the themes, that we acquire the skills to successfully adapt to the continuous ups and downs of life. The result of finding an appropriate balance is the

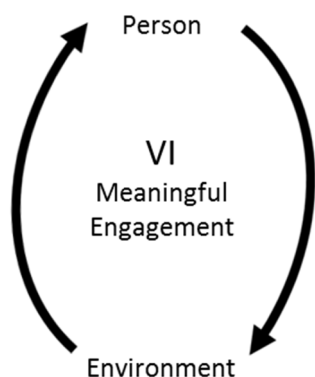


Figure 2. Vital Involvement

strength associated with each theme (e.g., Fidelity in adolescence; see Figure 1 for all strengths).

The second principle is Vital Involvement (VI), which is defined as the reciprocal and meaningful engagement between a person and his or her environment (see Figure 2; Erikson et al., 1986). VI emerged out of Erikson's observation that even in the

face of extreme psychosocial suffering, it is possible for

people to have a sense of agency, which allows for meaningful interaction with their environments. The principle of VI emphasizes the critical role of the physical and social environments in shaping who a person becomes over time and recognizes that both the person and their environment are active, living systems in constant states of change. Additionally, the principle of VI emphasizes that healthy psychosocial development occurs when a person is engaged in *meaningful* interactions with their environment. Meaningfulness, as defined by the person, is the crux of the principle of VI; without meaningful interactions the person and environment may continue to change, but their capacity for growth is limited.

Over the past several decades, Kivnick – a collaborator on Erikson’s final book *Vital Involvement in Old Age* (1986) – has further developed the principle of VI and introduced Vital Involvement Practice (VIP). VIP is a guided process of identifying and activating psychosocial strengths as a means of addressing challenges in clients and their environments (Kivnick & Stoffel, 2002; 2005). VIP was developed for use with health professionals working with elders, but is applicable across the life span and a variety of settings.

Lastly, the third principle - Life in Time – highlights the fact that psychosocial development does not simply occur in a linear fashion, marching from stage to stage. The main tenet of this principle is that individuals will both pre-work and re-work themes that are not central during particular stages, as life circumstances require. Meaning, there is a significant amount of anticipation and revision of qualities of the self throughout the life cycle (Kivnick & Wells, 2014).

In summary, Erikson’s theory – which includes the eight stages, their corresponding themes, and the three principles – articulates mechanisms through which psychosocial development occurs across the life span and made substantial contributions to our current conceptualization of adolescence and young adulthood. Although the complexity of Erikson’s theory in its entirety can be difficult to grasp (Hill & Burrow, 2012; Steingart, 1997), the richness provides fertile ground for future application and testing in areas such as identity development and young adulthood.

Resilience

Resilience is a two-dimensional construct describing the developmental process of successful adaption in the face of adversity (Luthar & Cicchetti, 2000; Masten, 2001). The two dimensions of resilience are risk and protection. Risk is typically defined as specific events or circumstances that exacerbate negative, stressful experiences for

individuals, families, and communities. Protection is defined as specific factors that have stress-moderating effects, over time (Rutter, 1985). Resilience results when protective factors mitigate and buffer the negative effects of risk.

The study of resilience in the U.S. emerged in the 1950's from the observation that many people and communities experience good psychosocial outcomes despite the presence of significant risk and adversity (Richardson, 2002; Werner & Smith, 1992). Since this time, the conceptualization and study of resilience has gone through three waves (Richardson, 2002, p. 308):

1. First Wave: Resilience is composed of particular qualities that are statistically associated with positive functioning.
2. Second Wave: Resilience is a coping process that results in healthy outcomes. This process is focused on how the qualities from the first wave are integrated and applied.
3. Third Wave: Resilience is driven by “motivational forces” in individuals and communities that undergird the integration and adaption process.

Many prominent scholars have built an extensive body of knowledge identifying risk and protective factors and how they interact to encourage or prevent healthy psychosocial development over time (e.g., Masten, 2001; Richardson, 2002; Rutter, 1985; Werner & Smith, 1992). Table 4 highlights some of the widely recognized factors that seem to be involved in the process of resilience in childhood and early adulthood. It is important to note that resilience is associated with genetic, social, psychological and learning factors (Wright, 1998; Masten, 2001).

Table 4

Widely recognized risk and protective factors for children and young adults (Masten et al., 2004; Rutter, 1985; Werner and Smith, 1992)

Risk Factors	Protective Factors
Difficult temperament	Easy temperament
Chronic poverty	Sociability
Disruption in family unit	Behavioral & emotional autonomy
Parent mental illness	Faith & prayer
Childhood mental illness	Strong internal locus of control
School problems	Motivation to succeed in the future
Delinquency	Problem-solving skills
Feelings of helplessness	Planfulness
	Scholastic competence & achievement
	Activity level
	Emotional support from family
	Adult support outside family
	Opportunities that increase competence & confidence
	Supportive adults who assist with realistic educational & vocational planning
	Presence of mentor/role model

In addition to developing an expansive list of characteristics, scholars have demonstrated that resilience is far more than a simple equation of protective and risk factors. Although some factors have one-to-one effects, many are interactive and have synergistic relationships (Luthar & Cicchetti, 2000; Olsson et al., 2003). For example, a child born with a difficult temperament can contribute to household stress and elicit poor parenting, both of which increase the likelihood of additional risk factors and create a negative chain reaction between the person, their environment, and society.

Furthermore, there is evidence to suggest that the timing of particular risk and protective factors could be important (Rutter, 1985; Werner & Smith, 1992). Masten et al. (2004) emphasized the developmental “window of opportunity” (p. 1091) during adolescence and the transition into adulthood, and showed that specific protective

factors (e.g., coping skills and adult support) appeared to have amplified long-term effects when introduced during this unique time in the life course. Other scholars found similar results with the timing of risk and protective factors in childhood (e.g., disruption to family unit in middle childhood and positive interactions between child and caregiver in early childhood; Werner & Smith, 1992).

In sum, decades of research have shown that most people are able to successfully adapt to adverse circumstances when given the appropriate internal skills and external supports (Masten, 2001; Werner & Smith, 1992). Additionally, the resilience literature demonstrates that “coping with stressful situations can be strengthening” (Rutter, 1985, p. 608) by building competence, mastery, and self-confidence (Masten, 2001; Rutter, 1985). Currently, the field is working towards the development of scientifically testable theories and interventions that can be used to prevent problems across the life span (Luthar & Cicchetti, 2000; Olsson et al., 2003).

Well-Being

Paralleling the study of resilience, scholars have narrowed in on specific traits associated with the construct of well-being. Although explorations of well-being have been occurring in many forms, over many years, the vast majority of the conceptual and empirical research has been done over the last four decades (Haight, 2006; Henderson & Knight, 2012; Ryff & Singer, 2008). Similar to biopsychosocial medicine, the study of well-being was a reaction to psychology’s insistent focus on psychopathology and unhappiness (Diener, Suh, Lucas, & Smith, 1999; Ryff, 1989). Currently, there are dozens of well-being frameworks and conceptualizations, thus only the two most widely discussed are presented here.

Subjective Well-Being

The most commonly used framework in the social and health sciences is Subjective Well-Being (SWB) (Jayawickreme, Forgeard, & Seligman, 2012). SWB emerged from the work of Wilson (1967) on the nature of “avowed happiness” (p. 294). Overtime, the exploration of happiness broadened and evolved into SWB, which consists of three dimensions: positive affect; negative affect; and life satisfaction (Diener, Emmons, Larsen, & Griffin, 1985; Diener et al., 1999). Or in other words, “how we think plus how we feel about our lives” (Jayawickreme et al., 2012, p. 331). The three dimensions of SWB can be used in combination, as one construct, or as individual components (Diener et al., 1999).

The study of SWB has progressed in a similar manner as the three waves of resiliency research (i.e., scholars started by identifying lists of factors that correlated with SWB and then moved into exploring the interactions between the correlates, followed by models that explain the underlying mechanisms). Throughout this line of research, SWB has been examined as both an outcome and a predictor variable, or as Diener et al. (1999) state, “bottom-up” or “top-down” processes (p. 278).

Outcomes.

Decades of research demonstrates that SWB is influenced by a complex relationship between genetics, cognitions, behaviors, and social environments (Diener et al., 1999, p. 295). Leading scholars summarize these findings by stating:

The happy person is blessed with a positive temperament, tends to look on the bright side of things, does not ruminate excessively about bad events, is living in an economically developed society, has social confidants, and possesses adequate resources for making progress toward valued goals (Diener et al., 1999, p. 295).

These findings indicate a strong connection between cognitive appraisal and SWB, even in the face of major illness and disability. For example, studies show a strong, positive correlation between health status and SWB, but this association only applies to self-reported health, as opposed to doctor-defined health (Diener et al., 1999). Scholars suspect that cognitive processes, such as social comparison, are involved in this process (Diener, 2012). This hypothesis is also supported by the findings that adaptation in SWB only occurs in some people following major life events such as divorce, unemployment, and disability (Lucas, 2007).

Predictors.

SWB has also been found to predict a number of important outcomes. There is a long line of research showing positive affect (one dimension of SWB) is beneficial and predictive of desirable outcomes across life domains such as social functioning, work, and health (Diener et al., 1999; Lyubomirsky, King, & Diener, 2005). For example, people with higher levels of positive affect are more likely to report positive interactions with peers, greater income and job satisfaction, and higher rates of fertility (Diener, 2012). In fact, these findings have been so compelling, Diener and Chan (2011) propose that higher levels of SWB could add four to ten years of life to an individual's life span and Lyubomirsky et al. (2005) propose that SWB could be the cause of success, rather than the effect.

In addition to the "bottom-up" and "top-down" findings described, the most recent development in this area is the creation of nation accounts of SWB to be used as indices alongside economic indicators such as the gross domestic product (Diener, 2012). Diener (2000; 2012) is advocating for these indicators to expand world-wide thinking about wellness and success and his efforts have resulted in the use of SWB indicators in

the United Kingdom, Chile, Japan, Australia, Bhutan, and at the Centers for Disease Control and Prevention in the U.S.

Psychological Well-Being

In 1989 Ryff questioned the conceptual foundation of SWB and has since developed a successful research career guided by her alternative conceptualization, known as Psychological Well-Being (PWB; Ryff, 2013). Ryff (1989) argued that the underlying principles of SWB had not been adequately explored or defined because two of SWB's most commonly used dimensions (happiness and life satisfaction) initially emerged as outcome variables in studies that were not explicitly assessing the construct of well-being (e.g., social changes in Bradburn, 1969; successful aging in Neugarten, Havighurst, & Tobin, 1961). Therefore, Ryff (1989) stated that "instruments were developed for other purposes, and these then became the standard bearers for defining positive functioning" (p. 1070) and researchers "have been immobilized by the absence of valid measures" and "loose conceptualizations" (p. 1070) of well-being ever since.

Ryff's (1989) alternative perspective, synthesized then-current thinking with longstanding psychological theories to develop a multidimensional model of psychological well-being. She did this by integrating key concepts from a wide range of prominent thinkers such as Maslow, Rogers, Jung, Allport, Erikson, Buhler, Neugarten, and Jahoda into six dimensions of well-being (i.e., self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth). She observed a significant overlap between these thinkers when it came to positive psychological functioning, thus her well-being framework focused on this convergence (Ryff, 2013). In contrast to SWB, Ryff's (2013) construct focused on "eudaimonic" approaches (i.e., sense of meaning, virtue, or purpose) to well-being rather than "hedonic" (feeling good, pleasure, or satisfaction).

After nearly three decades, Ryff's conceptualization of well-being has been used across a wide variety of scientific studies as an outcome, predictor, and moderating factor (Ryff, 2013). These studies span a variety of topic areas and disciplines; Table 5. presents a brief summary of key PWB findings, as presented by Ryff (2013) in her most recent review.

Table 5

Key findings associated with psychological well-being

Development and Aging
Aging is correlated with declines in purpose in life and personal growth
PWB is predicted by "feeling younger, but not wanting to be younger" (p. 14)
PWB changes as people encounter challenges
PWB is associated with social comparison, flexible self-perceptions, and coping strategies
Personality Correlates with PWB
Optimism
Life management strategies
Intentional activities
Empathy
Emotional intelligence
Independence
Interdependence
Family Experiences
Helping others promotes purpose and self-acceptance
Consistent marriage is associated with PWB (compared to divorced, widowed, or never married)
Single women report higher autonomy and personal growth than married women
Parenting promotes PWB in parents
Loss of a child predicts lower levels of PWB in parents
Loss of a parent in childhood predicts lower levels of PWB in adulthood
Physical or psychological violence in childhood predicts lower levels of PWB in adulthood
Work and Life Engagements
Conflict between work life and home life decreases PWB
"Positive spillover" (p. 17) between work and home life predicts PWB
Volunteering promotes PWB, especially in the elderly
Religious participation associated with higher levels of purpose and growth
Health and Biological Research
PWB is often "compromised" (p. 20) in people with physical illness and disability
Purpose in life is protective against some physical conditions (e.g., Alzheimer's, stroke, and MI)
Positive PWB is linked to lower stress hormones and inflammatory markers
Patterns of gene expression appear to be related to PWB

In summary, the constructs of SWB and PWB have substantially contributed to our current understanding of well-being. Although no single definition of well-being exists (Dodge, Daly, Huyton, & Sanders, 2012; Jayawickreme et al., 2012; John & Wright, 2005), these two lines of research reflect unique aspects of well-being, and in tandem, they demonstrate several key features of well-being. Both SWB and PWB conclude that well-being encompasses a number of dimensions, rather than one unifying construct. Both approaches acknowledge that positive and negative factors contribute distinct qualities to well-being (Diener, 2012); in other words, “well-being is not simply the flipside of psychological distress” (Ryff, 2012, p. 22). Lastly, SWB and PWB emphasize the importance of internal processes such as positive emotions and a sense of meaning (e.g., Diener et al., 1985; Ryff & Singer, 2008), while also recognizing the significant role of the social environment in the development of well-being (e.g., Diener, 2000; Ryff, 1989).

Social Work Perspective

Social work is a practice-based profession with a mission to “enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty” (NASW, 2008). Social workers carry out this mission through practice with individuals and groups, as well as through teaching, research, advocacy, and policy. Although the social work profession has much more to offer, three prominent elements will be described here as the “social work perspective.”

Social Justice

Social work’s commitment to social justice is explicit and unwavering. The profession arose to meet the needs of vulnerable populations and, for more than a

century, social workers have attempted to identify, understand, and rectify injustices across diverse populations (e.g., children who have suffered neglect and abuse, adults and children from racial and ethnic minority groups, adults and children living with chronic illnesses and disabilities; Specht & Courtney, 1994). Social work's commitment to social justice is grounded in the belief that all people have the right to dignity and that social systems should promote the health and well-being of everyone, with special attention paid to vulnerable populations (Hepworth et al., 2010; NASW, 2008).

Because of this focus on social justice, social workers are called to advocate for change "with and on behalf of clients" (NASW, 2008) at all levels of society. This approach to justice, on both the individual and community levels, is what distinguishes social work from other helping professions (Hardcastle & Powers, 2004; Hepworth et al., 2010); the underlying goal is to create systems that uphold individual, family, and community health. For example, psychology and medical professionals primarily work on the individual level, whereas public health professionals tend to work on the group or society level (Michalski & Kohout, 2011; Thomas, Sage, Dillenberg, & Guillory, 2002). Each of these professions values justice, but they approach it from the angle of their work with clients or patients. In contrast, social workers simultaneously serve people at both the individual and community levels and must wrestle with the definition of justice in often conflicting spheres (Pelton, 2001).

Since social justice is at the core of the social work profession, it influences all types of practice, including research. Social justice-oriented research is based upon the belief that "there are no value-free interactions between human beings" (Mertens, 2009; p. 76); every action represents an ethical statement about how the world works. This perspective requires social work researchers to engage in constant reflection about the intended and unintended effects of their work as well as their personal biases. In

particular, issues of power and privilege must be explicitly addressed and considered in research design, recruitment, and dissemination (Daley, 2010; Mertens, 2009).

Furthermore, the social justice imperative encourages researchers to apply their findings to pressing, real-world situations in an effort to advocate for social change.

Person in Environment

Because social workers advocate for social justice on multiple levels, there is a simultaneous focus on person and environment (a.k.a. person-in-environment). In contrast to other health-oriented disciplines, social workers uniquely examine and intervene with both the person *and* their environment, often at the same time (e.g., providing treatment for depression and a bus pass). This dual focus is rooted in social work's philosophical underpinnings in social constructionism and weaves throughout both practice and research. Social work scholars and practitioners operate on the belief that truth is constructed from social experiences and that social interventions can contribute to improvements in health and well-being. This emphasis on social relationships is a defining characteristic of social work practice (Payne, 2005; NASW; others), as social work's fundamental goal is to address social problems through social change (Hepworth et al., 2010; NASW, 2008).

The social work profession relies upon an ecological framework for carrying out its mission and values (Haight & Taylor, 2013; Hepworth et al., 2010). Generally speaking, ecological approaches describe the necessary and reciprocal interactions between connected systems. Ecological models have been developed across a variety of disciplines (e.g., biology, chemistry, sociology), but those from psychology have contributed most significantly to social work's person-in-environment approach. In particular, Bronfenbrenner's (1977) ecological model has played a prominent role in social work's understanding of human development. Bronfenbrenner (1977) created this

model in an attempt to broaden narrow conceptualizations of human behavior and the social environment, as he described here: “developmental psychology is the science of the strange behavior of children in strange situations with strange adults for the briefest possible periods of time” (p. 513).

Accounting for behavior in natural environments, as opposed to laboratory approximations, Bronfenbrenner’s model contains five nested systems: microsystem, mesosystem, exosystem, macrosystem, and chronosystem. The microsystem consists of an individual’s “immediate setting” (p. 514) such as home, work, or school. The mesosystem contains the connections and interactions between an individual’s microsystems (e.g., relationship between a child’s parent and their teacher). The exosystem encompasses the formal and informal social systems an individual interacts with directly or indirectly (through their microsystems) on a regular basis (e.g., transit system, healthcare system, and neighborhood). The macrosystem refers to the “overarching institutional patterns of the culture or subculture, such as the economic, social, educational, legal, and political systems, of which micro-, meso-, and exo- are the concrete manifestations” (Bronfenbrenner, 1977, p. 515). Lastly, the chronosystem represents the effects of time and history on an individual and their surrounding environments (e.g., the 911 terrorists’ attacks or the passage of the Affordable Care Act).

Elements of the ecological model are infused throughout all forms of social work practice. In assessment, social workers take a multidimensional approach by considering the biophysical, cognitive, emotional, behavioral, social, spiritual, and cultural aspects of a situation (Hepworth et al., 2010). Eco-maps can be an especially helpful tool for indicating internal and external characteristics (Hepworth et al., 2010). Social work interventions also operate from an ecological perspective; many common

micro-level interventions, such as Task-Centered, Crisis, and Solution-Focused treatments, take elements of the environment into account. For example, in a Task-Centered intervention the social worker and client consider the necessary internal and external conditions for successfully carrying out tasks, as well as identifying barriers and obstacles (Hepworth et al., 2010). Additionally, macro-level social work practice is undoubtedly grounded in an ecological approach as nearly all interventions target exo- or macrosystem problems, with a theoretical assumption that benefits to individuals, families, and communities will trickle down through the systems.

Solving Problems and Promoting Strengths

Solving problems is at the heart of the social work profession. Whether it is child abuse, homelessness, or unemployment, social workers are at the forefront of addressing society's most pressing problems and their effects on vulnerable populations. Through assessment, intervention, and research, social workers identify and address problems at the individual, family, and community level.

One problem in particular that is currently focal in the social work profession is that of mental illness. Social workers comprise 60% of the U.S. mental health workforce (NASW, 2015) and mental disorders are increasingly prevalent in our modern society (Kessler et al., 2005). Recent studies show that 25-30% of U.S. adults live with some form of mental illness and fewer than half of these people receive treatment (Kessler, Chiu, Demler, & Walters, 2005; National Alliance on Mental Illness [NAMI], 2013). Plus, researchers believe current statistics are likely underestimating the true prevalence of mental disorders due to stigma and challenges with reaching high-risk groups such as people in institutions or those who are homeless (Kessler et al., 2005). Studies also report approximately 20-35 % of youths ages 13 to 18 experience mental illness (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003; NAMI, 2013) with 50% of all mental

disorders emerging by age 14, and 75% by age 24 (NAMI, 2013). Additionally, mood disorders are the third most common cause of hospitalization for youth and adults (NAMI, 2013) and depression is the leading cause of disability in people ages 15 to 44 (National Institute of Mental Health, 2012).

While social workers play a crucial role in the diagnosis and treatment of mental illness, alongside other mental health professionals, they also bring a unique perspective to the workforce. NASW's (2008) code of ethics states that "social workers seek to enhance clients' capacity and opportunity to change and address their own needs." Implicit in this statement is the belief that clients are capable and have the right to solve their own problems. This approach, often referred to as the 'strengths perspective' (McMillen, Morris, & Sherraden, 2004; Saleebey, 2009), goes beyond other helping professions' principles of "beneficence and nonmaleficence" (e.g., American Psychological Association, 2015; American Nurses Association, 2015), requiring social workers to integrate client strengths into the assessment and treatment of problems. Saleebey (2009) describes this process as:

Everything you do as a social worker will be predicated, in some way, on helping to discover and embellish, explore and exploit clients' strengths and resources in the service of assisting them to achieve their goals, realize their dreams, and shed the irons of their own inhibitions and misgivings and society's domination (p. 1).

However, it should also be noted that social work scholars (e.g., McMillen et al., 2004; Saleebey, 2009; Weick, Rapp, Sullivan, & Kirsthardt, 1989) recognize the continuous tension between problems and strengths in social work, especially in the face of limited resources.

Despite its many challenges, the dual focus on solving problems and promoting strengths is a key element of the social work perspective. Problems and strengths are complementary aspects of human nature and are both needed for healthy growth and development. Social work's familiarity and expertise in this area makes it uniquely prepared to support prevention and healing efforts in individuals, families, and communities.

Summary

Each of these five theoretical frameworks adds to my understanding of the relationship between health and disease. The biopsychosocial model presents an approach to medicine that recognizes the important effects of psychosocial variables on physical health. Erikson's theory of psychosocial development offers a rich description and explanation of how individuals achieve a healthy sense of self by balancing positive and negative experiences, over the life cycle. Research on resilience demonstrates how many people successfully adapt in the face of adversity through the presence of internal and external characteristics, known as protective factors. Well-being scholars contribute the constructs of subjective well-being and psychological well-being as two primary constellations of characteristics associated with happiness and well-being. Lastly, the social work perspective emphasizes the importance of social justice, person-in-environment, and the promotion of strengths in addressing problems at the individual, family, and community levels.

Integration and Contributions of Theoretical Frameworks

In combination, the aforementioned theoretical frameworks have greatly contributed to my understanding of the transition to adulthood for young people living with rheumatic conditions. This section describes three essential themes emerging

across the frameworks and how these themes have shaped my thinking about the present study.

Health is Multidimensional and Integrative

The first theme cutting across frameworks is the description of health as many interrelated dimensions, which are both internal and external to the person. Although this may seem obvious and simplistic, scholars working in health-related fields continuously express the need to expand the notion of health beyond the physical and into a more holistic construct. The biopsychosocial model emphasizes the link between the biological and the psychosocial, with a particular focus on broadening the scope of medical practice to consider the two-way relationships between the biological and psychosocial elements of the patient. The other frameworks presented here (i.e., Erikson's theory of psychosocial health, resiliency, well-being, and the social work perspective) all present ways of understanding the relationships between the psychological and social aspects of life, with increasing attention paid to the biological mechanisms involved in these processes. Taken together, these five frameworks suggest that health is multidimensional and integrative, encompassing internal aspects (e.g., genetics, diseases, cognitions, and emotions) and external factors (e.g., relationships, experiences, and toxins).

This holistic approach to health has substantially influenced my understanding of the experience of growing up with a chronic disease. Most notably, this approach directs my attention to the often-invisible challenges occurring between the physical, emotional, and social aspects of life in young people with rheumatic conditions. As was previously mentioned in the literature review, many adolescents and young adults with rheumatic conditions experience long-term physical, psychological, and social difficulties; a multidimensional and integrative approach to health suggests these challenges may be

connected to each other, not simply occurring in isolation. For example, the principle of VI, emerging from Erikson's theory, indicates that psychosocial health depends on meaningful engagement between a person and their environment. If a young person is faced with deteriorating physical health, their capacity to interact with their social environment in meaningful ways could be limited, which could then stunt or harm their psychological development or vice versa. The resiliency and well-being literatures also show that these types of cyclical effects between dimensions of health are linked with biochemical pathways that can dampen the stress and immune systems, further contributing to declining health (Boehm et al., 2011; Friedman & Ryff, 2012; Manderscheid et al., 2010; Miyamoto et al., 2013; Rozanski & Kubzansky, 2005).

Such theoretical and empirical findings have significant implications for the health care system. As Engel (1977) stated nearly 40 years ago, "how physicians conceptualize disease... determines what are considered the proper boundaries of professional responsibility and ... attitudes toward and behavior with patients" (p. 129). This statement suggests that how people in power think about health and disease matters for patients and the health care system. If health and disease continue to be defined through the biomedical model alone, connections between the mind and the body will likely be ignored and patient care will remain "dehumanized" and "impersonal" (p v, Cassell, 2004).

However, if health care providers and the overarching system can continue to move towards a multidimensional and integrative approach to health, there are many ways to reduce suffering and promote healing in patients, families, and communities. The most obvious application of multidimensionality is the use of multidisciplinary teams. Typically, multidisciplinary teams involve members from a variety of health disciplines (e.g., medicine, nursing, social work, psychology) coming together to discuss their

parallel approaches to care. Even better, are integrative or interprofessional teams where each profession brings their expertise to the table, and together with the patient, the team develops a comprehensive plan of action (Boon, Verhoef, O'Hara, & Findlay, 2004; D'Amour & Oandasan, 2005).

Additionally, a multidimensional approach to health opens up the possibility of integrating therapies that fall outside the conventional parameters of the Western medical model, such as acupuncture, massage, yoga, or nutrition. In fact, a recent study showed nearly three quarters of adolescent participants with juvenile arthritis reported using at least one complementary or alternative therapy; however, less than half of these adolescents had discussed their use of such therapies with a health care provider (Seburg et al., 2012). Adopting a more holistic approach to health and disease would likely open up lines of communication between patients and providers, while also offering more treatment options.

Wellness is the Balance between Positive and Negative Experiences

A perspective shared by four of the five theoretical frameworks is dissatisfaction with the overemphasis on pathology in health professions (Diener et al., 1999; Rutter, 1985; Ryff, 1989; Saleeby, 2009). The resilience and well-being areas of psychology were explicitly developed in response to the disease-oriented biomedical model (Diener et al., 1999; Ryff, 1989), which has increasingly pervaded the social sciences over the last century (Engel, 1977; Weick, 1991). Both of these lines of research contribute decades of empirical evidence showing the existence and importance of protective factors in the face of adversity. The profession of social work has both problem-solving and strength-promotion at its core and also emphasizes the significant influence of systems in the development, prevention, and mitigation of pathology. Erikson's principle of Dynamic Balance of Opposites (DBO) explains how healthy psychosocial

development is inextricably tied to the need for both positive and negative experiences – Erikson described psychopathology as the result of an imbalance between positive and negative aspects of the self and its treatment as a re-balancing of the two qualities (Kivnick & Wells, 2014). Lastly, the principle of VI, clarifies that the constant balancing, between the negative and positive aspects of the self, occurs through engagement (meaningful or not) between the person and their environment.

These four frameworks have shaped my thinking about the strengths and challenges involved in growing up with a rheumatic disease in a number of ways. First, Erikson's theory and the resilience literature indicate how the experience of childhood-onset chronic illness can be viewed as both a risk and protective factor. Growing up with a chronic illness qualifies as a risk factor because it is associated with short- and long-term negative physical, psychological, and social outcomes (Luthar & Cicchetti, 2000). Nonetheless, chronic illness could also increase the likelihood of some positive experiences and characteristics such as empathy, planning, and purpose in life (Ostlie et al., 2009). Erikson's principle of DBO explains how negative experiences can stimulate the development of biopsychosocial strengths: through the psychosocial work of balancing the positive and negative experiences, the individual builds internal strengths and external supports, increasing their capacity to cope with stressful events (Kivnick & Wells, 2014).

Second, Erikson's theory, the construct of resilience, and the social work perspective demonstrate how the health care system (i.e., providers, insurance, medications, etc.) can function as both a risk and protective factor. All three of these frameworks highlight the importance of environmental factors in psychosocial development. For example, the principle of VI suggests health care providers likely play significant roles in the biological, psychological, and social development of young people

with rheumatic conditions. As a child grows up, they develop thoughts, feelings, and behaviors related to their disease. Although children and adolescents are influenced by a number of people in their environment, it seems likely that health care providers have influential roles for children with chronic conditions due to providers' knowledge and power related to their diseases (e.g., ability to identify and explain diseases, dispense treatments). Thus, health care providers are not only affecting the biological aspects of the child's development, they are also shaping the psychosocial aspects such as how young people think, feel, and act in relation to their diseases. When a patient feels as though they are being treated as less-than human or helpless, interactions between a patient and their provider go awry and the system can function as a risk factor, amplifying the negative experiences of their disease (Cassel, 2004; Weick, 1983). Conversely, when the fit between the patient's needs and the system is in-sync, the health care system (and its individual parts) can contribute substantially to health promotion, acting as a protective factor.

Third, the constructs of resilience and well-being, as well as Erikson's theory, suggest that long-term negative psychosocial outcomes associated with childhood-onset rheumatic diseases could be moderated or reduced by the presence of specific environmental supports. Although the rheumatology community has not yet developed or tested such interventions, resilience and well-being researchers have been documenting these types of effects for decades in high-risk youth (e.g., Bernat & Resnick, 2006; Resnick, Harris, & Blum, 1993; Suldo et al., 2009). Also, Erikson's (1986) principle of VI and Kivnick's (2010) VIP support the idea that given the appropriate environmental supports, young people can live productive and meaningful lives – which is what scholars and rheumatology professionals deem to be the ultimate goal of health care (e.g., Foster et al., 2003; Nigrovic & White, 2006; Ostlie et al., 2009).

Health and Wellness Change Over Time

Although a life span or developmental approach is promoted in resilience, well-being, and social work perspectives, Erikson's is the only theoretical framework that provides an explanation for how people change over time. The most apparent applications of Erikson's theory are the two themes corresponding with adolescence and young adulthood. These themes highlight specific psychosocial issues that are likely to be important during this time in the life span.

In adolescence, young people are primarily working on the balance between identity and role confusion. Undoubtedly, issues of identity are directly related to the process of growing up with a chronic, progressive disease. Many of the psychosocial challenges reported in the rheumatology literature describe identity-related struggles such as not being viewed as a sexual being (Packham & Hall, 2002b), not knowing when to disclose a diagnosis (Secor-Turner, Scal, Garwick, Horvath, & Wells, 2011), and anxiety about future parenting (Oslie et al., 2009). Erikson's theme of adolescence helps us understand that it is normal, and in fact healthy, for young people to struggle with and question their identity during this time of life. This theme also implies that it is typical for young people to need particular forms of support as they work toward finding an appropriate balance with their confusion. Articulating this balancing process demonstrates how living with a progressive disease may make the search for a cohesive sense of identity more complicated than usual due to insecurities about the future and the desire to be perceived as normal (Oslie et al., 2009; Secor-Turner et al., 2011).

