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Health-Related Quality of Life Experience of Young Adults Living With Psoriatic Arthritis

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Walden University

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Katie McCann

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2023

Abstract

Health-Related Quality of Life Experience in Young Adults

Living With Psoriatic Arthritis

by

Katie R. McCann

MS, Southern New Hampshire University, 2015

BA, Stockton University, 2010

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology Self-Design

Walden University

August 2023

Abstract

Psoriatic arthritis (PsA) is an inflammatory autoimmune disease that includes symptoms of arthritis, inflammation of tendons/ligaments, swelling of toes/fingers, and possible involvement of spinal joints. The disease activity of PsA causes structural damage to the joints impacting activities involved with an individual's quality of life (QOL). Existing PsA research on health-related quality of life (HRQOL) mainly shows results concerning children and adult/older adult populations there is a gap in the research on the young adult population living with PsA and their HRQOL. This qualitative study was conducted to gather the experiences of the HRQOL of young adults (18–25 years old) living with PsA. A generic qualitative approach was used to explore these experiences and better understand this population living with PsA. Interviews were conducted with each participant lasting 60–90 minutes. Questions for the interview drew from Wilson and Cleary's HRQOL conceptual framework. Common themes in the interviews were identified. Results revealed one overarching theme of hope and four subthemes, being diagnosed with PsA and participant's understanding of the diagnosis, the symptoms experienced living with PsA and the affects they have on their quality of life, how participants created their treatment plans for PsA and what their quality of life was like before and after medication, and the role of participant's doctors. This study may contribute to positive social change goal by shedding light on this population and offering a better understanding of members' HRQOL. This may help professionals in the psychological and medical fields approach treatment differently to tailor treatment plans to individuals' needs.

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Dedication

I dedicate this dissertation to my beautiful grandmother. I would not be here if it were not for your love and support. Even though you are not physically here, I will forever carry your soul in my heart. You will forever be my best friend. To my family and friends who believed in me, even when I felt like giving up. To my partner and stepdaughter, Chinedu and Liya, I would not have the strength to push myself and achieve my goals without you. You are my rock! I love you all and thank you for everything.

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Chapter 1: Introduction to the Study

Introduction

Psoriatic arthritis (PsA) is an immune-mediated inflammatory disease with symptoms including arthritis, inflammation of tendons/ligaments, swelling of fingers/toes, and, in some cases, effects to the spine (Bolt et al., 2021). The disease activity of PsA causes structural damage to the joints impacting activities involved in an individual's quality of life (QOL), such as walking or sleeping (Veale & Fearon, 2018). Physical limitations can result from structural damage and inflammation of the joints. Early detection is essential to minimize the amount of damage done to the joints (Simon et al., 2021). Men and women are equally impacted by the effects of PsA, including loss of QOL. Roughly 80% of the population diagnosed with PsA are diagnosed before having psoriasis (PsO). PsO is a chronic inflammatory skin disease that affects approximately 1–3% of the population (Simon et al., 2021). Of those with a previous diagnosis of PsO, approximately 30% will develop PsA within roughly 10 years of onset (Ohara et al., 2015).

Current studies on PsA represent adult/older adult populations regarding chronic illness, some focusing on PsA (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020). Within the PsA research, the young adult population does not have a strong representation, and more studies are needed to fully understand the experiences of this age group and QOL (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). The scholarly community lacks the understanding that young adults with arthritis have many problems in many domains regarding health-related quality of

life (HRQOL). Among the significant symptoms are depression, anxiety, mobility issues, and pain (Yan et al., 2020).

The scholarly community should understand the different levels of experiences and challenges those young adults living with PsA face in their day-to-day lives. Through this study, I aimed to explore these experiences and challenges. In Chapter 1, I provide a preview of the background literature on the research topic, a problem statement indicating the focused topic of concern, the purpose of the study, the research question, the conceptual framework, the nature of the study, definitions of terms not commonly known, assumptions, scope and delimitations, limitations, and the potential significance of the study to the discipline and social change, concluding with a summary of the main points of the chapter, as well as a transition to the literature review in Chapter 2.

Background

PsA destroys the joints and results in pain ranging from mild to severe (Zachariae, 2003, as cited in Xu et al., 2018). Ritchlin et al. (2017) stated that there are medications to treat PsA to target inflammation in the body's blood, cells, and tissues. There are three ways in which a patient can receive medication for PsA: orally, by self-injection, or by infusion (Xu et al., 2018). Patients can choose treatment approaches that are pharmacological or nonpharmacological with the help of their doctor or doctors (Keskin et al., 2020). The main goal of medication treatment is to reduce pain levels, slow progression, and improve HRQOL (Dures et al., 2017). However, there are concerns about the long-lasting side effects of these medications (Dures et al., 2017). There is complexity when diagnosing PsA, and often the disease has begun before joint symptoms

appear; the physical symptom of PsO can be a potential indicator for PsA (Myers et al., 2006, as cited in Husni et al., 2017). PsA is associated with sexual dysfunction (Shin et al., 2016) and sleep disturbance (Thomas & Calhoun, 2017). Sleep disturbance can lead to a high risk of hypertension, cardiovascular complications, and metabolism disorder (Thomas & Calhoun, 2017). Many patients experience pain-causing fatigue, challenges, limited mobility, and lower QOL (Dures et al., 2017).

Not all PsA patients respond well to traditional medication (approximately 11% to 16%) or want to be on such medication (Mease et al., 2020). Some patients turn to holistic approaches and new biologics to help reduce symptoms and possibly help them go into remission (Toussi et al., 2020). Patients who do not respond to traditional medication may seek out forms of exercise, physical therapy, or rehabilitation to reduce pain and disease activity (Perrotta et al., 2021). An essential factor of PsA treatment that is overlooked is sleep (Ostergaard et al., 2019), which should be a part of treatment planning (Palominos et al., 2020). Carter et al. (2019) found six areas of lower HRQOL: body image, functional limitation, daily activity limitation, social participation restrictions, family, and work-life restrictions.

The adult/older adult population represents current studies of chronic illness, some focusing on PsA and its long-term painful symptoms affecting extremities, joints, and skin (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020). Among the research on PsA, the young adult population is not strongly represented, and more studies are needed to have a fuller understanding of the experiences of this age group (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). The severity

of PsA is not understood like the similar condition of rheumatoid arthritis (RA) due to the latter diagnosis being more common and having been studied longer. However, patients with PsA have claimed that they experience more physical/emotional pains and poorer QOL than do patients with RA due to the disease having joint and skin components (Conaghan et al., 2020; Howells et al., 2018; Kim et al., 2020; Palominos et al., 2020; Parks et al., 2019). The population of 18- to 25-year old's with PsA are faced with unique challenges of developing a sense of self, making new career choices, and developing new social connections (Conaghan et al., 2020; Kim et al., 2020).

The research indicates a lack of significant evidence in understanding young adults' experiences with PsA and their QOL. More research is needed on this population (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). The literature has shown that for individuals with PsA, there is an impact on psychological (Howells et al., 2018; Kim et al., 2020; Parks et al., 2019; Yan et al., 2020) and physical functioning (Conaghan et al., 2020; Keskin et al., 2021; Palominos et al., 2020). The significant symptoms are depression, anxiety, mobility, and pain (Yan et al., 2020). The disease severity of PsA is not understood, as it is similar to RA. With RA, there is an understanding of the severity and a measurement. Patients with PsA have reported more physical and emotional pains due to the disease having joint and skin components. Therefore, their QOL and emotional health are poor. Quantitative research is abundant on PsA and how the disease affects QOL (Palominos et al., 2020); however, the literature reviewed did not explore the experiences of young adults with PsA and their QOL.

Problem Statement

The problem addressed by this study is that young adults with PsA face various challenges that are unique apart from adults and children. Members of this population are learning to find their identities and developing more complex social and intimate relationships (Kim et al., 2020). PsA tends to be diagnosed later in life. However, there is a small population whose members experience a diagnosis in young adulthood of PsA that affects the joints, skin, nails, mobility, and QOL, including but not limited to social life, education, work, family, and activities of daily living (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). Among the research on PsA, the young adult population is not strongly represented, and more studies are needed to have a fuller understanding of the experiences of this age group (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020).

Due to patients diagnosed with PsA having poorer HRQOL than the general population (Tezel et al., 2015), PsA provides a more complex way of living (Lee et al., 2010, as cited in Husni et al., 2017). PsA diminishes physical functioning, influencing a patient's self-worth (Husni et al., 2017). Tillett et al. (2012, as cited in Husni et al., 2017) stated that PsA patients had higher unemployment and work disability levels. The increased disability levels contributed to longer disease duration, worse physical function, a high number of affected joints, low education level, female gender, erosive disease, and manual labor (Tillett et al., 2012, as cited in Husni et al., 2017). PsA can also carry embarrassment, self-consciousness, and depression because of poor psychosocial functioning (Lee et al., 2010, as cited in Husni et al., 2017). PsA has affected

relationships (Husni et al., 2017). Studies have shown that PsA has harmfully affected the QOL of family members. However, family members and significant others could increase a patient's pain, physical disability, pain behaviors, and distress (Pereira et al., 2012, as cited in Husni et al., 2017). Husni et al. (2017) stated that PsA is a psychosocial burden, with better assessments becoming available to quantify this burden in patients.

The focus in most of the literature suggests the influence that PsA has on individuals psychologically (Howells et al., 2018; Kim et al., 2020; Parks et al., 2019; Yan et al., 2020) and on their physical functioning (Conaghan et al., 2020; Keskin et al., 2021; Palominos et al., 2020). Moreover, PsA decreases physical functioning, affecting a patient's self-worth (Husni et al., 2017). Those with PsA have poorer HRQOL than the general population (Tezel et al., 2015). PsA is often linked or compared to RA; however, besides the lack of rheumatoid factors, PsA has a skin component to its diagnosis (Husni et al., 2017). PsA leaves a patient battling two chronic conditions (i.e., PsO and arthritis; Husni et al., 2017). The battle of skin and joint conditions impacts patients' functional and cosmetic concerns with PsA (Husni et al., 2017). There is literature on PsA and the effects it has on QOL; however, it is primarily quantitative research with a lack of concentration in 18- to 25-year-old young adults (Conaghan et al., 2020; Howells et al., 2018; Kim et al., 2020; Palominos et al., 2020; Yan et al., 2020).

Purpose of the Study

This study, delivered through a generic qualitative design, explored the experiences of young adults with PsA and their HRQOL. This population's QOL may include but is not limited to the following: sleep, mental health, physical limitations,

medical care, reactions to medications, social connections, relationships, and support. A qualitative approach provided a comprehensive awareness of the experiences of these young adults and how this diagnosis of PsA challenges someone's QOL.

Research Question

What are the experiences of young adults with PsA and QOL?

Conceptual Framework

The Wilson and Cleary model presents five health concepts linked together (Ferrans et al., 2005). The relationship among the five health concepts is to provide a patient with the most informed health interventions (Ferrans et al., 2005). The first concept is biological and physical factors focusing on the function of cells, organs, and organ systems (Ojelabi et al., 2017). The second concept is system status, which indicates a patient's perspective on emotional, physical (abnormal), or cognitive state (Wilson & Cleary, 1995). The relationship between the first two concepts can be complex. Some physical abnormalities may not produce symptoms immediately, and some symptoms do not have a trace back to a physical abnormality, such as mental health disorders (Wilson & Cleary, 1995). The third concept is functional status, which measures a patient's ability to perform tasks such as activities of daily living (Wilson & Cleary, 1995). The fourth concept is general health perceptions, a patient's rating on how they view their health status concerning the previous three concepts (Wilson & Cleary, 1995). The fifth concept is the overall QOL, which is measured from the patient's perspective (Wilson & Cleary, 1995).

The framework relates to the study, the key research question, and the interview guide questions by addressing the five concepts concerning HRQOL. The interview guide and follow-up questions presented how the five concepts apply to Wilson and Cleary's (1995) HRQOL model. The following numbered questions show the relation and overlapping of the HRQOL model: physical/biological—4 and 7; symptoms—1 and 9; functional health —3, 9, 10, and 11; general health—2, 4, and 6; and overall QOL—5, 6, 8, 10, 11, and 12. The follow-up questions for each numbered question also apply to the HRQOL model and overlap with the five concepts. Once the data were collected from the interviews, the data were analyzed through Braun and Clarke's six-step thematic analysis.

Nature of the Study

To address the research question in this qualitative study, the specific research design included a generic qualitative approach with interviews of young adults diagnosed with PsA and their HRQOL. There were nine participants for this study to gain insight on the health related QOL of young adults. The number of participants varies depending on the nature of the study and the data collected (Kostere & Kostere, 2022). If the data collection consists of individual interviews, the recommended sample size for a qualitative study is eight to 15 participants (Kostere & Kostere, 2022). In a generic qualitative study, the researcher sets out to gather the perspective of an individual's opinion, beliefs, and experiences (Kennedy, 2016). Once the interviews were completed, the data were analyzed through Braun and Clarke's thematic six-step analysis. A generic qualitative approach does not follow a specific methodology; it must accommodate several worldviews (Kennedy, 2016). It is essential to understand that there are multiple

realities, and a researcher creates an analysis through a subjective viewpoint in a natural setting without limitations (Kennedy, 2016).

A generic qualitative semistructured interview was performed to gather information about this group of individuals. The interviews allowed experiences to be recorded and themes to emerge. This approach aligned with the problem of the study because there are not many qualitative studies that address the experiences of young adults diagnosed with PsA and their QOL. Interviewing young adults about their experiences and HRQOL helped in understanding how this disease affects this population. It also gave insight into providing better treatment to improve their QOL. Interviews showed what is lacking in the current approach and addressed what primary needs were not being met. This research design shed light on what is unknown about this population.

Definitions

Psoriatic arthritis (An immune-mediated inflammatory disease with musculoskeletal symptoms including arthritis, inflammation of tendons/ligaments, swelling of fingers/toes, and spinal involvement (Bolt et al., 2021).

Psoriasis (PsO): A chronic skin disease where the skin is irritated or inflamed and appears flaky, feels itchy, and causes pain (Howells et al., 2018).

Disease-modifying antirheumatic drugs (DMARDs): are a group of medications that decrease inflammation and pain. They are often called immunosuppressants or immunomodulators because these medications hold back or change how your immune system works. (Cleveland Clinic, 2022).

Biologics (biological DMARDs): Pharmacologically synthesized active proteins aimed to inhibit or imitate naturally occurring proteins (Tam & Geier, 2004). Biologics are DMARDs that are made using molecular biology. They are made up of proteins. Biologic DMARDs target specific molecules, cells and pathways that cause inflammation and damage tissue (Cleveland Clinic, 2022).

Conventional synthetic DMARDs: Synthetic disease-modifying antirheumatic drugs are immunosuppressive medications that do not target specific parts of the immune system. Instead, they have a dampening effect on it. (Cleveland Clinic, 2022).

Musculoskeletal system: Consists of bones, cartilage, ligaments, tendons, and connective tissues providing the framework for muscles and other soft tissues. Together, this supports body weight, posture, and movement (Cleveland Clinic, 2022).

Immunoreactivity: An immune reaction of an antibody to an antigen (Ogdie & Weiss, 2015).

Distal interphalangeal (DIP) joints The joints closest to the tips of the toes, fingers, and thumb (Gladman et al., 2005).

Prednisolone: A steroid medication to reduce inflammation and immunosuppressant (National Center for Biotechnology Information, 2022).

Thermotherapy: Uses heat and cold to reduce the swelling in inflamed joints (Perrotta et al., 2021).

Hydrotherapy The use of water to soothe pain and treat certain medical conditions (Centers for Disease Control and Prevention [CDC], 2021).

Rheumatic: Diseases affecting joints, tendons, ligaments, bones, and muscles (National Institute of Health, 2022).

Rheumatoid arthritis (RA): Disease that affects multiple joints, resulting in pain, swelling, and stiffness (National Institute of Health, 2022).

Epigenetics The study of how behavior and environment can cause changes to how genetics work (CDC, 2021).

