

2019

# Understanding the Lived Experience in Women With Psoriatic Disease Utilizing Alternative Interventions

Lisa Liimatainen  
*Walden University*

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>

 Part of the [Psychology Commons](#)

---

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact [ScholarWorks@waldenu.edu](mailto:ScholarWorks@waldenu.edu).

# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Lisa Liimatainen

has been found to be complete and satisfactory in all respects,  
and that any and all revisions required by  
the review committee have been made.

## Review Committee

Dr. Alethea Baker, Committee Chairperson, Psychology Faculty

Dr. Susan Rarick, Committee Member, Psychology Faculty

Dr. Brandy Benson, University Reviewer, Psychology Faculty

Chief Academic Officer  
Eric Riedel, Ph.D.

Walden University  
2019

Abstract

Understanding the Lived Experience in Women With Psoriatic Disease Utilizing  
Alternative Interventions

by

Lisa Liimatainen

MS, Walden University, 2012

BS, University of Phoenix, 2009

Dissertation Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Philosophy  
Psychology

Walden University

May 2019

## Abstract

Psoriatic disease (PD) is an autoimmune disease that affects millions of women and currently has no cure. Examining the lived experience of women with PD who choose to treat their disease with alternative methods may allow for deeper understanding of how mental health professionals can support their choices. Using phenomenology, this study looked at the experiences of these women through theories of self-efficacy and self-in-relation theory, theories that empower and speak to women. The participants consisted of women who reported a diagnosis of PD, who reported they had abstained from pharmaceutical interventions for at least the previous six months. The sample size consisted of 7 participants, recruited through social media, from various parts of the world. Explication was used to assess the data and consisted of the following: bracketing and phenomenological reduction, delineating units of meaning, clustering of units of meaning to form themes, summarizing each interview, and extracting general and unique themes from all interviews and making a composite summary. The findings of this study showed that the participants reported feeling capable of pursuing health options that aligned with their values and were not opposed to pharmaceutical options at some point. In addition, findings indicated participants felt minimal, if any, support from their medical care providers. The results of the study may facilitate positive social change by informing women with PD about the benefits of taking an active role in treatment planning. Further, this study's results may expand knowledge about treatment of women with PD and inform medical professionals, specifically mental health professionals, about what is important to these women in terms of a treatment plan.

Understanding the Lived Experience in Women With Psoriatic Disease Utilizing  
Alternative Interventions

by

Lisa Liimatainen

MS, Walden University, 2012

BS, University of Phoenix, 2009

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

May 2019

## Dedication

I dedicate this doctoral study to the amazing women who were brave enough to share their stories. May their stories continue to be shared, heard, and valued.

## Acknowledgments

To my committee chair, Dr. Alethea Baker and my second committee chair, Dr. Susan Rarick. I have been honored to have a dissertation committee of strong women. Your support has been an instrumental part not only in the successful completion of my dissertation, but in all areas of my life. I also owe my original chair, Dr. LeAnn Parker a debt of gratitude for starting my dissertation journey with me and believing in this topic that was so important to me.

To my children; Natalie, Samuel, Kiirsten, and Hanna, who have watched me for much of their lives work tirelessly pursuing this goal. You have been the greatest sources of encouragement day in and day out. I pray each of you find your passions and pursue your dreams with the value of hard work and sisu.

Lastly, to my family and friends. I do not have enough space to write each of your names individually but that does not minimize the roles each of you played. From my cousins, to my brother, to my dear friends, family, and co-workers, you have all supported me with a steadfast belief and encouragement. It has not gone unappreciated. I love you all.

## Table of Contents

Chapter 1: Introduction to the Study.....	1
Introduction.....	1
Background.....	2
Problem Statement.....	5
Purpose of the Study.....	7
Research Questions.....	7
Theoretical Framework.....	7
Nature of the Study.....	8
Definitions.....	9
Assumptions.....	10
Scope and Delimitations.....	10
Limitations.....	11
Significance.....	12
Summary.....	12
Chapter 2: Literature Review.....	14
Introduction.....	14
Literature Search Strategy.....	17
Theoretical Foundation.....	19
Self-in-Relation Theory.....	20
Self-Efficacy Theory.....	23
Psoriatic Disease.....	25



Differences in Gender .....	29
Quality of Life.....	30
Diagnosis of Psoriatic Disease .....	31
Treatment Options .....	33
Pharmaceutical Options .....	34
Alternative Treatments.....	36
Quality of Life.....	39
PD and Mental Health.....	42
Summary .....	46
Chapter 3: Research Methodology.....	48
Introduction.....	48
Research Design and Rationale .....	48
Role of the Researcher .....	51
Methodology.....	52
Participation Selection Logic .....	52
Instrumentation .....	55
Data Collection and Explication .....	56
Explication .....	57
Issues of Trustworthiness.....	59
Ethical Procedures .....	60
Summary .....	62
Chapter 4: Results .....	63