According to Erikson, young adulthood is the time of life when people focus on the balance between intimacy and isolation. This insight appears to be particularly relevant for young people living with rheumatic conditions as nearly all the recent studies examining long-term outcomes make note of the social challenges faced by these young

adults, such as: deciding whether to become a parent (Ostlie et al., 2009); concerns about romantic partners (Secor-Turner et al., 2011); and feelings of isolation due to restricted social activity (Ostlie et al., 2009; Packham & Hall, 2002). Erikson's theory normalizes such challenges and provides a framework for thinking about how critical it is for young adults to have social connections during this stage.

In addition to Erikson's stages and themes, the principle of Life in Time offers a framework for thinking about psychosocial development across the entire life span. As people age and move through the eight stages, they are continuously adapting to changes within themselves and their environments. Erikson stated that adaptation occurs through the psychological work of balancing themes during all eight stages, as well as through the pre-working and re-working of non-central themes (Erikson et al., 1986; Kivnick & Wells, 2014). This perspective illuminates how trauma and stress in childhood have the possibility to affect an individual's long-term ability to cope and adapt. For example, the principle of Life in Time may help explain why Packham and Hall (2002) found significant long-term differences in psychological health depending on the age of disease onset; elevated rates of depression in adulthood were correlated with onset in middle childhood whereas higher rates of anxiety in adulthood were associated with onset in adolescence. These patterns could be related to an individual's inability to find a healthy balance during the earlier stages, which then affected their psychosocial adaptation in the later stages. However, this principle also suggests that it is possible to re-work themes that were central in previous stages in an effort to improve one's ability to cope and adapt in the future. Therefore, the concepts of pre-working and re-working imply that an individual's long-term ability to cope with stress, such as in the case of rheumatic disease, is greatly affected by their willingness and ability to engage in opportunities for continual psychosocial development at every stage.

Erikson's concepts are particularly relevant to the development of mental health problems in adolescence and young adulthood. It is widely acknowledged that conditions such as depression and anxiety typically emerge between the ages of 15 and 25 (Beesdo, Knappe, & Pine, 2011; Kessler et al., 2005) and that young people are more likely to respond to treatment when it is delivered early in the course of their illness (NIMH, 2012). Additionally, suicide is the third leading cause of death in youth ages 15-24, with 16% of U.S. students in grades 9-12 reporting to "seriously consider" taking their own life in the past 12 months (CDC, 2015). Because of the sensitivity to mental illness during this time of life, resilience and well-being scholars emphasize the need for protective factors and environmental supports that will moderate the long-term trajectories of high-risk youth (Galambos, Barker, & Krahn, 2006; Masten et al., 2004).

Concluding Thoughts

The five theoretical frameworks (i.e., biopsychosocial model of medicine, Erikson's theory of psychosocial development over the life cycle, resilience, well-being, and the social work perspective) along with their integrated themes (i.e., Health is multidimensional and integrative, Wellness is the balance between positive and negative experiences, and Health and wellness change over time), serve as a sturdy foundation from which to examine the challenges and strengths of young adults living with childhood-onset rheumatic conditions. The knowledge and wisdom contained in these frameworks will guide the proceeding research design and analysis.

Chapter 4

Plan of Inquiry

This chapter describes my methodological approach and includes reflections about how my personal and professional experiences influenced the development and implementation of this study. I use first-person voice throughout because it is consistent with qualitative and narrative approaches (Gilgun, 2005b).

Qualitative Inquiry

Although qualitative inquiry can take many forms, the general definition put forth by Denzin and Lincoln (1994) is examining phenomena in their “natural states” (p. 2) and interpreting or making sense of phenomena based on the “meanings people bring to them” (p. 2). In the present study, qualitative inquiry facilitated the exploration of the lived experiences of growing up with childhood-onset rheumatic diseases.

More specifically, a qualitative approach was selected for four reasons. First, there is very little empirical research examining the subjective experience of growing up with or living as a young adult with childhood-onset rheumatic diseases (Hilderson et al., 2013). Many studies examine the epidemiology and treatment outcomes of rheumatic diseases, but there is a dearth of research considering the perspectives of the young people themselves. While both qualitative and quantitative approaches capture an individual’s experiences, qualitative methodologies privilege the subjective perspective because they are rooted in relativist ontologies (Creswell, 2007; Denzin & Lincoln, 1994; Patton, 2002). Relativism asserts that truth can take many forms and that each person creates their own, valid truths based on their unique experiences (Corbin & Strauss, 2008; Lincoln & Guba, 1985).

Second, since there is little research on the subjective experiences of young people living with rheumatic diseases, there is also a lack of knowledge about how to best support this population as they transition into adulthood (Eleftheriou et al., 2014; Stinson et al., 2008). Without a more nuanced understanding of young people's perceptions of themselves and their relationships with their environments, it is difficult to develop effective interventions and provide useful education for health care providers about what it is like to live with these conditions on a day-to-day basis. Qualitative methods allowed me to gather in-depth descriptions of participants' disease-related thoughts, feelings, and behaviors, as well as observe the complex interactions between participants and their social environments, over time.

Third, qualitative methodologies offer flexibility and allow the research process to unfold organically, without sacrificing rigor or quality (Creswell, 2007; Patton, 2002). This approach facilitates ongoing dialogue between participants and researchers about the complicated, dynamic relationships in individuals' lives. Although qualitative approaches can be time-consuming, they allow researchers to engage in an iterative process, simultaneously considering the uniqueness of each participant, the contexts of their physical and social environments, and the similarities and differences across participants (Crabtree & Miller, 1999; Riessman, 1993). Within qualitative studies, it is common for researchers to maintain contact with participants throughout the study while they co-create meaningful and accurate interpretations of the phenomena under investigation. Such processes contribute to the credibility and trustworthiness of qualitative studies (Lincoln & Guba, 1985), which will be discussed in subsequent sections of this dissertation.

Lastly, the subjective and reflective nature of qualitative inquiry provides an opportunity for researchers to use their personal and professional expertise to enhance the research process. Typically, the experiences, values, and perspectives of researchers are viewed as one of the most important tools or instruments used in qualitative data collection and analysis and are documented through the reflection process known as reflexivity (Creswell, 2007; Patton, 2002; Probst & Berenson, 2014). Therefore, my use of self in this study will be discussed in multiple Reflexivity Statements throughout the remaining sections of this dissertation.

Narrative Inquiry

Within the realm of qualitative inquiry, there are a variety of methodologies (Creswell, 2007; Patton, 2002). After careful consideration, I chose to adopt a narrative approach to data collection and analysis. I will use the terms “narrative” and “story” interchangeably, as is done by most narrative scholars (e.g., Josselson, Lieblich, & McAdams, 2003; Lieblich et al., 1998; Riessman, 1993).

Narrative approaches to research, sometimes referred to as narratology, emerged in the 1960's and 70's out of literary studies, in an effort to better understand “how humans construct the social world” (Bruner, 1991, p. 4). At this time, there was a growing sense among social scientists that methods from the natural sciences were limited in their ability to understand the complexities of human behavior and its relationships with the social environment (Bruner, 1991; Moen, 2006; Reissman, 1993). The “narrative revolution” (Lieblich et al., 1998, p. 1) provided an alternative to the “sterile” (Lieblich et al., 1998, p. 1) tools used in traditional research and allowed scientists to enter into the meaning-making process with their participants (Sandelowski, 1991).

Narrative approaches are based upon three key principles: 1) People make sense of their lives through stories; 2) Stories unfold over time; and 3) Storytelling is an inherently social process (Bruner, 1991; Josselson et al., 2003; Reissman, 1993). Decades of research, across many disciplines (e.g., anthropology, sociology, psychology, social work, medicine), demonstrates that storytelling is a universal human activity that is learned in childhood (Bruner, 1991; Crabtree & Miller, 1999; Lieblich et al., 1998; Reissman, 1993). When people tell stories, they interpret the connections between events in their lives and attempt to create cohesive representations of their subjective experiences over time. The result of this internal process is often a public presentation where the storyteller engages in a social exchange with his or her audience. In order for a story to be meaningful, the narrator must embed particular social and sequential features which signal to the audience the order and consequences of events (Freeman & Couchonnal, 2006; Josselson et al., 2003; Moen, 2006; Riessman & Quinney, 2005). Moreover, several scholars (e.g., Bruner, 1991; McAdams & Cox, 2010; McAdams et al., 2006) theorize that the narrative process goes beyond representing subjective experiences, to actually being at the crux of identity development. For example, McAdams and Cox (2010) state that identity is a "psychosocial construction" (p. 169) in which the self co-creates an "integrative story" (p. 169) with its surrounding environment.

I adopted a narrative approach in this study for several reasons. First, since I explored development over time, it seemed appropriate to capture chronological information in the form of stories. Also, considering that the purpose of this study was to target the major life transition between childhood and adulthood, it made sense to engage participants in a dialogue about a sequence of events, moving through the

conventional stages of childhood and young adulthood (e.g., Berger, 2011; Erikson, 1950).

Next, I used a narrative approach to capture extremely rich data. By their very nature, stories serve as a window into a person's inner dialogue and showcase the complex relationships continuously happening between a person and his or her environment (Crabtree & Miller, 1999; White & Epston, 1990). By observing and participating in the creation of illness narratives, I was able to collect multi-layered descriptions of participants' lived experiences, which facilitated my ability to enhance the understanding of what it is like to grow up with a chronic and progressive disease.

Lastly, a narrative approach was an appropriate fit with my specific purpose of learning about the lived experience of chronic disease. Narratives are commonly used in health care settings to collect information from patients about disease history, symptoms, and treatments and patient stories are used in medical education to teach students and professionals about disease experiences (Charon, 2001; Crabtree & Miller, 1999). Narratives are also used in social science and health research to examine the reciprocal relationships between chronic diseases and the social and emotional aspects of peoples' lives – an element often missing from purely quantitative measures (Crabtree & Miller, 1999; Sandelowski, 1991). Thus, narrative approaches offer an alternative or complementary view to the biomedical model, which tends to objectify peoples' bodies and reduce the disease experience to simple, observable symptoms (Charon, 2001; Frank, 1995). In this sense, narrative approaches not only contribute the subjective experience of the person living with a disease, but they also closely align with the values of social work to promote the dignity, worth, and self-determination of each person (Freeman & Couchonnal, 2006; Riessman & Quinney, 2005).

For all of the aforementioned reasons, I relied upon a qualitative, and specifically narrative, approach to carry out the purpose of this study. These methods allowed me to document and better understand the challenges, strengths, and supports in the narratives of young people living with rheumatic diseases, during the transition from adolescence and into adulthood.

Reflexivity Statement: Pre-writing

Reflexivity is a “methodological tool” (Pillow, 2003, p. 176) used in qualitative inquiry to critically examine the researcher’s role of self and their reciprocal relationships with participants, data, and methods (Pillow, 2003; Probst & Berenson, 2014). Reflexivity is a specific type of reflection that occurs throughout the research process and requires an honest, and sometimes uncomfortable, look at how knowledge is produced (Longhofer & Floersch, 2012; Pillow, 2003). This ongoing process is a “hallmark” (Probst & Berenson, 2014, p. 2) of qualitative research and it is how social work researchers “come to understand what we actually do” (Longhofer & Floersch, 2012, p. 513).

Since qualitative inquiry relies upon the researcher as its primary instrument (Patton, 2002; Pillow, 2003), it is crucial for researchers to continuously observe and question what their experiences, perspectives, and biases bring to a study, as well as how researchers are affected by the experiences and perspectives of the participants. This two-way process is what Probst and Berenson (2013) refer to as “the double arrow” (p. 1). Established qualitative researchers use reflexivity to sharpen their perceptual instruments and develop their voices by calling attention to their personal and professional relationships with the phenomena of interest. Although reflexivity can provide an important context for findings and strengthen trustworthiness and credibility (Lincoln & Guba, 1985; Patton, 2002; Probst & Berenson, 2014), it is also a tool for

increasing a researcher's awareness of and sensitivity to the messiness of qualitative ontologies and methods (Pillow, 2003). However, common criticisms of reflexivity should also be noted. Probst and Berenson (2013) describe the three primary criticisms about reflexivity in qualitative research: 1) researchers can spend too much time focusing on themselves; 2) accessing assumptions, biases, and motivations may not be as easy as simply making memos and debriefing with a peer throughout the research process; 3) it is difficult to assess whether reflexivity produces higher quality research.

In the present study, I used reflexivity throughout the entire research process. Based upon descriptions presented by Probst and Berenson (2013) about the various ways social work researchers incorporate reflexivity into their scientific writing, I discuss my process in three separate places throughout the dissertation. First, I present "pre-writing" (Probst and Berenson, 2013, p. 11) which describes how my personal and professional background is related to the purpose of this study, as well as key topics that I felt were important to keep in mind as I began the research process. Second, I describe my "ongoing writing" (Probst and Berenson, 2013, p. 11) at the end of the Study Design section which describes the content and process of my memoing throughout recruitment, data collection, analysis, and writing. Lastly, my final comments, called "post-writing" (Probst and Berenson, 2013, p. 12), are located in the Discussion chapter and describe my thoughts about how my personal and professional experiences could have influenced my interpretation and representation of the study's findings.

Pre-writing.

Personal and professional background

Nearly all aspects of my dissertation research have been influenced by my own experience of growing up with a rheumatic disease. I was diagnosed with juvenile rheumatoid arthritis when I was 18 months old and I have been living with it for over 30 years. Despite the ongoing, and sometimes severe, physical challenges I face, I have always struggled the most with the social and emotional aspects of living with a progressive, chronic disease. I realized this during college when I experienced my first bout of clinical depression. At that time, I had never met another person who shared my disease experiences and I was feeling increasingly isolated from my family and peers. Out of desperation, I called the Arthritis Foundation searching for a support group and was told that their groups were primarily for older people. The next day, I called back and asked if I could start a young adult group. They welcomed me with open arms and I started volunteering the next week.

I did not know it at the time, but my phone call to the Arthritis Foundation was the beginning of a new life for me. Not because my physical or emotional struggles would improve – they have in fact worsened over time – but because providing support to others has allowed me to derive meaning from my suffering. Over the last ten years, I have been involved with the Arthritis Foundation in every possible way (e.g., as a volunteer, staff person, and board member), and the original members of my young adult group are now some of my closest friends. In learning about the wide range of experiences associated with rheumatic diseases, I have been inspired to pursue a career where I can work toward improving the physical, social, and emotional health of young people living with rheumatic and other chronic diseases.

Initially, I assumed that becoming a physician was the only way to pursue this goal. However, I have since learned through my personal and professional experiences,

the many limitations inherent in the biomedical model, and consequently, the current health care system. Throughout my graduate education, I searched for a health-related scholarly community that would value the social and emotional experiences of chronic disease as much as the physical aspects. I took conceptual refuge in the profession of social work with the intention of developing a value-driven approach to applied health research that I could contribute to public health and medicine. During my time in the School of Social Work at the University of Minnesota, I have come to understand the crucial roles of human relationships, integrity, and social justice in academic research, as well as in the development and evaluation of psychosocial interventions. I have also observed a pressing need in the health care system for mental health services for young people with chronic medical conditions, and that this need is, in part, due to a lack of scientific understanding of psychosocial development in this population.

Furthermore, my own experience of becoming an adult living with a childhood-onset rheumatic disease has coincided with the recent international discussion in public health and medicine about how to care for populations and meet needs that have never existed before. Since being in graduate school, I have been called upon many times to share my disease story with health care professionals, and as a result, I have developed professional collaborations and expertise on the topic of health care transition. In many ways, my personal and professional experiences cannot be separated because they are both constantly informing each other.

From the moment I started volunteering at the Arthritis Foundation, I knew I wanted to develop clinical- and community-based interventions to improve the psychosocial health of young people with rheumatic conditions. Although this goal has

never wavered, it has taken me over 10 years to acquire the skills, knowledge, and credibility necessary to get to the point of conducting this study.

Considerations for this study

Undoubtedly, my personal and professional experiences shaped my dissertation work. I believe my knowledge and rich experiences contributed to the quality and meaningfulness of this study, but I was also mindful of the need to continuously reflect upon how my insider perspective was influencing my work. Here, I discuss four specific topics that I considered prior to the start of the study (thus, the future tense was retained).

First, I have extensive knowledge or “inside information” (Kanuha, 2000, p. 442) about medical terminology and common experiences related to rheumatic diseases (e.g., medication side effects, medical procedures, work- and school-related issues, emotional challenges, etc.). In addition to my own experiences with rheumatic conditions and their treatments, I have also served as an educator on these topics in a variety of capacities and have been involved in a number of arthritis-related research projects. My familiarity with these topics will certainly be beneficial in the sense that I will not have the need to ask many clarifying questions during interviews, but I will miss out on important data if I make assumptions and do not engage people in appropriate conversations about their own unique disease experiences. I imagine that I will have to find a balance between asking too many and not enough questions. Patton (2002) refers to this balance as “empathic neutrality” (p. 40) and emphasizes the importance of maintaining a degree of distance while also establishing a comfortable rapport. On a related note, it will be important for me to reflect upon the ways that I am both an insider and an outsider in relation to my participants. Kanuha (2000) describes the challenging process of

capitalizing on insider qualities while recognizing, at the same time, that we are all outsiders to each other's experiences.

Second, due to my formal and informal roles associated with being a social worker and arthritis advocate, I will need to resist the urge to be swept into the emotional ups and downs described by my participants. As Kanuha (2000) describes, this urge can be related to my experience as an insider as well as my sense of social justice, both of which can complicate the interviewing process. It will be necessary for me to be aware of my own emotional reactions and to develop strategies for bringing focus back to the research protocol. Similarly, I will also have to be mindful of my natural impulse to offer assistance to my research participants. Of course I will offer suggestions or information in the appropriate context (e.g., sharing information about the Arthritis Foundation or seeking support if someone is distressed), but, generally speaking, it will not be appropriate for me to make specific recommendations to participants about how they should improve their health in my role as a researcher. It will be important for me to reflect upon these urges and seek consultation if the need arises.

Third, I will have to carefully navigate dual relationships. Because of my prominent role in the local juvenile arthritis community and the limited prevalence of childhood-onset rheumatic diseases, it is likely that I will have prior relationships with some of the people who enroll in this study. In these situations it will be important for me to consider my relationships with each participant and reflect upon how prior, current, or future interactions are influencing our shared experience of this study. It will also be necessary for me to discuss these issues with participants when the need arises, paying particular attention to issues of privacy and confidentiality.

Lastly, I will need to be deliberate about how much information I disclose to participants regarding my own health status. After considering this issue for some time and across studies, I have observed that I can be most present with my participants if I reveal a few details about my health when we meet for the first time. In the past, when I intentionally withheld the fact that I lived with the same disease as research participants, I found myself paying too much attention to what I was or was not saying in an effort to avoid revealing any details that might skew my results. I learned from these experiences that intentionally trying to withhold all personal information distracts me during the interview and is not beneficial to the research process. However, it will be necessary for me to keep the focus of our interviews on the participants' experiences and not on mine. I will need to find ways of using self-disclosure during interviews as a tool that invites participants to engage in an authentic and relaxed manner, in addition to helping participants access their own experiences and stories (Kanuha, 2000; Probst & Berenson, 2014).

In summary, this dissertation study has been motivated by a combination of personal and professional factors, and is intimately connected to my own disease process. As I move through the phases of this study, I will need to continuously utilize and sharpen my reflexive skills in an effort to protect the trustworthiness and credibility of my work.

Study Design

Sampling.

As is typical in qualitative research, I used purposeful sampling to target "information-rich" (Patton, 2002, p. 230) participants who could offer meaningful insight

to the research questions (Marshall, 1996; Patton, 2002). More specifically, I applied a criterion sampling method which designates specific criteria that must be met by all participants (Patton, 2002). I used three criteria to determine eligibility for participation in the present study. First, since the research questions sought to understand the transition to adulthood, I targeted young adults ages 25-35 due to their enhanced cognitive abilities and the more complicated view of self that emerges in young adulthood compared with childhood or adolescence (Erikson, 1950; McAdams & Cox, 2010). I assumed that such developmental advances would increase the likelihood of participants being able to reflect upon their past and current disease experiences.

Second, in order to qualify for this study, young adults needed to report being diagnosed with childhood-onset rheumatic diseases. I initially assumed that this criterion would ensure participants had lived with their rheumatic conditions for a minimum of 10 years due to the consistent practice in rheumatology of only diagnosing pediatric conditions in children under the age of 16 (Jordan & McDonagh, 2006). However, I realized shortly after beginning recruitment that the practice of only diagnosing children under 16 did not hold true for participants who lacked access to pediatric rheumatologists (discussed below). Although this observation did not require a revision to the inclusion criterion (i.e., young adults still had to report being diagnosed with childhood-onset rheumatic conditions), it challenged my assumption that participants would have lived with their diseases for a minimum of 10 years (e.g., a 26-year-old participant was diagnosed with a childhood-onset rheumatic condition at 18 by an adult rheumatologist who believed that she had been living with her disease for at least four years).

Lastly, the third criterion was that participants needed to currently be prescribed medications for their rheumatic conditions by an adult-focused rheumatologist. Similar to above, I assumed this criterion would guarantee that participants were currently living with active disease and had completed the transfer of care from their pediatric provider. However, I realized after starting recruitment that many young adults did not have consistent access to pediatric rheumatologists in their childhood and therefore never went through the process of transferring their care because even as children they were primarily treated by adult rheumatologists. Again, this observation did not require me to revise the eligibility criteria, but it prompted me to consider the various pathways young people took to their current position.

In addition to the aforementioned criteria, half way through the study I also decided to restrict enrollment to women. Initial eligibility was not restricted based on sex because childhood-onset rheumatic conditions occur in both sexes. However, due to the unequal distribution of rheumatic diseases (i.e., females are two to four times more likely to live with rheumatic conditions than males; Lockshin, 2001), by the mid-way point of the study, only two men expressed interest in participating and they both lived three or more hours outside the Twin Cities metro area. Therefore, I decided to limit participation to women.

Sample size was determined by the purpose of the study as well as redundancy (Lincoln & Guba, 1985) or saturation (Corbin & Strauss, 2008). Since there are no rules in qualitative research regarding sample size (Patton, 2002), I determined – in consultation with Dr. Kivnick – that a minimum of 10 participants would be an appropriate target balance between depth and breadth for this exploratory, descriptive study. Saturation had occurred within many of the interview topics by the completion of the 10th

participant's interviews; however, each participant's narrative brought uniqueness to the interviews that prevented complete saturation. After observing a high level of redundancy, I enrolled two final participants to validate my decision to discontinue recruitment. In total, 12 participants enrolled in the study.

Recruitment.

I recruited participants through two main sources: the Arthritis Foundation and rheumatology clinics in the Twin Cities metropolitan area. The Arthritis Foundation (2015) is a national nonprofit organization that "helps conquer everyday battles through life-changing information and resources, access to optimal care, advancements in science and community connections." After receiving approval from the University of Minnesota's Institutional Review Board and permission from the Arthritis Foundation national office, I sent emails to the Upper Midwest region of the Arthritis Foundation and to five rheumatology clinics requesting distribution of study fliers. The Arthritis Foundation and two rheumatology clinics offered to share the study information with their patients by posting a flier (see Appendix A) in their offices. Arthritis Foundation staff also posted the flier on their Facebook page and sent the information through email to a list of young adults living in Minnesota and Wisconsin. Interested young adults contacted me directly. I determined eligibility by phone or email and provided a more detailed description of the study. Throughout the recruitment process, Dr. Kivnick provided guidance regarding enrollment decisions.

None of the enrolled participants learned about the study through their rheumatology clinics; however, I received calls from several interested people (who learned about the study from their clinics) who did not meet study criteria. Two participants were former students of mine who expressed a desire to participate in the

study after learning about my dissertation research in class. The majority of participants (10 of 12) learned about the study through the Arthritis Foundation; I had previously known four of the nine participants, to varying degrees, through my community involvement. It is likely that this sample differs from the wider population of young adult females living with childhood-onset rheumatic conditions because of their connections with the Arthritis Foundation and their willingness to participate in this research study. One could speculate that the women in this sample may be in better health than people who are not involved with the Arthritis Foundation because they may know others with their conditions, have access to more information, or might be more proactive in their disease management. However, these young adults could also be more severely affected by their diseases and that's why they sought out extra support. I could not locate any information in the research literature confirming these characteristics.

Data collection.

After confirming eligibility, I emailed interested participants the consent form (see Appendix B) and interview guide (see Appendix C), in case people wanted to review these forms prior to enrolling in the study. I told all participants that they did not have to prepare for the interviews but they were welcome to if it would make them feel more comfortable. Face to face, before beginning the first formal interview, I initiated a discussion about informed consent with all participants. During these conversations we talked about the voluntary nature of their participation and how their decisions to participate would not affect their relationships with the University of Minnesota, their health care providers, or the Arthritis Foundation. I also told them that they could stop the interviews at any time. Additionally, I explained the research process and told them that everything we talked about would be confidential and de-identified. I then gave all

participants the opportunity to select a pseudo-name and offered each person a \$50 gift card to a store of their choosing.

Although the exact questions varied depending on the content of the interviews, I developed a guide to provide structure and consistency using information from the rheumatology literature (e.g., important disease milestones, understudied topics) as well as information from the Life Strengths Interview Guide (Kivnick & Murray, 2001), which elicits responses regarding psychosocial development and VI. All interviews took place at an agreed upon location that was convenient for participants and private enough to discuss potentially difficult topics (e.g., work office, public library study spaces, participants' homes). I conducted all interviews, which were audio-recorded and transcribed by myself or a volunteer who completed HIPPA training and was added to the study's IRB application.

Upon enrollment in the study, twelve women living with childhood-onset rheumatic conditions participated in semi-structured, face-to-face interviews. I interviewed each participant up to three times, with an average of 4 hours face-to-face time per participant – resulting in 48 total hours of audio recording. In an effort to obtain in-depth data that would allow for a more nuanced understanding of the larger context of each participant's story (e.g., family dynamics, future goals), as well as specific experiences that influenced their psychosocial development over time, I conducted multiple interviews with each participant. Such in-depth understanding is precisely what rheumatology scholars and practitioners have been calling for in the scientific literature (e.g., LeBovidge et al., 2003; Gerhardt et al., 2008; Ostlie & Dale, 2007; Packham & Hall, 2002d).

During the interviews, I asked participants to tell their disease stories, including elements of the past, present, and future. As their stories unfolded, I asked questions about specific milestones and influential experiences, and prompted them to consider various aspects of themselves (e.g., physical, emotional, and spiritual) and their environments (e.g., family, school, work, and the health care system). Typically, the first interview with each person was upbeat and painted a broad picture of their disease story, as they saw it, with little prompting from me. Then, between meetings, I transcribed the interview and noted specific areas or events that might yield particularly helpful information. The second interview tended to be more emotional and serious than the first because we examined topics – usually difficult topics – that they had brushed over or didn't address in the initial meeting. For example, one participant briefly mentioned having bariatric surgery at the end of her first interview and described it as a minor detail, but when I brought it back up during the second and third interviews we spent over an hour talking about it and how it directly related to her disease. During the last part of the interviews, which occurred during the third meeting or at the end of the second, we focused on participants' reflections about how their disease experiences changed over time. I asked participants to discuss the hardest parts of living with their diseases, how they've learned to cope with them, and what wellness looked like in the midst of their disease-related challenges.

Similar to a therapeutic relationship, it took time to establish rapport with the participants, even the women I knew from other contexts. In order to ask very personal and sometimes difficult questions, I needed to get a feel for their language, sense of humor, and comfort level surrounding a variety of topics. Some women were immediately comfortable talking about their weight or worries for the future, for example,

while others were much more reserved. As the study progressed, I learned that it took at least an hour to form a trusting relationship, unique to this context, from which to move forward with gathering meaningful data.

During the final interviews, I explained next steps (i.e., transcribing, analyzing, and writing) and invited each participant to engage in the process as they were comfortable. All participants were sent several documents throughout the analysis and writing process: a Word document with an outline of their disease story; a Word document with quotations from their interviews that I proposed to use in my final dissertation; and a PDF of a poster presentation highlighting the preliminary findings of the study. In these emails, participants were given brief updates about the study and were invited to share their thoughts or concerns about the process.

Throughout the interview process, participants expressed a variety of thoughts and feelings about their experiences in the study. Nearly every participant noted during our first meeting that they chose to enroll in this study because of their frustrations with the health care system and the lack of understanding regarding the psychosocial aspects of rheumatic conditions. As the interviews progressed, several women stated that our discussions had triggered some difficult emotions. For example, Kim¹ said:

When I had met with you in August, some things really got, I got upset about some stuff and it was hard. I started to think a lot about how I want a family and how am I going to do that if I can't really move. And with my flare this summer it was just overwhelming.

¹ All names have been changed to protect the privacy of study participants.

Additionally, many participants commented on how the interviews gave them time to reflect upon their story and think about it in new ways. For instance, in her third interview, Luna said “it’s so interesting that when we say it like that it really shows me that the main thing to me has been the physicality of it and that’s just such an interesting observation.” Furthermore, several participants expressed appreciation about feeling understood, such as Stacy who said “This is helpful. Talking and knowing that you know what I am talking about. It’s like, ‘alright cool!’”

Reflexivity Statement: Ongoing Writing

As I moved through recruitment and data collection, there were several instances where I reflected upon how my personal and professional experiences might be influencing my interactions with participants. To illustrate these complex exchanges, I’ve included discussion of key issues and several excerpts (in italics) from my journaling/memoing.

Going into this study, I knew I had to be sensitive about how I disclosed and used my own health experiences throughout the process. Much to my surprise, my health came up very infrequently during the interviews. Eight of twelve participants knew I lived with arthritis prior to our first interview (i.e., through our personal or shared connections) and rarely brought it up. In the interviews with the four women who didn’t know about my health history, I mentioned that I lived with J.R.A. while explaining the purpose of this study and my motivations for doing it. Although these four women typically asked a few more questions than the others, my health still rarely came up. When questions surfaced, it was generally in the context of pregnancy, something I had recently been through and a common area of concern for women with rheumatic conditions. When participants asked about my health, I answered their questions and turned the focus

back to their story. This strategy seemed to provide enough shared information to build rapport, but not so much that it took away from the purpose of the interviews.