Assumptions

The assumptions listed below are necessary for the study's context because they entail what I, as the researcher, may have assumed when interviewing the participants. The assumptions of this study were the following: Each participant in the study answered all questions honestly. The diagnosis of PsA was as accurate as possible for each participant. Participants were diagnosed with PsA between the ages of 18 and 25. The in-depth interviews were relevant to exploring the experiences of young adults living with PsA and their HRQOL. Participants were open and honest about their HRQOL living with PsA. These assumptions were necessary to the study's context, for I did not have prior knowledge about the participants and their experiences with the phenomenon of interest.

Scope and Delimitations

The study's participants included adults aged 18–25 living with PsA. In this study, I focused on the daily HRQOL experiences these participants go through. Excluded from participating in the study were individuals who did not have a primary diagnosis of PsA. I also did not include any personal relationships with those with a

primary diagnosis of PsA in this age group to prevent preconceived biases of a preexisting relationship. Transferability was increased by explaining the context of the research to the participants.

Limitations

This study of young adults with PsA and their HRQOL had the potential to have limitations. When interviewing participants to obtain their experiences, I assumed that all would be truthful and honest in their responses. There was a possibility that participants would not be truthful about their QOL experiences. A second limitation of the study could have been recruiting participants. Gathering enough participants to saturate the data might have proven harder than expected. Participants should also have had a confirmed diagnosis of PsA, not just PsO. The participant may have had additional diagnoses; PsA should have been a primary diagnosis. Participants were between the ages of 18 and 25. A third limitation of the study was that participants met the interview criteria. A final limitation of the study was that participants were from the United States. Some aspects of a participant's life were not applied including living outside the United States. Potential bias may have occurred during the interview process due to my experience with having PsA. I reduced my potential bias by keeping a reflective journal of my thoughts and feelings throughout the research process about the study; the journal was shared and discussed with my dissertation chair.

Significance

Over the years, technology in health care has made vast improvements. The improvements have given the population the advantage of prolonging life (Patrick et al.,

2006). With the gift of prolonging life with the help of technology, the question now is the following: What is the QOL or HRQOL? Patrick et al. (2006) stated that health linked with QOL had become a part of public health. The World Health Organization (WHO) in 1948 declared a focus on "physical, mental, and social well-being and not merely the absence of disease or infirmity" (Patrick et al., 2006, p.51). The WHO Quality of Life Group has also incorporated its definition including health in QOL. Individuals perceive QOL from "the context of the culture and value system in which they live, and concerning their goals, expectations, standards, and concerns" (WHOQOL Group, 1996). HRQOL is measured in physical, psychological, and social aspects; this typically translates to the ability to function, perform activities of daily living, and what limitations are (Patrick et al., 2006).

This study was significant because it filled a gap in understanding the experiences of young adults diagnosed with PsA and their Individuals perceived HRQOL and how their functionality and basic needs were met. Individuals had a baseline of their essential needs to ensure that they were met. A baseline made it easier to gauge the QOL that this young adult population experiences with PsA. The outcome of this study sheds light on how young adults manage this disease and recognize how it affects their daily lives. The study results show common themes, giving a starting point for how to best support this population. This study may educate the medical providers of young adults with PsA to provide improved QOL.

Summary

PsA is an inflammatory immune disease with symptoms including arthritis, inflammation of tendons/ligaments, and swelling of fingers/toes, and it may affect spinal joints (Bolt et al., 2021). The disease activity of PsA causes structural damage to the joints and impacts an individual's QOL in areas such as dressing and cooking (Veale & Fearon, 2018). Early detection is essential to reduce damage to the joints (Simon et al., 2021). PsA affects men and women equally, including in their loss of QOL (Simon et al., 2021). The most current research on chronic illness concentrates on the adult/older adult population, with some focusing on PsA (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020). More studies are needed to understand the young adult population's experiences and QOL (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020).

Patients can treat PsA pharmacologically or nonpharmacologically (Keskin et al., 2020). Pharmacological or traditional medication can be prescribed in three ways: orally, by self-injection, and by infusion (Xu et al., 2018). Nonpharmacological treatments refer to holistic approaches to exercise, physical therapy, or rehabilitation (Perrotta et al., 2021; Toussi et al., 2020). The goal of treatment is to reduce symptoms and help them go into remission (Toussi et al., 2020). The problem addressed by this study was the unique challenges that the young adult population living with PsA faces in developing identity and more complex social and intimate relationships (Kim et al., 2020). PsA affects a small population of young adults, influencing their QOL (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). This study explored the experiences

of young adults and their HRQOL. The experiences included but were not limited to sleep, mental health, physical limitations, medical care, reactions to medications, social connections, relationships, and support.

The Wilson and Cleary model presents five health-related concepts (Ferrans et al., 2005) to support this study. Biological and physical factors are the first concept, focusing on the functions of cells, organs, and organ systems (Ojelabj et al., 2017). The second concept is system status, focusing on the patient's perspective on emotions, physical abnormalities, or cognitive state (Wilson & Cleary, 1995). The link between these concepts can be complex because one can exist without the other (Wilson & Cleary, 1995). The third concept is functional status, which measures the patient's ability to complete daily tasks (Wilson & Cleary, 1995). The fourth concept is general health, focusing on the patient's health perspective (Wilson & Cleary, 1995). The fifth concept is the overall QOL measured from the patient's perspective.

The study used a basic qualitative research design and a semistructured interview approach. There was the potential that 10–12 participants would be needed until the data were saturated. Definitions of the study are provided to help the reader better understand the vocabulary used. The study involved the assumption that all participants would answer them honestly. Participants were between 18 and 25 and had a primary diagnosis of PsA. Individuals outside this age range were excluded from the study, as were those who did not have a primary diagnosis of PsA and those who had any preexisting relationship with me. I, as the researcher, assumed that all participants would be honest with their experiences; this was a cause of a limitation.

Further limitations could have been a lack of participants to saturate the data, PsA being the primary diagnosis, the target age range, and participants only being from the United States. This study was significant because it helped fill the gap in the literature on understanding the experiences of young adults diagnosed with PsA and their HRQOL. The study may educate those who support these individuals, including medical providers, to offer improved QOL. Chapter 2 provides a more in-depth look at the Wilson and Cleary HRQOL model and the history of PsA, as well as a current overview of the research literature on PsA.

Chapter 2: Literature Review

Introduction

Through this generic qualitative study, I aimed to gain a deeper understanding of the experience of HRQOL in young adults diagnosed with PsA. The problem addressed by this study is that young adults living with PsA face challenges in their development that are unique compared to those of adults and children. Members of this population are learning to find their identities and developing more complex social and intimate relationships (Kim et al., 2020). PsA tends to be diagnosed later in life. However, there is a small population of young adults who face this diagnosis that affects the joints, skin, nails, mobility, and QOL, including but not limited to social life, education, family, activities of daily living, and work (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). PsA causes damage to the joints, making daily tasks (e.g., brushing teeth or getting dressed) difficult, influencing an individual's QOL (Veale & Fearon, 2018). Roughly 80% of the population diagnosed with PsA have a diagnosis of PsO, which affects approximately 1–3% of the population (Simon et al., 2021). PsO can be a potential indicator of PsA. Disease progression often begins before joint symptoms appear (Myers et al., 2006, as cited in Husni et al., 2017). Many patients experience pain-causing fatigue, challenges, limited mobility, and lower QOL (Dures et al., 2017).

PsA patients carry a stigma, feeling rejection, shame, and guilt (Feldman et al., 2014, as cited in Husni et al., 2017). Among the research on PsA, the young adult population is not strongly represented, and more research is needed to understand the

experiences of this age group (Conaghan et al.; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). In Chapter 2, I address the conceptual framework of Wilson and Cleary's HRQOL model, the history of PsA, and general information on PsA. I address the first model concept—PsA's biological and physical components—with subsections on medication, physical symptoms, and medication side effects; diagnosing and treating PsA; sexual dysfunction and sleep disturbances. I then address the second model concept—PsA symptom status—with subsections on sleep quality and foot pain. The third model concept—PsA functional health—is addressed, with a subsection on exercise. The fourth model concept is PsA general health, with a subsection on HRQOL and the workplace, and the fifth model concept is PsA overall QOL. A better understanding of the young adult population with PsA gives clear insight into how this disease affects an individual's QOL. There is also potential to provide better care for this population in different aspects of life by understanding their challenges.

Literature Search Strategy

Conducting the literature research for my study, I researched articles and related materials from within the past 5 years. In the further use of original articles, I used three central databases for my information: APA PsycInfo, Nursing Journals, and Google Scholar. The following key terms were used to find significant research articles related to my research topic: *chronic illness, mental health, young adult, adolescents, psoriatic arthritis, autoimmune disease, mental health hygiene, quality of life, quality of life theory, health-related quality of life, origins or history, medication, health-related quality of life conceptual model, Wilson and Cleary HRQOL, conceptual model, arthritis,*

osteoarthritis, rheumatoid arthritis, biologics side effects, nonbiologic drug-related side effects and adverse reactions, body image, hair loss, physical activity, exercise, fitness, physical exercise, physical appearance, association of, physical activity psoriatic arthritis, exercise and psoriatic arthritis, physical functional ability and psoriatic arthritis, hydrotherapy psoriatic arthritis, sleep in psoriatic arthritis, psoriatic arthritis disturbances, functional status in psoriatic arthritis, psoriatic, arthritis in functional status and work accommodations, and psoriatic arthritis and functional health.

The terms listed above were applied and used throughout the research process. I consistently documented the terms being used on a separate document until my literature review was complete. I used terms that would best suit my topic and followed the conceptual framework of Wilson and Cleary's HRQOL model to the best of my ability. Throughout my research, I found several overlapping articles when searching within different model concepts. The repeating articles indicated an overlap in the model and a lack of research on my topic of interest. I thoroughly discussed the limitations and overlapping of information with my chair and used library resources to help find significance in older articles for use in my research. I was encouraged to express the importance of the lack of research. Due to the limited research, I explored and gathered as much relevant information as possible until I exhausted the literature.

Conceptual Framework

HRQOL served as the conceptual framework for this study. Patrick and Erickson (1993, p 22) define the HRQOL" as the value assigned to the duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are

influenced by disease, injury, treatment, or policy.” The focus of HRQOL is the assessment of a patient’s functioning, satisfaction, and comparison to what is ideal (Megari, 2013). In general, HRQOL is broken down into three major domains: physical, psychological, and social functioning (Sprangers, 2002). The physical level is the ability to perform activities of daily living concerning the disease or treatment. The psychological level ranges from distress to a sense of well-being. The social functioning level measures the value of relationships, interactions, and societal integration (Megari, 2013).

Wilson and Cleary (1995) came up with a conceptual model of HRQOL to explain the multiple dimensions of health outcomes. The conceptual model integrates biological and psychological aspects of health outcomes (Megari, 2013). The model consists of five levels: physiological factors, symptom status, functional health, general health perceptions, and overall QOL (Megari, 2013). This model has been applied to many different populations, such as patients with cancer, arthritis, Parkinson’s disease, and HIV (Megari, 2013). The thought behind the model is that each level or dimension leads into the next. As Wilson and Cleary (2005) explained, “Physiological variables focus on cells, organs, and organ systems, though the assessment of symptom status shifts to the organism as a whole” (p. 59). Functional health is defined as an individual’s ability to acclimate to the environment. This process is measured objectively and subjectively over a period. General health perceptions are a personal view of health concepts, including mental health. The overall QOL is explained as a person’s expectations of their present experience (Sousa & Kwok, 2006).

QOL and HRQOL are terms interchangeably used when discussing areas of chronic disease. There has been a debate on including health in QOL and how it relates to happiness for centuries (Patrick et al., 2006). Patrick et al. (2006) mentioned that this debate dates to Aristotle and his recognition of how health is related to happiness and QOL. An individual's health status can range from the negative aspects of life to the more positive (Patrick et al., 2006).

Over the years, there have been vast improvements in the health care field, especially with technology. The advances in technology have given the population the capability of prolonging life (Patrick et al., 2006). Technology has now brought up the question of the quality of life or HRQOL. Patrick et al. (2006) stated that having health included in QOL has become part of public health. The WHO in 1948 declared a focus on “physical, mental, and social well-being and not merely the absence of disease or infirmity” (Patrick et al., 2006, p. 343). The WHO Quality of Life Group has also incorporated its definition including health in QOL. Their main idea comes from the individual's perspective and how they view their QOL from “the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns” (WHOQOL Group, 1996). HRQOL is measured in physical, psychological, and social aspects; this typically translates to the individual's ability to function and perform activities of daily living, as well as what the individual's limitations are (Patrick et al., 2006). The history of functionalism is accredited to Durkheim (1897/1951; Patrick et al., 2006). However, Parsons (1951) is the one who applied functionalism to health in the 1950s and defined it as “the state of optimum capacity for

the effective performance of valued tasks” (Parsons, 1958, p. 168, as cited in Patrick et al., 2006). When individuals are ill, the illness deviates them from performing functions assigned to their social role. From this point of view, these are the indicators of health and QOL and the basis of health status assessments.

HRQOL focuses on how individuals perceive functionality and basic needs being met. It is essential to comprehend the levels of individuals’ basic needs to know if they feel that they are functioning the way they perceive they should be and whether their basic needs are being met. Understanding these concepts allowed the opportunity to explore how the population of young adults (18–25 years old) living with PsA experience their QOL. The HRQOL model provided the dynamics and breakdown of what challenges this population faces daily.

Literature Review Related to Key Variables and/or Concepts

History of Psoriatic Arthritis

The history of PsA has not been given much attention within its rheumatic family (Pasero & Marson, 2006). There has been a heated debate between individuals who believe that PsA is a subset of RA and those who think that PsA is a separate disease (Pasero & Marson, 2006). Moll et al. (1974) stated that PsA was determined to be a different disease when it was proven that there were no rheumatoid factors found, and a specific type of protein was found on white blood cells. Pasero and Marson (2006) stated that tracing the history of PsA is challenging; however, PsA could not have been discovered before RA. At the beginning of the 19th century, dermatologists began to talk about PsA (Pasero & Marson, 2006). French dermatologist Jean Louis Marc Alibert

(1818) was the first to identify a connection between PsO and arthritis. Between 1818 and 1860, other dermatologists came across findings like those of Alibert (Cazenve, 1847). In 1860, the term “psoriasis arthritica” was introduced to the dermatology field by Pierre Ernest Bazin (1860). It was not until 1964 that “psoriatic arthritis” became introduced to rheumatology by Verna Wright (Blumberg et al., 1964). Moreover, Wright’s suggested terminology allowed PsA to be classified as a disease separate from RA (Blumberg et al., 1964).

General Information on Psoriatic Arthritis

PsA is an immune-mediated inflammatory disease with musculoskeletal symptoms including arthritis, inflammation of tendons/ligaments, swelling of fingers/toes, and spinal involvement (Bolt et al., 2021). PsA causes structural damage to the joints, making simple tasks (e.g., walking or opening a door) difficult and interfering with an individual’s QOL (Veale & Fearon, 2018). The inflammation and structural damage to the joints can result in physical limitations. Early detection is key to helping minimize the damage and limits on QOL (Simon et al., 2021). PsA affects men and women and their loss of QOL equally. Roughly 80% of the population diagnosed with PsA are diagnosed before having PsO. PsO is a chronic inflammatory skin disease that affects approximately 1–3% of the population (Simon et al., 2021). Of those with a previous diagnosis of PsO, approximately 30% develop PsA within about 10 years of onset (Ohara et al., 2015). Bolt et al. (2021) and Pennington and FitzGerald (2021) noted various genetic, epigenetic, cellular, and tissue markers along with imaging that is now used to diagnose and give a prognosis for PsA. Animal models are currently being used

to understand better how PsA develops and create better treatments to ultimately prevent the onset of PsA (Simon et al., 2021). Medical tests currently used to diagnose PsA are evolving and improving; however, there is still a long way ahead. Even though there have been improvements in detecting and treating the disease, remission is only achieved in 15% of patients (Hagege et al., 2020).