Setting .....	63
Demographics .....	64
Data Collection .....	65
Data Analysis .....	66
Evidence of Trustworthiness.....	69
Results.....	71
Summary.....	75
Chapter 5: Discussion, Conclusions, and Recommendations .....	77
Interpretation of Findings .....	78
Limitations of Study .....	80
Recommendations and Implications .....	81
Conclusion .....	83
References.....	84
Appendix A: Confidentiality Agreement.....	90
Appendix B: Interview Questions.....	92

## Chapter 1: Introduction to the Study

### **Introduction**

Psoriatic disease (PD) is an autoimmune disease that affects over 70,000,000 people worldwide (Eder, Chandran, & Gladman, 2012). The aim of this study was to look at the lived experiences of women with PD who have chosen to treat their disease without pharmaceutical intervention. PD consists of psoriasis and psoriatic arthritis (PsA). In much of the literature on PD, researchers have combined males and females in the same study or have looked only at specific pharmaceutical interventions. Thus, the literature does not cover the full scope of PD. Often, PsA and psoriasis have been separated in these studies (Eder et al., 2012; Lesuis, Befrits, Nyberg, & van Vollenhoven, 2012; Papoutsaki & Constanzo, 2013;).

A better understanding of the patient's decision-making process and the factors considered during that process may provide insight into the reason(s) for a person's choice to seek natural therapies (Dudlettes, 1986). Researchers have found that quality of life is lower in people with PD. However, there is a need to know how people treat their PD and how they decide on a means of treatment (Boehncke & Menter, 2013; Eder et al., 2012; Mease, 2012). Through this study, I sought to fill this gap in the literature. Participants in the study had the opportunity to openly discuss their thoughts and the factors they considered in order to decide on a treatment. This facilitated an increased understanding about their daily struggle with PD (Eder et al., 2012).

This study has the potential to facilitate positive social change in a number of ways. This study may help to further the knowledge base of mental health professionals

in regard to PD and the psychological comorbidity that often accompanies it (Ferreira, Abreu, Reis, & Figueiredo, 2016). The results of this study may inform women with PD about the benefits of taking an active role in their choice of treatment. In addition, the study's results add to the literature about treatment of women with PD and may inform medical professionals about what is important to these women when they consider a treatment plan.

This chapter provides brief background on the current literature, as well as the problem statement, purpose, and research question of the study. It includes an introduction to the study's theoretical framework, the nature of the study, definitions of key terms, and a discussion of the study's assumptions, delimitations, limitations, and significance.

### **Background**

PD has often been put in the same category as other chronic conditions or thought of as only a disease of the skin. Yet beyond the skin, there is a lot happening in the body in patients with PD. PD is an autoimmune disease experienced by approximately 1-3% of the world population, and currently there is no known cure (Eder et al., 2012).

PD consists of psoriasis and PsA. Psoriasis, a chronic inflammatory skin disorder, will usually present itself first. Skin cells reproduce at an accelerated rate, which results in patches of scaly skin on various areas of the body. Of those diagnosed with psoriasis, roughly 20% will develop PsA (Boehncke & Menter, 2013; Kotsis et al., 2012). PsA is an inflammatory seronegative spondyloarthropathy that primarily affects peripheral joints (Boehncke & Menter, 2013). Symptoms of PsA are centered around the

joints but can also affect the surrounding ligaments and tendons. These symptoms include stiffness, pain, swelling, and tenderness (Papoutsaki & Costanzo, 2013). These symptoms can be irregular and spontaneous, leaving people with a guessing game of which joint or area of the body will be affected next and for how long. The outside and the inside of the body are susceptible, leaving the person seemingly at the mercy of the disease.

While the specific causes of the disease are unknown, it is believed to be caused by multiple factors including genes, the immune system, and environmental factors (Starkebaum, 2015). Psoriasis is often seen and managed in a family practice environment (Magin, Adams, Heading, Pond, & Smith, 2009). There are a number of pharmaceutical treatment options for PD, meant to reduce inflammation in the body and treat the symptoms of the disease (Mease, 2012). However, some people who are diagnosed with PD choose to avoid pharmaceutical interventions in favor of a more natural route. Less literature exists on this population even though trends are showing an increase in complementary and alternative medicine (Su & Li, 2011).