Conversely, being aware of how my health experiences influenced the questions I asked and how I asked them, was much more challenging. The following memo demonstrates the complexities of this task:

As I talk to participants about their psychosocial development, I find myself reflecting upon my own adolescence and young adulthood. In hindsight, it is apparent that many of my mental health challenges were related to my disease. Certainly, family dynamics and genetic predispositions also played a role, but I was really struggling with anxiety and feelings of isolation because of my disease. Although most of my participants didn't describe experiencing the same severity of mental health issues as I did, all of them have described extreme feelings of isolation and despair. As we talk about these topics and I think about them, I'm trying to be careful about not projecting my feelings and experiences upon my participants while also being sensitive to the fact that these experiences and emotions appear to be common (based upon my 10 plus years of involvement with the Arthritis Foundation) and overlooked in the scientific literature. Walking this line is challenging, but I'm able to call upon my social work skills (e.g., awareness of my own agenda, ability to sit with ambiguity and discomfort, experience with difficult conversations) to work through many of the difficulties involved in doing this type of research. During these conversations I'm trying to find a balance between providing too many prompts (i.e., injecting my words into their story) and overlooking important experiences that they may not have the language to describe. I've noticed a dramatic difference in peoples'

abilities to talk about psychosocial topics between participants who have been involved in talk therapy and those who have not. This observation makes me to wonder if the people who haven't been to therapy are lacking the skills to talk about their emotional experiences, rather than lacking complex psychosocial experiences.

In this memo I reflected upon how my health experiences were a part of my interviewing process and how I attempted to navigate through the interviews with this self-knowledge. Undoubtedly, my mental health experiences shaped the questions I asked, but I continuously pushed myself to be aware of the fact that everyone's story is unique and valid. Additionally, conducting several interviews with each person gave me the opportunity to reflect upon my approach and language between meetings and follow up on particular issues if they seemed overlooked or too influenced by my perspective. For example, I would occasionally start the second interview by saying something like "I've listened to our last interview and would like to revisit our discussion about depression from a different angle." Or, I would say "I think I know what you meant by this statement, but could you provide a few more details?"

Reflecting on my use of language during the interviews made me think more about my status as both an insider and an outsider. It was obvious that living with a childhood-onset rheumatic disease made me an insider in the eyes of these women. Every participant used the terms "we" and "our disease" to describe experiences they assumed we shared. When this happened, I asked them to "say more" because my experience could be different or the audience for the findings of this study may not know anything about rheumatic diseases. Using Kanuha's (2000) term, I "mediated" (p. 443)

these situations by asking for clarification, which provided a necessary amount of separation between myself and my participants.

Interestingly, as the interviews progressed, I began to see myself as an outsider just as much as an insider, in two important ways. First, as was mentioned above, once the interviews began I noticed that my disease story was significantly different from that of most participants because of the severity of my mental health struggles. I came to this realization while immersing myself in the interviews and scientific literature, reflecting and de-briefing about what I was hearing, and my participation in Arthritis Foundation activities (described below). Acknowledging this key difference allowed me to cultivate a new sense of curiosity about others' emotional lives and embrace the differences within our similarities.

The second way in which I was an outsider was in my role as the researcher. Although this is true for all scientific studies, there were a few distinct ways in which my power and privilege played out in this study. The following excerpt describes one moment when this became clear:

During a recent interview I had a very emotional experience where the interviewee was describing the early days of camp and how she was one of the six original girls who went to the first arthritis camp in the country. I asked her if she's still close with these women and she said "all of the ones who are still alive." Of course I knew that people occasionally die from our disease, and it was even more common thirty years ago, but this story hit me particularly hard. She said "you would have really liked her, she was in graduate school for social work and public health when she died." That sent shivers down my spine and reminded me how severe our diseases can be and how privileged I felt to be

doing this work. Even though things have improved in my lifetime, there are still so many people suffering physically and emotionally because of these conditions. This was one of the few times during the study when I teared up during an interview and needed a few seconds to take it all in. The participant was not as emotional as I was in the moment, but she seemed touched by the fact that this story was so powerful for me. I thanked her for sharing this information with me and acknowledged that it is these types of stories that keep me motivated when I'm struggling.

This moment, along with several others, triggered strong emotions in me that are directly related to my disease and professional status. Even though I face constant physical and emotional challenges, I've been incredibly lucky. There are many young women living with my disease, including several of my participants, who will never have the privilege of going to graduate school, working full-time, or having a family because of the severity of their diseases. Facing this outsider reality throughout the interviews was one of the hardest parts of conducting this study. It wasn't just the fact that I was in a position of power as the researcher, it was also the stark contrast between what their bodies looked like next to mine. For a number of reasons, my disease is rarely visible to other people. In many ways this is a privilege, but in other ways it poses significant psychosocial challenges in my life. In the context of this study, the invisibility of my disease made me an outsider to important aspects of participants' disease experiences (e.g., bullying from kids at school, physical and psychosocial challenges of using a wheelchair). I tried to capitalize on the moments when it was obvious that I could not relate to particular experiences by calling attention to our differences and asking them to

explain what it felt like to live with such limitations. When these conversations occurred, participants seemed to appreciate my honesty and curiosity.

Lastly, I've reflected upon how my experiences with the Arthritis Foundation have shaped my assumptions about my participants and their stories. My role as the director of health and wellness at a summer camp for kids with rheumatic diseases has significantly impacted my thinking throughout the course of this study. The following memo highlights some of the overlaps between my role at camp and my role as researcher:

Last night we had our first camp meeting of 2015. Last year we had some push back from a couple of the medical providers about how we talked with the kids about depression and other “negative things”; one nurse in particular feels very strongly that we should not engage in conversations about negative things with the kids (e.g., medication side effects and emotional and social struggles). While I respect her enthusiasm for talking about positive things (e.g., biofeedback, massage, gratitude for medical advances), I also know that the illness experience is much more nuanced than she is willing or able to admit. Another comment that was made last night by this particular nurse was that most kids with arthritis are “just fine,” meaning that they do not experience the emotional and social struggles I’m frequently pointing out. I’ve been chewing on this conversation this morning and thinking about how it’s important for me to keep her perspective in mind as I describe and disseminate my study findings, but I also think there’s a story here that isn’t being told and it’s affecting the quality of care that children and young adults are receiving.

Examining my interactions with the camp medical providers helped me recognize that because of my past experiences (both personal and professional), I assume most young adults living with rheumatic diseases experience some level of emotional and social distress. Although my professional experiences (including this study) have taught me that there is a wide range of psychosocial challenges associated with growing up with rheumatic diseases, I am becoming increasingly frustrated with the lack of knowledge surrounding mental health struggles in young people living with rheumatic conditions. Additionally, these interactions have exposed my many frustrations (both personal and professional) with the biomedical model and the treatment of mental health in the U.S. health care system. By making these observations about my own assumptions and biases, I was able to bring a heightened awareness to my language and tone during the interviews. Hence, I made a concerted effort to ask about both negative and positive experiences in the health care system and attempted to ask about psychosocial challenges in non-judgmental ways. For example, instead of using diagnostic labels (e.g., depression, anxiety), I asked participants about their “emotional health” or “feelings” related to their disease (e.g., anger, sadness, frustration, nervousness).

Approach to Data Analysis

Two key sources guided my approach to data analysis: the narrative research model presented by Lieblich et al. (1998) and the principle of VI (Kivnick & Wells, 2014).

Lieblich et al.'s (1998) model offers strategies for narrowing in on specific elements of narrative interview data. The model consists of four categories: Holistic-Content; Categorical-Content; Holistic-Form; and Categorical-Form (see Table 6).

Generally, it makes sense to focus on one of the four categories, but Lieblich et al. (1998) note that narratives rarely exist in just one category.

Table 6

Classification of types of narrative analyses (Lieblich, et al., 1998)

	Content	Form
	Explicit and implicit content of narrative (i.e., who, what, why, when, etc.)	Structure of narrative (i.e., plot, sequence, time, style, metaphors, etc.)
Holistic Narrative as a whole	Focuses on content of the entire story.	Focuses on form of the entire story.
Categorical Relevant sections of narrative	Focuses on content of particular sections of the narrative.	Focuses on form of particular sections of the narrative.

Analysis in this study primarily resided in the Categorical-Content quadrant, with a focus on particular sections of the interview data (i.e., individual sentences or paragraphs). This type of analysis follows the four steps of content analysis outlined by Lieblich et al. (1998): selecting subtext; defining content categories; sorting material into categories; and drawing conclusions from the results. This process is guided by the research questions and does not necessarily follow this exact sequence (Lieblich, et al., 1998). Furthermore, there were aspects of the analysis process that incorporated a Holistic-Content approach, where specific sections of interviews were contextualized within their larger narratives. Each step of the analysis process is described below.

Selection of sub-text.

The principle of VI (Kivnick & Wells, 2014) guided the selection of sub-text from participant narratives. Sub-text is raw interview data that has been intentionally selected and removed from transcripts for use in content analysis (Lieblich et al., 1998). Since VI is the meaningful interaction between person and environment, the first step of data analysis was dissecting participant transcripts and categorizing data based on the four domains outlined by Kivnick and colleagues (Kivnick, Jefferys, & Heier, 2003; Kivnick, Wells, & Fredrick, 2014) and displayed in Figure 3. The four domains included: personal challenges; environmental barriers; personal strengths; and environmental supports. Domains 3 and 4 represent domains of well-being; domains 1 and 2 represent domains of ill-being.

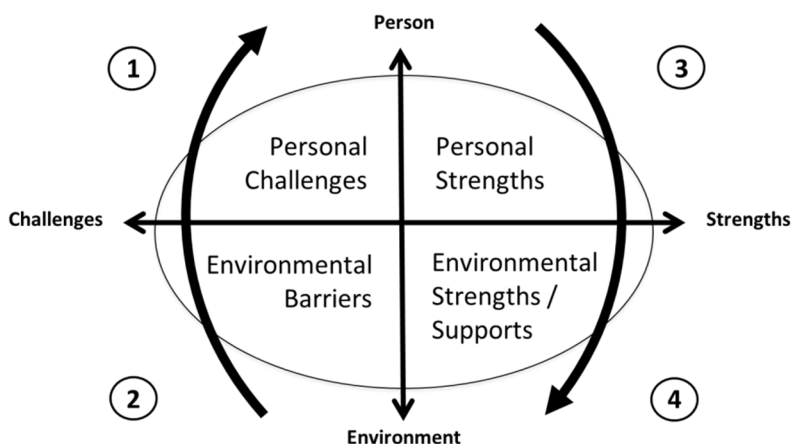


Figure 3. The four domains of Vital Involvement

Due to my familiarity from previous research experiences, I decided to use QSR International's NVivo 10 (2012) for the majority of my data management and coding procedures. Thus, I dissected the raw transcript data and organized the sub-text using NVivo. In the first step in this process, I created folders for each participant which contained their raw interview data and sub-folders (called nodes in NVivo) for each of

the four VI domains. Next, I coded (i.e., highlighted sub-text, dragged and dropped it into a node) units of raw data (i.e., sentences and paragraphs) using the four VI domains; nearly all raw data from the interview transcripts were coded in this initial process. From this point forward, only the sub-text within each of the VI domain folders was analyzed. There was considerable overlap between the four domains. Although some participants' comments were straightforward, most represented a complex interaction between a person and their environment (e.g., medications side effects were classified as personal challenges and environmental barriers). In the cases where there was significant overlap, I coded the sub-text in multiple domain folders.

Defining and sorting of the content categories.

Creating content categories comprised the majority of the data analysis process. During this phase, I attempted to organize the “undigested complexity of reality” (p. 463, Patton, 2002) into meaningful, descriptive themes. As Creswell (2007) describes, qualitative analysis typically proceeds in a spiral manner, with the researcher “moving in analytic circles” (p. 150). Creation of content categories, similar to open coding (Corbin & Strauss, 2008), occurred in three waves or circles, with continuous memoing and reflection.

In the first wave, I created preliminary categories and coded sub-text from the first four participants (a total of 12 interviews). This process involved both inductive and deductive analysis strategies. First, I carefully read through the sub-text of the first four participants, located in the VI domain nodes, and noted patterns across responses (i.e., an inductive approach). Some categories were immediately apparent (e.g., physical health), while others required a more elaborate analysis process. For example, it was clear that the health care system was a major focus of the interviews and that it needed

to be represented as both a barrier and a support, on multiple levels (e.g., interactions with providers, health insurance, medication side effects). However, creating a “health care system” category seemed too broad at this point in the analysis because it overlooked the nuances missing from the rheumatology literature. Therefore, I adapted my analysis approach by integrating a deductive strategy – I called upon Bronfenbrenner’s ecological model to facilitate my thinking about the complexity of the health care system. Instead of categorizing the sub-text in the environmental domains based on broad areas of life (e.g., health care, family, work), I created five categories grounded in the ecological model (i.e., microsystem, mesosystem, exosystem, macrosystem, chronosystem). After establishing the preliminary categories, I used them to code the sub-text of the first four participants and developed a final list of first wave categories (see Table 7).

Table 7

First wave categories

Personal Challenges
Physical
Psychosocial
Spiritual
Environmental Barriers
Microsystem
Mesosystem
Exosystem
Macrosystem
Chronosystem
Personal Strengths
Physical
Psychosocial
Spiritual
Environmental Supports
Microsystem
Mesosystem
Exosystem
Macrosystem
Chronosystem

During the second wave of analysis, I used the first wave categories to code the sub-text of the second four participants (a total of 10 interviews) in an effort to continue refining the categories. This process occurred in the following manner: I created nodes for the four VI domains for the second four participants; I created sub-nodes for all 16 categories (within their corresponding domains); and then I coded all sub-text. Throughout this process, I reflected upon the meaningfulness of the categories for each participant and considered which parts of the narratives were particularly important to tell, given the purpose of the study and gaps in the scientific literature.

Next, I combined the sub-text from the first eight participants into newly-created shared nodes for all 16 categories to facilitate comparison across participants. At this point, I did another careful reading of all sub-text in each of the 16 categories, considering the internal homogeneity (i.e., how the categories “hold together”, p. 465) and external heterogeneity (i.e., “bold” differences between categories; p. 465, Patton, 2002). Then, based on my comparing and contrasting, I made changes to the categories within the environmental barriers and environmental supports domains. After coding with the first wave categories for several months and considering their usefulness within and across participant narratives, I decided (in consultation with Dr. Kivnick) that the five ecological systems were providing too fine of analysis for the purposes of this study. For example, although a few participants made comments about barriers or supports in the meso-, exo-, macro-, or chronosystems, the vast majority of these discussions focused on aspects of participants’ microsystems.

Therefore, I replaced the five systems with the life domains that appeared to be most relevant to the purposes of this study (see Table 8) and re-coded all the shared data with the revised 14 categories. This evolving analysis process helped me better

understand what participants meant by the “health care system,” and more specifically, what was missing from their “health care.” Using both inductive and deductive strategies early in my analysis allowed me to consider various dimensions of “health care” and facilitated my thinking about the unique contributions of this study.

Table 8

Second wave categories

Personal Challenges
Physical
Psychosocial
Spiritual
Environmental Barriers
Health care
Relationships
School & work
Society & culture
Personal Strengths
Physical
Psychosocial
Spiritual
Environmental Supports
Health care
Relationships
School & work
Life hacks ²

Lastly, during the third wave of analysis, I further refined domain categories and outlined emergent themes. I began this final stage by creating nodes of the four VI domains for the last four participants (a total of 10 interviews), which included sub-nodes for the 14 categories from the second wave of analysis. Then I coded the sub-text from the last four participants. Next, I combined the coded sub-text from the last four participants with the shared sub-text from the first eight participants. At this point, I did one last careful reading of all the sub-text in each category and made three final

² This term was used by a participant to describe helpful tools in her environment so I decided to use the phrase as the category title.

revisions. First, I integrated the spiritual categories (under the personal challenges and strengths domains) with the psychosocial because I was not able to meaningfully differentiate between participants' psychological and spiritual challenges or strengths (e.g., struggles with the unfairness of their diseases and cultivating gratitude). Second, I eliminated the school and work categories (under the environmental barriers and supports domains) because I was able to incorporate the shared aspects of these categories with other existing categories (e.g., physical challenges, relationships) and the remaining school and work experiences were only specific to one or two participants. Third, I eliminated the society and culture categories (under the environmental barriers and supports domains) because most of these comments were related to health care and relationships and could therefore be integrated into these categories.

While coding the third round of participant narratives, I recognized that several themes were consistently emerging from each of the 14 second wave categories. Although I noted such themes early in my journaling (and debriefing with Dr. Kivnick), it wasn't clear until the end whether these themes should be included in this study or in a separate follow-up study. After much consideration, I decided to include the themes (see Table 9) because of their potential to address important gaps in the rheumatology literature. These themes are elucidated in the findings chapter of this dissertation.

Table 9

Final categories and emergent themes

Personal Challenges
Physical
Limitations & disability
Pain, stiffness, & fatigue
Medication side effects
Weight management
Psychosocial
Loss & grief

	Fear & anxiety
	Sadness, depression, & suicidal ideation
	Anger & frustration
	Acceptance
Environmental Barriers	
Health care	
Communication	
Compartmentalization	
Stigmatization	
Relationships	
Other people “don’t get it”	
Bringing people down	
Personal Strengths	
Physical	
Knowledge of body & limitations	
Activity modification	
Self-care	
Psychosocial	
Acceptance & integration	
“Stubbornness” & advocacy	
Career path	
Faith	
Searching for balance	
Environmental Supports	
Health care	
Communication	
Mental health professionals	
Relationships	
Family	
Friends	
Others with similar experiences	

Drawing conclusions.

Drawing conclusions, the final step in the analysis process outlined by Lieblich et al. (1998), involved organizing participants comments (a.k.a. sub-text) in a way that would tell a meaningful story about the categories and themes that emerged from this analysis process. The findings are presented in the subsequent chapter, but the process of putting it together is described here.

Throughout the three waves of analysis, I used various methods of viewing sub-text within its categories to “formulate a picture of the content universe” (Lieblich, et al.,

1998, p. 114). After the first wave, I printed and displayed the sub-text for each domain and its corresponding categories on my walls (see Figure 4). Viewing the sub-text in this way allowed me to see participants' comments in all 16 categories, from all four participants at the same time, which was not possible in NVivo. Even though I did not intend to do an in-depth analysis of each category for this study, seeing the data in this way allowed me to immediately see that themes were emerging.



Figure 4. Photo of first wave categories

By the end of the second wave, there was too much sub-text to physically manage so I created the shared category nodes in NVivo. This method allowed me to compare sub-text across participants within each category. At this point, I also created

an Excel workbook to keep track of the themes that continued to emerge from the categories.

Lastly, during the third wave, I continued to use the shared category nodes in NVivo, and I also created Word documents for each theme that contained direct quotations from participants that I wanted to highlight in the findings chapter. I also shared these documents with Dr. Kivnick as part of the auditing process described below.

Trustworthiness

As with all types of scientific research, it is important to consider the rigor and quality of this study. Because qualitative research is grounded in constructionist and interpretivist worldviews, notions of rigor and quality can vary dramatically from those used in positivistic approaches. Although there are many ways to define and address these topics in qualitative inquiry (Creswell, 2007; Patton, 2002), I employed the widely used criteria outlined by Lincoln and Guba (1985), who proposed the concept of trustworthiness as a way of thinking about qualitative rigor and quality. The four criteria described by Lincoln and Guba (1985) are credibility, transferability, dependability, and confirmability. Each will be discussed here along with the strategies I implemented to enhance the trustworthiness of the findings.

Credibility.

Credibility refers to the process of enhancing the truthfulness of research findings (Lincoln & Guba, 1985; Patton, 2002). If readers do not have confidence that the interpretations of the data represent the true experiences of the participants, the study has little to contribute to the scientific literature. Since qualitative research is designed to

elicit the multiple realities from lived experience, the approach loses its strength if findings do not represent these multiple realities. Lincoln & Guba (1985) suggest five techniques for enhancing the credibility of qualitative findings: 1) Activities increasing the probability that credible findings will be produced (i.e., prolonged engagement, persistent observation, and triangulation); 2) Peer debriefing; 3) Negative case analysis; 4) Referential adequacy; and 5) Member checking.

A variety of techniques were used in this study to strengthen credibility. Prolonged engagement, which Lincoln and Guba (1985) described as “the investment of sufficient time to achieve certain purposes” (p. 301), was the primary reason for conducting multiple interviews with each participant. Because I came into this study with a significant amount of knowledge about JA, I wanted to ensure that my findings were representing participants’ realities rather than mine. Meeting with each woman several times allowed me to obtain the “scope” (Lincoln & Guba, 1985) of experiences necessary for drawing meaningful conclusions. In contrast, persistent observation facilitated my exploration of “depth” (Lincoln & Guba, 1985) by permitting me to “identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued and focusing on them in detail” (p. 304). This process helped me determine the “things that really count” and sort out the “irrelevancies” (Lincoln & Guba, 1985, p. 304).

Furthermore, elements of peer debriefing, negative case analysis, and member checking were used throughout data collection and analysis. Peer debriefing occurs when a researcher discusses their motivations, biases, methods, and interpretations with someone outside the study for the purpose of “exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (Lincoln & Guba, p. 308).

However, I used the term “elements” above because, according to Lincoln and Guba (1985), debriefing is meant to be done with a peer, meaning someone who is familiar with the research topic and methods and is “neither junior nor senior” (p. 309).

Throughout the study, I continuously debriefed with several people (e.g., Dr. Kivnick, my husband, the volunteer who helped with transcribing, and a number of people from the arthritis community), but none of these people technically fit the definition of “peer” put forth by Lincoln and Guba (1985).

Similarly, elements of negative case analysis were used during the data analysis process. Lincoln and Guba (1985) define negative case analysis as working to “continuously to refine a hypothesis until it accounts for all known cases without exception” (p. 309). Although this process wasn’t used exactly as defined, I continuously searched for negative or outlying experiences and refined research questions and interpretations. For example, in the first few interviews several women felt strongly that narcotic pain medications are over prescribed and can lead to problems with addiction. These observations led me to speculate that there is an overemphasis on pain medication in the practice of adult rheumatology. Yet, after completing interviews with several other participants who were struggling to find a rheumatologist who would prescribe any pain medications, I came to see that this issue is far more nuanced than a simple over or under emphasis. These observations prompted me to revise my interpretations and refine how I asked the interview questions.

Lastly, member checking – the most important means for guarding against threats to credibility — occurs when “analytic categories, interpretations, and conclusions are tested with members of those stake-holding groups from whom the data were originally collected” (Lincoln & Guba, 1985, p. 314). Several forms of member

checking were built into the data collection and analysis process of this study. As was previously described, participants were emailed several documents and invited to share their thoughts, questions, and concerns. The first document was a two-to-three page Word document outlining their disease story, including dates and major milestones. In the email, I requested that they look over this document for accuracy and contact me with any edits or questions. The second email sent included updates on the status of the study and a PDF file of a poster presentation with preliminary findings. The final email contained a Word document with the quotations I hoped to use in the final draft of my report. In this last email, I asked them to review the quotations and send me questions, concerns, or additions that they wanted me to consider.

Transferability.

Transferability refers to the ability of qualitative research findings to be useful beyond the particular setting and population of the original study (Corbin & Strauss, 2008; Lincoln & Guba, 1985). These concepts are similar to the quantitative notion of external validity, but differ in what is expected from the researcher. Lincoln and Guba (1985) state that it is not the responsibility of the researcher to design a study that will produce the most applicable or transferable findings, but rather it is their responsibility to provide ample description of their methods, setting, and participant population so other scholars can determine whether their findings are relevant to a new population or setting. They differentiate between the sending and receiving ends of the findings (original researcher and following researchers or practitioners) and clearly state that the original researchers can only control the quality of information they send out into the world and therefore cannot make conclusions about how that information will be received by others. If a researcher designs and implements their study with

transferability in mind, they should put considerable effort into documenting their process and descriptions of the context of their study. This process not only improves the quality of each individual study, it also contributes to a greater understanding of the phenomena across studies.

The primary technique for promoting the transferability of qualitative findings is by providing thick description of research methods and findings (Creswell, 2007; Lincoln & Guba, 1985). Throughout this dissertation, I have presented a detailed description of this study's methods and findings, which will allow future scholars to evaluate the trustworthiness of its findings and determine if they are useful.

Dependability.

Lincoln and Guba (1985) use the term dependability to describe whether or not findings are consistent. They differentiate between instrument (human) unreliability and changes that occur throughout the research process in the phenomena being studied or the emergent research design. Both of these elements are pieces of dependability, but they do not all carry the same weight in terms of threats to the findings. In naturalistic inquiry, changes in the phenomena or design are not considered a threat to the credibility of the study, as they would be in a quantitative or positivistic research paradigm. However, unreliability in data collection or analysis by the human researcher(s) is a potential threat depending on the strategies taken to safeguard against it.

Triangulation (with multiple coders) and inquiry audits are suggested ways of protecting against threats to dependability (Creswell, 2007; Lincoln & Guba, 1985). An inquiry audit was used to increase dependability because using multiple coders was not

appropriate or possible in this dissertation study. The purpose of an inquiry audit is examination of the research process. Dr. Kivnick performed an ongoing audit by reading and making comments upon my journal entries, memos, content codes, and original transcripts. These comments and observations were also discussed during our regularly scheduled meetings.

Confirmability.

Lincoln and Guba (1985) present confirmability as an alternative way to think about researchers' objectivity. Confirmability exists when someone other than the researcher can confirm that the data and findings are true to the experiences of the participants and not simply a reflection of the researcher's own interests and perceptions. Lincoln and Guba (1985) state that "this definition removes the emphasis from the investigator and places it where it ought more logically to be: on the data themselves" (p. 300). Bolstering confirmability, enhances the trustworthiness of the findings by minimizing the likelihood that the researcher's experiences outweigh or overshadow participants' experiences.

Within a constructivist paradigm, it is assumed that the researcher will bring their experiences, perceptions, and biases into their work; nevertheless, it is their responsibility to be explicit about these characteristics and take appropriate precautions (Lincoln & Guba, 1985; Patton, 2002). The primary technique suggested by Lincoln and Guba (1985) for assessing confirmability is through a confirmability audit. In contrast to an inquiry audit (described above), the confirmability audit examines the accuracy of the findings. Although a formal audit was not completed in this study (i.e., I did not hire an outside professional), several components of the process were included. I maintained an audit trail throughout the research process, which contained all six records described by

Lincoln and Guba (1985): raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, reflexive notes, and instrument development information. Additionally, these materials were shared with Dr. Kivnick who assessed the confirmability of my findings by examining the audit trail for logical inferences, utility of category structure, and inquirer bias.

Chapter 5

Findings

The primary aim of the present study was to capture rich descriptions of the physical and psychosocial development of young people living with childhood-onset rheumatic diseases during the transition into adulthood. To accomplish this aim, I took a developmental and ecological approach in examining the personal and environmental factors that prevented and promoted healthy development in the narratives of 12 women who grew up with rheumatic diseases. Using the principle of VI, I organized the findings according to the four domains: personal challenges, environmental barriers, personal strengths, and environmental supports (see Figure 5). However, it should be noted that according to the principle of VI there are no clear lines between the four domains; there are constant, reciprocal interactions between the person and their environments, as well as their challenges and strengths.

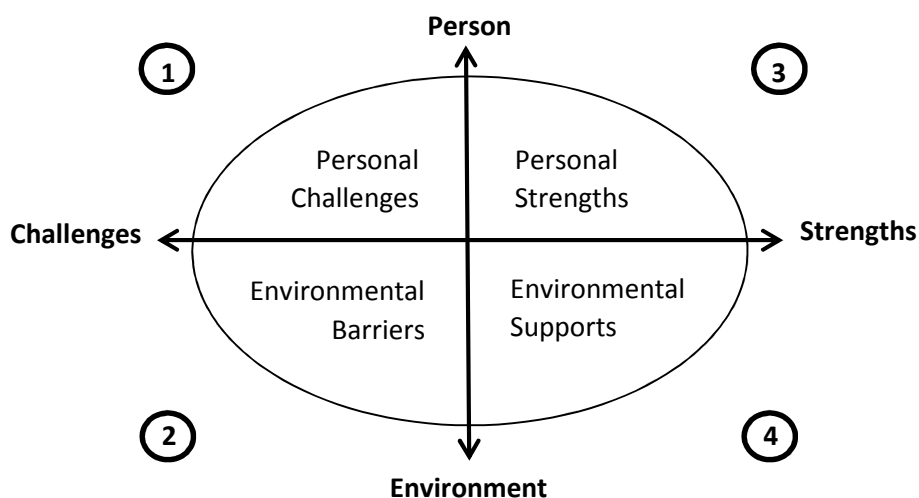


Figure 5. The four domains of VI

Participant Demographics

Twelve women living with childhood-onset rheumatic diseases participated in this study (see Table 10). At enrollment, the women's ages ranged from 26 to 35 years old, with a mean age of 31. Age of diagnosis ranged from 11 months to 18³ years old, with a mean age at diagnosis of seven. Participants reported being diagnosed with four primary rheumatic conditions: juvenile rheumatoid arthritis (JRA); systemic lupus erythematosus; psoriatic arthritis; and seronegative spondyloarthritis.

Table 10

Participant demographics

Pseudo name	Age at diagnosis	Age at enrollment	Primary diagnosis
Kim	7	29	Juvenile rheumatoid arthritis (JRA)
Angie	6	34	JRA
Luna	13	26	JRA
Stacy	4	35	JRA
Rachelle	12	33	Systemic lupus erythematosus (SLE)
Lisa	7	34	JRA
Amy	7	34	JRA
Maria	11 months	34	JRA
Maggie	8	30	JRA
Lauren	18	26	Psoriatic arthritis
Heather	2	31	Seronegative spondyloarthritis
Jamie	5	26	JRA

Eleven of the 12 participants were Caucasian and one identified as African American. Four participants were married and eight considered themselves single. Three women had children and one participant was pregnant. At the time of enrollment, ten participants lived in Minnesota (four in suburban settings, three in urban settings, and three in rural settings) and two participants lived in urban areas of Wisconsin. Since

³ Although this participant was legally an adult at diagnosis, she identifies as having a childhood-onset rheumatic condition because she was in high school at the time of diagnosis and her rheumatologist believed, in hindsight, that she was exhibiting symptoms for at least four years prior to the diagnosis.

this study explored the transition from childhood to adulthood, it was also important to consider where participants grew up. Five women grew up in states other than Minnesota (in both urban and rural areas) and of those who spent their childhoods in Minnesota, four lived in rural areas and three lived in suburban areas. As was described in the literature review, urban and rural status can significantly impact access to pediatric rheumatology services (Duke, 2007; Mayer et al., 2003). In fact, fewer than half of all participants reported receiving consistent care from pediatric rheumatologists as children.

As Table 11 illustrates, participants were living with a wide range of disease manifestations, as well as a multitude of medication side effects (medication side effects will be discussed in a subsequent section). Throughout the interviews, participants described damage in a variety of joints including: temporomandibular (i.e., jaw), neck, back, fingers, wrists, elbows, shoulders, toes, feet, ankles, knees, and hips. Additionally, all participants acquired secondary conditions over time that could be caused by or otherwise related to their rheumatic diseases. For example, three women were diagnosed with ulcerative colitis or Crohn's disease in late adolescence or early adulthood, which are autoimmune diseases that affect the GI tract, causing loose, bloody, and painful stools (Crohn's & Colitis Foundation of America, 2015), and are associated with several types of rheumatic conditions (Jacques & Elewaut, 2008; Leirisalo-Repo, Turunen, Stenman, Helenius, & Seppala, 1994).