It is challenging to identify PsA with the current tests available to physicians due to the duplication of symptoms from other illnesses; this results in about 15% of PsA patients being missed in dermatology clinics (Villani et al., 2015). Pennington and FitzGerald (2021) stated that there are significant challenges in diagnosing PsA: Early signs and symptoms of the disease tend to fluctuate, scans do not always detect inflammation, skin and nail PsO is not present in up to 10% of patients, approximately 10% of patients can test positive for RA or other inflammatory arthritis, and inflammatory markers can show up as normal or only slightly elevated. McGonagle et al. (2015) hypothesized that PsA is triggered by environmental factors in the gut, ligaments/tendons attached to the bone, or skin in patients genetically more susceptible to developing PsA. Through the years of studying PsA, it has become more evident that the disease begins much earlier in patients; some may think it starts years before PsA is diagnosed (Pennington & FitzGerald, 2021). Ogdie and Weiss (2015) reviewed “findings that PsO nail pitting and nail dystrophy are associated with the development of PsA” (p. 545), possibly explained by inflammation of the tendons/ligaments. Inflammation of the tendons/ligaments is linked to joint involvement, making PsO nail disease and possible predictor of developing PsA. In other words, it is a marker of increased

“immunoreactivity” (Ogdie & Weiss, 2015). However, patients without PsO are at a higher risk of developing PsA according to specific lifestyles, such as moderate drinking and smoking. However, no studies have shown whether there are risks to former and heavy drinkers or current and past smokers (Pennington & FitzGerald, 2021).

There are five patterns to PsA, as follows: (a) arthritis of joints closest to the tips of the toes, fingers, and thumb, referred to as the DIP joints; (b) deforming arthritis of small joints; (c) arthritis that affects joints on both sides of the body (similar to RA); (d) arthritis affecting fewer than five joints (large or small); and (e) arthritis affecting bones in the spine and nearby joints (Gladman et al., 2005). Gladman and Rahman (2001) stated that about 60% of PsA patients do not keep the same patterns throughout their disease. Patterns of PsA are not observed throughout the lifetime of the disease due to the nature of PsA being an inflammatory process of pain and swelling in the joints. Patients who have arthritis of the DIP joints can associate with this pattern (Gladman et al., 2005). A pattern of arthritis deforming the small joints creates a considerably significant level of disability in patients. The severe deformity can cause erosion to the hands, feet, and spine. This pattern of PsA is seen in about 5% of patients (Gladman et al., 2005). The symmetrical pattern of arthritis affecting the same joint on the opposite side of the body is like RA, the difference being that there is a lack of rheumatoid factors to give a PsA diagnosis. Arthritis distinguished in less than five joints is shown in about 50% of patients, indicating inflammation in both the small and large joints. The spinal arthritis pattern shows mainly in men and older adults and much later in the disease. The areas of

pain and stiffness tend to be the cervical, thoracic, and lumbar spine (Gladman et al., 2005).

Psoriatic Arthritis Biological and Physical Components

Medication

Symptoms of PsA can range from mild arthritis to severe pain that can be destructive, causing erosion of the joint to begin (Zachariae, 2003, as cited in Xu et al., 2018). It is essential to understand the patient's HRQOL and the characteristics presented (Ritchlin et al., 2017). Knowing these symptoms, the patient and the doctor can decide which types of treatment would be most appropriate for the patient (Ritchlin et al., 2017). Ritchlin et al. (2017) indicated that there are medications approved to treat PsA. Researchers have mentioned the approved treatments are drugs that reduce inflammation located in the blood, cells, and tissues in the body (Ritchlin et al., 2017). In addition to these types of treatments, there are three ways to administer the medication: oral, self-injection, and infusion. Sometimes, how the drug is prescribed to be taken can influence the patient's decision on the type of treatment they receive.

As the results showed from the clinical trials of Xu et al. (2018), oral medication and the least frequent dosing were chosen most often among patients to reduce joint pain and swelling. Patients also chose the medicines with the lowest serious side effects, lowest copayment, and highest clinical benefits (Xu et al., 2018). Xu et al. stated that perceptions of injections among patients involve fear, pain, or irritation at the injection site and the handling of temperature control for the injection. Oral medication was also chosen due to a lack of self-injection experience (Xu et al., 2018). There is a possibility

that the choice of self-injection could increase with experience and therefore receive medication less frequently (Xu et al., 2018). In addition, there is a travel component, such as having the means or mobility to access transportation, for patients who receive their medication by infusion, which can be an inconvenience (Xu et al., 2018). Most of the therapy treatments chosen among patients were associated with RA and PsO (Xu et al., 2018).

A condition related to PsA that causes chronic inflammation, fatigue, pain, stiffness, loss of physical function, and an impact on HRQOL is arthritis within the spine (Rohde et al., 2017). Treatment for spinal arthritis targets the same inflammation markers as PsA, and a new preferred treatment to try is, a treat-to-target strategy, the idea is to identify the area of inflammation and directly treat that area (Sepriano et al., 2017; Smolen et al., 2018). There are different routines of treatments designed to the severity of the disease. Treatments consist of pharmacological and non-pharmacological. Some non-pharmacological approaches are exercise, dieting, physical and occupational therapies, and mental health therapy. Examples of pharmacological approaches are anti-inflammatory medications, antirheumatic drugs, and biological medications. These types of treatments improve functionality, disease progression, and QOL (Keskin et al., 2020).

Rohde et al. (2020) looked at the benefits of types of medication that could improve patients' HRQOL. The study examined the following medications: non-steroidal anti-inflammatory drugs (NSAIDs), synthetic disease-modifying antirheumatic drugs (DMARDs), biological DMARDs, and prednisolone (Rohde et al., 2020). The medication provided better disease control, functionality, mobility, and less structural damage with

medication (Rohde et al., 2020). Biological DMARDs are chosen more often than other medications. Biologics are the only The Food and Drug Administration (FDA) approved PsA treatment shown to limit joint damage in clinical trials and meta-analysis (Saad et al., 2008, as cited in Khanna et al., 2019). In turn, biological treatments used for PsA compared with conventional synthetic disease-modifying antirheumatic drugs (csDMARD) found that biological treatments had a positive effect on both disease activity and the QOL. Patients with PsA treated with both csDMARD and bDMARD monotherapy have lowered the disease activity and positively influenced the QOL (Keskin et al., 2020).

Physical Symptoms and Medication Side Effects

The primary physical symptom patients report is pain, i.e., inflammation, swelling, and stiffness of the joints (Dures et al., 2017). Reduction of disease impact refers mainly to the patient's overall mental well-being, e.g., fatigue, emotional responses, poor sleep, and effect on relationships (Dures et al., 2017). Patients would like symptoms to improve positively, e.g., slowing down the progression, increasing independence, and increasing normalcy (Dures et al., 2017). Medications do have side effects; rheumatoid medications are not any different. Patients want to improve HRQOL; however, there are concerns about long-term side effects, how the medication is delivered (self-injection, oral, infusion), sickness, and ensuring qualifications are met to receive the medication (Dures et al., 2017). The goal for most patients and doctors is to manage active PsA when introducing therapy treatment to improve signs and symptoms of peripheral arthritis and skin disease quickly and safely (Lu et al., 2019).

Diagnosing and Treating PsA

Diagnosing and treating PsA can be difficult, and symptoms often start years before the diagnosis. Frequently, the physical appearance of PsO on the skin is known to happen before any joint symptoms occur (Myers et al., 2006, as cited in Husni et al., 2017). PsO is a chronic skin disease where the skin is irritated or inflamed and will appear flakey, feel itchy, and cause pain (Howells et al., 2018). In addition, to PsO on the skin, the patient's nails are affected by pitting, ridging, and nail plate separating (Dewing, 2015). In most cases, skin and nail changes will come first before joint and spinal symptoms (Myers et al., 2006, cited in Husni et al., 2017).

Sexual Dysfunction

There is also an association between PsO/PsA and sex. Patients with sexual dysfunction, especially those with genital/inverse involvement, are more likely found in individuals with PsO/PsA (Shin et al., 2016). For PsA patients, pain can be experienced all over the body, such as in their joints (hands, wrist, feet, hips, knees), muscles, back, and tendons/ligaments (Dures et al., 2017). The pain can be indicated by physical and mental fatigue, inflammation (joints and skin), swelling (joints and skin), and stiffness (Dures et al., 2017). These physical and biological symptoms leave patients with limited mobility, causing many challenges and lowering their QOL (Dures et al., 2017).

Sleep Disturbance

Long-term sleep disturbance could lead patients with PsA to develop hypertension, cardiovascular complications, and metabolism disorders (Thomas & Calhoun, 2017). In 2016, Chiu et al. did a cohort study on patients with PsO with

sleeping disorders. They found they had a significantly higher risk of ischemic heart and stroke events than those who do not have sleeping disorders. The example of this study shows that sleep disorders reduce the QOL and can also lead to potentially dangerous health effects (Smith et al., 2019). Due to the list of health-related issues, it can be concluded that sleep is an essential part of a patient's overall health and well-being (Jensen et al., 2018).

Psoriatic Arthritis Symptom Status

Clinical studies have shown that “holistic” approaches and new biologics have helped up to two-thirds of patients with PsA, reducing their symptoms or placing them into remission (Toussi et al., 2020). The other one-third of patients are referred to as non-responders or intolerant of medication, new or old, reducing their QOL (Perrotta et al., 2021). Those non responders to specifically to biologics can range from approximately 11 and 16% (Mease et al., 2020). Orbai et al. (2017) looked at a domain set that consisted of pain, function, fatigue, and HRQOL, with joint and skin activity of PsA. These domains were a guideline to study if exercise, physical therapy, and rehabilitation could play an essential role in reducing disease activity of patients with PsA (Perrotta et al., 2021). A patient’s self-esteem, physical well-being, and emotional well-being could be broken due to having PsA and alter their QOL (Roger-Silva et al., 2018).

Sleep Quality

Sleep quality is not something taken into consideration often in PsA and its impact on a patient's well-being (Ostergaard et al., 2019). Sleeping disorders concerning PsO and PsA are a problem not taken seriously in routine clinical practice (Henry et al.,

2016). For patients who have PsO or PsA, the lack of sleep quality is a symptom that is often overlooked during a routine medical examination (Krajewska-Wlodarczyk et al., 2018). PsA patients rated sleep disturbances, fatigue, depression, and anxiety as more critical than doctors (Orbai et al., 2017). Gezer et al. (2017) stated that sleep impairments should be a part of routine examinations for patients with PsA. There are numerous origins of sleep disturbances for patients with PsA (Gezer et al., 2017). Gezer et al. (2017), Krajewska-Wlodarczyk et al. (2018), and Palominos et al. (2020) stated there are nonpharmacological and pharmacological therapeutic methods to aid in improving quality of sleep for patients with PsA. Some non-pharmacological therapeutic methods are psychotherapy, sleep hygiene, and behavioral activation treatments. Pharmacological therapeutic methods consist of prescribed sleeping medications and sleep aids. Focusing on therapeutic sleep strategies to improve sleep could improve a patient's QOL with PsA (Palominos et al., 2020).

Foot Pain

Carter et al. (2019) did a qualitative study focusing on foot and ankle structure and function of PsA. The study consisted of individuals from rheumatology outpatient clinics and resulted in three themes. The pain symptoms, for those in the study, were described as persistent and unpredictable. Individuals expressed having foot pain anywhere between three months to five years. Foot pain was relative; it depended on the time of day, level of activity, and how long the individual lived with PsA. The pain was brought on by most walking activities, weather changes, shoe wear, disease activity, and

body weight. Many reported their feet were the most impacted by PsA than other places in their body.

Six areas were identified that impacted individuals with PsA in their feet, altered body image, functional limitations, daily activity limitations, social participation restrictions, family, and work-life restrictions. Altered body image came with a physical change in the feet, and restrictions to the types of footwear an individual can wear, regardless of the situation, can negatively affect body image. Individuals felt embarrassed by the appearance of their feet due to the changing of the skin and toenails deforming, swelling, and gait. Many would attempt to hide PsA by clothes covering their feet, closed shoes, not saying anything about the disease, and limiting public interaction. Functional limitations impacted the ability to sit, stand, walk, and function normally. Activity levels and time of day can determine the severity of foot pain in the individual. Foot problems have led to pain, stiffness, swelling, plantar skin PsO, corn, calluses, toe deformity, ankle surgery, and uncomfortable footwear.

Daily activity limitations are reduced or modified, such as shopping, cleaning, cooking, and home maintenance. Sleep and driving were also affected; changing positions or trying to maintain one place can increase foot pain. Another cause of foot pain is the individual's physical inability to practice proper foot hygiene, nail cutting, skincare, and taking shoes and socks on and off. Several individuals practiced pain avoidance behavior, feeling stuck at home, frustrated, decreased motivation, and a sense of losing control. The avoidance behavior also had a negative emotional impact, such as anxiety, bad temper, depression, embarrassment, helplessness, and low self-worth. Many

individuals did not feel understood, reinforcing several of these feelings and emotions. Some did try to cope by accepting their limitations and others pushed through the foot pain to maintain a sense of control. Social participation restrictions are linked back to many functional limitations and negative body image when it came to social involvement. Maintaining friendships and participating in social activities was a difficult task to undertake due to foot problems. Many feared injuries in social gatherings, walking, crowds, public transportation, and concerts. Limitations and pain disrupt family life impact. Most individuals stated they would be in negative moods and felt like a burden. They did not feel understood and felt the need to hide their pain. However, some individuals had family members with PsA and felt a level of understanding. The work-life impact of foot pain caused by PsA makes it difficult for several individuals to perform their jobs. Some will end up with long-term disability or the loss of paid work. Most stated it is hard for them to perform their job roles due to stiffness and swelling of the foot. It takes longer to get to places, slower at completing tasks, and cannot wear proper footwear for specific jobs (business shoes or safety shoes). Walking for any job causes enough pain, and without shoe support can provoke feelings of dread and embarrassment.

A list of intrinsic and mediating factors influenced the severity of foot problems in individuals with PsA, in this study. The intrinsic factors were demographic, disease (onset/activity), foot and ankle (severity or foot problem), and psychological. Social support, self-care strategies, climate (foot symptoms and footwear choice), and health care support were the mediating factors. The study resulted in young age, female gender,

lower socioeconomic status, later disease diagnosis, longer disease duration, and high disease course variability with greater severity of foot disease impact. The individual's emotional well-being was sadness and frustration, and they could cope by accepting and adapting to limitations that affected daily life. They had positive social support, self-care, found footwear, and access to health care. Individuals could self-manage foot care to reduce symptoms and give a sense of relief and control. Some saw a positive connection between health care and health care professionals. Foot symptoms improved by understanding the disease and knowledge of nonpharmacological interventions to manage foot problems.

Psoriatic Arthritis Functional Health

"Pain is a sensory and emotional experience" (International Association for the Study of Pain, 2016, p. 352). Patients with PsA can experience pain along with fatigue and anxiety. A combination of these symptoms often contributes to patients not attending work and increased disability, which can result in low productivity and unemployment (Betteridge et al., 2016). Moreover, PsA decreases physical functioning, which can influence a patient's self-worth (Husni et al., 2017). Tillett et al. 2012, (as cited in Husni et al., 2017), stated that PsA patients had higher unemployment and work disability levels. The higher levels contributed to longer disease duration, worse physical function, a high number of affected joints, low education level, female gender, erosive disease, and manual labor (Tillett et al., 2012, as cited in Husni et al., 2017). PsA has been linked to a significant burden on patients and society (Kawalec & Malinowski, 2015). Kawalec and Malinowski (2015) stated there are yearly costs indirectly associated with work disability

in the United States and direct and indirect costs from patients with PsA that continue to increase with worsening physical function and disease activity.

Husni et al. (2017) suggested evaluations for patients with PsA should include topics such as depression, anxiety, and overall functioning. Additionally, Husni et al. suggested that social and family support should be evaluated through a clinical interview. The interviews would inquire about family relationships and how the pain of PsA has affected these relationships (Husni et al., 2017). Studies have shown that PsA has negatively influenced the QOL of family members. However, family members and significant others could increase a patient's pain, physical disability, pain behaviors, and distress (Pereira et al., 2012, as cited in Husni et al., 2017). Husni et al. stated PsA is a psychosocial burden, with better assessments becoming available to quantify this burden in patients. There have also been improvements in treatments for PsA providing better QOL (Husni et al., 2017). Further assessments and management of PsA should include patients' psychological and physical concerns (Husni et al., 2017).