Table 11

Participants' disease manifestations

Blindness (caused by iritis)
Bursitis
Colitis and Crohn's disease
Fevers
Fibromyalgia (widespread musculoskeletal pain)
Heart failure
Iritis (inflammation of the iris)
Joint fusions (as a result of disease progression and surgery)
Joint replacements
Limited range of motion
Lyme's disease
Muscle tension (shoulders, neck, back)
Migraine headaches (caused by destruction of the temporomandibular joint)
Psychosis and stroke (caused by neuropsychiatric lupus)
Raynaud's syndrome (narrowing of small arteries that causes fingers and toes to be numb and cold)
Scoliosis
Tendonitis
Ulnar drift (hand deformity)

Some participants had external indicators or visible deformities from their conditions (e.g., swollen and red joints, restricted functioning, use of wheelchair), while others looked like typical women in their 20's or 30's. In fact, most of the physical challenges displayed in Table 11. were invisible or hidden. In this sample, there didn't appear to be a correlation between disease severity (i.e., disease activity; increased risk of mortality) and outward symptoms. For example, Rachelle experienced some of the most serious complications of rheumatic conditions (e.g., heart failure, stroke), yet from the outside, there were no visible signs of her disease.

Personal Challenges

According to VI, the personal challenges domain represents threats to one's healthy psychosocial development that originate in the person themselves (Kivnick et al., 2003). Such threats can be caused by genetic factors, disease, disability, or ineffective

coping mechanisms. Two primary categories emerged as important threats to participants' development over time: physical and psychosocial.

Physical

Within the physical category, four themes arose as participants talked about their physical health challenges: limitations and disability; pain, stiffness, and fatigue; medication side effects; and weight management.

Limitations and disability.

Although everyone's disease manifested differently, all 12 women discussed physical limitations that made daily life challenging. Both Heather and Lauren described struggles with bathing and showering. Heather said: "It's just so hard to get in and out of the tub. If I had a decent size tub that was equipped, I would definitely take them more. My knees just hurt so badly and I can't get up." And Lauren said: "When I am flaring, showering is the hardest thing. I try to use my elbow and the bathroom wall to squeeze shampoo." Others talked about having a hard time cleaning their house, buttoning clothes, typing on the computer, and holding their newborn baby. Maria also described her challenges with grocery shopping:

I can't even tell you how many times, after I first starting living alone, that I spent the time and energy to grocery shop and then I'd be staring into the pantry and I couldn't eat a damn thing because I couldn't open anything. I'd end up having to call and order take-out because I couldn't get a damn thing opened. If I grocery shop, I can't move for two days. People don't realize how hard it is. If I have two days off in a row, I rest in the morning, grocery shop in the afternoon, and then I am flat on my back in bed the next day so I can go back to work.

Because of their physical limitations, everyone discussed the need to quit activities or reduce their activity level. For most, this withdrawal process started in childhood with sports or gym class and continued to the present day with school, work, and hobbies. This was equally true for women with mild disease as it was for those with severe disease. For example:

When I hit high school and it got competitive, it was just too much for my body. I did swim team and I was so excited to get to junior high where they had swim team because my doctors always said that was the best thing. But that wasn't the case for me; that's what caused my hip problem.

The hardest part has been not being able to do all the things I would like to do with my physical body; having to stop doing the things that I want to do. It was really, really, really, really, really hard to back down in dance.

For my job, I had to drive and help elderly clients in and out of cars and I wasn't comfortable with it. I had to quit because I had to dilate my eye 3 times a day and I couldn't drive. I can hardly drive myself, let alone other people.

While everyone described periods of time where their disease was well managed or in remission, it seemed as though the good periods were few and far between, and getting less frequent over time. There also appeared to be a snowballing effect with time; everyone talked about how their disease has continued to change, and most described increasing disability and the collection of new conditions with each passing year. For instance, Heather said "The flares are getting worse and more debilitating. I'm losing more and more functioning every time and I don't bounce back to where I was before."

Pain, stiffness, and fatigue.

All participants struggled with pain, stiffness, and fatigue. While the severity and location of the pain was constantly in flux with medications, surgeries, and flares, everyone noted that some level of “soreness” or pain was present at all times. For instance, Maria said “Everything hurts. Over the years, I’ve been diagnosed with myopathy (muscle weakness), myositis (inflammation of muscle tissue), Raynaud’s, avascular necrosis (death of bone tissue), and fibromyalgia. So when providers ask what hurts, I have no idea.” Others also described a low-grade, chronic “achiness” that was sometimes more difficult to manage than the severe peaks or flares because of its persistence. Stacy said “It’s like I have the flu all the time. There is a general body ache and my whole body is like ugh.” When asked to describe what her disease feels like, Lauren explained it like this: “My old roommate phrased it the best way. One morning she said ‘you look like a horse that slipped passed the first bullet.’ I was like, ‘yep that’s how I feel, take me out back and shoot me.’”

Because of the pain and stiffness, most participants described challenges with sleeping and fatigue. Starting in childhood, many stated that they weren’t able to keep up with their peers. For example, Angie said, “I could never stay out as late and I didn’t have the same energy as other people” and Stacy said, “I definitely couldn’t do what my friends were doing in college.” As participants moved into adulthood and their diseases progressed, getting an adequate amount of sleep was even more challenging. Maria said, “It’s always been a challenge. I am a horrible sleeper because of pain, repositioning, getting stiff. I really only sleep in chunks of like 2-3 hours and then I’m up again.” These same struggles were echoed by other participants and most people said their fatigue is one of the hardest parts of living with a rheumatic condition because it

interferes with all aspects of life. Stacy described how her fatigue affects her at work: “I’m so tired and there’s definitely times where I’m getting up to walk around my office because if I don’t get up, I’m going to fall asleep.” And, Heather talked about how her lack of sleep and uncontrolled disease make it hard for her to work full-time:

My disease has progressed because of medications not working and some days I have to take a nap. Like I will sit down and I physically cannot do anything. I have to rest and sleep for an hour if I want to be able to do anything.

As a result of the pain, stiffness, and fatigue, many participants described feeling “old,” even from a very young age. Lauren said, “I was basically born as an 80 year old man” and Luna said, “I feel so aged and so old. Whenever I have a birthday I always joke that I’m turning 95.” During these conversations, people also expressed concerns about their energy level in the future. For example Kim said, “The hardest thing right now is that I kind of feel like I’m old. So how is it actually going to be when I am old?” and Amy said, “Am I going to be like an old person forever?”

Medication side effects.

All participants who had taken medications to treat their disease (i.e., 11 of the 12), experienced unpleasant side effects (see Table 12 for a list of all medication side effects discussed during the interviews). Although there was a wide range in severity, everyone stated that side effects negatively influenced their day-to-day functioning. The most commonly reported side effects were weight management, gastrointestinal (GI) problems, infections, and heightened emotions. Due to its pervasiveness, weight management will be discussed separately, in the following section.

Table 12

Medication side effects reported by participants

Medication side effects
Acid reflux
Adrenal insufficiency (prevents the adrenal glands from producing enough of certain hormones)
Avascular necrosis (death of bone tissue from lack of blood supply)
Broken bones (as a result of the osteoporosis and avascular necrosis)
Cardiomyopathy (disease of heart muscle)
Cataracts
Cushing syndrome
Esophagus ulcers
Facial hair growth
Hair loss
Heightened emotions (e.g., depression, anxiety, irritability)
Infections (e.g., yeast, sinus, ear, pneumonia, pertussis, staph, c. difficile)
Nausea
Osteoporosis
Primary immunodeficiency disease (weakening of the immune system)
Stomach ulcers
Weight gain

Nearly all participants experienced nausea or acid reflux due to their medications. Kim described the state of her stomach as “blown to shit⁴” and Amy talked about a time in high school when she was really struggling with nausea:

I was puking constantly. It was kind of a joke, we knew it was too much when one time my mom and I went through a drive-thru, I puked right away and she just kept eating her lunch like nothing was happening.

⁴ A number of swear words appear in direct quotations throughout this chapter. I decided to leave all swear words unedited in an effort to preserve the authenticity and emotionality of participants’ comments.

Infections⁵ were another prominent topic of discussion, ranging from minor annoyances to major and life-threatening. Several women reported being embarrassed and irritated by frequent infections. For example, Kim talked about the awkwardness of explaining to boyfriends why she often gets vaginal yeast infections; Lauren said she feels like she's "on the Oregon Trail" because she developed rheumatic fever a few years ago; and Amy had to quit a job working at a daycare because she was sick all the time. More extreme infections were reported as well. Angie had to eventually stop taking biologic medications because she had over 20 hospitalizations in two years due to "massive infections" and Amy had a series of infections that caused her to miss a significant amount of time from work:

Last fall, I had a paper cut and got a staph infection from it, thanks to my medications. So I ended up in the hospital for a week with IV antibiotics. I was out just a few weeks and then I got c diff. from the antibiotics. That went on for months and months and months. They were almost to the point of having to do a stool transplant.

Heightened emotions were also discussed as common medication side effects, and of prednisone, in particular. Maggie described herself as "a big ball of emotions" when she's taking a combination of methotrexate and prednisone and said her mom hated it when she was growing up because she would "turn into a monster, have mood swings, and be angry all the time." Similarly, Lisa said changes in her prednisone dose make her feel like she might "burst" and that she "cries her eyes out" for no apparent

⁵ Infections themselves are not caused by the medications, but due to the fact that most treatments work by suppressing the over-active immune systems of people with rheumatic conditions, infections are more common than in the general population (Gartlehner et al., 2008).

reason. Additionally, Lauren said prednisone makes her crabby and irrational: “like if my sister said ‘hey, the sky is blue today,’ I would say, ‘FU I wish it was purple.’”

Less common – but equally frustrating – side effects were also described by several participants. For example, Heather, who was struggling with active inflammation in her eyes at the time of our interviews, talked about the vicious cycle that occurs with steroid eye drops: “I have inflammation, so I start the drops, which triggers the cataracts and the eye pressure. Then, I need laser surgery to take down the eye pressure.” Also, numerous broken bones were reported as a result of the prednisone, which increases the risk of osteoporosis (Lukert & Raisz, 1990). Rachele and Amy both talked about how breaking bones has been an ongoing issue. Rachele said, “I have broken lots of bones: both ankles, two times each; one wrist; and one finger.” And Amy said:

They were related to the prednisone. I broke the first bone during my senior year of high school. It never healed, and then my first year of college my surgeon put a screw in to fix it. Then, I was two weeks into recovery, and I tripped and fell down the stairs and broke the same exact bone on the other foot.

Weight management

One of the most prominent themes discussed during the interviews was challenges related to weight management - nine of 12 participants described gaining and losing weight as one of the hardest parts of living with a rheumatic condition. Peoples’ narratives about their weight gain were strikingly similar:

Up until I was age 13, I was so skinny. I didn’t eat anything. My meds took away my appetite. Then one summer they changed my meds and I had my appetite back and I ate everything I could. It’s the prednisone; I hate prednisone. If they

could take out the munchy aspect and the hungry feeling, it would be an amazing drug. I hate my ass. I absolutely hate it. I can love every other part of my body, even my jiggly arms, if I could just lose my ass, my life would be great.

I went from being so skinny as a child that I had to drink Ensure to try and put weight on to so much prednisone and limited ability for activity because the severe inflammation. My weight really fluctuates with my steroid dosage. It doesn't matter how much I work out; I'm going to have a moon face⁶. The only thing that annoys me is other people's perception and the fact that my face doesn't match my body. My face is super swollen and overweight compared to my body. I know people who are 150 lbs. heavier than me, but their face is much skinnier. And when people look at you, they really judge your face.

When I was first diagnosed, I gained about 30 lbs. Then the weight fluctuated between about 97 and 120. And then the biggest I've been was about 180, when I was in college. I was so sick and they couldn't get me off the steroids. They were trying lots of medications and nothing would work. Then the weight came off as the prednisone decreased and I was down to 110. Now anytime I get sick, the prednisone increases and I gain the weight back.

When I was in high school, I had a bad flare and was given a steroid shot. I gained 50 lbs. in a month. I went back to school and everyone was like "did you have your wisdom teeth out? What happened?" It was bad. I got bright red stretch marks everywhere. I wouldn't wear t-shirts or shorts or anything. A few

⁶ Corticosteroids often cause rounding of the face with prolonged exposure (Huscher et al., 2009).

years later, I was on really high doses of prednisone for a long time so I gained ... I was up pretty high. Then after my hip replacement, I got off the prednisone for a couple years and I lost over a 125 pounds. It was great. And then in 2006, I flared really bad and was back on 60 mgs for several months and I gained all of it back. You work to try and get it off, you just get going on something and then something happens.

Shortly after I was diagnosed, during freshman year of college, I gained 50 pounds in a few months. When I went in I was 150 lbs., playing soccer and skiing, and by the time I left I was 230 lbs.

As these quotations illustrate, weight gain is a common side effect of corticosteroids, which are often used to reduce inflammation in people living with rheumatic conditions (Huscher et al., 2009). Many participants gained large amounts of weight during flares when they were prescribed high doses of prednisone, and then struggled to lose the weight after their disease was under control.

Losing the weight has been complicated by a number of factors for these women. Nearly everyone discussed elements of their childhood and family environment that likely contributed to their struggles with weight management in adulthood. For example:

Both my mom and dad are overweight. My dad is diabetic and my mom has been heavy as long as I have been alive. Growing up, we ate whatever we wanted and it wasn't like, "oh, we shouldn't have cake every time family gets together?"

I come from a bigger family that's always struggled with weight and food issues, so that doesn't help. That was my mom's thing, my daughter's in pain, I'm going to give her a tube of Pringles. "It will get better, have some chips. It will get better,

have some cookies.” Out of her lack of dealing with my stuff, it got transferred into the food.

It’s like alcohol, like nicotine, this stuff is addicting. I could never drink a drop of alcohol again in my life and I would be just fine. I can quit smoking, but I cannot quit sugar because it’s been in my body ever since I was little, because that’s what parents do. “You want a snack? Here let’s give you a treat for being so good.” Here is a stick of sugar.

Physical limitations have also made it difficult to lose the weight. Amy described how she works out most days of the week and still can’t lose the weight because her disease restricts the types of exercise she can do: “I wish I could just go run for two hours or use the new ellipticals at the gym. That would make it a lot easier.” Other people talked about how their physical limitations prevent them from preparing or eating healthy foods:

It’s just easier for me; the bag of chips is already open versus the orange that I have to peel or an apple that I need to slice. I can open the cheese stick myself but I can’t make a peanut butter sandwich.

Everything is about convenience: what can I eat with a swollen jaw? What can I open and prepare with swollen hands and elbows? How taxing is it going to be? People are like “you should pack an apple for lunch because then you can just chew it.” I can’t physically bite into an apple. To eat an apple, I have to cut it up, and I can’t do that either. So I eat applesauce cups. Even if you buy the organic, it’s not as healthy, but I can’t physically do it.

Several women described taking extreme measures to get the weight off. Stacy had bariatric surgery just over two years ago and Rachelle tried to lose weight by stopping her medications and trying to expel calories and water from her body:

I would just stop taking the prednisone because I wanted to lose weight. And then when I would get sick from not taking the prednisone, I was like well how else can I lose weight? So I started taking laxatives and diuretics because I wanted to be back to myself.

During the interviews, it became clear that gaining weight not only threatened participants' physical health, it also affected their sense of self and interfered with how they thought others' perceived them. Lauren wondered if her weight "holds her back." She asked, "Is that why I didn't the job?" or "If I was thinner would I be in a relationship?" Others shared similar concerns about their weight and how others view it:

It's not so much my weight that bothers me, it's people's perception of it. If they see you have a bag of m&m's, then they're like "You shouldn't eat that much chocolate. Why are you having desert? That's why you put on 20 pounds." And it's like, yeah I'm not saying that I couldn't eat healthier, but that's not why I put on 20 pounds in two weeks. It's not the m&m's, it's the infusions of 3,000 mg of Solu-Medrol⁷ and the 80 mg of prednisone I take every day.

⁷ Solu-Medrol is a corticosteroid commonly used to treat inflammation in rheumatic conditions. It is typically delivered by IV infusion (Smith, Ahern, & Roberts-Thomson, 1990).

When I'm a little thinner, I have these nice, big brown eyes and when I'm more moon-faced my eyes look like slits. I look like I'm drunk or high all the time. It looks like I'm half asleep. That's not how I see myself.

It sounds superficial, but it's not. It was everything. I just blew up. It's strange to look at pictures of you and not see you. I hate it. That is not me. It's also society. They look at people who are overweight and they assume that you're lazy or that you don't eat healthy. I've even heard doctors make statements about patients who have gained weight. I'm thinking, you give them this poison and yet you make these statements. How dare you. It's pathetic.

Psychosocial

This category describes the complex psychosocial challenges faced by participants. Five key themes emerged: loss and grief; fear and anxiety; sadness, depression, and suicidal ideation; anger and frustration; and acceptance. As the findings unfolded, it became clear that most psychosocial challenges were related to or explained by loss and grief.

Loss and grief.

As is evident from the physical challenges described above, these 12 women have endured a significant number of disease-related losses. Most losses stem from the inability to complete a physical task or the anticipation of not being able to complete a task in the future. Luna described her first major physical loss like this: "It was like I blinked and I didn't have a wrist anymore. It ate up all the cartilage; all those little bones had fused. It was totally shot. I couldn't believe how powerful my disease was." Similarly, Jaime explained how recent changes in her left elbow have affected her functioning: "It

really sucks. I wish it was my right elbow because that's my good arm. I'm left handed and when I want to do things like play racket ball and volley ball, that's my good arm. Well, apparently not anymore." And Lisa talked about the difficult decisions she often has to make when she faces another surgery: "You have to figure out which joint you want functioning and which fused. You have to trade off; you can either have the strength or the range of motion, but not both."

Such physical losses always had psychosocial ramifications. Maria, described how her 20-year old self's wish to get married was "blown to hell" because of her progressing disease and Luna talked about a loss of freedom when she stated: "It breaks my heart every day. I want to be like wanderlust, peace out; I'm moving to Germany, I don't need any meds. But it's just not the case." Likewise, Lauren shared how she felt after being diagnosed in late adolescence and how her disease has affected her life planning:

I had a perfectly normal childhood until a week ago when this was all thrown at me. It was irritating as a young person who grew up in the suburbs and heard, "you can be anything you want" because after being diagnosed, there was a new stipulation: "you can be anything you want, unless it doesn't have health insurance." This was not something my peers had to think about. Before the diagnosis, I had goals; I wanted to go to law school. But I didn't really get what having JRA meant; now, I think you don't really get to pick what you want to do for the rest of your life.

And Heather discussed how she continuously struggles with the decision to have more children because of the health challenges encountered with past pregnancies:

When I told my primary doctor that we're looking into adoption and probably aren't going to have any more kids, she almost did a cartwheel. She's happy that she doesn't have to worry about it, but I'm never going to stop wanting to have my own kids. But at the same time, it doesn't look pretty afterwards and miscarriages are no fun. Do I want to put myself through that again? Is it worth it?

As these quotations illustrate, participants faced a series of never-ending physical and psychosocial losses and threats of future losses. However, while the ubiquity of loss was evident, participants responses to the losses (i.e., how they grieved) took many forms and changed over time. Specifically, I observed four primary responses to loss: Fear and anxiety; Sadness, depression, and suicidal ideation; Anger and frustration; and Acceptance.

Fear and anxiety.

Nearly every participant discussed feelings of fear and anxiety related to their disease and/or its treatments. Additionally, at least half of the women reported being diagnosed with an anxiety disorder and/or prescribed anxiety medication at some point in their life. Participants discussed four main areas of life that induced fear and anxiety: their health, medications, work, and family planning.

Anxiety about future health was a common topic of conversation during the interviews. For most, anxiety was triggered by the loss or threat of the loss of physical functioning. For example Amy said, "It's scary. What's going to happen? What's life going to look like? Am I going to be bionic, have every joint replaced by the time I'm 60?" Luna and Jaime expressed similar concerns. Luna said, "Some days are really good and I can live pretty close to what I think of as a normal life, and some days are so bad they make just an intense fear of the future. Like, how am I going to survive?" And Jamie

said, “It just terrifies me. Am I going to be 50 and not able to do anything that I want to do?”

Medications were also frequently discussed as sources of fear and anxiety. Worrying about side effects was a common experience. Jamie said: “We don’t know all the side effects. That’s what really scares me. Do I want to be able to move and then end up having issues somewhere else?” Amy talked about her constant fear of infections, triggered by her severe reaction to a paper cut several years ago: “Ending up in the hospital from a paper cut was really nerve wrecking. Now, every time I get a cut, I’m like, Oh my gosh, now what?” Rachelle voiced similar concerns about a particular medication:

It is an oral immunosuppressant and they don’t really know the mechanisms for which it works, but supposedly it works. I think it is safe, but I am at higher risk for lymphomas and other cancers. There is another condition... progressive multifocal leukoencephalopathy, it’s like mad cow disease in humans. It’s always been really strange because every time I get sick I don’t want to die from this condition because everybody who gets it dies. If I have a fever, I’m like “Oh no!”

Participants also expressed doubt, and consequently anxiety, about whether existing medications can adequately treat their disease and manage symptoms. Nearly everyone described a process of cycling through medications and constantly searching for something better. Amy said: “I’ll be on them for a year or two and they’ll just quit working” and Kim said, in reference to the biologics: “They just haven’t been the miracle I hoped they would be.” Others talked about similar challenges:

They just haven't worked. It's like they sort of help a little bit, but then it kind of dwindles out. They might make it more tolerable for a while, but I've never had any time since I was a teenager where the arthritis wasn't bothering me in some way.

They think the biologics are going to save us when, let's be honest, it's a frickin' band aide until they stop working. Let's be realistic please. What is this going to look like for me in 20 years? Are these biologics really going to sustain me that long? I've been on Remicade four times in the past and it didn't do anything, so I am really, really, really nervous.

I saved IV infusions for last, but now it has been infusions for last couple years. I held out as long as I could for the last drug just because there were no other drugs out there. Why did I hammer through them so fast? It just feels like end of the road.

Most participants also described anxiety about their future work and family situations. Luna, who is a yoga instructor, talked about her fears for the future:

I am living in fear a lot. Like my chosen career path really scares me because there are a lot of times when I can't even practice what I preach. I just think, I am not going to be able to do this forever. What should I do for a job or a life if I can't count on my physical body?

Likewise, Kim discussed her worries about family planning:

I don't know if it's just my age or if it's because my health is starting to sort of go downhill, but I feel kind of a rush to settle down and find somebody before there's

the big landslide of my health deteriorating. And then thinking about getting older and having kids, I'm already having a really tough time staying awake at 1 in the afternoon. How am I going to have enough energy to be with kids when I'm 50?

Sadness, depression, and suicidal ideation.

The topics of sadness, depression, and suicide surfaced in nearly all interviews. All 12 participants talked about feeling sad or depressed⁸ at some point in relation to their disease. Many of these emotions were in response to losses and were likely manifestations of grief. For instance, Lisa talked about being “bummed” after failed surgeries and Luna said: “I can still totally remember my life as an abled-body. A big part of me is sad and yearns for those days in the way that my body used to be able to move and feel.” Other participants described similar feelings:

I definitely was depressed when I first got diagnosed. There's all this stuff you start thinking about; I am picturing all of these worst case scenarios and reading the side effects of the meds and it is like great, everything is bad.

When I was little I was told numerous times, “most kids grow out of this.” So when I went into remission during my teenage years, I was like, “Yes! It's gone!” Then it was really depressing when it came back again. Like, “What did I do!?”

One of the times I was taking methotrexate and my dose was super high, my body wasn't taking it well and my hair started falling out, in handfuls. It was so

⁸ Participants used the words “sad” and “depressed” interchangeably and so I am doing the same. Unless it's noted, the term “depression” is not a diagnostic label.

interesting to feel how attached I was to this physical thing. My hair was falling out and I never knew I cared about it like that. It was devastating. It makes you feel really weak and really sad and not a woman anymore. I don't know what you're questioning, but you're questioning it all.

In addition to their disease, participants also reported feelings of sadness about the state of the health care system and its inability to meet their needs. For example, Luna said: "It has always seemed like a real guessing game with the medications. There's no rhyme or reason to this disease. It has a complete mind of its own and it makes my heart sad." And Lisa said: "You just get tired of the fight. Your body is betraying itself and living in that reality everyday sucks. And then you're fighting the system, you're fighting with insurance companies, with doctors who don't even listen to you."

Furthermore, one of the most striking patterns that emerged from the interviews was the frequent discussion of suicide. Although none of the women reported a legitimate plan to carry out a suicide attempt at any point in their life, at least half of the participants described thoughts of suicide in relation to their disease. Maggie recalled a time in college when she was feeling overwhelmed and said: "It all bottled up and I didn't know what to do anymore. I thought I'm just going to jump out a window and make it easy." Heather expressed more recent thoughts of suicide during a horrible flare: "You get to the point where you're flaring for so long that you're thinking about wanting to kill yourself all the time." And Maria reported similar feelings during a flare several years ago:

It's four in the morning, you can't move, you're in tears, you're in so much pain, and you haven't eaten in 3 days because you haven't been able to reach your

face. Is it time to call an ambulance? Or, is life not worth living anymore? We've all had those moments at four in the morning when the world is asleep and you're lying in bed by yourself.

Although most participants recognized that their sadness or depression could be considered abnormal or disordered compared to their "healthy" peers, they also felt strongly that their emotional reactions were not exaggerated or pathological in the context of their severe losses. For example, Kim, who sees a therapist and has been diagnosed with depression said: "I don't consider it to be depression. I think a lot of my symptoms have more to do with shit that's happened that is legitimate for me to be concerned about." Similarly, Luna stated:

Nurses have tried to tell me that I was depressed and put me on antidepressants ever since I was young. I don't write off those drugs for people who need them, but I have situational depression. It's just because of what's happening. I have a lot of emotional heartache over it, like anybody would. Every time a nurse has tried to play that angle with me and I'm like, "I have a life-long chronic illness; you'd probably have to worry if I wasn't depressed."

It seemed as though participants contextualized and justified their sadness and depression in these ways due to the constant changes in their physical health. Heather summarized her thoughts on the matter like this:

We're not always depressed. When we feel fine, we feel fine. It's like a roller coaster ride. I would never think about killing myself when I'm feeling good. You go through these periods of depression because you're in so much pain and the disease is attacking your body. I never have emotional issues with my arthritis

until I get in a really bad flare. Then, I'm not myself and I'm super crabby because I feel like I'm worthless.

Anger and frustration.

Anger and frustration were also common emotions expressed and exhibited throughout the interviews. Akin to fear and sadness, some women described feeling angry or frustrated in the face of loss. Luna stated, "On bad days, it's super frustrating. I feel weak physically if I can't grip things or open things or button clothes." And several others described feeling "crabby" or "upset" during flares. Lauren said: "When I don't feel good, I don't want to deal with anything because I am cranky." And Maria described frustration over her loss of control:

The biggest thing is the unpredictability of it. It's hard to make a life plan because you never know where you're going to be. You can't count on finishing tomorrow because you might not be able to move your fingers. And you're never able to commit 100%. Just trying to plan your life is the most frustrating thing to me. Even after 30 years, it's still really hard for me to learn strategies to cope with the unpredictability. I like to plan and be in control. That's the most frustrating part of the disease and I don't see that changing in my lifetime. There's always hope you'll get through this or they'll come out with a better med, but that's something that I don't see changing in my lifetime. Some people can get their disease under control or they can plan – especially kids in this new generation who have grown up with the biologics and they just don't have the deformity and limitations – but I will always have these deformities and limitations and my disease will always be like this. I don't see the possibility of the light at the end of the tunnel. Even if my pain gets better, there's still that erratic part of the disease.

While every participant reported feelings of anger and frustration related to their disease, Heather articulated what can happen when these feelings get “bottled up”:

There was one time when I was flaring and I could barely walk. I was trying to get my shoes on and I got pushed over the edge. I said “just give me a fucking gun” right in front of my 7-year old kid. It was the worst thing ever. I was being a little serious, but not. I was just done. I was thinking why the hell am I doing this to myself? My husband was like “shut up, don’t talk like that.” And my kid said “do you want to shoot your foot off, mom?” Yes, “I want to shoot my foot off.” But oh my God no, that’s not what I meant.

Heather’s comment, along with the previous comments about suicide, indicated a sort of existential wrestling or questioning over the unfairness of having to live with rheumatic diseases. For example, Stacy said, “I wasn’t depressed, but there was just that anger, like why the hell do I have this?” And Heather articulated how her disease has made her question her spiritual beliefs: “I’m a little pissed off. If there was a God, why would I have to go through so much shit?” Luna mirrored similar sentiments when she said:

I have always resented that this disease took away my movement. I was just pissed when I was diagnosed. My whole life is moving. Why would I get something that would restrict my movement? This is not fair. Give some lazy person who likes to sit on their couch and play video games this disease. Please do not give it to me. I’m the wrong person. I promise I’m the wrong person.

Acceptance.

Because of their physical and emotional challenges, all participants struggled with the process of accepting their diseases. For most, this began with avoidance or denial in childhood and adolescence. As Angie said: "I think that level of denial, like denying the disease and that I didn't want to deal with it that started at a very early age for me." Maggie described similar feelings in response to her doctor's recommendation that she should have her hip replaced as an adolescent: "They told me when I was 12 that my hip needed to be replaced and I was like nope, not going to happen."

Nearly everyone talked about using "busyness" at some point in their life to distract themselves and avoid thinking about the reality of their situation. Angie said, "The busier I was, the less I had to think about how I was feeling, and the easier it was."

Kim described similar behaviors:

For a really long time it was easy for me to be working and not have to think about life, regular life. It's an easy excuse. Nobody really questions why you would want to work more. I think that was a good escape for a long time.

Although avoidance and distraction can be useful coping mechanisms for some stressors, all participants noted that such tactics only delayed the inevitable, and several people discussed how their avoidance fueled poor and sometimes dangerous decisions. At least four participants talked about how their early avoidance and denial prevented them from meeting other kids with rheumatic conditions, and ultimately caused them to feel isolated. As adults, these women regretted their earlier decisions and wished they would have been more open to participating in disease-related activities (e.g., Arthritis Foundation camps) and meeting other kids.

Rachelle described how denial of her worsening health in early adulthood contributed to her expulsion from college twice because she was “too proud” to register with disability services. After her first year, she was put on academic probation for too many absences. During her second year, she brought doctors’ letters to her professors, but they wouldn’t “honor” them because she still hadn’t registered. She was officially “kicked out” after her second year, which she said “was a tough cookie to swallow.” But then she went back to the same school, a second time, and was “kicked out” again after a year for the same reason. Going through this process taught her that she couldn’t “do school and manage [her] health at the same time.”

Angie even attributed her addiction to pain medication to her sense of denial:

I just wanted to be normal. I wanted to play soccer, go to college, and go to grad school. I just wanted that normal life I guess. But all the while, my denial contributed to how I felt about myself. Growing up I always had a supportive family and social network, but it didn’t change how I felt about myself on the inside. I barreled through it and did not deal with it until finally it blew up in my face. I was at a crossroad, taking 300mg of oxycodone a day and I remember thinking, I don’t really care if I live or die. I never attempted suicide, but I didn’t have any hope for the future. I was like okay, if I don’t start to deal with this and have some acceptance, it’s going to deal with me and I am going to end up dead. Who knows if I would have ever had drug problems without the arthritis, but my addiction was directly related to my disease and how I felt about myself. In recovery, at least 80% of my 12-step work has been about my arthritis. I just hated my arthritis and had zero acceptance.