Exercise

Perrotta et al. (2021) stated that the management of PsA should concentrate on general cardiovascular conditioning, strengthening exercises, improvement of articular motion, and education regarding patient health entering physical therapy. There are subgroups to physical therapy to help reduce joint pain. Thermotherapy uses heat and cold to reduce the swelling in inflamed joints (Perrotta et al., 2021). Paraffin baths are helpful for the hands and feet and help reduce swelling and pain (Perrotta et al., 2021). Additionally, Perrotta et al. stated exercise is a lifetime strategy to manage any

inflammatory disease according to clinical guidelines to reduce symptoms, disability, and comorbidity. Sveaas et al. (2017) studied cardiorespiratory and strength exercise toward disease activity in patients with inflammatory diseases. The researchers found quality evidence of a reduction in disease activity.

Clinical studies were performed in different exercise, and physical therapy approaches to see what areas may improve for patients with PsA. One clinical trial studied high-intensity interval training, also known as HIIT. Thomsen et al. (2019) wanted to learn if there is a potential impact on disease activity and if there were any long-lasting effects of doing this specific form of exercise. The study results did not appear to affect disease activity or pain significantly. However, patients reported their fatigue improved over the nine months of engaging in HIIT workouts (Thomsen et al., 2019). Roger-Silva et al. (2018) conducted another study using a resistance exercise program for patients with PsA. The areas of focus in the study were the upper limbs, lower limbs, and trunk. Throughout twelve weeks, patients saw improvement in functional capacity, disease activity, the general QOL, and a benefit towards pain (Roger-Silva et al., 2018). Van den Bosch and Coates (2018) showed hydrotherapy could be effective for patients with PsA. The reported benefits of hydrotherapy are as follows an improvement in physical function, energy, sleep, cognitive function, ability to work, and participation in activities of daily living (Vanden Bosch & Coates, 2018).

There are not many clinical studies done about the benefits of exercise and its effects on PsA (Kessler et al., 2021). Some of the reasons are the lack of exercise promotion by the rheumatologist, a patient's belief in fear of pain, fatigue, and lack of

time (Liu et al., 2020). Kessler et al. (2021) stated that 73% of patients wanted to know more about exercise and advice on what physical activity to perform, and 50% on rehabilitation programs. The clinical studies that have been done show there is a benefit to exercise, and information should be shared among those with rheumatic diseases. Physical activity has improved several areas of HRQOL (Kessler et al., 2021). The encouragement of exercise or any physical activity, preferably supervised, should be a priority for healthcare and healthcare professionals, especially for PsA (Kessler et al., 2021).

Psoriatic Arthritis General Health

Patients diagnosed with PsA have poorer HRQOL than the general population (Tezel et al., 2015). PsA has been closely related to or compared to RA. The difference between the two conditions is RA does not have a skin component, leaving PsA combating two chronic conditions, i.e., PsO and arthritis (Husni et al., 2017). The battle of skin and joint conditions results in most patients' functional and cosmetic concerns with PsA (Husni et al., 2017). Patients with PsA who have PsO carry embarrassment, self-consciousness, and depression because of poor psychosocial functioning (Lee et al., 2010, as cited in Husni et al., 2017).

Patients diagnosed with PsA experience the stigma of PsA through feelings of rejection, shame, and guilt (Feldman et al., 2014, as cited in Husni et al., 2017). Patients with PsA have reported more physical and emotional pains due to joint and skin components. Physical symptoms can be difficult for patients to manage. Husni et al. (2017) explain the interpretation of a stressor will indicate how a patient will experience

the pain. The amount of awareness of the pain will influence the intensity of the experience (Husni et al., 2017).

Patients think that others understanding their condition(s) can reduce the stressors of judgment, shame, touch, being touched, and the idea of transferring the disease (Meneguín et al., 2020). Some patients try to push their bodies to their limits to maintain a sense of control (Boyington et al., 2015). Some patients try to separate themselves from their conditions in that it is not a part of their self-identification (Boyington et al., 2015). To improve QOL, many patients learn to accept their condition(s) and believe in the science of medication (Boyington et al., 2015; Meneguín et al., 2020).

Patients diagnosed with PsA are thought to have a higher risk for sleep disturbances, fatigue, anxiety, and depression, which can significantly affect HRQOL (Husni et al., 2017). Long-term sleep disturbances can affect daily functioning, difficulty concentrating, impairment in school or work performance, and driving/transportation accidents (Watson et al., 2015).

Health-Related Quality of Life and the Workplace

Berkovic et al. (2019) did a qualitative study looking at the experiences of younger people having arthritis in the workplace. The study consisted of men and women and resulted in three themes. Individuals reported arthritis influenced the choice of career path before entering the workforce and career changes along the way as symptoms progressed/changed. Many felt limited in career choice and changed careers earlier than expected due to joint pain and weakness in skill or strength. Individuals stated they stayed away from physically demanding jobs or took jobs they could sit at a desk. Several

indicated they used their knowledge and experience of the disease to guide career choices, i.e., their experiences hindered them from taking on clinical type work, and others were drawn towards clinical type roles.

Individuals feared transition back into the workplace, due to previous job injuries, or becoming a burden to a new employer with the need for accommodations. The employed and unemployed perceived the thought of being a burden or liability. They found themselves an increased risk that an employer would not want to take on. Promotions were a stressor to some due to the risk of discrimination if they could not complete all tasks. Many did not want to tell colleagues about their arthritis. When their arthritis was revealed to others, several individuals were surprised by the acceptance and support, especially by managers. Some gave examples of their managers' understanding when they needed to take time off from work for doctor appointments or adjust to make things more manageable at work. However, many individuals felt work accommodations were a burden to others. Some gave examples of asking others for help to do tasks, handing off a job to someone else entirely, or being embarrassed to ask for something, i.e., a standing desk.

Several individuals expressed the impact arthritis has personally and professionally. Some felt as though their work environment changed them personally, therefore impacting the workplace. This resulted in lower productivity at work with the need for support and flexible hours. Others viewed support in the workplace as positively affecting their functioning. Physical symptoms such as physical pain and fatigue would reduce productivity for individuals. Some individuals would have to take several breaks

or are too fatigued to do anything. Many highlighted reducing work hours to maintain a healthy work-life balance was essential to continue functioning in the workplace. Some would work part-time or take time off, then work back up to a manageable number of hours. Managing sick leave and missing work was a difficult task to navigate. Many tried not to use the time for their arthritis symptoms. By using sick time more often, for arthritic reasons, individuals run the risk of unpaid time off, leading to financial hardship, increased stress, and fatigue.

Psoriatic Arthritis Overall Quality of Life

QOL can improve among patients with PsA/PsO. Meneguín et al. (2020) stated that QOL could improve by educating others about these diseases. Pain, anxiety /depression, and fatigue are independently associated with sleep disorders (Gezer et al., 2017; Palominos et al., 2020; Haugeberg et al., 2020). Sleep disorders have clinical relevance in PsO and PsA patients (Gezer et al., 2017 & Sacmaci et al., 2019). However, sleep disturbances are more severe in PsA patients than in PsO patients (Wong et al., 2017). Duvetorp et al. (2019) did a Nordic survey that reported 16 % of PsO patients stated they had sleep disturbances but 45% of PsA. In their study, Gezer et al. (2017) observed that 85% of patients with PsA experienced a sleeping disorder. It appears that pain is the guiding influence of sleep disturbances in patients with PsA (Haugeberg et al., 2020). In addition, fatigue is the most impactful on HRQOL in patients with PsA and PsO (Orbai et al., 2017). Patients with PsA reported that fatigue is mainly related to impaired physical function, pain, and psychological stress (Gudu & Gossec, 2018).

Biological, physical, behavioral/psychological, and social experiences are the complex makeup of work disability (Laisne et al., 2012, as cited in Cochrane et al., 2017). Globally, adults are estimated to be in their peak income-earning years between the ages of 18-64, with a proportion of those individuals affected by arthritis (WHO, 2019). Arthritis affects young adults in transition from school to the workforce and experience lower levels of employment and productivity challenges than their healthy peers (Berkovic et al., 2020; Jetha, 2018). Evidence suggests that middle-aged adults are being forced into retirement early due to arthritis (Laires et al., 2018). Research has found that unexpected fares, fatigue, and physical functioning concerning arthritis have made the workplace more challenging for these individuals (Oakman et al., 2017). However, a study by Berkovic et al. (2020) encouraged communication with employers for individuals with arthritis to show they are not seen as burdens in the workplace. The study by Cochrane et al. (2017) stated that waiting for clinical interventions for arthritis, support from the workplace was vital, and 60% of individuals indicated their employer was aware and helpful with their employment.

Summary and Conclusions

PsA can range from mild arthritis to severe pain, causing destruction and erosion of the joints (Zachariae, 2003, as cited in Xu et al., 2018). Ritchlin et al. (2017) indicated there are medications approved to treat PsA. The medications approved for PsA are drugs to target inflammation in the blood, cells, and tissues in the body (Ritchlin et al., 2017). Patients can choose how to receive medications, along with their doctor, orally, self-injection, or infusion (Xu et al., 2018). The treatment approach can be pharmacological

and nonpharmacological, presenting positive benefits to patients (Keskin et al., 2020). The main goal of medication treatment is to reduce pain levels, slow progression, and improve HRQOL (Dures et al., 2017). However, there are concerns about the long-lasting side effects of these medications (Dures et al., 2017). Diagnosing PsA can be complex. Often the disease has begun to progress before joint symptoms appear; however, physical symptoms such as PsO can indicate potential PsA (Myers et al., 2006, as cited in Husni et al., 2017). Sexual dysfunction can also be associated with PsA (Shin et al., 2016). Many patients experience pain-causing fatigue, challenges, limited mobility, and lower QOL (Dures et al., 2017). Sleep disturbance can lead patients with PsA to a higher risk of hypertension, cardiovascular complications, and metabolism disorder (Thomas & Calhoun, 2017).

Traditional medication may not always be the answer. Holistic approaches and new biologics have helped two-thirds of patients with PsA reduce symptoms or go into remission (Toussi et al., 2020). Some patients do not respond to medications, approximately 11 to 16% (Mease et al., 2020). These patients seek exercise, physical therapy, and rehabilitation to reduce disease activity (Perrotta et al., 2021). Sleep is an overlooked symptom of PsA (Ostergaard et al., 2019) and is overlooked during routine medical examinations (Krajewska- Wlodarczyk et al., 2018). Sleep hygiene should be a part of treatment planning (Palominos et al., 2020). Foot pain in PsA patients can interfere with HRQOL (Carter et al., 2019). Carter et al. (2019) found six areas of lower HRQOL: body image; functional limitation; daily activity limitation; social participation restrictions; family; and work-life restrictions.

Patients diagnosed with PsA have a poorer HRQOL than the general population (Tezel et al., 2015). Many patients battle with PsA and PsO, and those with both conditions have physical and cosmetic concerns (Husni et al., 2017). PsA patients carry around a level of stigma, feeling rejection, shame, and guilt (Feldman et al., 2014, as cited in Husni et al., 2017). Meneguín et al. (2020) stated that QOL for PsA patients could improve by educating others about the disease. The workplace is an example of a where to start education due to the challenges for patients with PsA with unexpected flares, fatigue, and physical functioning (Oakman et al., 2019). Berkovic et al. (2019) encouraged communication with employers for patients not to be seen as burdens in the workplace and to reduce the cycle of limitations and productivity.

Current studies represent the adult/ older adult population regarding chronic illness, some focusing on PsA and the long-term painful symptoms affecting extremities, joints, and skin. (Conaghan et al., 2020; Howells et al. 2018; Palominos et al., 2020). Among the research on PsA, the young adult population is not strongly represented, and more studies are needed to have a fuller understanding of the experiences of this age group (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). Through a basic qualitative research method, I can obtain the experiences of this age group and the challenges they face. The literature has shown that individuals with PsA show there is an impact on their psychological (Howells et al., 2018; Kim et al., 2020; Parks et al., 2019; Yan et al., 2020) and physical functioning (Conaghan et al., 2020; Keskin et al., 2021; Palominos et al., 2020). Yan et al. (2020) indicated in their study that children with arthritis showed problems in many domains regarding HRQOL.

Among the significant symptoms are depression, anxiety, mobility, and pain. One domain not studied among those with PsA is sleep. The severity of PsA is not understood like the similar condition of RA due to the diagnosis being more common and studied longer. However, patients with PsA have claimed there are more physical and emotional pains than RA due to the disease having joint and skin components that the QOL and emotional health is poor (Conaghan et al., 2020; Howells et al., 2018; Kim et al., 2020; Palominos et al., 2020; Parks et al., 2019). There is some literature on PsA, and the effects have on the QOL; though, it is primarily quantitative research with a concentration on the physical and psychological impact of the condition (Conaghan et al., 2020; Howells et al., 2018; Kim et al., 2020; Palominos et al., 2020; Yan et al., 2020). This population of 18–25-year old's, are faced with unique challenges of developing a sense of self, making new career choices, and developing new social connections (Conaghan et al., 2020; Kim et al., 2020). Chapter 3 provided an overview of a generic qualitative research and study design approach.

Chapter 3: Research Method

Introduction

In this study, I aimed to explore the experiences of young adults with PsA and their HRQOL. The young adult population's QOL included but was not limited to the following: sleep, mental health, physical limitations, medical care, reactions to medications, social connections, relationships, and support. This study provides a comprehensive awareness of the experiences of these young adults and how this diagnosis of PsA challenges someone's QOL. In this chapter, I provide an in-depth description of the study's research methods, design, and rationale. The study was conducted in agreement with Walden University's Institutional Review Board (IRB) guidelines to ensure the ethical protection of research participants. Chapter 3 includes an overview of my role as the researcher, describing my interaction with the study participants and revealing any personal/professional relationship I had with the participants. The discussion of the role of the researcher also includes how biases and ethical issues were managed. In addressing the study methodology, I describe the population selection/criteria and how the participants were contacted. I also address instrumentation, identifying the instrument and sources for data collection. Further, I describe the data analysis plan for connection of the data and coding. Issues of trustworthiness establishing credibility, transferability, dependability, and confirmability are addressed, along with ethical procedures describing agreements and the treatment of human participants, which were included in the IRB application. Chapter 3 concludes with a summary of its main points.

Research Design and Rationale

In this section, I restate the research question and present the research design. I also provide the rationale for deciding on a generic qualitative method for this study.

Research Question

What are the experiences of young adults with PsA and QOL?

Generic Qualitative Research Design Rationale

This study used a qualitative research design to explore the experiences of young adults with PsA and their HRQOL. Kennedy (2016) stated that generic qualitative research starts with understanding what is not yet defined. To conduct qualitative research, the researcher studies their chosen subject in their natural setting, trying to comprehend the phenomenon and the significance people give to it (Aspers & Corte, 2019). Although there is no clear definition of qualitative research (Aspers & Corte, 2019), qualitative research has grown significantly over the past five decades (Flick, 2007). The field has grown into new areas, courses have been developed, methods have flourished, arguments about its future have been advanced and criticized, and journals and books have deepened over time (Flick, 2007). Qualitative research helps researchers gain a deeper understanding of a phenomenon to give to the scientific community (Aspers & Corte, 2019). Researchers ask questions about a pre-given variable and try to find new characteristics within the phenomenon (Aspers & Corte, 2019). It is essential that the findings be understood and applicable to many, as well as viewed in a practical way (Aspers & Corte, 2019). Qualitative research can provide insight and possible social

change related to the lack of understanding of the experiences of the young adult population with PsA.

Generic Qualitative Research

A researcher conducting a generic qualitative study sets out to gather the perspective of an individual's opinion, beliefs, and experiences (Kennedy, 2016). This qualitative approach does not follow a specific methodology; it must accommodate several worldviews (Kennedy, 2016). It is essential to understand that there are multiple realities, and a researcher creates an analysis through a subjective viewpoint in a natural setting without limitations (Kennedy, 2016). Reviewing the literature research, it appeared that there is not an abundance of information on PsA (Howells et al., 2018). The studies that have been done are either on the adult/older adult or child populations. There is even less information on the young adult population and their experiences.