In addition to avoidance and denial, participants delayed their acceptance process by trying to “fight” or “beat” their diseases. Luna said: “I was like, oh I am a total badass. I can beat this with my mind and food. So I stopped taking my meds, and in hindsight, this was probably the worst decision for my physical body.” Kim also reflected upon how her desire to “beat” her disease influenced her decision to lie about her health condition on her application to the U.S. Army:

My grandpa was really hard on me growing up. I was one of two girls on my mom’s side and he had been in the Army in WWII. I just wanted to please him and do something tough. With the JRA and being a girl, I just wanted to show people that I could do what I wanted to do. I really wanted to be in the army so I lied on my application and enlisted at 18. I actually still have the paper at home. You have to go through every disease and initial next to it saying that you don’t have it. I knew it was wrong but I was pretty confident that I could do it, so I didn’t think it was that big of a deal.

Kim went on to explain that she participated in basic training for two years before she had a major fall, which eventually resulted in a shoulder replacement. After the fall, Kim was discharged from the Army for lying on her application and was forced to pay back the tuition the U.S. government paid during her first year of college.

Overall, most participants stated that accepting the reality of living with a chronic, progressive disease has been the most difficult part. As Lauren said:

You can get past most physical things, but dealing with the mental side is the hardest part. You have to accept that you have to deal with the physical

otherwise you can't get through it. Realizing wow, it's not just limping because I ran too hard, it's realizing, this is shitty and forever.

Heather and Luna shared similar thoughts and said that even as adults, they still struggle to accept their conditions. Heather, who was in the process of having her right eye removed during this study, said: "I'm very sarcastic when I talk about my disease because I still don't want to face the fact that I don't want to have my eye sucked out of my head." Rachele admitted that her avoidance still prevents her from taking care of herself as she should: "I push through things that I probably shouldn't. Like when I recently broke my foot, I walked on it for a week before I went to see a doctor." And Luna stated: "We've been on the hard drugs all our life, getting shots every week and it still doesn't sink in that yeah, you're going to have to live with this forever and do stuff differently."

Environmental Barriers

Although a variety of environmental barriers and challenges surfaced in the interviews, I focused on the two most common categories: Health care and Relationships.

Health Care

Challenges and barriers in the health care system were the most commonly discussed topics in the interviews. Participants expressed very strong feelings about their experiences within the health care system and emphasized how these experiences had significant effects on their health and wellness. Three key themes emerged from the data: Communication; Compartmentalization; and Stigmatization.

Most conversations about the health care system centered on frustrating behaviors of adult-focused rheumatologists; however, two caveats should be noted about the context of these findings. First, my primary intention during the interviews and data analysis was to elucidate the psychosocial experiences of the 12 participants, not to critique or exploit specific health care providers. Based on the information gathered in the interviews, I made conclusions about how these 12 women felt about interacting with the health care system, while fully recognizing that these findings are based upon participants' perceptions of their experiences. Second, participants discussed their health care challenges by predominately focusing on their interactions with providers despite the fact that many of their frustrations were beyond the control of their providers. Several participants acknowledged this gap and I certainly took the complexity of these issues into account as I interpreted the data. Therefore, the themes presented in this section represent barriers across multiple, interacting levels of the health care system.

Communication.

Participants described a number of communication challenges that made them feel as though they weren't being heard. Several women talked about a lack of provider "social skills." For example, Stacy said "They're standing up and walking towards the door while you're talking... guess I'm not going to bring up the next thing on my list today." Two other participants expressed feeling belittled when rheumatologists told them they didn't have time to read the medical records these women had physically transferred⁹ during their transition from pediatric rheumatology. For instance, Maggie said:

⁹ All participants recalled picking up paper copies of their pediatric records and physically transporting them to their new clinics because their care was received prior to the electronic medical record.

The doctor was upset that I transferred my records; she said “I don’t need to see all this.” I said, “Yes you do, this is my life.” She said, “Looking at your labs, I don’t think you have arthritis.” “What? Did you even read any of my stuff?” She said, “I don’t have time for that.”

Similarly, Rachelle described an experience when rheumatology providers disregarded basic communication skills:

When I was in the hospital, the doctors would come to see the patient next to me and they didn’t knock on the door or say “hi.” As they were leaving, I asked if they were in rheumatology and if someone could answer my questions and he looked at me and just kept walking. He was in my room, didn’t knock on the door, and didn’t say a word to me. He also had six other people with him and they didn’t say a word. Also during that stay, I was referred to by staff as the room number. I have a name. It wasn’t even patient X, it was room X.

As we discussed these experiences, it was clear that one of the key elements missing from these interactions was listening. All 12 participants expressed frustrations about not feeling heard by their rheumatology providers. For example, several women said:

Don’t just throw pills at me and tell me to go away. If doctors would take the time to listen, they would see that we don’t lie, we know our bodies, we know what works, and we know what doesn’t work. If they would just take a minute and stop reading the test results.

I wish they would be willing to listen and shut up. Some of the doctors I've seen in the last few years, they walk in the door and all they do is talk and talk and talk. They hardly ask you any questions about yourself.

I'm the patient, let me talk. You have no idea who I am. If you let me talk and I tell you my story, and if you're actually listening, you'll hear a lot more of what's actually going on than just I don't feel good, give me antibiotics. My body needs help, so how are you going to help it? You keeping me here for two and a half hours and giving me nothing but feeling like you can give yourself a pat on the back and a sticker on your nose because you told me to take probiotics and give some poop samples, if that's really what does it for you, then I would have given you a sticker on the way in and saved a couple hundred bucks and stayed at home and drank some electrolytes.

He just didn't listen. For a while I felt like something was happening. I didn't know what was going on, but I was telling him I think we need to do this and we need to do that and he said "I've been doing this for 30 years. I know what I'm doing, just sit back and let me do my job." Then I went in for what I thought was just a cough, to my primary care doctor, and that's when we found out about the heart failure.

Additionally, several participants reported feeling jaded because their providers not only disregarded their perspectives, but also told them what they should do or how they should feel. For example, Luna, who is a professional yoga instructor, was told by her rheumatologist that she shouldn't do yoga anymore because it was hard on her joints. Others described similar experiences:

The doctor said something like “why is this so concerning to you?” I was like dude, you don’t understand what this is like. I’m not even thirty and things aren’t going to get better. My body is already going to crap and I’m not that old. This is my reality. And he’s like “well, it’s not that big of a deal.”

They can’t really empathize. They see you every six months and check in, but this is my day-to-day, my disease is a big part of my life. Just because you think that it’s not that big of a deal to take a medication once a week versus every other week, that is a big deal to me.

Problems with communication were also discussed at the system level. Rachelle described an experience she had at a hospital where she experienced a series of frustrating interactions:

I went in for an appointment, waited 45 minutes to see her, and then she sent me to the ER. I waited 9 hours and the people at the desk were horrible, rude. I can’t sit for 9 hours and then be treated like crap. I understand they’re busy, but you can’t treat people like that.

Further, participants talked about difficulties reaching their rheumatologists. For example, Amy has been struggling to find a rheumatologist in her area because she’s frustrated by clinic policies: “It’s very hard to get in with them. If you’re in a flare they make you go see your primary doctor first.” And Rachelle described an instance when she was flaring and needed medication:

I couldn’t get a hold of the doctor. I would call two weeks before I needed the refill and I would just keep calling. So it was about two weeks before I got the

prednisone I needed. I had called his secretary, the doctor, and left multiple messages.

Compartmentalization.

Another common theme throughout the interviews was that participants felt as though their providers, and the wider health care system, narrowed in on specific aspects of their diseases and then acted as if their diseases were cut-off or separated from all their other areas of their lives. This theme surfaced in every interview and participants' comments about the limited perspectives of their providers were nearly identical. For example:

It has always been really closed picture. You are here for JRA and these are the things we will talk about. Nothing like "oh you can't sleep so you are taking Trazodone? How does that relate to JRA? And depression too?" It is all very private and departmentalized.

I definitely don't think my doctors ever think about the holistic piece of it, or whatever comes along with it - depression anxiety, energy conservation, fatigue, and chronic pain. That has never been talked about in appointments.

They need to look at it as a holistic thing and teach people more about that, especially the food part. They should focus more on mental health too. It needs to be addressed and providers need to be more comfortable talking about it and not shying away from it. It's such a big part of the disease and how we cope with it. At least address it. In my experience, it's never been addressed.

As these quotations illustrate, participants reported that their adult-focused rheumatologists rarely, if ever, inquired about how their disease affected their mental health. And the few women, whose providers had asked about this area of their life, were prescribed medication for anxiety or depression without receiving a recommendation or referral for counseling. These patterns were particularly concerning given the mental health struggles (e.g., eating disorders, depression, anxiety, suicidal ideation, and addiction) experienced by these women.

Likewise, discussions about pain management were a common source of frustration for participants. Most indicated that their rheumatologists had never asked about their level of pain or its management. Heather explained her experience like this:

This is a chronic disease that causes a lot of pain, in a lot of people. If my disease is not being controlled by the medications that are available, then you need to at least control the pain so I can have a functioning life. And I don't think they get that. I have yet to find a rheumatologist who will have that conversation and be proactive.

Further, when participants initiated conversations about pain management during appointments, they felt as though providers' responses were invalidating and unhelpful. For example, during college, Amy had a failed hip replacement surgery which was causing her a tremendous amount of pain and a provider told her to accept the state of her hip and "just go on disability." Luna and Stacy expressed similar frustrations:

When I say "I'm in pain," I'm in pain. Why would I make this shit up? Why would I want to be in pain? The doctors turn to me and are like "yeah, you just don't look like you're in pain."

My doctors don't want me to be on pain meds, but they don't give me other solutions. What do you want me to do? Not go to work and not function? Or, do you want me to stay active like you tell me? I want to stay active with my kids, go to work, and be functioning in society. I had one rheumatologist who flat out told me that I shouldn't work anymore. I have a 3 year old at home. What? My husband works in construction and he doesn't make that much money and we never know what's going to be there. I have to work. Social security and disability benefits would never be enough to support 3 kids. But it's kind of like a black and white thing to them.

In addition to challenges with providers, the above comments illustrate how the wider health care system also compartmentalizes participants' lives. Because of the fact that insurance is often linked to work or income status, people were forced to make major life decisions to protect their health and health insurance. Several participants were struggling to build well-rounded, meaningful lives because the "system"¹⁰ imposed restrictions on their work status. For example, Maria described being "stuck" in a job she didn't want because she needed health insurance: "I was in a toxic work situation; I had to stay there for a year because I had to wait until I found something that would be more permanent." Rachele and Heather expressed frustrations with Social Security and Disability Insurance (SSDI) because it restricted how much money they could make. Rachele explained that the guidelines for SSDI were "not conducive to self-sufficiency or independence" because "at any given point, I couldn't have more than \$2,000." Heather

¹⁰ Participants used the term "system" to refer to federal, state, and local laws and policies that determined benefits for health insurance and Social Security and Disability Insurance.

was in the midst of sorting out this dilemma during her participation in this study. She had just finished her first semester of graduate school and was forced to take a leave of absence because of her health. She was considering whether it would be worth it to return to school: "In my mind, it's like is it worth it? I probably won't even get SSDI if I was working part time because you can only make like \$800 dollars a month." Maria was in a similar situation:

I qualify for SSDI completely. I could quit tomorrow and wouldn't have to work a day in my life if I didn't want to. But then you can't work at all. You can make minimum wage, 10 hours a week and you can't go to school full time. So then what am I supposed to do? I could volunteer and make a fulfilling life, but I want to contribute. I want to pay into the system. I want to be independent. Even if I plan and save up money to live, what the hell am I going to do for health insurance? It's always the health insurance component that's the scary part.

Lastly, participants frequently discussed frustrations with insurance coverage. It seems as though the health care system may be diminishing health by operating from such a restricted perspective regarding what is "medically necessary." Several women described challenges accessing important health-related tools such as: massage, acupuncture, probiotics, essential oils, sufficient amounts of physical and occupation therapy, and adaptive devices (e.g. splints, braces, and orthotics). Luna was particularly upset when she was told by her insurance company that they didn't want "maintenance patients" in physical therapy and therefore she was limited to a certain number of sessions despite the fact that she wanted to continue learning how to manage her pain through physical activity. Maria also experienced a number of challenges related to

insurance coverage. She described three aspects of her everyday life that are not considered “necessary” and therefore not covered by insurance:

Function wise I’ve always been able to chew and talk and swallow, but I’m very messy and my teeth look horrible. I’d like to get jaw surgery, but you have to do the orthodontia work and as an adult the orthodontia work isn’t covered.

I have custom foot orthotics too that are no longer covered by insurance, so I pay out of pocket to help keep the feet a little bit straighter. It’s really hard to walk when your feet aren’t straight and you put more pressure on your hips and knees.

I went to a motorized wheelchair which is a whole thing because then you have to get a van for it with a lift, and insurance doesn’t pay for the vans. Without a van, I had no way to get my chair back and forth to work.

Stigmatization.

Not only did participants report challenges with the compartmentalization of their health, but they also reported feeling shamed and humiliated by some of their health care experiences. Many of these discussions built upon the topics described above, such as work status and pain management. Heather shared an experience that left her feeling marginalized because her rheumatologist disregarded her values and abilities:

He told me to find a desk job. We talked about it because I was going to grad school and he was like, “We need to find you a desk job.” Really? That’s not my

long term goal. You're sitting in front of me with my CRP¹¹ that's crazy high and you're telling me to find a desk job? Do you understand that it's really hard for me to get up to go to that desk job? I can barely get my socks and shoes on. Mornings are really frickin bad sometimes and I can barely get up and function. I'd rather be poor than have a job I don't like. I don't want to go to a job 8 hours a day, 40 hours a week and not like it. No, I would rather budget wisely and do something I'm feeling content with in life.

Heather was particularly frustrated with this situation because she felt like her provider wasn't treating her like a competent, capable adult. Maria expressed similar sentiments about recommendations she has received to change professions because of her health:

How would your psychological or emotional well-being be if you worked every day in a job you didn't want? Plus having the stress of a chronic illness on top of that? I would not be a healthy person and I probably wouldn't be able to keep a job. It takes a lot of motivation for me to get up to go to work physically on days when I can't move, or am in pain, or haven't slept in 24 hours, and I still go to work. Part of that is because I have the motivation and love my job that much.

Participants who took narcotic pain medications also felt stigmatized by their providers and the wider health care system.

I hate being on pain medications because I feel like it's really stigmatized. I know what it's like, I've worked with addicts in the past and I don't want to go there. But, there's always a risk of addiction and that's really scary to me. You slowly

¹¹ C-reactive protein is a protein produced by the liver that increases when there is active inflammation in the body.

need more and more to make it work and I'm 31. That's really scary. Every time I walk into a provider's office, they give me the same lecture: "You're on fentanyl, do you know what that's going to look like? You're only 31! You need to get off that!" No shit! I know. I got that. You don't have to lecture me.

Besides the fatigue, the next hardest thing is dealing with chronic pain and the stigma about pain meds in the health care system. Because on the one hand, for acute pain, they say "stay on top of pain, don't let it get too bad" but when it is something more chronic, it is like "YOU CANT TAKE THAT. It's bad!" So it's really hard to abide by health care standards and come up with other ways to help with pain. It is not easy. Definitely not easy.

Similarly, nearly all participants discussed concerns about being stigmatized for their mental health struggles. For example, Lisa talked about feeling judged by her providers because of her emotional reactions to her disease and medications and said: "For the most part we're not whack-a-doodles or drug-seekers." Because of such concerns, many avoided talking about their mental health all together. For example, Heather, a social worker, said:

If I were to walk into an office for a mental health appointment, I know what I can and cannot say. I don't want to go to them and say "I just want to die" because then they'll think I just want to die and that I'm crazy and they'll put all these diagnoses on my chart and that's the last thing I want. So I'm not going to get everything I need out of an appointment because if I say something, it's going to trigger something on your end. It makes me not want to express all my feelings to you.

The topic of ageism also surfaced throughout the interviews. Stacy reported that one rheumatologist told her she was “too young” to be in pain and Luna described this experience with her first adult-focused rheumatologist:

She was like “Oh you look great compared to most of my patients, they’re all deteriorated.” And I’m like “Most of your patients are 80 so let’s not play this comparison game because I don’t ever want to look like that.” Her recommendation was for me to sit around in the waiting room and see the people who come in and out of her office and check my assumptions about my disease. What? She was like “Yeah, because you really don’t look that bad.”

People also discussed ageism at the system level. Many participants were frustrated by the fact that the health care system discriminates against young people with chronic health conditions by not offering affordable insurance options that meet their needs. For example, Lauren and Maria stated:

I can’t go and buy the cheapest crash and burn insurance that my peers buy. That is one of my biggest pet peeves; it is so unfair. This is forever and no one wants to help us. It is so frustrating.

Healthy young people can just buy cheap, catastrophic insurance and they’ll be fine, but I go to the doctor every week, I get labs every other week, I get biologic infusions every week. I need hard core health insurance without it lapsing even 24 hours.

Relationships

In addition to health care providers, participants described challenges interacting with all types of people in their lives. Two primary themes emerged with regards to relationships with other people: Other people “don’t get it” and Bringing people down.

Other people “don’t get it.”

Whether they were talking about family members, friends, colleagues, or health care providers, the phrase “they just don’t get it” was used by every participant to describe the challenges of relating to people who don’t have rheumatic diseases. For most, these difficulties began in childhood:

One of the hardest things about growing up with arthritis was not the arthritis, but the fact that people didn’t believe that kids can get arthritis or that it’s severe. They say “it’s like my grandma” whose hands hurt and she can’t knit as much or garden anymore. Also, you have to deal with teachers and principals and them not believing that in the morning you may be functioning fine, and by the afternoon you can’t move. It’s not because you did anything wrong, it’s just your disease. That was the biggest struggle.

The hardest part was trying to talk about it with people who didn’t go to arthritis camp. At camp, we’d talk about everything and then I would go back home and try to talk to my friends. They were like, “I don’t know what you’re talking about, I don’t have this, I don’t have to take medication, I don’t really care.” I was like okay, I can’t talk to my friends and I don’t want to talk to my parents.

In adulthood, these challenges continued and often created significant social tensions, across settings.

At my job, it's hard because people don't understand that I can't get stuff off the bottom shelf. They'll say, "You're 30 years old and you can't kneel on the floor?" No, I can't because I can't get up. "Well, maybe you should work out more." I have arthritis. "No you don't. You're 30, you don't have arthritis."

I think my arthritis creates a wall between me and other people my age. Girls my age can go dancing all night long and I cannot. I can dance all night long at a wedding because I know I'm off the next day and can lie in bed or sit in the shower and recover. I can't do everything they can do. But they're like, "You work two jobs and you can't go dancing until 3 am?" No, I can't because I have to go home and recover.

Trying to explain it to my husband has probably been the hardest part. It is hard to explain to other people what you're going through and it can be really frustrating when people say things like "oh, you'll be fine" or certain things really irk me sometimes. I know you're trying to be supportive, but you don't get it, so stop.

It's not just the rheumatology community; its government and everyone. What is JRA? What does it even mean? People think of – it's one of two extremes – either you're old, rickety, in a wheelchair or it's some person who won Survivor. That's not reality. It's great to strive for, but it's not reality. I had a lot of people

saying “Well, if she can do that, why can’t you? If you would just exercise more maybe you could be....” Really?

As these quotations demonstrate, some social challenges are related to reasonable misunderstandings about rheumatic conditions. However, even when participants understood that disconnections were happening for legitimate reasons, the experiences weren’t any less stressful. For example, Lisa and Luna described how they have a hard time interacting with well-intentioned people. Luna said “The main comment I get is, ‘oh, but you’re so positive, you’re so happy.’ People say that to me all the time. And I wish they didn’t say anything.” And Lisa said:

People come up to me and say “Oh, you’re such an inspiration; you’re in so much pain every day.” I don’t need that negative stuff around me, you’re trying to be positive, but really you’re negative because you’re trying to force the woe is me, inspirational blah, blah, blah.

Moreover, participants talked about how living with a rheumatic disease has made them more easily annoyed by other people. Kim and Lisa described it like this:

It’s difficult for me to find people who are worthwhile to have as friends. Or that are going to understand. One of my girlfriends, she has nothing wrong with her and it’s the smallest things that make her go over the edge. I’m just annoyed. I don’t know how to relate to some of my friends. They have no problems in their life but they always have something to complain about. I don’t know what to talk to them about.

Sometimes my PCA's will make comments and I just look at them like you have no right to say any of that to me, you don't get it. You're just wasting your breath. It means nothing to me because you haven't gone through anything.

Lastly, people described how they alter their behaviors to decrease the stress associated with interacting with other people. Heather and Luna gave these examples:

After my next surgery, I probably won't leave my house. I hate telling my story. I don't want to tell everybody over and over again because I get sick of telling it. It's a lot of work. And it's like, oh gosh, I don't want to talk about it.

It is a lot easier for me to tell people that I can't have kids, then I don't want to. They look at me like, "you are so mean." It's not that simple. So I choose the verbiage of, "I can't have kids." Then they feel bad for you and it is like, "No, it is fine!"

Bringing people down.

As the above quotations illustrate, participants described many challenging aspects of interacting with people who didn't understand what it was like to live with a rheumatic condition. In particular, these women struggled to have honest conversations with important people in their life because they didn't want to make other people "feel bad" or "bring them down." For many, these challenges emerged in childhood. For example, Maggie talked about an experience with her mom that still makes it difficult for her to talk about her disease with people who don't understand:

I remember having one conversation with my mom and it freaked her out. She got up and left my room and I was like okay, did I piss her off? Did I say the

wrong thing? Did I scare her? I don't know. She's like I'm sorry this is just a lot for me to handle. And I was like, it's a lot for *me* to handle.

Similarly, Jamie described how a recent conversation with her mom – about the re-emergence of her arthritis in adulthood – required her to withhold her own feelings to protect her mom:

My mom was devastated when she found out that I had it again. I think almost as devastated as I was. She started crying. Yeah, she's like "I just didn't want you to have to go through that again" and I was like "I know, I'll be okay." Like I was comforting *her*.

As these women grew up, these challenges spilled over into adult relationships. Several people described how they avoided talking about their true feelings with their partners:

Even when I talk about it with my boyfriend now, I'm very hesitant because there's really nothing anyone else can do about it. Just generally people feel bad and then you can't do anything. So what's the point of me sharing it?

Let's be honest, it's scary because you don't want to lose that person. It's not like you want to go and bitch to them about your problems. I don't want to annoy him and make it sound like I'm whining because I wouldn't want to listen to my spouse whine all the time. I'm not going to bitch about it to my husband because I don't want to bring him down. I think we might keep a lot of that inside because we don't want to bring our family down.

Personal Strengths

Despite the many challenges faced by participants, all 12 of these women have cultivated and accumulated a number of internal resources that helped them create a sense of wellness and well-being. Three primary categories of personal strengths are described: physical, psychosocial, and spiritual.

Physical

Three key themes emerged from the interviews that explain how participants learned to manage their health and disease: Knowledge of body and limitations; Activity modification; and Self-care.

Knowledge of body and limitations.

Every participant described a process of coming to know and trust their body over time. For most, this process involved an element of trial and error. Maria concisely summarized her progression, by saying, "I'm stubborn, but I'm not stupid anymore." Other participants made similar comments about how they learned by pushing their physical limits:

I had to learn my boundaries with the meds. I had one beer and felt like I'd had an entire bottle of whisky. We all try it, but then you're sicker than a dog and it's not fun. Now that I am older, I know how it affects me so I know what and when I can drink.

I'm learning to work with the disease instead of trying to fight it. For 27 years I just tried to deny and fight it and pretend it wasn't there. So now I am okay if I

need to go rest or take a nap. I am not always happy about it; it's not always what I want to do. But I will do it because I know it will make me feel better.

Through these experiences, participants learned a significant amount about how their bodies worked. For example, Amy talked about the nuances of her pain tolerance. She said, "I've realized over the last few years that I have a very high tolerance for joint, bone, and muscle pain, but it's totally different when it's a headache. When it comes to headaches, I'm such a wimp!" Similarly, Stacy decided not to breastfeed after third child because she had learned from previous pregnancies that her disease would flare immediately and she needed to go back on medications to keep her pain under control. And Rachelle has learned how her body responds to medications: "I'm very sensitive to prednisone. For some people 5 mg does nothing, for me 5 mg really works and I can tell a difference."

Such knowledge helped participants make informed decisions by allowing them to weigh the costs and benefits of each situation. Amy talked about going through this process when she considered where to attend college. She said:

I went back and forth and decided I didn't want to live in the dorms. I knew my body well enough to know that I was probably going to flare when I started college anyways, so I made the decision to stay here with my doctor and have the least amount of stress possible.

Likewise, Lisa described going through this weighing process when she considered whether or not to have children. She said:

At some point I wanted to have kids, before I met other women with arthritis who said how hard it was. Then I was like, maybe not. That ship hasn't totally sailed

yet, but with having my hip replaced, I'm not sure how that would fly. Especially too with my bone mass issues, because I know kids pull off a lot of calcium. So I'm thinking it might not be a good idea, I don't know if that's something I'd want to do.

Over time, each participant came to their own understanding of what was best for their body, in the context of their life. Lauren described her perspective like this:

"Optimism is great, but you need a dose of being realistic. If you have both hips and knees replaced, just because you can run a marathon, doesn't mean you should." And Luna shared her realistic outlook about her career:

I've always had to be really real with it. I can't have a job where I stand all the time. I can't have a job where I sit all the time. I don't have the personality to be somewhere all day and so that would stress out my mind which would stress my body.

Activity modification.

Using the knowledge they gained about their bodies and diseases, participants discussed continuously discovering new ways of modifying their activities to meet their ever-changing needs. Some modifications happened naturally, such as becoming ambidextrous or changing the way they put on their pants. Others involved purchasing items that would reduce their pain and make life a little easier. For instance, Luna said "thank God I found Birkenstocks" and Amy said "I love camping, but I do it my way, with a car and an air mattress."

More challenging modifications required gradual, psychological shifts. Both Amy and Luna have adapted their favorite physical activities to accommodate their ongoing

feet challenges. Amy fulfilled her dream of completing a marathon by become an avid rollerblader. She said:

Yeah, I switched and did the inline marathon instead of the running marathon. You make compromises and you figure it out. Rollerblading is kind of my thing now. It has been the best exercise I've found and I feel completely normal when I'm doing it. It's a good workout, it doesn't hurt anything, and I can even do it with a broken foot. Rollerblades are just like casts!

Luna made similar comments about skiing:

I loved snowboarding, but it was too hard with the flexible boots. That's when I started skiing. My friends have to help me into the ski boots – I have two friends holding the boot open so I can put my swollen ass foot in there – and then I crank it down because the ski boots are nice and solid.

Maria and Angie also talked about how, over time, they found ways to modify their activities and conserve energy. Maria, a child life specialist, has come to use her motorized wheelchair more often:

I work at a large children's hospital so there's a lot of running around. I'll have a meeting in this building and then all of a sudden there's a trauma, so I run back to the other building. I use my chair for distances at work and when I'm having a day where the knees are more swollen and I'm hobbling around. I used to hobble and push through it, but then I would end up flaring and not being able to move for 3 days. So instead of that, now I use my wheelchair as much as I can.

Angie, an occupational therapist, went from working full-time to part-time and put her daughter in daycare one extra day a week to conserve energy and manage pain:

The work thing has been huge. When I went to part time, my arthritis changed drastically. I felt a little out of it being 30 years old and working part time, but it's been really great for me. I know I could work full time if I was sitting at a desk or if I wasn't on my feet, but I love the work I do.

We ended up paying for daycare on Wednesdays so I could do the grocery shopping and that sort of stuff. If someone would have told me that I would pay for daycare for a day that I'm not working, I would have been like "you're kidding me." But now, Wednesdays are my saving grace.

Several women also talked about incorporating other people into their modification process. Maria described how having chores as a child taught her important lessons about how to manage a household:

My sister and I each had chores and even if I was flaring or in the hospital, I was still responsible for those chores. My parents were like, "You're going to have to figure out a way when you're an adult to get this done." So I would save up my money and pay my sister to do my chores. Which is kind of what I do now, I pay people to do my chores when I can't. Or, when I was feeling good, I would trade and do her chores for her and then we'd trade. I kind of do that now too with friends. I'll help them study for exams or help watch their kids and then they'll come over when I'm not feeling good and do a couple loads of laundry for me or clean my bathroom. So at the time I was like this is not fair, I can't even move and you expect me to clean the bathroom? But, it taught me that you have to save your money and when you're feeling good you have to do more or you have

to conserve your energy and think about things. It definitely taught me about pacing and balancing things and knowing your body.

Lisa, a middle school band teacher, relies heavily on braces made by her occupational therapist when she was in college. She said:

I play with my left hand even though they said it couldn't be done. I have been a left handed trumpet player since 6th grade. I just had to adapt my trumpet and other instruments, with help from my OT. She has been my lifeline for adapting. Once a month, we would take a different instrument and she would say, "Here is a trombone how would you hold it?" So when I flare, I have all these different kinds of hand braces and I know which one to use for each instrument.

And, Luna also described getting help from people in her life. She said when her hands were really "messed up," she would order groceries online, have them delivered, and invite a few friends over to help chop and package vegetables.

Self-care.

Participants described a number of tools that helped them stay healthy. While most people mentioned the importance of taking their medications regularly, many also shared Luna's sentiments about wanting to "be on the least amount of drugs possible." For this reason, the majority of the self-care conversations focused on non-medical tools and activities.

Exercise was the most commonly discussed self-care strategy. Participants described a wide range of activities, including: stretching, tai chi, rollerblading, yoga, swimming, elliptical machines, strength training, biking, and dancing with the Wii. Even

though every participant experienced physical challenges with exercise, there was widespread agreement that movement, in some capacity, was the best thing for their disease and overall health.

I'm never going to get rid of the disease, but I can work within my limitations. I can go for a walk as long as it's not going to be 5 miles. I'm going to feel better if I can go for that walk. It's going to make me feel emotionally better, physically better, and it makes me feel like I'm taking care of myself. It also motivates me to continue taking care of myself in the future. When I'm exercising regularly, I feel like I have so much energy and I feel better about myself. My joints creak when I start something new, but when I keep doing it, it gets better.

There are times where I would have horrendous days at work and I was like I can go home and sit on the couch and eat a bag of chips or I can go to the gym, work it out, and jam out to the music. It helps so much.

That's why I love yoga so much. It helps me feel strong in my limited body. It will keep the physical body strong, like every little tissue and attachment, and joint, and bone, and muscle, and skin and fasciae and everything is going to stay lubricated.