Generic qualitative research focuses on words and language for data collection versus the numbers and measurements used in quantitative analysis (Kostere & Kostere, 2022). The focus of data collection is to get a deeper understanding of the individual's experiences (Kostere & Kostere, 2022). Percy et al. (2015) stated that data collection is structured and mainly presented in a semistructured interview format focusing on real-world issues and events. A conversational interview can be appropriate if the study requires a more in-depth exploration (Kostere & Kostere, 2022). Generic qualitative studies tend to have a smaller number of participants; however, some researchers will use larger sample sizes to represent better the population being studied (Percy et al., 2015). If the information provided by the study is rich, transparent, and fairly represented, the

study can be generalized to that population outside of the sample (Percy et al., 2015). The generic qualitative research approach was appropriate for this study due to the focus on a specific topic, population, and experiences.

Role of the Researcher

My role as the qualitative researcher was to gather the experiences of the young adult population with PsA and their HRQOL. In the role of researcher, it was essential to keep written notes throughout collecting data, known as *field notes*. These notes pertained to information observed during the interviews, such as body language or facial expressions, as questions were asked. As the researcher, I maintained honesty as biases arose during the research process, even when the information went against my beliefs. My role as the researcher was to recruit participants between the ages of 18 and 25 with the primary diagnosis of PsA.

Over the years as a mental health therapist, I have encountered several patients with chronic illnesses in this young adult population: however, I have encountered none with a diagnosis of PsA. The participants for this study came from all over the United States. Any personal or professional relationships were not included in this study. As the researcher, I was aware of my biases. To reduce biases, I kept a reflective journal to record any thoughts and feelings that might arise throughout the research process. I discussed these entries with my dissertation chair to clear my thoughts and refocus on the research. My role as the researcher was to explain to the participants the need for them to be open and honest about their experiences and enforce participant confidentiality.

Qualitative Methodology

This section provides strategic information about the methodology used for future researchers to replicate this study. The section lays out the population and sampling procedures and the inclusion and exclusion criteria for the study.

Participant Selection Logic

The number of participants varies depending on the nature of the study and the data collected (Kostere & Kostere, 2022). If the data collection consists of individual interviews, the recommended sample size for a qualitative study is eight to 15 participants (Kostere & Kostere, 2022). In this study, the number of participants to be recruited was 10–12. The most important was that the researcher has enough data to answer the research question (Kostere & Kostere, 2022). It is common for a researcher to reduce the number of participants if the data reach data saturation (Kostere & Kostere, 2022). Charmaz (2014) stated that data would reach saturation when there is no longer fresh data that brings up theoretical questions. Data saturation may be reached during data collection, and no new information is added (Kostere & Kostere, 2022).

The sampling process is selecting parts of the population being studied to represent the whole (Hejazi, 2006). By the researcher viewing the sample as representing the whole, the analysis of the data is more comprehensive (Hejazi, 2006). Sampling is performed generally in two formats: probability and nonprobability (Naderifar et al., 2017). The focus of this study fell under the format of nonprobability. Typically, nonprobability method sampling is available to the researcher or handpicked by the researcher (Naderifar et al., 2017). The nonprobability method does not give an equal

opportunity for participants to be chosen for the study (Naderifar et al., 2017). This sampling method makes it difficult to see if the findings can be applied to the population generally (Naderifar et al., 2017). The different types of nonprobability method sampling are convenient, purposeful, and quota (Naderifar et al., 2017).

Snowball sampling is a purposeful or convenient sampling method (Naderifar et al., 2017). Snowball sampling is used to access a unique population with specific characteristics (Naderifar et al., 2017). The purpose behind snowball sampling is that the first few participants can recommend others to the study (Naderifar et al., 2017). Polit-O'Hara and Beck (2006) referred to snowball sampling as the "chain method." This sampling method can be practical and time efficient for researchers, gaining participants who can be challenging to find (Naderifar et al., 2017). *Snowball sampling* is a gradual process that will grow over time (Naderifar et al., 2017). For this reason, convenience/purposeful sampling is weak. However, the population is typically homogenous and reduces bias, making this sampling a reliable option (Naderifar et al., 2017).

The snowball sampling method allows the researcher to communicate better with future samples connected to the first sample (Polit-O'Hara & Beck, 2006). Recruiting participants in this method is a good way for the researcher to network among individuals unwilling to reveal their identities (Hejazi, 2006). It could have been challenging to recruit young adults to participate in the study due to the stigma surrounding PsA. Many may not trust the type of research or are unsure about opening up to a "stranger." If there was reassurance from an acquaintance, future samples would be willing to participate in the study.

Inclusion and Exclusion Criteria

The research study's selection criteria were used to choose participants from the young adult population diagnosed with PsA before the interview. The inclusion criteria included young adults between 18 and 25 years old. From this population, the study consisted of men and women of all races living throughout the United States. Each participant had a primary diagnosis of PsA diagnosed by a physician. There were roughly 10–12 participants chosen to be interviewed about their HRQOL experiences.

The focus of this study was to fill the gap of the lack of information about the young adult population and their HRQOL experiences. Therefore, this study excluded any participants outside the age range set and any individual living outside of the United States. Participants may have had any other diagnosed autoimmune disease or other illness. The primary diagnosis could only be PsA; if it was not, participants were excluded from the study.

Instrumentation

The development of the instrument for this qualitative study was based on the HRQOL conceptual framework concepts created by Wilson and Cleary. The HRQOL model contains five concepts: biological/physical, symptoms, functional status, general health, and overall QOL (Wilson & Cleary, 1995). From these five concepts, the interview guide (Appendix A) was developed. Participants were asked in-depth questions about their HRQOL. There were approximately three questions for each of the concepts. The following numbered questions show the relation and overlapping of the HRQOL model: physical/biological—4 and 7; symptoms—1 and 9; functional health—3, 9, 10,

and 11; general health—2, 4, and 6; and overall QOL—5, 6, 8, 10, 11, and 12. The follow-up questions for each numbered question also apply to the HRQOL model and overlap with the five concepts. At the beginning of the interview, each participant was informed of their rights. Participants were reminded that their participation was entirely voluntary. They had the right to stop at any time without penalties and refuse to answer any question they wished not to reply to due to the nature of the question. If at any point the interview ran long or the participant requested to stop due to time, a second interview could take place. Any questions participants had about the study or forms were highly encouraged.

I used a 60-minute researcher-developed interview guide for data collection. Interviews are frequently used to collect information in a qualitative study (Taylor, 2005). The most common format used in qualitative studies is semi structured interviews (DiCicco-Bloom & Crab-tree 2006). Semi structured interviews are used frequently due to the versatility and flexibility of the format (DiCicco-Bloom & Crab-tree 2006). The semi structured format can be used for individual and group settings (DiCicco-Bloom & Crab-tree 2006). Galletta (2012) stated that semi structured interviews are most successful due to the fluency in responses between the interviewer and participants. This format allows the interviewer to ask follow-up questions to the participant's responses and allows the participant to express their experience freely (Polit & Beck, 2010). Questions are developed using prior knowledge of the studied topic, creating an interview guide (Kallio et al., 2016). The interview guide covers the main topics of the research question and provides some structure to the interview (Kallio et al., 2016). Due to this

method of interviewing, the researcher can explore the main topics and collect similar types of information (Kallio et al., 2016). The data collected using this method will allow participants to answer questions about their experiences living with PsA and their QOL. Sufficient data were achieved when the data from the interviews indicated repetitive information and there were reoccurring themes. Once the interviews were completed using the interview guide, I presented the experiences of young adults living with PsA and their QOL. A qualitative expert panel from Walden University reviewed the instrument for consistency with the research question and the validity of the content.

Procedures for Pilot Study

A mock interview was performed to gauge the timing and clarity of the questions. The semi structured interviews for the research study were open ended, focusing on one family member and one friend with autoimmune disorders. The interview guide was piloted to check for any uncertainties in the interview questions. The pilot study allowed feedback from the participants to provide any changes and suggestions to the interview questions. The interviews were digitally recorded, transcribed by me, and given to my chair for review and feedback.

Procedures for Recruitment, Participation, and Data Collection

I contacted various social media support group administrators and explained the research study's purpose and the participants needed based on the inclusion criteria. I also explained the procedures in place for the study and stated that all participation was voluntary. I reviewed the IRB guidelines at Walden University and upheld confidentiality for all participants. I asked the administrators of these social media groups to share the

recruitment flyer (Appendix B) with other social media outlets that met the inclusion criteria for the study. I also extended the recruitment to Facebook Ads, The Psoriasis and Psoriatic Arthritis Alliance, Arthritis Foundation, and The National Psoriasis Foundation. I waited for young adult participants to respond to the recruitment flyer who were willing to participate in the research study. Once recruitment was fulfilled, I planned to collect data every other day. Each participant was informed of the purpose and goal of the study. A recruitment flyer was created to provide each participant with an overview of the study. Contact information was also provided on how to participate in the interview process. The flyer was posted on several online support groups, including Facebook and Instagram. The flyer was also posted to Facebook Ads, The Psoriasis and Psoriatic Arthritis Alliance, Arthritis Foundation, and The National Psoriasis Foundation. The recruitment flyer served as a base of information for individuals to understand the purpose of the study, inclusion criteria, and contact information to use to be interviewed for the study. The participants who volunteered for the study and met the inclusion criteria were first sent the consent form to say “I consent” via email. Once consent was given via email, participants received the interview guide. After initial contact with each participant, they were provided the information on the purpose of the study and interview. Collecting data lasted for one 11-week term. If recruitment had resulted in too few participants, my backup plan was to find support groups that met in person and hand out recruitment flyers.

I used appropriate platforms to conduct interviews via Zoom, FaceTime, Google Apps, telephone, and, if possible, face to face. Emailing was an option if other media did

not adhere to a participant's needs. For face-to-face interviews, I had a secure place to interview participants in my office I shared with a colleague to guarantee safety for both parties. The semi structured interview guide was created using the literature review as a reference for questions to gain an understanding of young adults with PsA HRQOL experiences.

Each participant was debriefed before exiting the study. Needham and Sands (2010) defined debriefing as the opportunity to discuss feelings, reactions, and circumstances after the interview from the participant's perspective. Debriefing also allows the researcher to evaluate if any follow-up care is needed (Needham & Sands, 2010). Participants had the opportunity to write or verbalize any comments or follow-up questions. Suppose there were any barriers for the participant, such as difficulty answering a question or being in pain from their PsA/additional autoimmune condition they may have diagnosed. In that case, the interview ended, and participants had the choice to continue to do a follow up interview or leave the study. After the debrief, participants were offered information on how to obtain mental health services if requested.

Data Analysis Plan

The application Otter.ai service was used to assist in transcribing the interviews. Otter.ai is a transcriber service to aid in transcribing interviews (Otter.ai, 2022). Using Otter.ai provided better time management of self-transcribing interviews with a 95% accuracy level (Otter.ai, 2022). Once Otter.ai finished transcribing interviews, I reviewed each interview for accuracy. My next steps were to go through each transcription to begin

coding and developing categories and emerging themes. I used Braun and Clarke's (2006) six thematic analyses to assist in identifying codes, categories, and emerging themes. The following are the six steps to Braun and Clarke's (2006) thematic analysis:

1. Familiarized myself with the data by reading the data and writing down any initial patterns.
2. Generated initial codes by identifying initial interests.
3. Searched for themes by categorizing codes into potential themes.
4. Reviewed themes by checking if there is enough data to support each theme.
5. Defined and named the themes by refining the specifics of each theme and generating names for each theme.
6. Producing the report is the final step for analysis by providing examples that relate to the research question.

Each of the interviews were organized using Microsoft Excel Spreadsheet and NVivo. NVivo is a software program created to help organize and manage qualitative data (QSR International, 2022). NVivo can assist in identifying and creating themes derived from the interviews. Hand-coding was performed to analyze the data to ensure the study's trustworthiness. Themes and possible subthemes were documented within the data analysis process and thoroughly discussed in Chapter 4.

Issues of Trustworthiness

This section discussed the issues of trustworthiness. The section was organized using the following four areas: credibility, transferability, dependability, and confirmability.

Credibility

In qualitative studies, credibility establishes that the research findings provide truthful information gathered from the data (Korstjens & Moser, 2018). The research findings should represent original data from the participants and be correctly interpreted with their original views (Korstjens & Moser, 2018). Credibility is internal validity in qualitative studies and focuses on truth value (Korstjens & Moser, 2018). There are a few strategies to ensure credibility, such as prolonged engagement, persistent observation, triangulation, and member checking (Korstjens & Moser, 2018). For this qualitative study, I gathered data from young adults living with PsA and their HRQOL experiences. The strategy that was used for credibility is member checking. Member checking was used for validation. Creswell (2007) stated member checking is a way to verify I had accurately depicted the experiences of each participant. Member checking consisted of each participant being granted the opportunity to review their interview for accuracy (Korstjens & Moser, 2018). Any feedback or corrections needed were discussed with each participant.

Transferability

Korstjens and Moser (2018) defined *transferability* as 'the degree to which the results of the study can be transferred to other contexts or settings with other respondents'

(p. 121). Fellow researchers can repeat the study with a detailed description of how the study will be conducted (Korstjens & Moser, 2018). I assured transferability by providing an explanation of sampling and a comprehensive description of the context and participants.

Dependability

Korstjens and Moser (2018) have defined *dependability* as the “stability of findings over time” (p.121). Dependability is focused on the supporting data of the participant's study evaluation (Korstjens & Moser, 2018). A strategy for dependability is audit trials through notetaking, interviewing, recording, and transcriptions (Korstjens & Moser, 2018). Audit trials were used in this qualitative study to determine dependability. Keeping track of detailed documentation, using my journaling notes and a codebook, pertaining to the study was conducted for this qualitative study.

Confirmability

Confirmability is established by ensuring data and interpretations of the findings are rooted in the data (Korstejns & Moser, 2018). Interpretations should not come from the viewpoint or preferences of the researcher but from the data analysis (Korstjens & Moser, 2018). Audit trials can show confirmability through comprehensive data collection, analysis, and an explanation of the analysis (Korstjens & Moser, 2018). The audit trials were stored using Excel and Otter.

Ethical Procedures

I conducted this study under Walden University's IRB guidelines and all state and federal regulations in the United States. Doing so ensured the protection of all

participants of the research study. Data collection began once receiving Walden University's IRB approval. Following Walden's IRB guidelines, all collected data was protected. Due to the sensitive nature of collecting data on personal experiences, confidentiality was strictly in place. Each participant was required to sign and return the consent form provided by Walden University's IRB. I restated the priorities of establishing confidentiality to help secure reassurance that participants sharing their personal experiences will be protected.

Treatment of Human Participants

I sent each participant through email indicating the researcher's name, the dissertation's title, and the study's purpose. Participants expected this email from the researcher as it was informed at the point of contact. Due to possible safety issues for the participants and researcher, a confidential number and the researcher's Walden email address were provided to protect both parties. I reassured participants confidentiality was the utmost priority. In this email, participants were provided with Walden University's IRB consent form. The consent form informed the participant of their right to volunteer for the research study. Each participant had the rights to the following for the research study; to decline volunteering for the research study, maintain confidentiality, hold the researcher accountable for privacy, and understand how the research data that was used. I also informed each participant that data collection took place in a confidential office with sound machines, inside and outside of the office, for privacy purposes for in-person and virtual interviews.

Treatment of the Data

All information collected throughout the research study remained confidential. Participants had their name, number, and address stripped from the demographic sheet to permit confidentiality. The data was kept for future research, and participants' identities were preserved by maintaining the numeric identifier they were given at the start of the research study. The data will only be kept for the dissertation chair, committee members, and myself to adhere to the American Psychological Association (2010). The guideline indicates confidential information must be kept for up to seven years before the information can be destroyed. Data remained confidential and stored on a USB drive and a password-protected file.

Summary

Chapter 3 provides information on the design and rationale of the research study. This study laid out the use of a generic qualitative design. I chose a generic qualitative method to gather the experiences of young adults living with PsA and their HRQOL. Semi-structured interviews were conducted to collect these experiences of HRQOL. My job as the researcher was to capture everything during the interviews. Field notes were made throughout the data collecting process. These notes captured observations of the participant's body language and facial expressions, in addition to recording each interview.

The qualitative methodology for this study was laid out to explain the participant selection logic, the inclusion/exclusion criteria, instrumentation, pilot study procedures, procedures for recruitment, participation, data collection, data analysis plan, issues of

trustworthiness, and ethics. Participant selection logic was based on a sample size suggested for generic qualitative studies. The sample size that was used for this study is 10–12 participants. Snowball sampling was conducted to gather participants for the study. The inclusion and exclusion criteria state the age groups, number of participants, and what qualifies a person to participate in the study. Instrumentation discussed how the instrument for the study was developed. The instrument was based on the conceptual framework concepts by Wilson and Cleary. Procedures for the pilot study allowed the interview guide to be tested with family and friends to see if any changes needed to be made.

The section about procedures for recruitment, participation, and data collection reviewed how recruitment will occur for the study using social media and a recruitment flyer. The platform of how the interviews were conducted is also explained. Participants were given details of the research and learn how to contact the researcher to be in the study. The data analysis plan explained the use of Otter and NVivo to help organize data and use the six steps of thematic analysis to code data. Issues of trustworthiness reviewed how credibility, transferability, and confirmability were established. Finally, the ethics section reviewed the use of the IRB, the treatment of human participants, and the treatment of the data emphasizing the importance of confidentiality. After data collection was completed, a discussion of the results about themes and possible sub-themes will be expressed thoroughly in Chapter 4.

Chapter 4: Results

Introduction

PsA is a chronic illness that tends to be diagnosed later in life. However, there is a small population whose members experience a diagnosis of PsA in young adulthood that affects the joints, skin, nails, mobility, and QOL (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). Throughout the research, the young adult population is not strongly represented, and further studies are needed to have a more in-depth knowledge of the experiences of this age group (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). Among patients diagnosed with PsA having poorer HRQOL than the general population (Tezel et al., 2015), PsA also provides a more complex way of living (Lee et al., 2010, as cited in Husni et al., 2017). PsA reduces physical functioning, affecting a patient's self-worth (Husni et al., 2017).

Through this generic qualitative study, I aimed to explore the experiences of young adults with PsA and their HRQOL. Nine young adults diagnosed with PsA were interviewed through email and video calls. The study was driven by one research question. I used Braun and Clarke's (2006) six thematic steps to analyze the data, and four themes emerged. Wilson and Cleary's (1995) five health-related concepts served as the study's conceptual framework. My research question was the following: What are the experiences of young adults with PsA and their QOL?

In this chapter, the results of this generic qualitative study are presented. The chapter begins with an explanation of the pilot study and a research study description. The demographics and characteristics of the participants are described. I then discuss the

study's data collection process, including the number of participants, location, duration, how information was recorded, and variations during data collection. In addressing data analysis, I discuss codes, categories, and themes that emerged from the data collection. I then outline evidence of trustworthiness, including credibility, transferability, dependability, and confirmability. Finally, I discuss the study's results, including examples from the data and a summary.

Pilot Study

The pilot study aimed to test the study's instrument and how to conduct interviews. The pilot study guidelines included not using participants used in the study; I was able to interview one family member and one friend with a primary diagnosis of PsA. Before the interview, I asked both participants to treat this as a formal interview conducted in a confidential setting. After conducting the interviews, I was able to gain insight into how to conduct future interviews and how to ask follow-up questions. I also honed my skills by taking diary notes during the interviews. The interviews were recorded and transcribed. The pilot study was not conducted until I obtained Walden University IRB approval.

Setting

Before the interviews for the study began, it was essential to have a confidential environment to allow the participants to be open and honest throughout the interview. Due to the location of the participants who responded, holding any face-to-face interviews was not applicable. The platforms used for the interviews were video calls using Zoom and confidential email. I concluded two video call interviews and seven

email interviews for the study. Each participant was asked to ensure they were in a confidential environment for the interview. There were no external factors to influence the results of this study.

Demographics

The study consisted of nine participants, seven women and two men. All participants were 18–25 years old with the primary diagnosis of PsA and living in the United States. Two of the participants did disclose where they were from within the country. One participant was from the South, and the second was from the Pacific Northwest. Participants varied in the severity of their PsA and how long they had PsA.

Table 1

Participant Demographics

Participant #	Gender	Age
1	F	22
2	F	25
3	F	19
4	F	19
5	F	23
6	F	20
7	F	20
8	M	25
9	M	23

Data Collection

The research study instrument was a 60- to 90-minute interview guide that consisted of 13 main questions with numerous follow-up questions. These questions focused on obtaining the experiences of young adults living with PsA and their QOL. Walden University’s IRB initially approved data collection on February 20, 2023, approval number 02-20-23-1043157. A change form was submitted to Walden’s IRB to

include additional organizations and was approved on March 8, 2023. Once approval was given, I began the data collection process. I reached out to administrators of several social media support group platforms. Each message was sent to the group administrator, explaining the purpose of the research study and what was needed for recruitment. I asked permission to post the recruitment flyer made for the study that included participant requirements. Over time I received emails from participants who met the criteria to participate in the study. To further recruit, I used snowball sampling, asking participants to share my flyer with other potential participants.

There were nine participants in the study, seven females and two males. Seven interviews were conducted by email, and two were conducted by video call, which took approximately 90 minutes. Participants were asked to share their experiences living with PsA in areas related to doctors, understanding medication(s) and treatment, symptoms, and effects of PsA. Otter (<https://otter.ai/>) was used to record and transcribe each interview. To ensure accuracy, I read and listened to each interview transcription. Member checking was implemented by emailing participants to review their transcripts, and any feedback was incorporated into the interview. There were not any unusual circumstances encountered during the data collection process.

Data Analysis

I used the six-step thematic analysis by Braun and Clarke (2006) to analyze the data collection. Braun and Clarke's thematic analysis model assisted in reducing the data to create codes, categories, and themes. In order to maintain confidentiality for all participants, the participants were referred to as P1–P9. The first step in thematic analysis

is to familiarize oneself with the data. After I completed data collection and member checking to ensure accuracy, I familiarized myself with the interviews to prepare for the coding process. In the second step in thematic analysis, I began to identify similarities among the transcripts to create initial codes.

Along with manual hand-coding, I used the software program NVivo to assist with organizing, analyzing, and coding the data. The software program was used as a reference only. Manual hand-coding allows continuous looking at the transcripts' data and labeling dominant information. A codebook was created to keep track of and organize codes. Throughout this process, new codes were added to the codebook, which allowed me to see emerging categories and themes.

With the help of NVivo software, 226 codes were analyzed in the first coding cycle. To further streamline and organize the data, a second coding cycle to refine to 50 codes was analyzed. Grouping codes completed the third and fourth steps in the thematic analysis to make categories and emergent themes and ensure that there were enough data to support the themes. After finalizing 50 codes and grouping, I analyzed nine categories. The fifth step in the thematic analysis is to identify emergent themes. Once I completed creating the nine categories, I could define and name four emergent themes. In the final step of thematic analysis, I added the final codes, categories, and themes to the document. There were no discrepant cases found in the data analysis process.

Evidence of Trustworthiness

Credibility

Credibility was established, in that the research findings provided truthful information gathered from the data (Korstjens & Moser, 2018). The research findings represented original data from the participants and were correctly interpreted with their original views (Korstjens & Moser, 2018). Credibility is internal validity in qualitative studies and focuses on truth value (Korstjens & Moser, 2018). Creswell (2007) stated that member checking is a way to verify that a researcher has accurately depicted the experiences of each participant. Credibility was established through member checking (Korstjens & Moser, 2018). Member checking consisted of each participant being granted the opportunity to review their interview for accuracy (Korstjens & Moser, 2018). For this qualitative study, I gathered data from young adults living with PsA and their HRQOL experiences. Any feedback or corrections needed were discussed with each participant. All participants reported that the information within their transcript was accurately represented. If any further information was requested by the participant concerning the research study, it was provided on an as-needed basis.

Transferability

Korstjens and Moser (2018) defined *transferability* as “the degree to which the study results can be transferred to other contexts or settings with other respondents” (p. 121). Fellow researchers can repeat the study with a detailed description of how the study will be conducted (Korstjens & Moser, 2018). Transferability was accomplished by providing the demographics and ensuring that participants had a primary diagnosis of

PsA. An explanation of sampling and a comprehensive description of the context and participants while keeping confidentiality were provided for fellow researchers to duplicate.

Dependability

Korstjens and Moser (2018) defined *dependability* as the "stability of findings over time" (p. 121). Dependability is focused on the supporting data of the participant's study evaluation (Korstjens & Moser, 2018). Dependability was established using audit trials through notetaking, interviewing, recording, and transcriptions (Korstjens & Moser, 2018). I kept track of detailed documentation, using my journaling notes and a codebook, that pertained to this qualitative study. A pilot study was conducted to ensure that interview questions were significant to the research study.

Confirmability

Confirmability was established by ensuring that interpretations of the findings were rooted in the data (Korstjens & Moser, 2018). Interpretations did not come from the viewpoint or preferences of the researcher but from the data analysis (Korstjens & Moser, 2018). I would kindly ask participants to clarify statements throughout the interviewing process to confirm accuracy. Audit trials showed confirmability through comprehensive data collection, analysis, and analysis explanation (Korstjens & Moser, 2018). With each interview, I did not give the participants my perspective of my own experience. I was an active listener to each participant to verify the information that was provided.

Results

In relation to the main research question for this study, one overarching theme and four subthemes emerged from the data analysis report. All nine participants answered 13 main questions and several follow-up questions. Participants were asked in-depth questions about their HRQOL. There were approximately three questions for each of the concepts. The following numbered questions show the relation and overlapping of the HRQOL model: physical/biological—4 and 7; symptoms—1 and 9; functional health—3, 9, 10, and 11; general health—2, 4, and 6; and overall QOL—5, 6, 8, 10, 11, and 12. The follow-up questions for each numbered question also apply to the HRQOL model and overlap with the five concepts. The questions pertained to each participant's experiences living with PsA and their QOL.

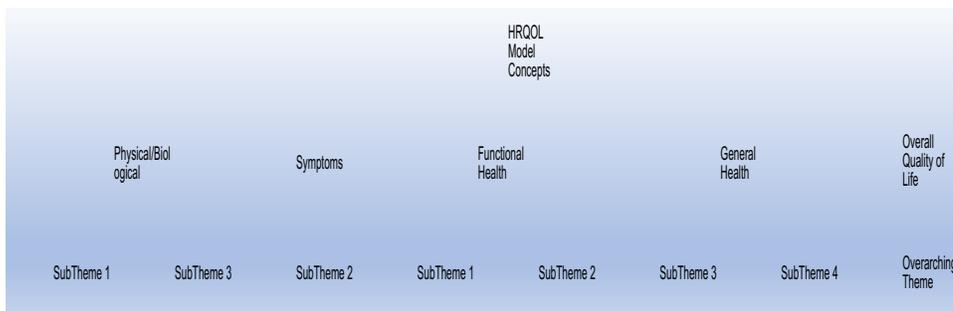
Table 2

Emerging Themes

Overarching theme	Subthemes
Hope and quality of life	<ol style="list-style-type: none"> 1. Being diagnosed with PsA and participant's understanding of the diagnosis 2. The symptoms experienced living with PsA and the effects they have on their quality of life 3. How participants created their treatment plans for PsA and what their quality of life was like before and after medication 4. What was the role of participants' doctors?

Figure 1

Health-Related Quality of Life Model Concepts and Themes



Research Question

What are the experiences of young adults with PsA and their QOL?

Overarching Theme/Health-Related Quality of Life Model Concept: Hope and Quality of Life/Overall Quality of Life

Throughout the data analysis process, an overarching theme among the participants was hope. A few participants shared feelings of relief when they were diagnosed with PsA. Participants indicated that they were ecstatic they finally had an answer to the symptoms they had been experiencing. The formal diagnosis allowed participants to have hope of feeling better. With the diagnosis, a treatment plan could now take form. Several of the participants were included in their treatment planning with their doctors. While waiting for their prescribed medication, they specified that their QOL was low. Many participants were experiencing pain, inflammation, and fatigue. However, once on medication, participants articulated that their pain had reduced, and physical movement became more manageable. One participant voiced her ability to do things she once could before being diagnosed with PsA. Even though several participants

conveyed their diagnosis of PsA and felt like life was getting "ripped away" from them, they had "hope" their circumstances would improve.

P6 shared,

The actual diagnosis came as somewhat of a relief—I had been in so much pain without any explanation for a few months, and even though obviously no one wants to be told that they have a chronic illness, being able to put a name to my symptoms and begin the path of medications/applying for accommodations/meeting others with PsA was heartening. Before being diagnosed, I was beginning to despair that I'd ever find an answer (other doctors not at CAC were very confused by my symptoms), so to be told that I wasn't crazy and that I did actually have something wrong with me was a (small) victory. In the moment when I got the call from the CAC office though, I totally started crying in front of my professor at office hours. (She was very kind.) ... Definitely! My medication took its sweet time to kick in (3 months before I noticed any improvement), but since then they've worked beautifully and I'm 95% back to normal.

P8 shared,

It was a type of relief to finally know what was going on. But then after that had settled it was it was still kind of like, I still have questions, and I still don't really know what is going on or why it's happening. So, it was nice to know what I have, but it's unsettling to not know what's going to happen.

P2 shared, “They certainly have. My foot dactylitis has subsided and I no longer have frequent bouts of pain that prevent me from walking. My scalp has cleared up so I’m much less self-conscious about the flakiness (or lack thereof).” P7 shared,

First medication I was on and within like a day or two are already feeling better. Just in terms of general moving like I was able to, I think, sit on the ground, and stand up, which was a really big milestone because I was pretty much bedridden before. It had gotten to the point where I was constantly in a period of flaring. I just completely like it was a struggle to just go to the bathroom. Embrel has made it to where I’m able to, to work even to move around to not feel like such a drag on society.

Subtheme 1/Health-Related Quality of Life Model Shared Concepts: Being Diagnosed With Psoriatic Arthritis and Participant’s Understanding of the Diagnosis/Physical/Biological; Functional Health; General Health

This theme emerged with participants’ responses from their experiences through the diagnosis process. The theme also aligns with the framework concepts: physical/biological, functional health, and general health. Each participant varied in the time it took to be diagnosed, ranging from as little as two weeks to a few years. Every person who participated in the study was diagnosed with PsA with confirmation using various medical tests. Some of the tests performed included blood panels, MRIs, and X-rays. Most participants did not receive much education when they were diagnosed. Any education received was through pamphlets, research, or brief conversations with their doctors. A couple of participants were given an education on the disease and what they

could expect from having PsA. After receiving the news of their diagnosis, expressed disbelief, sadness, and fear. However, some of the participants did share feelings of relief to finally have an answer to the various symptoms they had been experiencing. Almost all participants stated they would share their diagnosis with family, friends, and employers. However, sharing was on a need-to-know situation or people for whom they were close and received support. Many participants expressed difficulty working, mainly when the job entailed being on their feet for an extended period. P2 shared, “Roughly a year. My blood work did not indicate an autoimmune disease. However, I met the criteria via CASPER. I did not. Most information was sought out and received through medical journals.” P3 shared, “Two appointments, about 6 months. Yes, MRI of the sacral region. I received very little education, as when I was diagnosed, I was in nursing school and my mother is a nurse and also has PsA.”

P9 shared,

It was difficult working in healthcare with a suppressed immune system during a pandemic, but I was very careful about masking and handwashing, so I was able to avoid the worst of it. I did get sick fairly frequently though. I have a lot of pain standing all day, but I didn't really have time to sit because it was so busy, so I just had to suck it up and deal with it.

P4 shared,

I was scared. I was diagnosed right after I turned 18. I felt like my body was failing me. Openly share, I usually share with people because sometimes I have bad days and can't be as physically active.

They make sure I am hydrating and monitoring my symptoms. I did share my diagnosis with my previous employer that I'm not at anymore. I had to majorly cut my hours and they were very accommodating.