After learning about participants' struggles with fatigue, it was not surprising to hear that sleep was the second most commonly discussed aspect of self-care. Even though sleep was challenging for many women, most knew what their body needed and were working on creating a lifestyle that could meet their needs. For example, Kim said, "I've always made sleep a big priority. If I set my conditions up right, I sleep well." And Angie said:

Oh I love to sleep. My husband and I joke that we are an old couple because I have to get so much sleep. For my arthritis, I have always been someone who has to have at least 8 hours of sleep. So we are in bed by 8:30 and sleep by 9. I struggled with a newborn and not sleeping, but I love to nap. If I have a day off, I try to take a nap. That is huge self-care.

Diet also surfaced as a key strategy for self-care, which made sense given participants' challenges with weight management and GI complications. Several women said they avoided specific items such as: "processed" or "packaged" foods, sugar, fast food, caffeine, or alcohol. Many also emphasized the importance of incorporating healthy behaviors like drinking water and eating fresh fruits and vegetables. For example Kim said when she eats fresh food her "stomach hurts less" and she "feels better overall."

Massage was also discussed as an important tool for self-care, with a particular emphasis on pain management and relaxation. Nearly every participant reported receiving relief from massage, even though the frequency was limited due to cost concerns. Stacy said "I get a lot of knots throughout my back. So it's to loosen that up and make me feel better overall." And Luna stated:

I do massage and he's a body worker so he's very skilled. He works on the structural components. It's amazing. So subtle, but it puts me back into place. I don't know if I adjust the way I walk with my f-ed up ankle, but my whole pelvis keeps getting out of whack. And my right side will get longer than my left side, which means I'm putting even more pressure on my ankle. So that will be the first thing we'll do. And then, he'll break up the tension in my upper back and it always feels good for people to work on my arms and break up some of that stuff.

Although massage was the most commonly discussed strategy for relaxation and pain management, participants also discussed: acupuncture, guided imagery, progressive muscle relaxation, meditation, essential oils, and transcutaneous electrical nerve stimulation (TENS).

Psychosocial

This category explores the many ways that people coped with their diseases and their corresponding challenges. Four primary themes emerged: Acceptance and integration; Stubbornness and advocacy; Career path; Faith; and Searching for balance.

Acceptance and integration.

The most stimulating discussions in the interviews were related to how participants continuously worked on accepting their disease and integrating it into their lives. Participants described acceptance as the process of recognizing and admitting to themselves and others that they are living with a chronic, progressive disease. This process included internal and external components such as: acknowledging losses and limitations; realizing there's a lot of "emotional shit happening" because of their physical experiences; thinking about potential future consequences of the disease and its treatments; and taking ownership of their diseases and their management. Every participant described some combination of these components. For example, Kim said: "Acceptance comes from understanding that I'm going to have to manage the arthritis for the rest of my life" and Angie said:

When I say acceptance, I mean recognizing how I think about my arthritis and the limitations it has on me and my body. It means knowing that I am someone

that has a chronic disability and that my arthritis will always be with me and it pretty much has formed my entire life or at least impacted my entire life.

As the aforementioned descriptions of psychosocial challenges indicated, most participants will continue to lose pieces of themselves over time, and therefore, acceptance will be an ongoing process. While there was uniqueness to each person's experience, there also appeared to be a developmental pattern occurring in participants' acceptance narratives. Everyone described coming closer to acceptance with each passing year, and particularly with major life changes. For example, Lisa talked about a series of "knocks over the head" that started in college when she realized that in order to live independently she would need the assistance of Personal Care Attendants. Now, over 15 years later, as a successful music teacher, she is experiencing another "knock over the head" because she is in the process of accepting that she won't be able to work full-time much longer due to the severity of her disease.

While Lisa's acceptance process mirrored her losses, each loss or "knock over the head" also seemed to provide an opportunity for psychological growth. Lisa described her acceptance process like this:

In my Christian circles, you can have a wound and people know that there's a wound there, but when you finally have a scar, it heals and it doesn't need to be a wound anymore. So I guess that's kind of how I would sum it up. I'm still dealing with my disease every day, but it's not a wound to me anymore. It's just part of life. Now my next step is to stop pretending that it isn't there. Not that I really do, but I don't have to prove myself anymore. I am who I am and it's okay if I say I'm not going to do something tonight. My limitations don't determine who I am or what I give to my kids or where I'm going from here.

Lisa's comment about not needing to "prove" herself anymore was a common theme throughout all 12 narratives. As participants moved into young adulthood, they described a process of "settling in" with their disease and themselves. Several people described it like this:

I would say I have learned to appreciate my arthritis more as just a part of who I am and try not to fight it as much. I am enough, just as I am. I don't need to be anybody else and there's a reason why I am the way that I am.

I have learned a lot from my arthritis, like what is important to me and what compiles me. I didn't start learning that until I had some acceptance. The arthritis contributes to my personality and characteristics; it is lot of who I am, but not what I am. I don't see myself as the disease, but aspects of the disease have formed more about me than I realized.

Acceptance has been like freedom. Like a weight had been lifted off my shoulders. It makes me feel more wholesome. Just freedom from how I felt when I wasn't whole. It's that drastic of a difference, but it was a process.

As participants talked about acceptance, they explained that part of the process is integrating their disease with the rest of their life. Just as participants described using avoidance, distraction, and "fighting" to separate themselves from their diseases, several women talked about learning to "work with" and "appreciate" their diseases as intentional acts of acceptance in adulthood. For example, Angie and Luna said this:

Rather than trying to beat or deny the arthritis, which I did for 28 years, I'm just trying to work with it and appreciate it. By appreciating it, I try to do Arthritis

Foundation walks and stuff like participating in this study, which brings the arthritis up, as opposed to not interacting with it at all.

As I've gotten older, I've accepted that it's not going anywhere and that things need to change to run parallel with the disease and use it as a tool. I try to use it for what it is and just let it be power in knowledge and acceptance and let it trickle into every relationship and every idea.

Stubbornness and advocacy.

The most common strength identified by participants was being "stubborn." In response to the question, "What have you learned about yourself from growing up with a rheumatic condition?" all 12 women described themselves as being "stubborn" or as a "fighter." Jamie and Maggie said it like this:

I've always described myself as someone who's very persistent and I won't give up. I think that has a lot to do with the medical stuff. In general, I think you're shaped a lot by what you go through when you're young. So it taught me not to give up and that I'm a fighter.

I've learned that I can do anything I put my mind to and work hard for. People tell me, and I prove them wrong. I remember growing up, it was so different back in the early 90's, "don't run, don't exercise, lay still and your pain will go away." And my parents wouldn't let me do anything! I love my parents, but there were so many road blocks. "You can't do this and you can't do that." And now, I'm like I can do anything. People are going to tell me no and I'm going to just keep doing it anyways.

And Amy, who said, “I don’t have red hair for nothing,” described a powerful experience where she used her stubbornness to cope with a stressful situation:

My junior year of high school, when my face blew up from the prednisone, you could see the whispers and stares. The stretch marks were all over my arms, all the way down my legs and they were bright red. Everywhere I went, people would stare. For a while I wouldn’t wear shorts or go swimming, but after about six months, I just decided you know what, screw it, let them stare. I’m not going to give up something I love. When I wore my swimsuit, people would literally just stare and I would stare right back at them.

While participants talked about their stubbornness being useful in all types of situations, most of our conversations focused on how it played out in health care interactions. For many, stubbornness was a key ingredient, when paired with their hard-earned knowledge and expertise of their bodies and the health care system, to produce important advocacy skills. Amy and Luna shared two experiences that illustrate how their stubbornness helped them advocate for their needs:

After my hip replacement, everybody was telling me that it was fine and I knew something wasn’t right. The orthopedic doctor who did the surgery said “oh, it’s fine.” Nope it’s not. Wrong answer. I can’t even tell you how many doctors I went to. I even called and talked to doctors in Oregon; I was going to go out to Oregon to see a doctor there. I couldn’t even do a leg lift and the doctors just kept putting me off. Finally, I did some research on my own and found what looked to be the exact symptoms. I talked to the surgeon and he agreed with me and offered to fix it even though he had never done that type of surgery. I’m like, “oh no, I’m not

your guinea pig.” So I found someone else to do the surgery and then it was fine. I’m a pain in the butt if you ask the doctors!

Before this appointment, I was wondering, “Should I do some PT? Should I get orthotics?” Then I get there and he wanted to do a fusion in my ankle. He was like “I would put pins right here” and I said “Hold on. Putting pins in my foot sounds like a definite loss of range of motion.” And he said “Well, you don’t have that much range of motion right now, so it wouldn’t really make a difference.” I was like, “Yeah, so I’m this crazy kind of person who wakes up every day hoping that today is better than yesterday, otherwise I would probably kill myself. And putting pins in my foot just feels like a total nail in the coffin. I think the body wants to heal itself and it just needs to be put in the right environment.” I’m like doc, “I really believe that a joint could reform itself. I don’t how, but maybe it could and if your only solution is pins in my foot, then I’ve got to get out of here.”

As participants reflected upon their challenges with health care providers and the wider system, most came to the conclusion that it was their responsibility to advocate for themselves and fight for what they needed. For example, Angie discussed how she had high expectations for her providers and said, “If I have a doctor that won’t meet those expectations, I will find a new one.” And Kim and Rachelle expressed similar thoughts about their health care experiences:

I tell him how it is. He’s trying to tell me that I have Lupus and I said “no.” He tried to change my meds and I said “no, I want to get rid of meds, not add meds.” So I’ve become more combative over time.

I will go in and tell them what they need to do and when they need to do it. I don't really care how they respond. I don't want to be mean, but I want quality care.

Nobody is going to care more about me than me.

Career path.

One of the primary ways participants learned to cope with and accept their disease is through their educational and professional pursuits. Participants appeared to benefit from these experiences in several important ways.

First, several women recognized early that while their disease would likely limit their physical potential, they could make up for it by performing at a high level academically and professionally. It was clear from the interviews that being "smart" or an "overachiever" was a shared characteristic across narratives. For example, both Maria and Rachelle talked about being the top 5% of their high school classes and more than half of all participants had earned or were in the process of earning graduate degrees. In particular, Stacy, a nurse, discussed how she quickly moved into supervisory and educational roles in her profession because she knew it would be impossible for her to "work on the floor." And Maria is the process of transitioning out of full-time practice as a child life specialist to obtaining her PhD and creating a more flexible and less physically demanding career in higher education.

Second, nearly all participants discussed how living with a childhood-onset rheumatic disease has positively impacted their career path. Angie said she was "groomed" for her job as an OT because of her experiences in the health care system. Similarly, Heather said that her medical experiences have helped her become a better social worker because "I'm really good at advocating for myself and I know the medical

system.” Maria also said that growing up with a rheumatic disease makes her better at her job because it “adds an intuition or empathy that can enhance your skillset.”

Although every participant talked about how their disease influenced their career, four women discussed this topic in great detail. Kim, a special education teacher described it like this:

I think my arthritis is probably one of the reasons why I’m successful at my job and with my kids. All the kids I work with have some sort of exceptionality and they’re going to have to figure it out. Nobody is going to give them accommodations unless they ask for it or figure it out on their own. So how can I help you figure that part out? I think most of the time, whether it’s a kid or adult, somebody just wants to be heard. I am willing to give those kids that space and to listen to them.

Lisa’s disease has impacted her career choices in several ways. First, in spite of her 6th grade band director – who told her it was impossible to play the trumpet with her left hand – Lisa has worked as a music teacher and left-handed band director for over 10 years. Second, she encountered a variety of “discrimination and accessibility issues” throughout her time in school, which inspired her to become an advocate for people living with disabilities. Third, her acceptance and foresight of her progressing disease, prompted her to obtain a Master’s in Education, with an emphasis in technology. Her future goal is to become an adjunct faculty at a university and “teach people how to teach,” with a focus on kids with disabilities.

Luna's career decisions have been directly related to her disease experiences. She always loved to move and when she was in college she started paying more attention to how her body felt when she moved in certain ways:

Even in my worst flares, I was still at the gym trying to work with the body of today. I wanted to know, "What's the best way to move?" I figured I couldn't be the only person in the world that felt like that. Whether someone's had a limb amputated or they have MS or whatever they're dealing with, I'm sure there are people who still want to move within the capacity of their bodies of today. So I started asking myself, "What if I could be skilled in every modality, learn everything about anatomy and physiology, and be certified in yoga, Pilates, running or swimming?"

This process of self-exploration, lead Luna to the idea of becoming an adaptive personal trainer – a job she had never heard of before. Since dreaming up this job in college, she has become a certified yoga instructor and is in the process of building a successful career helping people with all body types move in ways that support their physical and emotional health.

Maggie's career path has been positively influenced by her disease in two ways. First, she credits her arthritis for leading her to her chosen career as an x ray and MRI technician:

Being diagnosed so young, I got to know all my x-ray techs really well. I knew their names and they gave me tons of stickers, so I loved them. I started to talk to my parents and I'm like I think I want to be an x-ray tech. I told my doctors about it and they're like "do you want to come in and job shadow?" "Yeah, I do that

would be awesome.” I just fell in love with it. Honestly, without the arthritis, I don’t know what I would have done. I think about that all the time. It’s more than just a disease. It sucks, but it’s helped shaped who I am and my purpose. It’s really cool to think that this has steered my career path.

Maggie also explained how having arthritis allowed her to work as a counselor and staff member at a local Arthritis Foundation summer camp, which taught her important life skills she uses everyday:

Being a counselor at camp, you have to worry about so many different things. Every kid is different and you can’t treat them the same. I think that helped me a lot with my job now. It taught me how to work with so many different types of people.

Furthermore, as participants talked about how their disease experience positively impacted their career paths, several women also described how the skills they’ve gained in their work, helped them take better care of themselves. Several people commented on how they probably receive a higher quality of health care because their jobs teach them the “right questions to ask” and how to be more “assertive” in talking with providers.

Maria also said:

I’ve learned a lot in my schooling and in my child life career that I use on myself. I’ve learned so much about mental health in my job and how people have chemical imbalances. Also, like learning biofeedback, hypnosis, or guided imagery. I use that so much with my patients and I use it on myself now. I think that helps. If I didn’t have this as a career, I don’t think I would have as many tools for coping.

Faith.

All 12 participants discussed believing in something larger than themselves and described how these beliefs carried them through hard times. Although most women noted moments where they questioned their faith, nearly everyone came to believe, with time, that “things happen for a reason” and that their disease was no exception. For example, Luna talked about a difficult time when her body was flaring and she had to take a leave of absence from college:

I think that everything happens for a good reason. Things don't just happen; they didn't just happen to me. I can see the meaning in it all. It didn't feel right and my body was giving me this major signal that it wasn't going to work out.

After leaving school, Luna enrolled in a yoga class which resulted in her meeting people who have been instrumental in her emerging career as a yoga instructor. In hindsight, Luna sees this as a crucial moment in the development of her career and how she presently copes with her disease.

As Luna's experience illustrates, over time, people came to believe that even when an experience didn't make sense in the moment, there was usually a larger force at play. Trusting in a life force or God seemed to allow people to recognize and rely upon their own strength in the face of pain and suffering. For example, several people stated:

I know there are reasons we are given things that we can handle. My disease brings me back to what's important and makes me think about how I'm going to spend my energy. Until you're challenged to live out those beliefs every day, you don't know how strong you are or what you really believe in.

This is the thing that I was given and I'm supposed to learn how to live my best with it. Everybody has their thing that they're supposed to figure out. I try to do the best that I can and that's all I really can do. It's a lot different now than a year or two ago, there's been a lot more self-reflection on how everybody has their stuff and this just happens to me mine. It could be a lot worse and I can manage it. And maybe I'm stronger than I thought in a physical sense, probably a mental sense too. I wouldn't have recognized that without having the diagnosis.

We're promised in the bible that life is going to come with troubles. We have that promise. And I don't think this is some gift. There's a scripture in second Corinthians that says "my grace is sufficient for you." Basically, you're being made strong through this weakness; it's not because of any lesson God wants me to learn or any nonsense like that, but I can learn in the process. If I didn't, it would be a waste of a really interesting experience. And, that I can do it. I don't think I would have these different experiences if God didn't trust that I could make it through.

As participants moved into a space of accepting their diseases and even, at times, seeing it as a source of strength, they were able to recognize the "gifts", "blessings", and positive experiences their disease brought into their lives. Many said their disease gave them "perspective" and allowed them to appreciate unique characteristics about themselves. For instance, Kim said growing up with JRA "made me good at life" and Rachelle said:

In 2009, after my stroke, everybody thought that... well, things were bad with my health. I couldn't drive, I couldn't remember who the president was, I couldn't do

anything. The doctor was just amazed that I was functioning and that I came back. She said that doesn't usually happen. She said people are usually very reliant on other people afterwards. You look at that and I am an outlier, I acknowledge that. And I look at my upbringing and statistically speaking, I should not be where I am. I've always come out on top. I'm very adaptable. I've been blessed with the ability to adapt. Through these things, I can say God is good and it brings comfort.

Some people also felt grateful for the "benefits" they've received through their involvement with the Arthritis Foundation. Maria and Amy described several examples:

There are benefits from having JA and from being involved in the Arthritis Foundation, lots of intangible things like networking, coping skills, mentors, and friendships. I think kids with JA have a lot more coping strategies in their tool box than a lot of other kids or even adults. We're better able to handle unpredictability and the stresses that come with life. Also we have empathy for other people, and not just for people with health conditions, but people who are in a different situation or are different from what society thinks is normal. Or just someone who is stressed and having a hard day. Sometimes we're a little less judgmental because we think about what they are going through and what might make them like that. The arthritis has also made me fiercely loyal. And I can't put a price on the friends I've made, friends with arthritis or who don't, that I've met through Foundation events; people I would have never met otherwise.

I think about all the really cool people that I would not have met. I just think about how different life would be, so many people I wouldn't have met, so many things I

wouldn't have done, just how different life would be. It makes you appreciate things. And when you are feeling better, it makes you appreciate that so much more.

In addition to being grateful, many participants have found purpose and derived meaning by using their disease experiences to help other people. Luna talked about using her disease as a “tool for making my life mean something” and several others explained it like this:

I like doing advocacy stuff¹² with the Arthritis Foundation because I feel I am doing something other than just sitting there and taking pills. I like helping people. I think it is therapeutic for me. I can talk and help others understand, and for better or for worse, make people who matter understand. Like at Payless it doesn't matter if the manager knows versus getting a congress person to understand who can affect actual change. It can be better for somebody else later. If my arthritis is already here, there is not any point on sitting on it quietly.

In Luke they talk about this man who was born blind and people ask if he was born this way because his parents sinned. And Jesus said, “no he was born this way so that God could be glorified.” He basically said, it is what it is, but through his experience God will be gloried. And I feel like it's a similar situation for me. I can share my experiences with other people, I can be an inspiration, and I can help other people cope. You have to find meaning in it or it's a waste. It makes it all worthless. Then you're just a bump on a log. I remember I made a joke when I

¹² This participant travelled to Washington DC for an event called the Advocacy Summit. During this event, people living with rheumatic diseases tell their stories to legislators and help advance arthritis-related legislation.

was in college and I had no plan for the rest of life, I was like: "I'm going to make lupus work for me. That's what I'm going to do; I'm going to give it a run for its money" And I think, so far, so good. I wouldn't be doing this if I didn't have a chronic condition. It just wouldn't happen.

I was an Arthritis Foundation board member when I was 16 and that's when I realized I could help another person cope because of my disease. I realized, "I have the skills to do this and I'm good at this." Being on the board gave me a platform and helped me realize that helping people cope was something I could do for the rest of my life. All the educating and teaching I do in my career now as a child life specialist, that skillset of being a speaker, started with the Foundation and the make them cry and pull out your checkbook type of events. Having the skillset and confidence to tell my story in front of a large audience started by talking to 100 business men in suits when I was 8 years old. I learned I could do it.

Searching for balance.

In response to the question, "What does wellness look like in the midst of your disease?" every participant responded by talking about finding balance and doing the things that made them "happy." For example, Jamie and Lisa described it like this:

Wellness to me has kind of always looked the same and it's very holistic, everything that you can possibly think of and the balance of it. Having social friendships and healthy diet, being able to have the spiritual component. For me, a big thing is daily, feeling at ease and not feeling full of stress and anxiety. Just coming home and doing your normal routine and being okay with that and being

happy. And being able to get through the ups and downs, they're always going to come. For me with medical stuff, it's always been about trying to keep all those supports and not just rely on one thing. And being mindful of what you need in the moment.

I'd say the key word would be balance between all your areas of life and reminding yourself that you're a whole person. You're not what your doctors tell you, it's just a part of who you are. It's really what you make of it, people can't come and force you into what they want you to be. You need to be who you are and figure out what you want out of life.

Interestingly, even though everyone talked about the importance of balance, it looked different for each participant. Some women emphasized the importance of spending time alone and focusing on their internal experiences:

Wellness for me takes on more of an internal pace. When I think of wellness I think less about the physical and more about the emotional. I will never be pain free or where I don't have arthritis or medical appointments, but I can learn how to not suffer emotionally. So when I think of wellness, I think of spirituality and I think of self-care kind of stuff. For me, it's better when I am more in touch with the spiritual and emotional stuff.

Wellness is finding a place in your body, mind and spirit where you can be happy. We're not going to be physically well, but how can we still be well? It's your mind. It's your attitude. It's your spirit, your hope. And then hopefully your physicality will follow. It's being okay, settled, and happy in your situation, in

today. Because you really can't worry about what yesterday was and you can't worry about what tomorrow's going to be.

While others talked more about the physical aspects of wellness. For example, Amy said wellness is: "Feeling well enough and strong enough to do what I want to do" and Heather said:

Wellness is being able to do the things that keep me well and moving. When I'm well, I like to be physically active, I like to get out and do things, I like to be able to go on a bike ride, go for a walk, and go swimming. Being able to do the things that I like to do. If I'm not feeling good, that means I'm not well and I can't do the things that make me happy and keep me going.

Additionally, Lisa and Kim discussed the importance of enjoying their lives and recognized that sometimes their choices may seem antithetical to wellness:

I know I am probably working my body to the grave, but I would rather do what I want to do in this life before I can't. Instead of prolonging my life and not do anything fun, I'd rather have it be at my hand, than my disease's hand.

There are things that I could do to be more well, but I'm choosing to not do them because I'm trying to balance being an adult with enjoying life. I want to be planful and I want to set myself for as much success as I can, but I have also recognized that I have to love my life and love my choices and love what I'm doing now and that might not always set me up for the best course later. But I have to be willing to take risks with whatever life gives me. I'm trying to take things more week by week than I used to and day by day. So I know I'm kind of

purposefully choosing not to have complete wellness, but I understand why and I'm okay with that too.

Environmental Supports

Health Care

The challenges faced by participants in the health care system were undeniable; nonetheless, every person also described positive interactions with providers and talked about how these interactions contributed to the development of their disease management and self-advocacy skills. Two themes in particular emerged with regard to the health care system: communication and mental health professionals.

Communication.

Due to the fact that participants often felt invalidated or not heard by their providers or the wider health care system, experiences of being heard stood out during our conversations. Many fondly recalled memories of their first rheumatology providers and described how their communication styles made them feel cared for and valued:

She was so cool! I loved her; she was so brash and so sweet. I always appreciated how she would call my house after appointments to see how I was doing. That was awesome. And when I lived in Cali and she was in Reno for a conference, she even came up to Tahoe and visited me at my work. And I worked on the beach!

I was afraid to transition to an adult rheumatologist and I waited as long as I could. I could tell him what was wrong, tell him what I needed, tell him what worked, and what didn't work. We were so in sync. I had his home phone number

and I could call him up and say, “Can I get this med. to get me through this or that?” At the last appointment, I cried.

He was like another dad to me. He knew everything off the top of his head. He could tell anybody my story from day one without looking at a note. And I knew that he wouldn't do anything for me that he wouldn't do for his own kid. I trusted that he knew what he was doing and that he was going to do what was absolutely best. He was awesome. I don't know if I'd be where I am without him. Not that there aren't other good doctors, but he pushed me. There were times I was mad at him, but I totally trusted him. I knew that whatever was going on, he would figure it out.

I think she was great for me as a young person because I still needed kind of a parental figure to kick me in the ass, but she was still empathetic. And being forgiving for not being the perfect patient. As a young person you need wiggle room to make mistakes and not get yelled at by the provider because your parents are already going to get pissed at you.

As participants got older, there seemed to be a shift in the type of communication they preferred. When they were younger, they wanted someone to “push” them or give them a “kick in the ass”, but as they got older they wanted to be listened to, respected, and treated like an expert. Many women described having this sort of relationship with a provider at some point in their life.

My current rheumatologist is fantastic. At my first appointment, I walked in, he shook my hand and said, “Tell me your story. What's going on? What do you need? What have you been on? What doesn't work? What do you like? What are

your goals?” And now, I can email him and he’ll put scripts in for me. He understands and trusts my judgment.

My new rheumatologist asks questions and listens. She says: “What do you think we should be doing? Is what we’re doing working? Should we try something different?” She has the medical degree, but I have 21 years of experience living with lupus and she acknowledges that.

I’m finally seeing a pain management specialist who’s actually interested in my CRP levels, my labs, and my biologics. She knows and understands. I told her Remicade is working, but in three months it might not and I’m nervous to go off my pain meds because if I do and I have to go back on them, they might not work as well. She totally understood and trusted my judgment.

Advocacy was one characteristic in particular that seemed to foster a sense of trust and collaboration between participants and their providers. Several women described situations where a provider “fought” for them when something wasn’t right. Amy discussed a time when a provider helped her get the care she needed from a surgeon who thought she was drug-seeking: “My primary doctor got really mad and had to take over. She’s going to do right by her patients, even if it costs her, and you don’t find that very often.” Lisa and Lauren talked about similar situations where a provider advocated for their needs:

My rheumatologist would always shoot me up with cortisone shots, especially my hand and wrists early on. And I actually may have gotten one of his nurses fired because she would never tell him that I called. When I finally got into to see him, he was like, “This is bad, why haven’t you come to see me?” and I said, “I told

her out there” and he flung the door open and let her have it. He said, “Don’t you understand that she might not even be able to take care of herself because you waited for two weeks?” The next time I came back, she was gone.

When I switched from my dad’s health insurance to Medicaid, they tried to tell me I didn’t need methotrexate because it was a “maintenance drug.” She got the letter and freaked! My sister could hear her yelling on the phone from down the hall and she was like “this is a woman on a mission!” Maybe it is because I am a strong female who respects strong females, but I like that she didn’t sugar coat things. And, she was this itty-bitty lady yelling at you.

Lastly, participants talked about the importance of health care being “personal.” For some, this meant providers shared personal information with their patients. For example, Angie and Lisa talked about it like this:

My husband always jokes and says, “You like your doctors to be friends” and it’s kind of true. Even my OB will chat with me about her kids for like 20 minutes. I like a doctor that will take a little more time personally.

You need to know your patients and doctors have to be open on their ends too. Like my rheumatologist is Jewish so I say “Happy Hanukkah” to him. And I know he plays jazz piano and that my surgeon operated on his shoulder too. It’s like the things that aren’t okay to be shared, need to be shared because you need to have that relationship and honesty.

Lisa’s comment illustrates how she wants to connect with her providers on a human level before she opens herself up to being vulnerable, physically or emotionally.

Similarly, other participants expressed appreciation for human qualities such as humor, honesty, and comfort:

Even when she talked about pregnancy, I was like, “this is not on my radar, but it might be something I want to do in the future or at least have the option.” It was the first time I had ever thought about infertility. She was like, “If you want to do that, it’s great, but I am going to be coming to your bedroom!” because she knew I appreciated her humor. Then she said, “No, we will stop these drugs and start safer drugs, you just have to let me know.”

My doctor was good because she was being real. Like when I gained a bunch of weight she said, “I told you not to balloon up! We need to fix this, what are we going to do?” She said, “let’s make a plan and get the weight off because once the weight is off your joints, you will feel better about everything else.” She wasn’t perfect, but I was smiling so I think that’s why she continued to talk to me the way she did. I was okay with it. I was just thinking “she cares, she really cares.”

The only thing that kept me afloat was the super awesome nurses. They were a hoot and a half! We’d schedule my appointments at ten, because it was a two hour infusion and from 10 to 11 we watched The Price is Right and then at 11 we watched Jeopardy. And that was my whole infusion.

Mental health professionals.

While fewer than half of all participants had interacted with a mental health professional in their lifetime, the women who used this part of the health care system described significant emotional and physical benefits. Most commonly, people discussed

the “tools” they learned or acquired from working with a therapist or counselor. Angie said during her time in treatment for her narcotic addiction, she received “the tools to survive life, on life’s terms” and still refers to her “impact letters¹³” to remind her how difficult her life was before she “accepted” her arthritis. She also described how she learned to reframe her thinking, which she said repeatedly is a work-in-progress, requiring daily practice: “When I start to get into that place of being fearful, or self-pity, or angry I can change my thinking about it. I can start to be grateful instead of angry, hopeful instead of hopeless.” Luna’s therapist helped her learn “ways to not get overwhelmed or beat myself up” and Stacy credits the psychologist on her bariatric surgery team with helping her realize that she “emotionally eats and uses food as a “crutch” when she’s depressed or in pain. Maria and Kim also talked about gaining skills (e.g., biofeedback, progressive muscle relaxation, and deep breathing) that helped them release some of the tension they carry around because of their diseases.

Additionally, several people stated that they benefited from having a designated person in their life who listens to their struggles and provides emotional support. Kim said talking with her therapist about her disease helped her realize that she “can’t control everything,” while Luna and Maggie said:

I have only seen my therapist for about 5 months. It is a new thing that I just insisted upon doing for myself because I didn’t know what I was going to do with my head. I was just like, “It’s too full, it’s too full. I’m losing it.” I’ve found that talking to an impartial party, just seems to help. We don’t even have to say

¹³ Angie explained that people in residential treatment for addiction commonly receive impact letters from family and friends describing how the addiction affected them.

anything big or hammer through major things like fixing my life. Just talking it out seems to help.

I actually really enjoy it. I always feel better and I can pretty much tell her anything. Everybody can tell a difference. They're like you're happier, you're more yourself, you're not as stressed out, and you're not keeping things in. Because before I had a therapist, I would call and talk to my friend about everything and she actually got annoyed when I called her at 3:00 in the morning. She said, "I love you, you're my best friend, but you need to talk to someone."

Relationships

When participants discussed how they cope with the challenges associated with their disease, everyone talked about the importance of social support. There were three primary sources of support described: Family, Friends, and Others with similar experiences.

Family.

Because all of these women had been diagnosed with rheumatic conditions during childhood or adolescence, parents were important sources of support. Everyone expressed appreciation for how their parents, typically their moms, managed their diseases during the early parts of their lives. Luna talked about how her mom saved and documented "every medical record, every lab, every appointment" and how her dad injected her medication in the back of her arm with a "little squeeze." Similarly, Lauren described how her mom immediately assumed responsibility for her care after the diagnosis, even though she was a senior in high school:

My mom asked the doctor, "Okay, what do we do now?" and I just didn't get it. I stared back and said, "That's a bummer. So I should take some Tylenol?" I had no concept, it was over my head. Whether or not my mom understood, she just said, "Alright, what do we need to do?" She just went into fix it mode, which was good because I needed that ... I just didn't get it. She asked questions that you should ask with any diagnosis, like next steps, follow up, which drugs do we take... and I was just like, "So, can I go now?"

Several participants also talked about how grateful they were that their parents didn't "baby" or "coddle" them because of their health condition. Amy and Maria said it like this:

When I was first diagnosed, my rheumatologist told both my mom and I that it was not a good idea for me to be lying on the couch. "She needs to be up moving." My mom took that very seriously. There were days where she'd be like, "get up, get up, come on we're going to the pool." And I credit my mom for that; I mean that couldn't have been easy for her when her kid was in that much pain.

My parents were not coddling. I can totally understand how parents would baby and coddle a sick kid, but my parents treated me very much like my sister, who was completely healthy. And it was tough love sometimes. "I don't care that your sister doesn't have to get up at 5:30 in the morning and do physical therapy before she goes to school, you do. So suck it up and get your ass out of bed." Or, "I don't care that she doesn't have to miss this or that, you do. This is your life, deal with it."

Due to all the shared experiences, many people stated that their mom or dad “gets it” more than anyone else who doesn’t live with a chronic disease. For example, Luna described it like this:

We talk about my disease all the time. If there was a person that I knew that didn’t have this disease but could feel it, in pure empathy, it’s my mom. She’s watched me through it all, so she really understands.

Even though parents continued to be an important source of support in adulthood, participants who were married talked how their husbands became equally important in their day-to-day functioning. Angie and Jamie talked about it like this:

I was blessed with a husband that is 50/50. He is not, “You take care of the house and kids and I just come home from work”; it’s a partnership. We support each other and both make sacrifices. And, being married helps, because financially, we can afford me working part time.

My husband is super trying to understand things and giving me massages and different things. He says, “Take a warm bath or do what you need to feel comfortable.” He has also helped me with talking to my doctor. When I first started seeing my rheumatologist, I had to sit and have a conversation with my husband about it. I had to mentally prepare myself with questions, I actually wrote them down. I even practiced saying them with my husband. Then, the first time I went, I had my husband come with me and that helped a lot.

Friends.

Despite the many social challenges participants faced, most said they had a few friends (without arthritis) who provided functional and emotional support. For functional support, Luna described how her friends help with food preparation and that her “posse” goes with her to doctor’s appointments and IV infusions. And Maria, who is not currently married or in a romantic relationship, said this about her friends:

I have at least four friends that I know would give up their life for me and would let me move in with them and their family, would support me in a nursing home, would take care of me financially. I know that if it gets to that point and I can’t work, I have people who will support me financially and practically. And the fact that I have more than one person, who would do that, is more than most people can say who are married.

Participants also talked about receiving emotional support from their friends. This type of support typically entailed people “listening” or “validating” their struggles. For example, Lauren said:

When I was really sick I could talk to them about it and they were great. They didn’t get it, but they were like, “Hey, I don’t get it, but I am happy to let you sit here and bitch about being in pain.”

Maggie discussed this type of support as well and described how her friend also asks her questions and wants to learn more about her experience:

That’s when I met my best friend. I was having a hard time at work and he was like, “Do you want to talk?” And then he went online and asked, “So, it affects you this way and this way and you’re on this medication. Have you tried this therapy? Does heat help? Does water help?” I don’t have people who really care and

want to know. I was like, "Who are you and where have you been all my life?!" It was awesome. It was a light bulb; there are people who don't have arthritis who actually care and want to understand? If I need him day or night, I can call him. When we're out and about, he's like, "How are your joints? Should we slow down?" It's just really nice to have that relationship. I talk to him about my arthritis and he actually, genuinely cares. I have friends who are like, "that's nice," or "that sucks," or "I'm sorry to hear that." But he does research and actually finds stuff out.

Others with similar experiences.

The presence of people with similar experiences seemed to be one the most powerful environmental supports or protective factors described by participants. Interestingly, many of these support people were not living with rheumatic diseases, but rather, such people had other life experiences that increased their sensitivity to what it's like to live with a chronic disease. People included in this category were friends who were health care providers and people living with other types of chronic diseases or disabilities. Several people described benefits from these types of connections:

One of my best friends has had type 1 diabetes, for six years now. I don't know if that has necessarily brought us closer, but we're in the same boat of not knowing what life carries. We have to live differently than other 26-year-olds and are throwing down a pretty different path.

I don't think I opened up to anyone about my arthritis until I met my husband. When we met, he had just finished his occupational therapy because he had been hit head-on by a drunk driver. We had the same things health wise and the

same fears about relationships. I always thought “no one is going to want to put up with this forever, you know?” So I think we were picked to be together for a reason. He has a lot of fears and health conditions that come along with his traumatic brain injury and the fact that we can talk about it makes for a stronger relationship.

My friend inspired me to play wheelchair basketball, we were the Flyers. That was a whole new entry into disability culture; I had never been a part of it until then. I was just a kid in a wheel chair at my school, but there was this whole other group of people I didn't even know about. That was cool. And, I learned about a lot of other conditions like spina bifida and cerebral palsy. The hardest part about being a young person with arthritis was not having people that understood what was going on. So when you find those few friends that are like you, they're gold. I need to be with my peeps.

Considering the isolation described by many participants, it was not surprising to hear that knowing other people with rheumatic conditions played a prominent role in the psychosocial health of those with such experiences. Three themes in particular emerged from these discussions.

First, participants talked about having access to helpful information through these relationships. Several women shared these examples:

And we tap into each other for ... like my one friend is older, but she just got her first hip replacement and called me before to ask questions. And she was the one who got me to have custom foot orthotics. Just things like that. Help each other out.

It's great because you have a reference for when things are acting up. You can say, "Hey, I know you have this problem, do you find that...?" Or, for example, my eyes have been funny lately and someone I know has really bad iritis so I was like, "What were your systems before you were diagnosed? Am I being dramatic or what?" It's especially nice asking a younger person rather than calling the doctor.

I can call them anytime day or night, talk about anything, work problems, medication issues. I have really close friends but when I talk with them about stuff not working, they're like, "we don't get it." I want to be able to say, "I don't like this side effect and that side effect." Before I started taking my last drug I asked, "What am I looking out for? What are good things? What are bad things?" It's just nice to have that.

Second, people discussed becoming more grateful about their own health status by knowing people with more advanced or severe rheumatic conditions. Angie explained this by saying, "I had to live off their experiences, I had to draw from theirs." For some, these experiences have been motivating because of the fear they induced. For example, Lisa and Luna shared how interactions with others helped them understand the power of their disease:

I think I find a little peace with my disease because I've met people older than us that didn't have the drugs, didn't have those opportunities, and seeing what's happened to their physical bodies is incredible and a place I never want to be.

I'll never forget when I was in 9th, grade a friend of mine had surgery and didn't survive. The arthritis actually went into his organs and that was the first time I realized this crap can kill you, it doesn't just hurt like hell. So that was a big thing, an eye opener for sure. It scared the bejeebers out of me.

Lauren and Jamie also described how knowing others with similar diseases has changed their perspectives. Lauren said:

I feel very lucky. For the most part my arthritis is pretty... like I have all of my joints, I haven't had any surgeries, and I am not deformed. Someone I know had both hips replaced before they went to college. So it gives me perspective, more than the average person.

And Jamie credited her grandpa, who has lived with JA for over 50 years, with inspiring her to stay active and maintain a positive outlook:

I keep reminding myself that it's all about the outlook you have. Every time I get down about things, I just think about my grandpa. He's in his 70's and plays golf as much as he wants, walking the whole time, and he bikes every morning. I don't even know how he does it in general, on top of having arthritis. If he can do it, I can do it too.

Finally, several participants described particular benefits that have come from participating in Arthritis Foundation camps and being part of the "camp family." These experiences were described as "life changing" and the following comments illustrate how camp contributed to participants' sense of belongingness and identity:

My parents always said I learned so much at camp. It's weird, you go as one person and six days later you come back as somebody new. That's a good thing.

After I started going, I felt more okay and like I could deal with it. And it gave me a plan about how to figure out situations and how to deal with them. I learned a lot from camp.

Camp was the one constant. I always say that I know camp better than any house I've ever lived in. The staff always yells at me at night when I don't have a flash light and I'm like, "I know every rock and hole in this place." Camp is like coming home. Camp graduation was more special to me than my high school graduation. For sure.

My camp friends are like siblings. And it's funny because I refer to them as my brothers and sisters. Camp is the end all, be all for me. Everyone at Disney says it's the "happiest place on earth" and I'm like "it's second." Camp is the happiest place on earth.

Chapter 6

Discussion

Summary of Major Findings

The primary aim of this study was to describe the physical and psychosocial development of young adults living with childhood-onset rheumatic diseases during the transition to adulthood. Participants' disease narratives were analyzed using the principle of VI, which describes psychosocial development as occurring through constant, reciprocal interactions between the person and their environments. Based on the four VI domains, three research questions guided this inquiry:

- 1) What are the personal challenges and environmental barriers faced by young adults living with childhood-onset rheumatic diseases?
- 2) What are the personal strengths and environmental supports used by young adults living with childhood-onset rheumatic diseases to maintain psychosocial health and wellness?
- 3) How did these challenges, barriers, strengths, and supports develop over time, from childhood and into adulthood?

Figure 6 highlights the categories and themes that emerged from the interviews and a summary of the findings for each research question is described below.

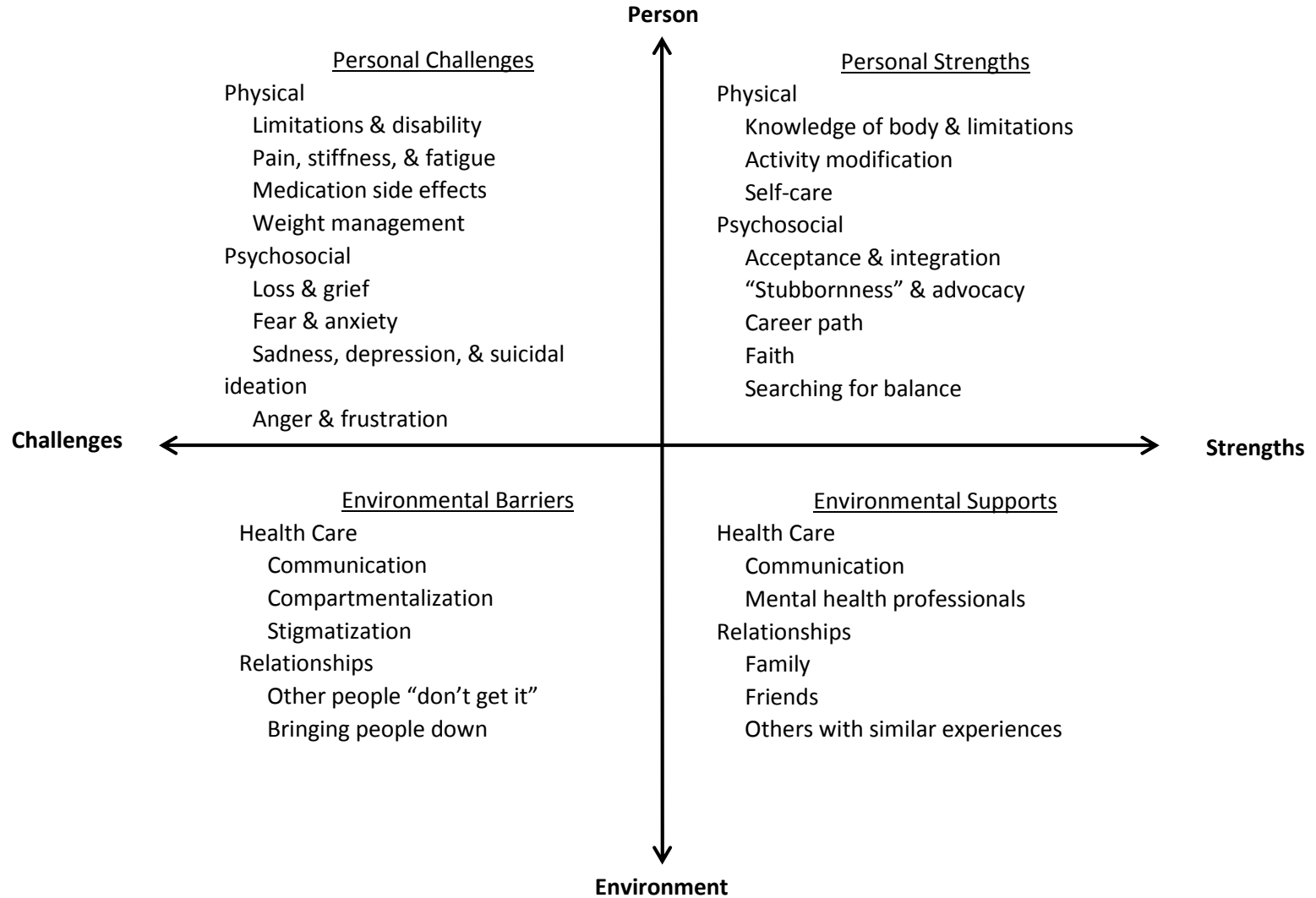


Figure 6. Summary of VI domains, categories, and themes.

1) What are the personal challenges and environmental barriers faced by young adults living with childhood-onset rheumatic diseases?

Four primary categories emerged regarding the personal challenges and environmental barriers faced by participants: physical, psychosocial, health care, and relationships. There were a variety of physical challenges described, but four themes (i.e., limitations and disability; pain, stiffness, and fatigue; medication side effects; and weight management) were discussed by all 12 women. Despite the wide range of disease severity, every participant described life-altering symptoms caused by their disease or its treatments. Participants also discussed the interconnections between the four physical themes. For example, several people described how their disease caused pain, stiffness, and fatigue, which caused limitations and disability; then they needed to take more medications, which caused more negative side effects. These descriptions sounded like an ongoing cycle or, as Lisa said, a “catch 22” that was difficult to escape.

Participants unanimously reported that the psychosocial challenges, which mirrored their physical challenges, were the most difficult parts of growing up with rheumatic diseases. When they were flaring and experiencing increased disease activity and pain, their emotions plummeted. Although this “emotional rollercoaster” wasn’t surprising (because of my professional and personal experiences), the severity of the “downs” was striking. Participants described their depressed moods as if the physical and emotional heaviness of their conditions deflated them and left them, momentarily, as a shell of their former selves. This emotional heaviness appeared to be primarily a grief reaction to their present and future losses; participants’ descriptions of fear, sadness, anger, and avoidance, seemed to be intermingling responses to their actual and perceived physical and psychosocial losses (e.g., loss of functioning, loss of normalcy, loss of control).

The second most challenging aspect of growing up with rheumatic conditions was not feeling heard or understood by other people in their lives, which typically resulted in feelings of isolation. Participants described many interactions with the health care system as barriers to their psychosocial health, and in particular, they struggled with challenges related to communication, compartmentalization, and stigmatization. These women wanted to be heard, literally and figuratively, and their medical experiences were particularly frustrating because they viewed health care providers as people who are supposed to help them feel better, not worse. In fact, many participants stated that interactions with providers and the system were often “worse” or more stressful than the physical challenges of living with the diseases themselves. Regarding their adult-focused rheumatologists, participants frequently felt frustrated and sad because they expected their rheumatologists to understand what they were going through more than other people because of their education and training. Instead, they described being treated as “just patients with a disease” rather than as “whole people.”

Participants also struggled with how their diseases impacted their relationships outside the health care system. The two themes, other people “don’t get it” and bringing people down, described common elements of relationships that prevented participants from connecting with others. These women struggled to build close relationships with people who didn’t understand or seem to care about their disease experiences. They said they wanted other people to “walk the path” with them, but they often didn’t know how to maintain close relationships with people who weren’t also “damaged.”

2) What are the personal strengths and environmental supports used by young adults living with childhood-onset rheumatic diseases to maintain health and wellness?

Despite, and sometimes in spite of, the many physical, psychosocial, and environmental challenges faced by participants, all 12 women discussed being well in a variety of ways. Physically, their health conditions were progressing, but each person described knowing their body and its limitations, modifying their activities, and practicing self-care in an effort to manage their disease and mitigate its negative effects. In combination, these three strategies supported participants' meaningful engagement with important people and activities in their lives.

However, before participants could fully capitalize on these wellness strategies, they described the need to psychologically "accept" their diseases. While everyone's process looked slightly different, the underlying notion was the same: acceptance was a prerequisite for physical and psychosocial wellness. Without accepting the fact that they were living with progressive, chronic diseases, these women could not successfully move towards creating a well-rounded, balanced life – which was how all 12 participants defined wellness. Yet, acceptance was not described as a particular moment in time that came and went. For some, acceptance was a way of life (i.e., integrated into every moment), and for others it was a series of specific moments in time. Regardless of how it happened, each woman talked about the continuous and important role of acceptance in her disease management and overall wellness.

As participants moved through their unique acceptance processes, they worked on integrating their diseases with other areas of their lives – in direct opposition to their experiences of compartmentalization. In fact, integration seemed to be one of the primary methods of living out their acceptance. Participants integrated their diseases by:

taking ownership of their health conditions and treatments; pursuing careers that allowed them to “give back” and advocate for others with similar experiences; participating in disease-related activities; and finding meaning and purpose in their physical and emotional suffering. By consciously putting themselves in situations where they were required to acknowledge and interact with their diseases, they continued to move towards a more complete acceptance of their health conditions.

While participants discussed their psychosocial development, it was clear that they had all received functional and emotional support from key people in their lives. Many women talked about the important role of health care providers. Despite their frustrations with the health care system, every participant had at least one provider who they felt “genuinely cared” about them. These relationships were crucial in participants’ development of disease management skills, as well as other life skills such as believing in themselves and “fighting” for what they needed.

Family, friends, and others with similar experiences also played significant roles in participants’ psychosocial development. For most women, their mothers assumed the role of primary caregiver during childhood and slowly relinquished control to their daughters as they approached young adulthood. This relationship tended to revolve around functional support, but some women reported receiving significant emotional support from their parents as well. As adults, participants relied upon their parents much less frequently and preferred to seek support from spouses, friends, or professionals. Participants made clear distinctions between the people in their lives who “understood” what it was like to grow up with a chronic disease and those who didn’t. Some participants included their parents in the understanding group, while others did not. Participants who transitioned into adulthood with peers who also lived with rheumatic

conditions talked extensively about the benefits of knowing other people who understood what they were experiencing.

3) How did these challenges, barriers, strengths, and supports develop over time, from childhood and into adulthood?

All initial interviews began with me asking each participant to “tell their story.” Naturally, they started with childhood and discussed what it was like to grow up with a chronic disease. Although it depended on the age of diagnosis, most participants recalled childhood memories of “gross” tasting medications, painful medical procedures, and feelings of “being different” from their peers. As was previously mentioned, many also had fond memories of their first rheumatologists (some were pediatric-focused and others were not due to limited access to pediatric rheumatologists) and disease-related activities such as arthritis camp.

Regarding psychosocial development in childhood, every participant described coping with the challenges of living with a chronic disease by avoidance, denial, and distraction. These strategies were typically learned from or encouraged by their parents and health care providers and allowed participants to partake in developmentally appropriate activities (e.g., playing sports, attending “sleepovers” with their friends) despite their physical challenges. However, even though avoiding their diseases helped them cope with daily tasks in the moment, all participants described a welling up of difficult emotions as they moved into adolescence and young adulthood. Further, most participants noted that they intentionally withheld their negative emotions from their parents and health care providers because they didn’t want to be perceived as being “weak” or as giving up the “fight.” Numerous women also discussed how being told by parents and providers that their diseases would likely go into remission reinforced their avoidance and ultimately complicated their acceptance processes.

As participants moved into late adolescence and early adulthood, they described a number of “stupid” decisions that they attributed to denying and avoiding their diseases. Although risk taking and poor decision making are hallmarks of adolescent development for all young people (Berger, 2011; Bernat & Resnick, 2006), the consequences of poor decisions for these women seemed disproportionately severe because of their health conditions. Specifically, participants described the need to “prove” that they could “beat” their diseases if they just tried harder. This mentality manifested in a variety of situations in which participants made decisions to lie about their health status to themselves and others.

In adulthood, participants described increased physical, emotional, and social challenges. Physically, their conditions progressed and resulted in increased chronic pain, joint damage, limitations, and fatigue; most women didn’t experience their first major physical losses (e.g., joint replacements) until their early to mid-20’s. Consequently, emotional and social struggles became more frequent and severe as the women had to make major life decisions about relationships, careers, and their health. Moreover, participants became increasingly frustrated with the quality of their health care over time, as they transitioned from pediatric to adult-focused rheumatology providers. In particular, women talked about providers’ lack of sensitivity to issues related to chronic pain and the emotional ups-and-downs of living with chronic health conditions.

In response to their constant struggles, all participants developed important psychosocial strengths and supports over time, which allowed them to survive – and often thrive – in the face of their diseases. Acceptance played a crucial role in the development of all identified personal strengths (see Figure 6). The sooner participants acknowledged and accepted the fact that they were going to live with their diseases for the rest of their lives, the sooner they were able to take responsibility for their health and

wellness. All participants' acceptance processes gradually unfolded over time, but each of the 12 women talked about how these psychological milestones primarily occurred during the transition into adulthood.

In hindsight, participants also discussed three aspects of family life that could be protective of long-term physical and psychosocial health. First, because most participants struggled with weight management, nearly everyone emphasized the importance of learning how to take care of their bodies from an early age. Comments about parents being "overweight," not eating healthy foods, and not being physically active were common and participants unanimously reported that they wished their parents would have made healthier lifestyle choices when they were younger.

Second, similar to making healthy choices for their physical health, participants discussed the importance of parents and health care providers creating open and safe emotional environments. Many said they didn't feel like they could talk honestly to their parents or providers about the emotional challenges they were experiencing, which consequently stunted their acceptance processes and made it harder for them to learn to cope in adulthood. In response to these challenges, participants wished their parents and providers would have allowed them to talk about their struggles without feeling judged or as if they were disappointing them. Essentially, they were (and still are) seeking validation for their struggles.

Third, being involved in disease-related activities from an early age seemed to offer tremendous benefits for long-term health and wellness. Women who participated in disease-related social activities since childhood reported numerous benefits and those who weren't involved in these activities regretted their decisions and believed that such involvement may have strengthened their psychosocial health during the transition into adulthood. Additionally, several participants commented that initiating involvement in

disease-related activities may be easiest in early childhood due to the social and emotional sensitivity associated with adolescence.

Reflexivity Statement: Post-writing

Throughout the course of this study, I continuously noted the similarities between my disease experiences and those of my participants (e.g., uncontrolled pain, emotional ups and downs, difficulties relating to others, making meaning out of my disease through my career). These observations made me reflect upon my interview approach (e.g., what questions I asked and how I asked them), my analysis procedures (e.g., my interpretations of participants' comments, what data I was analyzing and which I was leaving out) and consider the benefits and consequences of these overlaps. As I wrote about experiences that resonated with my own, I questioned whether my interpretations were reflecting participants' stories, my story, or both. Throughout this process, I frequently looked back at the raw interview data and communicated with participants to make sure that I was not misrepresenting their thoughts or taking their words out of context.

Undoubtedly, I shared many experiences with my participants. My insider status allowed me to easily jump into each person's story and understand contextual factors such as: names, dosages, and side effects of medications; common emotional and social challenges faced by young women living with hidden conditions; and the positive experiences that can come from being part of the local arthritis community. It seemed as though our shared knowledge and experiences accelerated, and perhaps deepened, the initial rapport building and allowed me to quickly earn their trust, which was evidenced by their disclosure of extremely personal information after talking with me for only an hour or two.

However, constantly comparing my own story to that of my participants also highlighted substantial differences in our disease-related experiences. For example, I could not relate to two key themes that emerged from participants' stories: gaining excessive weight from prednisone and applying for SSDI. Noting these types of differences early in the interviewing process helped me better appreciate the wide range of experiences associated with growing up with rheumatic diseases and understand how my previous perceptions about the severity of other peoples' diseases were sometimes narrow and misinformed. For instance, the most challenging part of the reflexivity process for me was managing my assumptions and biases regarding mental health. Because of my personal and professional experiences, I've come to believe that most young people living with rheumatic conditions are also facing significant emotional and social challenges. Throughout the study, I was continuously struck by how similar participants' descriptions were about their mental health struggles, regardless of the severity of their rheumatic diseases. As I reflected upon my reactions, I realized that I had preconceived notions about the relationships between psychosocial and physical health. I learned that I had expected people with visible deformities to have more emotional and social challenges than those without (including myself), and that is not what I observed in these 12 women. Every person's story was unique and contained its own constellation of challenges, barriers, strengths, and supports; no one person's physical or emotional suffering was greater than anyone else's.

Although constant comparison is a defining feature of all qualitative analysis (Creswell, 2007; Patton, 2002), I believe that consciously filtering the data through my own story, in addition to comparing across participants' stories, prompted me to more critically examine the areas where there were differences. While this could be viewed in a negative light, ultimately, I think it enhanced the quality of this study because the

closer I looked the more differences and nuances I found. Even though I shared many experiences with my participants, our reactions and contexts varied dramatically.

Contributions and Significance

Findings from this study make contributions to our understanding of the long-term outcomes of childhood-onset rheumatic conditions, health care transition, and developmental theory.

Long-term outcomes.

Scholars in the rheumatology literature widely acknowledge the need for a better understanding of childhood-onset diseases and treatment manifestations across the lifespan (Hersh et al., 2011; Ostlie et al., 2007; Packham & Hall, 2002a-d). While major leaps have been made in understanding the biochemical mechanisms of rheumatic conditions over the last several decades, little attention has been paid to quality of life and the psychosocial aspects of living as an adult with a childhood-onset rheumatic condition (Duffy, 2004; Foster et al., 2003). Findings from this study describe the psychosocial experiences of 12 women living with rheumatic conditions, and how they changed during the transition into adulthood. The emergent themes build upon previous studies and made unique contributions to the scientific literature.

The psychosocial struggles described by participants in this study echo, almost word-for-word, the long-term challenges reported by Ostlie et al. (2007; 2009). In particular, there are similarities in participants' struggles to cope with disease-related losses, the "rollercoaster" of emotions, and relating to other people who weren't living with chronic diseases. These findings are also consistent with those reported by other rheumatology scholars (e.g., Bidwell et al., 2009; Gerhardt et al., 2008; LeBovidge et al., 2003; Moorthy et al., 2010; Packham & Hall, 2002b Packham & Hall, 2002d) who

demonstrate impaired psychosocial functioning in young people living with rheumatic conditions. Consistency across studies indicates that the long-term psychosocial outcomes of childhood-onset rheumatic conditions may be equally, if not more, challenging as the physical outcomes.

Furthermore, findings from this study make several unique contributions to our understanding of the long-term outcomes of childhood-onset rheumatic diseases. First, this is the first study to describe significant challenges with weight management in women growing up with rheumatic conditions. Despite the fact that weight gain is a widely acknowledged side effect of corticosteroids (Huscher et al., 2009), no studies have explored the physical or psychosocial implications of this issue for young adults living with childhood-onset rheumatic conditions. Second, this study describes personal strengths and environmental supports that appear to protect against the negative effects of physical and psychosocial challenges. While elements of these factors have been alluded to in previous studies (e.g., Ostlie et al., 2009; Packham & Hall, 2002c), this is the first study to explicitly examine protective factors in the lives of young people living with rheumatic conditions. Third, this is the first study to describe the complex emotions of young adults with rheumatic conditions as part of a life-long grief process that includes the continuous need for and attainment of disease acceptance and integration. These findings support scholars' hypotheses (e.g., Dahlquist, 2003; LeBovidge et al., 2003; Ostlie et al., 2009) that inconsistent levels of psychopathology could be related to undocumented psychosocial processes and protective factors.

Health care transition.

Considering the increasing evidence showing that most children living with rheumatic conditions will have active disease into adulthood (Hayward & Wallace, 2009; Hazel et al., 2010; Hersh et al., 2011; McDonagh, 2007), it is essential that scholars and

health care providers understand the needs and experiences of young adults as they transition into the adult-focused health care system. Findings from this study echo Ostlie et al.'s (2007; 2009) descriptions of health care transition from young adults living with rheumatic conditions. Participants in the current study described significant challenges with patient-provider communication and many were frustrated with the quality of their care because they felt as though providers were minimizing their pain and pathologizing their emotional struggles. Participants also reported that they wanted to have honest and open conversations with their adult rheumatologists about sensitive issues such as disease progression and pregnancy, wanted to be treated as experts of their own bodies, and wanted more individualized and personal care.

In addition to frustrations with communication, participants in this study also described feeling compartmentalized and stigmatized in the U.S. health care system, and specifically with their adult-focused rheumatology providers. These frustrations are consistent with criticisms of the biomedical model generally (e.g., Cassell, 2004; Charon, 2001; Engel, 1977; Frank, 1995) and underlie recent calls for more integrated medical care (e.g., Snyderman & Weil, 2002; Stineman & Streim, 2010; Wade & Halligan, 2004) and increased patient advocacy (e.g., GotTransition.org, 2015; Patient-Centered Outcomes Research Institute, 2015).

Developmental theory.

Despite the constant demands for 'developmentally appropriate care' during the transition into adulthood (e.g., AAP, 2011; Eleftheriou et al., 2014; McDonagh, 2008; White, 2008), there is a dearth of developmental theory in the rheumatology and health care transition literatures. This study begins to address this gap by using Erikson's theory of psychosocial development to analyze the transition to adulthood for young people living with rheumatic conditions. More specifically, Erikson's theory, and its three

corresponding principles (i.e., Dynamic Balance of Opposites, VI, and Life in Time), reveal several important aspects of healthy psychosocial development in adolescence and young adulthood.

First, the developmental approach used in this study illustrates the importance of both positive and negative experiences in psychosocial growth. Erikson's theory posits that healthy psychosocial development occurs through the psychological work of balancing the negative (dystonic) and positive (syntonic) aspects of the self (Kivnick & Wells, 2014). Participants described many types of balancing during the transition into adulthood (e.g., working full-time versus part-time; being in physical pain versus developing an addiction to pain medication) and each woman identified physical and psychological balance as the defining features of wellness. These findings support Erikson's theory, which states that healthy development results from the interactions between negative and positive experiences.

Second, findings from this study highlight the importance of the reciprocal interactions between participants and their environments. Using the four domains of VI (i.e., personal challenges, environmental barriers, personal strengths, and environmental supports) allowed me to identify and understand how each domain contributed to participants' overall wellness. Participants' social environments played prominent roles in the development of both challenges and strengths (e.g., providers roles in feelings of frustration or autonomy; friends roles in feelings of isolation or belongingness) and participants played equally important roles in the ongoing development of their social environments (e.g., bringing down family members by talking about their diseases; pursuing careers and volunteer positions where they could give back to others living with rheumatic conditions). These findings demonstrate that when given the appropriate

supports, some young adults with rheumatic diseases are able to strengthen their own psychosocial health, as well as make substantial contributions to others.

Third, findings from this study document the importance of change over time. Using a developmental approach allowed me to describe how participants' perceptions of their physical, emotional, and social health changed over time. Findings show that particular psychosocial experiences (e.g., loss, grief, and acceptance) occurred in cyclical patterns and were typically related to changes in disease status or environmental factors. These findings are consistent with Ostlie et al.'s (2009) study and support Erikson's notions of pre-working and re-working critical themes throughout the life course (Kivnick & Wells, 2014).