Subtheme 2/Health-Related Quality of Life Model Shared Concepts: The Symptoms Experienced Living With Psoriatic Arthritis and the Effects They Have on Their Quality of Life/Symptoms and Functional Health

Participants shared the many symptoms they experienced at the first signs of PsA. One of the most common symptoms participants shared is they had PsO as their first sign of PsA. Participants also experienced fatigue, joint pain, swelling, and nail pitting symptoms. Due to the many symptoms of PsA, participants used different ways to manage the effects of these symptoms. All participants stated they use medication to manage their symptoms primarily. Some medicines mentioned throughout the interviews were Embrel, Humira, Tremfya, prednisone, methotrexate, and NSAIDs. Many of the participants made diet changes to help reduce inflammation and swelling. Participants noticed healthier food options made them feel better and lessened the chance of flare-ups. Some followed restrictions of gluten-free, no dairy, no sugar, and cutting out most processed or fried foods. A variation of exercises helped most participants manage their symptoms. Among the assortment of exercises, the most popular ones were walking and stretching.

Due to their PsA symptoms, managing and completing tasks has shown to be complicated. Physical changes to the participant's joints contributed to making tasks challenging. Some physical changes were found in the hands, knees, and hip joints. The

joint damage participants experienced has made things such as car trips, turning on faucets, typing, holding a knife (grip strength), going to the bathroom, and tasks requiring arm strength. In addition to functions severely straining participants, sleep was another component affected by physical changes. Most stated they have difficulty getting comfortable or their fatigue has made them sleep too much. Participants were asked if they had experienced any emotional changes since initially being diagnosed with PsA. All participants shared they have experienced feelings of anger, sadness (depression), and frustration.

P1 shared,

I first had psoriasis at the age of 3 in various areas of my body. When I was 8, I had a severe trigger finger leading to a full-on flare when I was 10...with medicine, diet and fitness. I can't remember life before being diagnosed. The deterioration in joints affected. Yes, I feel as though I can never get comfortable. Especially with my knees and hips being affected.

P8 stated,

Um, so it was probably around May of last year when I started noticing. I didn't know it wasn't related at the time. But I thought I had hemorrhoids. And it turned out later turned out to be it was misdiagnosed as Lichen Sclerosis and then it turned out to be psoriasis. And then, probably I can't remember exactly if that happened first. Or around the same time. My middle finger on my right hand just kind of started getting like a little stiff. I couldn't tell you exactly what happened

at first. It might have been like the actual psoriasis itself, but it was around the same time they both started happening.

Subtheme 3/Health-Related Quality of Life Model Shared Concepts: How Participants Created Their Treatment Plans for Psoriatic Arthritis and What Their Quality of Life Was Like Before and After Medication/General Health and Physical/Biological

Devising a treatment plan is an essential step in treating PsA. Most participants indicated their doctors included them in creating a treatment plan that would work for them. Participants understood they had to take medication(s) to combat PsA symptoms. Before starting a treatment-plan and taking medication(s), participants revealed low QOL. Several participants found getting through the day-to-day presented with challenges. Despite not receiving much education, participants felt comfortable with the medication(s) they agreed to take with their doctors. With the help of medication(s), participants divulged their QOL improved. Generally, participants experienced less pain, clearer skin, and moved around more easily.

P3 shared,

Yes, however I was immediately put on medications I felt terrible all the time. I hurt so bad and was sleeping all the time while trying to manage college, friends, family and my boyfriend. It really was rough because people don't understand what it feels like. First was meloxicam which didn't work and tore up my stomach. I am now on Humira which helps a little bit, but I would still rate my pain at a 5/10 on average. Yes, I did lots of research on my

medications. Humira has improved my quality of life. I am awake much more now and am able to do more. I still feel weak, and I am in pain at almost all times but it's knocked it down enough to where I can still live my life.

P8 shared,

It's hard to say like my primary care provider was like, as I mentioned, I really, really like my primary care provider. And she took into account like, what I felt, and she was really straightforward with me and said that I was the first patient she had that that she was prescribing such a high dose of prednisone for it. She's like, I've never because I was on 80 milligrams a day tapering down and she said, I've never done this before. And as long as you're okay with this is probably going to help you out quite a bit. You're going to feel some of the heavier side effects of the prednisone and the methotrexate hopefully, she was very straightforward saying it's probably going to take about six months for you to see the full effects of the methotrexate, but you know, in the meantime, until you can see a rheumatologist you're going to be on prednisone and hopefully get some of your life back. And I was very grateful for that. My dermatologist talked to me about the injectable that I'm on the Tremfya and said that I'd be like the perfect candidate to start on an injectable. kind of told me what it does, how it works. She's another really great provider that I have. The rheumatologist it really didn't feel like she added anything more to my plan other than just like okay, we're going to up the dose of this, continue doing this and we'll see in a couple of

months, see how you're doing. So, I felt very included when my primary care provider and the dermatologist but not so much by the rheumatologist.

Only with the injectable I had to wait for, for authorization for the injectable which ended up not really taking that long. But there was a lot of hiccups in the way where it's like it's a very expensive medication. And they figured out how much they could cover and how like it I can only do this if I've already been showing to be on methotrexate for a certain amount of time that if that's the first line of defense, if that's not working, then we can start on this other one. Luckily, I didn't really experience too much of that myself. Like I didn't have to deal too much with the insurance company. I think my dermatologist office helped out a lot with that. The only true financial hiccup on my end was just like trying to figure out the manufacturer of the of the drug has like a like a patient support program where they take care of the large co pays. So that's the only thing I had to figure out on my own otherwise, it's been fine. My insurance has been fairly easy to deal with. Overall, my quality of life was low before starting the medications.

P2 shared,

I was put on biologics (TFN inhibitors) to suppress aspects of my immune system. I do not understand the finer details of why this works. I do. They certainly have. My foot dactylitis has subsided and I no longer have frequent bouts of pain that prevent me from walking. My scalp has cleared up so I'm much less self-conscious about the flakiness (or lack thereof).

Subtheme 4/Health-Related Quality of Life Model Concept: What Was the Role of Participant's Doctors/General Health

After the first signs of PsA were established, all participants sought medical attention. Medical professionals shared the same credentials with all providers who had MDs, such as primary care physicians, rheumatologists, dermatologists, and other specialists. Participants did not seek further medical attention. There was a fluctuation in each participant's time to be seen by a specialist doctor. The average amount of time a majority of the participants waited was three months. However, some participants postponed a year or so to contact a doctor. Participants expressed difficulty getting an appointment with a specialist due to Covid.

P2 shared,

I did not schedule for a year or so. I assumed it was just dry skin and dandruff.

Follow-up: I did not (did not seek other medical care while waiting to see a specialist). Follow-up: Dermatologist (saw a specialist first). Follow-up: No difficulty once it was determined I needed one (to see a specialist). Maybe 2 months due to Covid burden on doctors (time to see a specialist).

P3 shared, "Yes, I have a family history, so my mom immediately knew."

Follow-up: Yes, I also have EDS, POTS, and what they believe to be MCAS. (Did seek other medical care while waiting to see a specialist). Follow-up: Specialist. (Saw a specialist first). Follow-up: I was seen in about three months; this was during the height of covid." (Time to see a specialist).

P9 shared,

I nonchalantly mentioned it to my PCP thinking that he would just tell me it's nothing take Advil, but he ended up referring me to a rheumatologist saying that he thinks it's PsA.

It was a 3 month wait for rheum, so I was taking a lot of NSAIDs, and I used a compression bandage when my dominant wrist started to act up. PCP I was diagnosed when I was in school in a foreign country and they had only 2 rheumatologists, so it was a 3 month wait.

Summary

Each of the participants underwent a diagnosis process. The PsA diagnosis was confirmed for each participant through blood tests, MRIs, and X-rays. When diagnosed, participants received little education about the disease. However, little education was given through pamphlets, participants' research, or brief conversations with their doctors. Participants were asked about their reactions to the news of being diagnosed with PsA. Most voiced feelings of disbelief, sadness, and fear. Two participants additionally conveyed feelings of relief. They had an answer to the symptoms they had been experiencing. Sharing the diagnosis with others, such as family, friends, and employers, was common among the participants. Mostly the information was shared on a need-to-know basis. Work for participants was difficult, mainly if it entailed being on their feet for an extended period.

The most common sign of PsA for each participant was PsO as their first symptom. Participants experienced fatigue, joint pain, swelling, and nail pitting, among other symptoms. Participants shared ways they managed their disease. Medication was

the first line of defense, such as Embrel, Humira, Tremfya, prednisone, methotrexate, and NSAIDs. Participants also changed their diets to help reduce inflammation and future flare-ups. Some followed diet restrictions like no dairy, gluten-free, no sugar, and cutting out most processed foods. The exercise was another way participants managed their PsA symptoms. Walking and stretching were among the most common exercises performed by participants.

Along with work, physical changes created challenges for participants to complete everyday tasks such as car trips, holding a knife (grip strength), going to the bathroom, and tasks requiring arm strength. Participants experienced physical changes in the hands, knees, and hip joints. Sleep also became a hurdle to overcome. Many participants had trouble sleeping comfortably, or significant fatigue equaled sleeping too much. Participants also voiced emotional changes, indicating feelings of anger, sadness (depression), and frustration.

Treatment planning is an essential step in treating PsA. Participants articulated their doctors included them in their treatment plan. Medication(s) were the core of their treatment plans. Participants understood the importance of taking medication(s). Before starting a treatment plan, participants revealed a low QOL. Many participants found there were challenges presented in the day-to-day. Although participants communicated, they did not receive much education, they felt comfortable with the medication(s) they agreed upon with their doctors. Participants divulged their QOL improved with the help of medication(s). Overall, participants experienced less pain, clearer skin, and moved around more easily.

Once participants experienced their first signs of PsA, they sought medical attention. Participants contacted primary care physicians, rheumatologists, dermatologists, and other specialists. The average period to see a specialist was three months. Some participants postponed contacting a doctor for a year or more. Covid posed some difficulty in getting an appointment with a specialist. In Chapter 4 I also explored the participants' demographics, the research setting, data analysis, evidence of trustworthiness, a thorough explanation of the results, and a summary. Chapter 5 contains information on the interpretation of the findings, limitations of the study, recommendations, implications, and conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this generic qualitative research study, I aimed to explore the experiences of young adults with PsA and their QOL. There is literature on PsA and the effects it has on QOL; however, it is primarily quantitative research with a lack of concentration in 18- to 25-year-old young adults (Conaghan et al., 2020; Howells et al., 2018; Kim et al., 2020; Palominos et al., 2020; Yan et al., 2020). I delved into the experiences of nine young adults diagnosed with PsA and what their QOL was like while living with the disease. I collected data through in-depth semi structured interviews. The interviews were performed through email and video calls. A generic qualitative study approach was used to gather and analyze data to understand the experiences that these nine participants disclosed.

The nine semi structured interviews revealed the QOL these young adults experienced having PsA. Before beginning treatment for PsA, their QOL was low and demanding. Participants imparted information about difficult things, what it was like to receive news of the diagnosis, how they managed their PsA, accepting treatment, and education about their treatment. For the remnants of Chapter 5, I will provide the interpretation of the findings to support the information in Chapter 2, study limitations, recommendations, implications (social change), and the study's conclusion.

The findings of this research study to understand the experiences of young adults with PsA and their QOL included the following overarching theme and subthemes:

-Overarching theme: Hope and quality of life

Subthemes:

1. Being diagnosed with PsA and participant's understanding of the diagnosis
2. The symptoms experienced living with PsA and the effects they have on their quality of life.
3. How participants created their treatment plans for PsA and what their quality of life was like before and after medication
4. What was the role of participants' doctors?

Interpretation of the Findings

The literature review in Chapter 2 relayed information indicating that young adults face challenges in their development that are unique compared to those of adults and children. Members of this population are learning to find their identities and developing more complex social and intimate relationships (Kim et al., 2020). PsA tends to be diagnosed later in life. However, there is a small population of young adults who face this diagnosis that affects the joints, skin, nails, mobility, and QOL, including but not limited to social life, education, family, activities of daily living, and work (Conaghan et al., 2020; Howells et al., 2018; Palominos et al., 2020; Yan et al., 2020). The findings in this study validated that members of the young adult population diagnosed with PsA face their own challenges apart from those of adults and children. The findings are represented by an overarching theme and four subthemes that emerged from the semi structured interviews.

Overarching Theme: Hope and Quality of Life

In the overarching theme of hope, participants shared feelings of relief once diagnosed with PsA. Participants indicated that they were ecstatic that they finally had an answer to the symptoms they had been experiencing. The formal diagnosis allowed participants to have hope of feeling better. With the diagnosis, a treatment plan could now take form. Prior to medication or a treatment plan, participants indicated that their QOL was low, as they were experiencing pain, inflammation, and fatigue. Once on medication, participants articulated that their pain had reduced, and physical movement became more manageable. One participant voiced her ability to do things she once could before being diagnosed with PsA. Even though several participants conveyed their diagnosis of PsA and felt like life was getting "ripped away" from them, they had "hope" that their circumstances would improve.

As mentioned in the literature, Rohde et al. (2020) looked at the benefits of types of medication that could improve patients' HRQOL. The study examined the following medications: NSAIDs, synthetic DMARDs, biological DMARDs, and prednisolone (Rohde et al., 2020). The medication provided better disease control, functionality, and mobility and less structural damage (Rohde et al., 2020). Biological DMARDs are chosen more often than other medications. Biologics are the only FDA-approved PsA treatment shown to limit joint damage in clinical trials and meta-analysis (Saad et al., 2008, as cited in Khanna et al., 2019). This study expands upon the knowledge of how medications can improve QOL. It provides the hope participants voiced.

Subtheme 1/Health-Related Quality of Life Model Shared Concepts: Being Diagnosed With Psoriatic Arthritis and Participant's Understanding of the Diagnosis/Physical/ Biological; Functional Health; General Health

In the first subtheme, participants disclosed their experiences through the diagnosis process. The time frame varied for each participant to get diagnosed. Each participant received their formal diagnosis by performing various medical tests, blood panels, MRIs, and X-rays. The education participants received needed to be more extensive. Much information was delivered through pamphlets, participant research, or brief conversations with their doctors. Participants divulged several feelings about their reactions to being diagnosed with PsA. The main feeling that was expressed was relief. Participants were elated that they finally had an answer to the various symptoms they had been experiencing. Participants shared their diagnosis with family, friends, and employers. However, sharing was on a need-to-know situation or was to people with whom they were close and received support. Many participants expressed difficulty working, mainly when the job entailed being on their feet for an extended period.

It is challenging to identify PsA with the current tests available to physicians due to the duplication of symptoms from other illnesses; this results in about 15% of PsA patients being missed in dermatology clinics (Villani et al., 2015). Pennington and FitzGerald (2021) stated that there are significant challenges in diagnosing PsA: Early signs and symptoms of the disease tend to fluctuate, scans do not always detect inflammation, skin and nail PsO is not present in up to 10% of patients, approximately 10% of patients can test positive for RA or other inflammatory arthritis, and

inflammatory markers can show up as normal or only slightly elevated. The participants' experiences built upon the literature indicating how they had to go through various medical testing to see if they truly had PsA.

Husni et al. (2017) suggested that evaluations for patients with PsA should include topics such as depression, anxiety, and overall functioning. Additionally, Husni et al. suggested that social and family support should be evaluated through a clinical interview. The interviews would inquire about family relationships and how the pain of PsA has affected these relationships (Husni et al., 2017). Studies have shown that PsA has negatively influenced the QOL of family members. However, family members and significant others could increase a patient's pain, physical disability, pain behaviors, and distress (Pereira et al., 2012, as cited in Husni et al., 2017). Through this study, the participants conveyed how PsA influences family and friend relationships. The experiences the participants shared built upon the literature. Participants voiced that they told those who would be supportive of them.; most told others on "a need-to-know basis."