Limitations and Threats to Trustworthiness

Although these findings made several contributions to the scientific literature, they should be considered within the context of the study's limitations. Two limitations in particular may have influenced the trustworthiness of the findings.

First, while this study relied upon elements of prolonged engagement, persistent observation, peer debriefing, and member checking, several threats to credibility remained. One of the primary aims of the study was to describe psychosocial development over time, yet data were collected over a very short time frame (the longest time between interviews was four months). Consequently, findings related to changes over time were based upon retrospective snapshots of complex developmental processes. Ideally, this study would have followed participants over longer periods of time, but these methods would not have been appropriate within the constraints of the dissertation process. If possible, I would like to follow-up with participants in the future,

as all 12 women stated that they would like to participate in further research examining the psychosocial development of young people living with rheumatic conditions.

Second, although qualitative findings are not meant to be generalized (Lincoln & Guba, 1985), transferability could be limited due to the homogeneity of the sample. All participants were women; 11 of 12 were white/Caucasian; nine of 12 lived with JRA (as opposed to the multitude of other childhood-onset rheumatic conditions); and over half were pursuing or had obtained graduate degrees. Additionally, nine of 12 women had various levels of involvement with the Arthritis Foundation, which is how they were recruited for participation in this study. While their involvement itself was not a limitation, it's possible that the cumulative findings may represent developmental patterns that differ from young adults with no previous or current involvement with the Arthritis Foundation.

Implications for Research and Practice

Each year, thousands of children with rheumatic conditions reach adulthood and must learn how to build productive and meaningful lives in the midst of living with progressive, chronic diseases. Therefore, scholars and practitioners must strive to better understand and respond to the experiences of such young people as they transition into adulthood. Findings from the present study, along with those from previous studies, suggest that many young adults with rheumatic conditions are experiencing significant emotional and social struggles and that the extent of these struggles may not be accurately represented in the scientific literature or managed in the health care system. In addition to addressing challenges, it is crucial for researchers and practitioners to understand the strengths and supports that promote healthy psychosocial development in young people growing up with rheumatic conditions. The findings from this study illuminate several important topics for future consideration.

Research

To make progress in the scientific understanding of what it's like to grow up with rheumatic conditions, researchers must continue to assess the prevalence, severity, and nuances of the physical, psychosocial, and environmental challenges faced by young people living with rheumatic conditions.

Epidemiology of rheumatic conditions.

While conceptualizations of all aspects of rheumatic conditions are likely to continue evolving, it is important for researchers and practitioners to understand the scope of the problem at any given point in time. I couldn't locate any estimates of the number of people over age 18 living with childhood-onset rheumatic conditions, which makes it difficult to assess any aspect of health in this population. Consequently, an important step in working towards filling the aforementioned gaps in the literature is to identify the prevalence and epidemiology of these conditions across the lifespan and describe long-term disease-related outcomes. With regards to psychosocial health, it would also be useful to have estimates of the number of children and adults living with childhood-onset rheumatic conditions who meet the diagnostic criteria for having mental disorders, are prescribed psychotropic medications, receive disability services at school or work, and receive benefits from SSDI. There is no current information in the scientific literature regarding these issues.

Obtaining such figures could be facilitated by organizations such as the Arthritis Foundation or the Childhood Arthritis & Rheumatology Research Alliance (CARRA), as both organizations include research as a key part of their missions (Arthritis Foundation, 2015b; CARRA; 2015) and have access to a wide range of people living with rheumatic conditions. In addition, federal data bases such as the National Survey for Children with

Special Health Care Needs (NS-CSHCN; 2015) and The National Longitudinal Study of Adolescent to Adult Health (Add Health; 2015) possess data that could address several rheumatology-related research questions.

Conceptualizing health and disease.

While researchers and practitioners have made considerable progress in recent decades in defining and classifying childhood-onset rheumatic conditions (Jordan & McDonough, 2006; Weiss & Ilowite, 2007), there has been little discussion of the conceptualization of the social or emotional aspects of these conditions in childhood or beyond. Further, the few scholars who have explored these issues do so from a biomedical or pathological framework (e.g., symptoms of depression or anxiety; days missed from school or work; SSDI status).

Findings from the current study highlight a number of important psychosocial content areas that require further examination (e.g., weight management; chronic pain and fatigue; loss and grief; and the emotional “rollercoaster”). Future studies should explore the frequency and significance of such topics and scholars should work to better understand the unique developmental trajectories of this population. For example, participants’ comments raise several questions about loss and grief and their relationships to mental illness. What are normal or acceptable (versus abnormal or pathological) psychosocial reactions to the accumulating losses associated with growing up with a progressive, chronic disease? And, at what point does grief become pathological in this population, at this time in their life? These widespread experiences are particularly important to understand, in terms of treatment and prevention, given the fact that mental health challenges tend to emerge for the general population during adolescence and the transition to adulthood (NAMI, 2013).

In addition to generating a long list of specific topics that need clarification, participants' comments about feeling pathologized and stigmatized by the health care system suggest that their emotional and social experiences are often misunderstood and mismanaged by researchers and providers alike. Based on the nearly identical descriptions emerging from participants narratives – along with my professional and personal experiences – I'm hypothesizing that a key part of the disconnect between young people and their providers is related to how researchers and health care providers conceptualize psychosocial health (i.e., mental, emotional, and social health) and illness. The biomedical model, which underlies most contemporary conceptualizations of health and disease, reduces health-related experiences to isolated, malfunctioning pieces of the body (Cassell, 2004; Charon, 2001). In the case of psychosocial experiences (or "mental health" as it is commonly described) scholars and providers operating from a biomedical framework attempt to identify and manipulate particular chemicals or pathways that are believed to cause negative symptoms. While this approach can bring temporary relief from specific distressing symptoms, it does not address the interconnections between symptoms, the biological or environmental causes of symptoms, or strategies for preventing symptoms. Findings from this study suggest that this limited perspective may be working against one of the primary goal of medicine – to do no harm – by dissecting and minimizing the important connections between peoples' physical and psychosocial health.

In an effort to counterbalance the problem-oriented biomedical approach commonly used in the rheumatology literature, I intentionally designed this study to examine the problems and strengths of this population. Findings indicate that growing up with a chronic illness has the potential to promote the development of a number of essential life skills and that disease acceptance may undergird or mediate this

developmental process. For example, acceptance appeared to play a critical role in the ability of participants to make major life decisions related to their health, careers, or family planning. Further, disease acceptance appeared to play a protective role in the development and treatment of mental illness for a number of participants. Consequently, further examination of disease-related acceptance, and its development over time, could produce valuable information for practitioner and patient use in future interventions. In particular, Erikson's eight themes of psychosocial development and Kivnick's work on VI delineate crucial pathways that may be helpful in explaining the relationships between loss, grief, acceptance, integration, and balance over time. This type of work could also be important for thinking about how young peoples' psychosocial development will continue to change into middle and late adulthood.

Operationalizing health and disease.

Undoubtedly, the ways in which scholars and practitioners conceptualize physical and psychosocial health are related to how these concepts are operationalized in assessment and measurement tools. Findings from this study indicate that the psychosocial health of young people growing up with rheumatic conditions is dynamic and intimately connected to their physical health. In order to more accurately represent this complex relationship, existing health-related tools should be adapted or new tools created. In particular, many common tools for assessing depression include questions about sleeping and eating behaviors, fatigue, and feelings of hopelessness (e.g., Beck Depression Inventory; APA, 2015; Patient Health Questionnaire [PHQ-9]; Kroenke & Spitzer, 2002). For example, the PHQ-9 includes the following questions. How often have you been bothered over the last two weeks by: trouble falling or staying asleep, or sleeping too much?; feeling tired or having little energy?; poor appetite or overeating?; feeling down, depressed, or hopeless? If someone responds with "Nearly every day" for

all of these, it's likely they will be classified or labelled as having a mental health problem when many of these symptoms may be related to a flare, medication side effects, or a grief reaction to their progressing health conditions (Callahan, Kaplan, & Pincus, 1991). While being classified as having a mental health problem may be harmless or beneficial in some settings (e.g., when this tool is solely used to prompt a conversation between a patient and their provider), it could also be a barrier to receiving appropriate medical or mental health care in others (e.g., a person could be perceived as having depression and their flare may go unnoticed).

Such measurement and assessment issues reveal the need for tools that are more appropriate for young people growing up with chronic health conditions. Building on the expanding conceptualizations of health and disease discussed above, I have several recommendations. First, assuming that commonly used tools such as the PHQ-9 will continue to be widely used, they should be adapted to indicate the overall physical health status of the respondent. For example, one question could be added to the tool asking whether the person lives with a chronic disease and/or chronic pain, followed by a question about whether they are currently experiencing a flare of their condition. Simply adding these two questions would contextualize their symptoms and give researchers and practitioners critical information about the overall health of the respondent.

Second, scholars should work towards the development of biopsychosocial tools that capture multiple areas of health along with negative and positive dimensions. Building upon existing quality of life tools may be a good first step in this direction as many of these tools incorporate various aspects of health (e.g., physical, social, and psychological). Additionally, findings from this study indicate that tools designed for use with young people living with childhood-onset rheumatic conditions should also include

questions about the following topics: self-care (e.g., diet, exercise, massage); relationships with people with similar experiences; quality of relationships with health care providers; loss and grief; pain management; and coping mechanisms.

Increased variety in research methodologies.

As scholars continue to expand our understanding of what it's like to grow up with childhood-onset rheumatic conditions they should be sensitive to the strengths and limitations of particular methodologies. Nearly all research in the rheumatology literature comes from a positivistic framework using data gathered with large-scale, closed-ended surveys. While this type of research contributes valuable information, it only captures a small fraction of peoples' experiences. Findings from this study suggest that the psychosocial aspects of life with rheumatic diseases are far more complex than the literature describes (e.g., there are positive experiences in addition to negative experiences; disease-related emotions and thoughts are dynamic and related to both transient and long-term physical manifestations of disease).

Any single methodology is likely insufficient for describing or understanding these various dimensions. In order for the field to move towards an appropriately nuanced conceptualization of psychosocial health, I recommend that scholars incorporate an increased variety of methodologies. In particular, if scholars want to move towards a more integrated, person-centered perspective (as much of health care claims to be), it will be important to rely upon subjective methodologies which examine how people living with these conditions perceive their health and health care. Additionally, if scholars and practitioners truly want to improve the health of young people, they should invite them to participate in the research process and contribute to discussions about research goals and priorities.

Practice¹⁴

Social work

Findings from this study have a number of implications specific to social work practice. Despite the fact that there is little mention of social work in the rheumatology literature, social workers are uniquely prepared to support young people with chronic diseases as they transition into adulthood in both direct and community practice settings.

Direct practice.

Although there are endless possibilities for the ways in which social workers could intervene through direct practice with young people growing up with rheumatic diseases, three specific recommendations are described here.

Biopsychosocial interventions

First, mental health practitioners should use the findings from this study (and others) to adapt existing interventions to meet the unique biopsychosocial needs of young people living with childhood-onset rheumatic conditions. The most significant implication for direct social work practice is the powerful connection between the mind and the body. While many practitioners may have an abstract notion of how one's physical health can reciprocally impact the psychosocial, it is critical for them to consider and explicitly discuss how this connection plays out in the day-to-day life of their clients. For example, in Cognitive Behavioral Therapy (CBT) it is important for practitioners to work with their clients to articulate how each person's thinking is affected by physical pain, fatigue, medications, and functional limitations (and the interaction of all four).

¹⁴ Although I am making a distinction here between research and practice, it is important to note that there is a constant feedback loop between researchers and practitioners and many health care professionals serve in both capacities.

Based upon this study's findings, it seems as though many peoples' cognitive abilities are negatively affected when their disease is flaring. In fact these changes can be so dramatic at times that many participants described feeling like a different person during their flares. Mental health practitioners can help clients better understand their changing cognitive states and how to work with them rather than ignore or fight against them. For example, they could do this by helping clients articulate and document their physical experiences – something that may be especially important for people living with invisible conditions – along with their corresponding thoughts and emotions. Together, the practitioner and client could set goals which are in-line with their ever-changing physical conditions. Incorporating Vital Involvement Practice (VIP; Kivnick & Stoffel, 2002; 2005) into such interventions could be particularly helpful as this model facilitates the process of identifying personal and environmental challenges and strengths and illustrates how clients can use their existing strengths and supports to overcome challenges.

Further, mental health practitioners should be sensitive to the emotional isolation experienced by many young people growing up with chronic diseases. Nearly every participant in this study expressed the need for safe people and spaces where they could be emotionally vulnerable, talk about their struggles, and receive validation. Ideally, social workers and other mental health practitioners could be one source of emotional support for this population. However, in order for clients to feel safe they need practitioners to make concerted efforts to listen to their disease stories and understand how their psychosocial functioning is affected (negatively and positively) by their health conditions. Narrative approaches may be uniquely suited for this type of rapport building because they access and support client expertise while also providing crucial information for practitioners (White & Epston, 1990).

Care coordination.

Second, social workers should participate in care coordination for young people living with chronic diseases. Due to the nature of chronic conditions, most people with such conditions require a variety of health care services (e.g., clinic appointments with general and specialty providers; in-patient care for surgeries and crisis management; lab tests and imaging; occupational and physical therapy; IV infusions; and medication management). Learning to navigate the system can be an overwhelming process. In recent years, many large health care systems have created care coordinator positions as a means of alleviating some of the burden placed on patients and their families (Agency for Healthcare Research and Quality [AHRQ], 2015). Social workers are uniquely prepared to serve in this capacity because of the profession's skillset which includes: a biopsychosocial perspective; familiarity with community resources and federal and state policies (e.g., SSDI); ability to assess for and intervene with persons experiencing psychopathology; strengths-based practice; and social justice-informed advocacy (Shanske, Arnold, Carvalho, & Rein, 2012).

This skillset could be particularly useful in care coordination for young people growing up with rheumatic conditions due to the complex nature of their health status. For example, several participants described how managing their appointments, paying medical bills, and searching for information online about SSDI or health insurance was a "full-time job" and many stated that interacting with the various levels of the health care system was the most stressful part of living with their conditions. These comments suggest that people's overall health could benefit from the support provided through care coordination. In fact, one participant said that she needs someone to "walk the path" with her and questioned why people with rheumatic diseases don't have this support when other conditions such as diabetes or cancer often have these services built into

treatment protocols. Ideally, all rheumatology clinics could employ at least one full-time social worker who could: help patients learn about their conditions and set goals; help patients organize their appointments and treatments; connect with resources within and outside the health care agency (e.g., mental health services, complementary therapies, pharmacy, etc.); and provide information and advocacy about health insurance and SSDI.

Transition services.

Third, another practice issue related to care coordination is the provision of transition services. As was previously discussed, pediatric-focused settings typically provide a great deal of guidance and support to families as they learn to navigate the health care system after a child is diagnosed with a chronic disease. However, as children grow up and transition into adulthood, there is a lack of support and training for young people as they take over the management of their health conditions and services (AAP, 2011; Eleftheriou et al., 2014). The concerns associated with this lack of support in the health care transition of young people living with rheumatic conditions has been widely discussed in the scientific literature, yet few interventions have been developed to address this urgent practice need (McDonagh, 2008; White et al., 2012).

Based upon the dynamic and complex psychosocial experiences that emerged in this study, my recommendation is for transition services to be developed and delivered by social workers (in collaboration with other health care providers) due to our expertise regarding mental health and the person-in-environment approach. It would be useful for patients and health care agencies if all rheumatology clinics could create a transition counselor position or adapt a care coordinator position to encompass services specific to the transition from pediatric to adult-focused rheumatology. A social worker in this position would help rheumatology departments adopt the best-practice

recommendations in the scientific literature (see pp. 25-27), provide counseling to patients (e.g., age-appropriate disease and health care management; psychoeducation for patients and their families; education and career counseling; family planning; and referral to community resources); and work on quality improvement for the transition program.

Community practice.

Community needs assessments.

Similar to the gap in knowledge discussed above regarding the lack of epidemiological data for long-term outcomes of childhood-onset rheumatic conditions, there is also a paucity of information for professionals and persons living with these conditions about the resources available for support. In my 10 plus years of experience with the Arthritis Foundation and American College of Rheumatology, I have yet to find any community-level information about resources other than the location of rheumatology clinics or Arthritis Foundation programs. Participants expressed similar frustrations and discussed their need for specific resources (e.g., mental health services and complementary therapies; youth-friendly health services; weight management programs; and disability and rehabilitation counselors) as well as the need for help in finding existing resources. These gaps indicate that many communities could benefit from comprehensive needs and assets assessments and the organization and dissemination of the findings. Community-oriented social workers possess the necessary skills to conduct such projects and could also determine how suitable existing services are for people growing up with childhood-onset rheumatic conditions (e.g., does the agency have experience with similar populations; how easy is it for the agency to adapt their services; how do they assess the needs of their clients, etc.). Compiling a publically

available catalog with a rating system for local resources could offer significant and immediate benefits for this population and their caregivers.

Program development and evaluation.

Once local communities have a better understanding of which resources exist, social workers could develop and evaluate programs designed to meet the biopsychosocial needs of this population. Since findings from this study suggest that knowing other people with similar experiences may be protective against challenges during the transition to adulthood, creating opportunities for young people to meet others with similar conditions could be a logical first step. For example, here in Minnesota, the Arthritis Foundation organizes several events throughout the year where families and young adults can connect with others (e.g., annual family fun day; Juvenile Arthritis Family Network [monthly support group]; national juvenile arthritis conference). Because parents and health care providers are most likely to initiate conversations with young people about participation in disease-related activities, it is important for them to understand the diverse long-term benefits associated with such activities. Scholars and providers should partner with organizations, such as the Arthritis Foundation, to use a variety of sources (e.g., websites, medical education and training, social services, etc.) in evaluating and disseminating information about disease-related activities and their long-term benefits through a variety of sources.

Another suggestion that emerged from participants in this study was creating more educational programs for young people and their families. While several of the events described above have educational components, their primary objective is typically social. Therefore social workers in academic or health care settings should collaborate with staff at organizations like the Arthritis Foundation to create, evaluate, and educate about programs targeted at important areas of development such as:

nutrition and weight management; physical activity; complementary therapies; transition into adulthood; family planning; coping and stress reduction). Such programs could include large group, small group, or individual components and could incorporate health-related professionals in a number of ways. For example, a social worker could organize and facilitate a small-group discussion about pregnancy and family planning with a panel of experts such as an adult rheumatologist, obstetrician, and young adults who have children.

In addition to creating such opportunities for people living with rheumatic conditions, it could also be important to create training programs for professionals who work with these young people and their families. Because it is unlikely that many clinics or organizations have the resources to staff social workers or other professionals with expertise regarding the psychosocial aspects of childhood-onset chronic diseases, providing half- or full-day trainings could be a good way to help all staff members make progress in these areas. For example, I have recently been hired by several YMCA camps to develop and implement on-site trainings for their staff discussing the connections between physical and mental health and offering practical suggestions for how summer camp staff can be sensitive to these issues. In the future, I hope to expand my audience beyond camps, to clinics, hospitals, mental health agencies, and continuing education programs in professional and academic institutions.

Leadership opportunities for young people.

In addition to education, it was clear from my interviews that participants could have benefited from opportunities to observe and practice their disease-related advocacy skills in childhood and adolescence (e.g., identifying and asking for what they need from parents and providers; learning how to navigate the health care system). Several participants obtained these skills by participating in Arthritis Foundation activities

such as serving on a board of directors or speaking at fundraising events, but most others did not engage in these activities and now wish (as adults) that they had known about these types of leadership opportunities and had had people in their life to encourage their participation.

These findings have implications not only for organizations such as the Arthritis Foundation, but also for health care and academic institutions. If we want young people to learn how to manage their own health and advocate for themselves, then we need to create opportunities for them to observe and acquire such skills. Certainly the Arthritis Foundation has the potential to increase their existing leadership positions for young people through advisory committees, boards of directors, and internships. Another avenue for building these skills is through the 30 Arthritis Foundation summer camps across the U.S. For example, I am presently involved in the development and evaluation of two local Arthritis Foundation summer camps for children ages 8-18 years old. For those under 18, we offer programming that teaches advocacy skills and we are continuously working to provide as many opportunities as possible for the children and adolescents to observe and talk with the staff (most of whom are former campers who also live with rheumatic conditions) about how they've learned to manage their own conditions. For the staff over 18, we offer a counselor-in-training program and encourage young adults to join the camp planning committees.

Health care and academic institutions can also offer leadership opportunities for young people through a number of venues. As health care shifts toward more community-level and patient-centered models of care, there should be an increasing need for patients to participate in advisory boards and quality improvement projects (discussed further below). Similarly, as more researchers incorporate community-engaged methods, young people could be involved in providing valuable information

about content areas, recruitment strategies, and dissemination. Because these types of activities may require professionals to be innovative and think outside traditional decision making models, community-oriented social workers would be ideal candidates for coordinating such efforts and engaging young people.

Advocacy.

Unlike many other health care professionals, social workers are trained and called to advocate on behalf of their clients (NASW, 2008). Although such advocacy can happen in a variety of settings (e.g., hospitals; lobbying organizations; federal, state, and county agencies), the goal is the same across settings: work towards system-level change in an effort to improve the well-being of vulnerable populations and society as a whole.

While completing needs assessments and developing programs, social workers are well positioned to identify a number of systemic barriers to the health and wellness of young people growing up with chronic diseases. Once these issues are identified, social workers should advocate for change at system and leadership levels. Findings from this study indicate several important areas for such increased advocacy.

All participants in this study described challenges related to health insurance; access and coverage were the main issues discussed. With regards to access, people struggled with how many insurance policies are tied to employment. For example, several women stated that they had stayed in jobs that were having a negative impact on their physical or emotional health because they needed access to the insurance. While the Affordable Care Act (DHHS, 2015) offers promise with regards to unraveling the tie between health insurance and employment, the Act will take many years to implement and each state is ultimately responsible for its own process. With regards to

coverage, participants expressed frustrations with the lack of coverage for items that were deemed “not medically necessary” (e.g., orthotics, orthodontics, vans for transporting wheelchairs) despite the significant positive impact these items had on their day-to-day functioning. These women also had to make tough financial decisions because services such as physical therapy, massage, nutrition counseling, and mental health care were only covered under certain situations. For example, nearly all participants stated that they would like to have access to ongoing talk therapy in stressful times, but their insurance will only cover a certain number of sessions and requires a diagnosis.

In order to make progress on these issues, social workers should advocate for changes in federal and state policies that regulate how people can access insurance and what types of services are covered. With regards to accessing health insurance, it is important for social workers to continue voicing concerns about how challenging it is for people with chronic health conditions to have their insurance linked to employment. Even though many such people (especially young people) would like to work full-time, steady employment isn't always possible and their employment status may have to keep changing as their conditions progress. Another key issue raised by participants was the frustrations with SSDI. Many felt like they needed to use this benefit to access health insurance, although would much prefer to have kept working. Social workers should advocate for greater sensitivity in this federal policy with regards to young people who want to maintain their independence but also need some support financially and/or access to insurance. In terms of coverage, participants expressed many frustrations with how few services and activities related to disease prevention were covered by their health insurance plans (e.g., exercise, nutrition counseling, pain management, and talk

therapy). Social workers should work towards improving such benefits and educating policy makers on the positive long-term outcomes of preventative measures.

Medicine

Naturally findings from this study have implications for the health care system and its providers. Although most of the topics discussed in this dissertation relate to large-scale, system changes that need to develop over time, there are several steps that medical professionals can take immediately to work towards a more integrated, holistic approach.

Education and training.

One of the most straightforward applications of these study findings is to medical education and training programs for health care professionals. Information about the psychosocial experiences of people growing up with childhood-onset rheumatic conditions could be incorporated into such programs in a number of ways. Speakers could be brought in to present research findings or to tell their stories. For example, over the past 10 years I've been invited to speak about my personal and professional experiences at a variety of events and training workshops. Such one-time events could be an appropriate place for someone like myself to discuss topics from this study such as: weight-management; loss and grief; and identity development.

Patient stories and research findings can also be incorporated into in-person and online curricula (informally or formally). Informally, faculty and educators can assign readings or pod-casts that highlight the complex nature of childhood-onset chronic conditions and allow time for discussions. Educators can also be mindful about choosing case examples that highlight both the physical and psychosocial aspects of disease. Formally, program directors can require students to take specific courses that are

designed to broaden their thinking beyond the biomedical model. Programs can also develop and require students and trainees to engage in experiential learning (i.e., residencies, internships, and fellowships) that focuses on issues related to psychosocial development or health care transition.

Quality improvement.

Another important implication of this study is the need for increased quality improvement (QI). It was clear from participants' comments that many rheumatology-related health care services could benefit from systematic evaluations and enhancements of their processes and outcomes. QI, as defined by the Health Resources and Services Administration (HRSA; 2015), is a specific form of evaluation that is done in health care settings, by health care providers and includes four key elements: examination of systems and processes; focus on patients; focus on being part of a team; and focus on data. Through this process interdisciplinary teams ask questions such as "Is our clinic meeting its goals for health outcomes?" and "Are patients satisfied with the care they are receiving?" and collect quantitative and qualitative data to document the state of their practice. Then practice protocols are adapted or created to improve designated outcomes. Such QI should be an ongoing process with respect to evaluating short- and long-term outcomes in the lifelong care of individuals with childhood-onset rheumatic conditions.

Based on what I heard from participants, several aspects of care need to be evaluated and improved. First, nearly everyone described feeling unheard by their adult rheumatologists. They also described feeling that the adult rheumatologists provided little value to their lives beyond writing prescriptions, but *should* be providing much more. In an effort to enhance the quality of rheumatology care, clinics should examine patient, provider, and agency expectations along with patient satisfaction to determine where

gaps exist, with a particular focus on patient-centered communication and cultural competence.

As mentioned above, another area for improvement is care coordination. The women in this study expressed the need for more support in the management of their diseases, their treatments, and in accessing services within health care agencies and community organizations. Transition services, a specialized form of care coordination, also need improvement to ensure that children, adolescents, and adults are receiving developmentally appropriate care (e.g., education and counselling about sex and pregnancy, prognosis, and preventative strategies such as diet and exercise). Finally, participants in this study felt stigmatized by providers (rheumatology and others) because of chronic pain and its corresponding mental health challenges. Rheumatology clinics and providers should explicitly examine how satisfied their patients are with these aspects of their care and find ways to appropriately assess and support such critical components of day-to-day life.

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Appendix A: Recruitment flier

**Did you grow up with a
rheumatic condition?**




You're invited to participate in a study at
the University of Minnesota.

We are trying to learn more about promoting wellness in
young adults living with rheumatic diseases.


You may qualify if you:

- 1) Are between the ages 25 and 35
- 2) Were diagnosed with a rheumatic condition before the age of 18.

All participants will receive a \$50 gift card.



For more information, please call Courtney Wells at
651-373-6651 or email at kell0725@umn.edu



Appendix B. Consent form

CONSENT FORM

Wellness in the midst of disease: A narrative analysis of growing up with a rheumatic condition

You are invited to be in a research study exploring strategies for creating and maintaining wellness while living with a childhood-onset rheumatic disease. You were selected as a possible participant in this study for the following reasons:

1. You are between the ages of 25 and 35,
2. Were diagnosed with a rheumatic disease by a pediatric rheumatologist,
3. Are currently in the care of an adult rheumatologist,
4. Are currently taking medication for your rheumatic disease.

I ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Courtney Kellerman Wells, a Ph.D. candidate in the School of Social Work at the University of Minnesota.

Background Information: The purpose of this study is to learn more about how young adults living with rheumatic diseases have come to find a sense of wellness despite the challenges of chronic disease. I plan to use the information gathered in this study to train health care professionals who work with young people living with chronic health conditions.

Procedures: If you agree to be in this study, I will ask you to participate in up to 3 one hour-long interviews. I will tape record the interviews so that I can transcribe it at a later time. I will ask you questions about your experience growing up with a rheumatic disease and what it is like to live with it now. I will also ask you how you've learned to deal with the challenging aspects of living with a chronic disease.

Risks and Benefits of being in the Study: This study has several risks including sharing personal information during the interview and a commitment of time to complete the interview. You will receive a \$50 gift card as a token of appreciation for your time. There are no other direct benefits to participation in the study, but your participation would help others by adding to the understanding of what it's like to grow up with a rheumatic disease.

Confidentiality: The records of this study will be kept private. In any sort of report I might publish, I will not include any information that will make it possible to identify a subject. Research data and audio recordings will be stored securely and only researchers will have access to this information. Study data will be encrypted according to current University policy for protection of confidentiality.

Voluntary Nature of the Study: Participation in this study is voluntary. Your decision to participate will not affect your current or future relationship with the University of Minnesota, your health care provider, or the Arthritis Foundation. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions: The researcher conducting this study is Courtney Kellerman Wells at the University of Minnesota. You may ask any questions you have now. If you have questions later, you are encouraged to contact Courtney Kellerman Wells at 651-373-6651 or kell0725@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), you are encouraged to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Print Your Name

Your Signature
Today's Date

Print Name of Interviewer

Signature of Interviewer

Today's Date

Appendix C: Interview Guide

Demographic information:

- Current age
- Diagnosis/es

First question:

One of the main goals of this project is to learn more about what it's like to grow up with a rheumatic disease. I am trying to do this by listening to peoples' stories. So I am going to start by asking you to tell your story, as it relates to your disease. If you could start from the beginning, most likely when you were diagnosed, then we'll go from there. And if you don't remember because you were too little, you can talk about what other people have told you or just start with the first memory you have of your disease. I will ask about a few specific milestones or areas as we talk.

Major topics to discuss as their story unfolds:

- Diagnosis: Age, early symptoms, process
- Memories of medications, procedures, interactions with health care providers from childhood
- Limitations related to school and work
- Puberty and adolescence
- Peer and romantic relationships
- Emotional and spiritual health
- Meeting other people with your disease
- Transitioning care from pediatric to adult health care providers
- Moving out of your parents' house
- Choosing a career or line of work
- Treatments, procedures, hospitalizations, medication side effects

Second question:

Now that we've discussed your disease experience up until this point, let's spend some time talking about how things are now.

- How do you currently spend your time?
- What are you good at?
- How does your disease affect your day-to-day functioning?
- What is the state of your health?
- How do you take care of yourself and try to stay healthy?

Third question:

We've covered a lot of ground and in our last question I'd like to spend a little time reflecting back on what you've learned about growing up with a rheumatic disease.

- What have been the most challenging times or aspects?
- How have these challenges changed over time?
- What do you worry about for the future?
- How have you learned to cope with or deal with your disease and the stress that comes with it? Are there ways you wish you could cope better?
- What have you learned about yourself?
- How has your thinking about your disease changed over time?
- Have there been any rewards or benefits from your experience?
- If you could go back in time and talk with your younger self, what would you say?
- What would you like health care providers to know about the process of growing up with a rheumatic disease?
- How do you define wellness or well-being at this point in your life, in the midst of your disease?

Fourth question:

Would you be willing to give me feedback about my findings throughout the course of this study?

Would you be interested in participating in other interviews or focus groups in the future?