Subtheme 2/Health-Related Quality of Life Model Shared Concepts: The Symptoms Experienced Living With Psoriatic Arthritis and the Effects They Have on Their Quality of Life/Symptoms and Functional Health

Participants revealed the many symptoms they experienced as the first signs of PsA. The most common symptom participants stated they experienced was PsO. Other common symptoms experienced were fatigue, joint pain, swelling, and nail pitting. Due to the many symptoms of PsA, participants used different ways to manage the effects of these symptoms. All participants stated that they used medication to manage their

symptoms primarily. Some medicines mentioned throughout the interviews were Embrel, Humira, Tremfya, prednisone, methotrexate, and NSAIDs. Participants also implemented diet changes to help decrease inflammation and swelling. The healthier food choices and following diet restrictions aided participants in the decrease of flare-ups. A variety of exercises helped most participants manage their symptoms. Among the various exercises, the most popular ones were walking and stretching.

Due to symptoms, managing and completing tasks was complicated, with physical changes contributing to the challenge. Physical changes were found in the hands, knees, and hip joints. The joint damage participants experienced had made things such as car trips, turning on faucets, typing, holding a knife (grip strength), going to the bathroom, and tasks requiring arm strength difficult. Sleep was another component affected by physical changes. Most stated that they had difficulty getting comfortable or their fatigue had made them sleep too much. Participants were asked if they had experienced any emotional changes since initially being diagnosed with PsA. All participants shared that they had experienced feelings of anger, sadness (depression), and frustration.

Ohara et al. (2015) mentioned that of those with a previous diagnosis of PsO, approximately 30% develop PsA within about 10 years of onset. This study expands upon this with most of the participants having PsO as their first symptom of PsA. The literature also mentioned, through the years of studying PsA, that it has become more evident that the disease begins much earlier in patients; some think it starts years before PsA is diagnosed (Pennington & FitzGerald, 2021). Ogdie and Weiss (2015) reviewed “findings that psoriasis nail pitting and nail dystrophy are associated with the development of PsA”

(p. 545), possibly explained by inflammation of the tendons/ligaments. Inflammation of the tendons/ligaments is linked to joint involvement, making PsO nail disease a possible predictor of developing PsA. In other words, it is a marker of increased “immunoreactivity” (Ogdie & Weiss, 2015). Several participants expressed experiences of inflammation, nail pitting, and joint pain as part of their initial symptoms of PsA.

Sleep quality and its impact on a patient's well-being is not something taken into consideration often in PsA (Ostergaard et al., 2019). PsA patients rated sleep disturbances, fatigue, depression, and anxiety as more critical than doctors (Orbai et al., 2017). Gezer et al. (2017) stated that sleep impairments should be a part of routine examinations for patients with PsA. There are numerous origins of sleep disturbances for patients with PsA (Gezer et al., 2017). In this study, participants articulated that they had difficulty sleeping and getting comfortable. Although participants did not share if they brought their concerns to a doctor’s attention, sleep quality had an impact on the participant s’ well-being.

Subtheme 3/Health-Related Quality of Life Model Shared Concepts: How Participants Created Their Treatment Plans for Psoriatic Arthritis and What Their Quality of Life Was Like Before and After Medication/General Health and Physical/Biological

In the third subtheme, participants shared their experiences of treatment planning. They shared that their doctors included them in the treatment planning process. Participants expressed that they understood that taking medication(s) was a part of their treatment to combat PsA symptoms. Participants reported low QOL before starting a

treatment plan and taking medication(s). Several participants found that getting through the day-to-day presented challenges. Despite not receiving much education, participants felt comfortable with the medication(s) they agreed to take with their doctors. With the help of medication(s), participants divulged improved QOL. Generally, participants experienced less pain and clearer skin, and they moved around more easily.

The literature in Chapter 2 indicated that patients with PsA have reported more physical and emotional pains, than the general population due to joint and skin components. Physical symptoms can be difficult for patients to manage. Husni et al. (2017) explained that the interpretation of a stressor will indicate how a patient will experience the pain. The amount of awareness of the pain will influence the intensity of the experience (Husni et al., 2017). Patients think that others understanding their condition(s) can reduce the stressors of judgment, shame, touch, being touched, and the idea of transferring the disease (Meneguín et al., 2020). To improve QOL, many patients learn to accept their condition(s) and believe in the science of medication (Boyington et al., 2015; Meneguín et al., 2020). The results from the interview process proved that participants had difficulty managing daily tasks due to their PsA symptoms. The study further proved how the introduction of medication(s) improved the QOL of each participant.

Subtheme 4/Health-Related Quality of Life Model Concept: What Was the Role of Participants' Doctors/General Health

In the fourth subtheme, participants sought medical attention due to the ailments of their symptoms. Medical professionals shared the same credentials with all providers

who had MDs, such as primary care physicians, rheumatologists, dermatologists, and other specialists. Participants did not seek additional medical attention when they saw their doctors'. The time in which they saw their doctors varied. However, the average wait time for participants, once an appointment was scheduled, was 3 months.

Participants also revealed that there were difficulty scheduling appointments during the Covid pandemic. The literature in Chapter 2 indicates those patients sought treatment from rheumatologists and dermatologists. Some literature examples from Chapter 2, Patients can choose treatment approaches that are pharmacological or nonpharmacological with the help of their doctor or doctors (Keskin et al., 2020).

Knowing these symptoms, the patient and the doctor can decide which types of treatment would be most appropriate for the patient (Ritchlin et al., 2017). Ritchlin et al. (2017) indicated that there are medications approved to treat PsA. The goal for most patients and doctors is to manage active PsA when introducing therapy treatment to improve signs and symptoms of peripheral arthritis and skin disease quickly and safely (Lu et al., 2019).

Patients can choose how to receive medications, along with their doctor (i.e., orally, by self-injection, or by infusion; Xu et al., 2018). However, this study not only supports participants seeking medical attention from these specialists, but also builds upon the literature. Participants shared their experiences with doctors and the type of doctors they saw. Participants sharing their experiences with doctors gives further insight to treatment and education.

Conceptual Framework Findings

HRQOL served as the conceptual framework for this study. Patrick and Erickson (1993, p 22) define the HRQOL “as the value assigned to the duration of life as modified by the impairments, functional states, perceptions, and social opportunities influenced by disease, injury, treatment, or policy.” The focus of HRQOL is the assessment of a patient's functioning, satisfaction, and comparison of what is ideal (Megari, 2013). In general, HRQOL is divided into three major domains: physical, psychological, and social functioning (Sprangers, 2002). The physical level is the ability to perform activities of daily living concerning the disease or treatment. The psychological level ranges from distress to a sense of well-being. The social functioning level measures the value of relationships, interactions, and societal integration (Megari, 2013).

The Wilson and Cleary model presents five health concepts linked together (Ferrans et al., 2005). Understanding the relationship among these concepts provides a patient with the most informed health interventions (Ferrans et al., 2005). The first concept is biological and physical factors, focusing on the function of cells, organs, and organ systems (Ojelabi et al., 2017). The second concept is system status, which indicates a patient's perspective on emotional, physical (abnormal), or cognitive state (Wilson & Cleary, 1995). The relationship between the first two concepts can be complex. Some physical abnormalities may not produce symptoms immediately, and some symptoms do not have a trace back to a physical abnormality, such as mental health disorders (Wilson & Cleary, 1995). The third concept is functional status, which measures a patient's ability to perform tasks such as activities of daily living (Wilson & Cleary, 1995). The fourth

concept is general health perceptions, a patient's health status rating concerning the previous three concepts (Wilson & Cleary, 1995). The fifth concept is the overall QOL, measured from the patient's perspective (Wilson & Cleary, 1995).

This study's participants helped confirm and demonstrate how Wilson and Cleary's HRQOL model concepts link together. Most subthemes in the study revealed no sequential order to the HRQOL model concepts. In the interviews, participants unveiled the symptoms they experienced, the medication they took, and how these experiences influenced their daily life. While the diagnosis brought emotions ranging from sadness and frustration to feelings of relief, participants explained how either state influenced other aspects of their lives. HRQOL is measured on physical, psychological, and social aspects; this typically translates to the individual's ability to function and perform activities of daily living, as well as what the individual's limitations are (Patrick et al., 2006)

Limitations of the Study

This study of young adults with PsA and their HRQOL, some limitations and trustworthiness developed while conducting the study. As I was interviewing participants to obtain their experiences, the first limitation of the study was based on the assumption that participants were honest in their responses. Due to trusting participants to be truthful about their quality-of-life experiences, this could not be factually checked. The second limitation of the study surrounded recruiting participants. Gathering enough participants to saturate the data might have proven more problematic than expected. Recruitment had its challenges. First, recruiting within the strict age range of 18–25 proved difficult.

Secondly, this age range also presented challenges to being interviewed and elaborating on the information that participants provided. A third limitation of the study was that participants met the interview criteria. Participants had a confirmed diagnosis of PsA, not just PsO. Some participants had additional diagnoses; PsA was a primary diagnosis. Participants were between the ages of 18 and 25. A final limitation of the study was that participants were from the United States. Some aspects of a participant's life were only applicable in the United States. The limitation to the United States excluded participants who were willing to be interviewed. The potential bias due to my experience with having PsA did not occur. I reduced my bias by keeping a reflective journal of my thoughts and feelings throughout the research process about the study; the journal was shared and discussed with my dissertation chair.

Recommendations

This study was performed to explore the experiences of young adults with PsA and their QOL. Current studies on this research conducted are mainly quantitative research. The age group also targeted primarily in other studies are adults and children. The young adult population is vastly understudied, let alone PsA. Further qualitative studies could expand upon the five different subtypes of PsA to see if experiences vary within the population. Gender, ethnicity, and economic status could also be factors future researchers could explore. Looking at these factors could provide different experiences and perspectives of the disease in future qualitative studies.

As stated in the limitations, recruitment was a significant hurdle to overcome. A couple of recommendations to help alleviate recruitment challenges are to expand the age

range to 30 years old and to open the study to international participation. Opening the age range 18-30 and internationally may make recruitment easier. Making these changes may also allow us to see how countries respond to PsA and what types of support are given. Future research findings could be compared to this study to see if the QOL differs in other parts of the world.

Implications

PsA continues to be an autoimmune disease that is immensely understudied, along with many other autoimmune diseases in general. Understanding the experiences of those diagnosed with PsA, especially young adults, is imperative to social change. The more information that is gathered will help improve care for those who are diagnosed with PsA. Many studies have focused on general information on PsA and types of symptoms. However, if there was more of an understanding of what individuals go through daily, there could be an improvement in medical care, mental health care, education, and other supports in a person's life. This study provided insight into the challenges young adults face daily and how their experiences impact positive social change.

Based on the experiences participants imparted in the study, one of the first steps to positive social change would be to provide all options for individuals to have the types of medications available to increase their QOL. Many participants in the study shared their QOL improved after taking medication. Participants also expressed the importance of supplements to help aid in their treatment. Identifying medications and supplements that have increased their QOL, participants have positively impacted social change with their experiences. By having more knowledge of medications and supplements,

individuals can have more input on their treatment plans and be better prepared for any side effects they could experience from the medication. Another positive social change found among the participants is the support they receive. Most shared they keep things to friends, family, and employers on a need-to-know basis. They told people whom they knew would give them the support they needed. Overall, it is eminent for individuals with PsA to be offered the support they need to improve their QOL. This study shed light on how to increase the QOL of young adults with PsA. These shared experiences will help grow improvement in health care, mental health, education, and support.

Conclusion

Using a qualitative study approach, I explored the experiences of nine young adults with PsA and their QOL. The participants disclosed what it is like to be diagnosed with PsA and their QOL. The study's findings revealed that living with PsA as a young adult has its challenges. The results also disclosed the need for improvement in certain areas like education and understanding what this population handles daily. This qualitative study supported previous research regarding how participants were prescribed medication, the symptoms they experienced, how they faced difficulties doing activities of daily living, and the support they received. The study's findings also revealed feelings of hope. Participants found ways to help manage their PsA, and within these outcomes, they shared how their QOL increased.

As a scholar, it is crucial to promote positive social change. Understanding the experiences this population of young adults' encounters will help improve the kind of care they receive. Due to the lack of information in this area, participants aided in filling

the gap in the research. Additionally, this study highlighted a much-needed understanding of this population and what they combat each day being diagnosed with PsA.

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Appendix A: Interview Guide

Thank you for your participation in this interview. Sharing your medical and life experiences is sensitive and could be difficult to discuss. Please note all information will be kept confidential and the researcher will only use the information for research purposes only. For your participation in the study, you will receive a \$10 Visa gift card.

1. Can you please tell me what were the first signs of PsA for you?

2. After noticing the signs of PsA, did you schedule a doctor's appointment right away?

Follow-Up: While waiting to see a PCP or Specialist, did you seek out other medical care in the interim?

Follow-Up: For the scheduled appointment, can you tell me what type of doctor did you see first, a PCP or Specialist?

Follow Up: Did you have difficulty or challenges finding a PsA specialist? How quickly were you seen?

3. Can you tell me if transportation has ever been an issue to get to doctor appointments?

4. How long did it take to get a diagnosis?

Follow Up: Did the doctor order lab work and/or imaging to confirm the diagnosis?

Follow Up: Did you receive educational support or information upon getting the PsA diagnosis? (If yes, can you please tell me what type of education or information you received?)

5. What was your reaction when you first found out you had PsA?

6. Did the doctor include you in your PsA treatment plan before being prescribed medications?

Follow Up: If you were prescribed medications and while awaiting approvals or authorization from the insurance company, how was your quality of life?

7. If you were prescribed medications, can you tell me if you understand the type of medication, you were taking and the reason(s) why?

Follow-Up: Do you feel comfortable in your knowledge about the medications?

Follow-Up: Can you please tell me if the medications have improved your quality of life? [If you do not take medications, can you tell me the reason?]

8. While pregnant and after being pregnant, how was your quality of life? (Females only)

9. How do you manage the PsA disease?

Follow Up: Are there difficult tasks for you to do now than before you were diagnosed? If so, what are they?

Follow-Up: Have you observed any physical changes after being diagnosed with PsA?

Follow-Up: Is sleep a difficult task? How do you feel about that?

Follow-Up: Have you noticed any emotional changes after being diagnosed with PsA?

Follow-Up: Were there any diet changes after being diagnosed with PsA?

10. Is this diagnosis something you keep to yourself or openly share? How do you feel about that?

Follow-Up: If you openly shared your diagnosis with family and friends, how are you treated by your family and friends?

11. After being diagnosed with PsA, can you tell me if you openly shared your diagnosis with your employer? (If yes, did you reduce the amount you worked? Were accommodation provided or offered?)

12. What was your quality of life while working? What was it like during the Pandemic? Was work an issue?

13. What other experiences would you like to share we did not touch upon?

Appendix B: Recruitment Flyer

Exploring the Experiences of Young Adults Living with Psoriatic Arthritis and their Health-Related Quality of Life

Study conducted for completion for a dissertation under:
Walden University

- Volunteers between the ages of 18-25 are needed to take part in a research study about the experiences of young adults living with psoriatic arthritis and their health-related quality of life.
- Your participation in this study may help providers better understand how young adults experience a diagnosis of psoriatic arthritis.
- As a participant of this study, you will be asked a series of interview questions to share your experience living with psoriatic arthritis and health-related quality of life.
- If at any point you feel uncomfortable you may choose not to answer a question(s). You may also leave the study at any time. Information collected will be under a numerical number, so no one will know who you are other than the researcher.
- Participants will receive a \$10 Visa gift card at the completion of the interview for time taken to partake in the study.

Are you eligible?

- Young adult between the ages of 18-25
- Psoriatic Arthritis as your primary diagnosis

Location:

- In-person or virtual interviews by appointment- appointments may take 60-90 minutes.
- In-person interviews will take place at The First Building.

ARE YOU BETWEEN THE AGES
OF 18-25 LIVING WITH
PSORIATIC ARTHRITIS?
YOU MAY BE ELIGIBLE TO
PARTICIPATE IN A
RESEARCH STUDY!

IF YOU ARE UNSURE IF YOU ARE ELIGIBLE FOR
THE STUDY, PLEASE CALL OR EMAIL:

- RESEARCHER: Katie McCann
- Study Supervisor: Dr. Ethel Perry, PHD