Males and females are equally vulnerable to PD, with women being more likely to discontinue their pharmaceutical interventions for PD due to lack of effectiveness and side effects and to suffer worse quality of life (Eder et al., 2012). In the context of living day to day with PD, it can be overwhelming to choose a treatment plan. However, it is not known how and why women choose their type of treatment. Women may tend to consider how others in the family may be affected. Family obligations can combine with a woman's need for full-time employment—at a time when she may also worry about the

hereditary nature of PD and whether or not her child or children will be affected.

Numerous studies have shown that those with PD suffer from a lower quality of life, but what is missing is understanding of how this population decides on a treatment plan and why those with PD may choose a nonpharmaceutical approach over conventional medicine (Boehncke & Menter, 2013; Eder et al., 2012; Mease, 2012). A Swedish study on psoriatic patients found that female patients (as opposed to male patients) tended to believe that they had an influence over their disease. This belief can lead patients to take greater responsibility for the disease (Lesuis et al., 2012). Women are the specific population for this study due to their quality of life being lower than men in this population and due to women receiving less benefit with current pharmaceutical options (Eder et al., 2012). A better understanding of this population has the potential to help health care professionals in varying capacities to be of greater support.

Lastly, those with PsA have a higher risk of mental illness. Those with psoriasis have a 39% greater chance of being diagnosed with depression and a 31% higher risk of being diagnosed with anxiety (Leavitt, 2015). While this increase is staggering, it was noted by Leavitt (2015) that depression and anxiety may result not only from the disease, but also from the treatment. Mental health professionals need to be aware of the impact that PD has on those affected while also developing an understanding of how to access and serve this population. Psychodermatology is a new area of medicine that looks specifically at the “interaction of body and skin” (Jafferany, 2011, p. 1). This field helps connect the varying components involved in a disease such as PD. In addition, mental health professionals should be aware of the psychosocial aspect of the disease and how

individuals cope with PD and interact in the world around them. With ongoing support, members of this population may cope and even thrive.

### **Problem Statement**

Research indicates that PD dramatically reduces patients' quality of life. For example, PD can impair a person's relationships, social life, and routine, day-to-day activities. PD should not only be considered a physical disease; the psychological impact of the disease also needs to be addressed (Grozdev et al., 2012). Currently, there is no known cure for PD, so improvement of patients' quality of life is the goal via symptom management. As mentioned earlier, there are many options for pharmaceutical treatment of PD, and researchers continue to find ways to reduce inflammation in the body. These options are meant to treat symptoms of the disease (Mease, 2012).

While it is known that women tend to have less success with pharmaceutical interventions for PD, it is not known how a treatment plan is decided on by a woman with PD. It is difficult to know if this limited pharmaceutical treatment success impacts the treatment choice or if these women are even aware of the increased risk of side effects. Many medical doctors prescribe medication for PD—often, patients receive numerous medications in an effort to combat the disease—but they may do so without understanding the personal implications of treatment for the patient.

As mentioned above, decisions about treatment options for PD are difficult, especially as women see themselves as relational (Surrey, 1985). Women tend to view themselves in terms of their relationships, whether personal or professional. Unfortunately, the problem is that women with PD are being underserved even though

they are a vulnerable population that is likely to suffer from negative psychological impacts of a disease with no cure (Magin et al., 2009).

Previous studies have sought to examine the psychological effects of psoriasis or PsA (Boehncke & Menter, 2013; Grozdev et al., 2012; Magin et al., 2009; Sarilar, Koic, & Dervinja, 2011) without specifically looking at females or treatment option considerations. Female patients have been shown to respond less to pharmaceutical interventions and to suffer more side effects, yet they are often combined with males in these studies. None of the studies that have been conducted sought to examine the decision-making process of this population and how patients come to decide on a treatment plan. The Swedish study mentioned earlier found that women tend to feel that they have more influence over the disease, which may lead them to take greater responsibility over their disease (Lesuis et al., 2012), yet how this may manifest is not known. Examining the lived experiences of women with PD who have chosen to treat their disease nonpharmaceutically could lead to a better understanding of this population and how its members can best be served.

An understanding of the decision-making process may help mental health professionals obtain perspective on the complexities of a disease that is as pervasive as PD. Mental health professionals need to be cognizant of women diagnosed with PD, as they have an increased risk of anxiety and depression. As complementary and alternative therapies have been increasing in popularity (Kelly, Cudney, & Wienert, 2012), mental health professionals also need to be able to adjust their tools to properly serve this population.



### **Purpose of the Study**

The purpose of this study was to examine the lived experience of women with PD who had chosen to eschew pharmaceutical intervention in favor of natural alternatives. The study helps to fill a gap in the literature regarding how women make decisions about treatment of PD. Another purpose of the study was to provide increased understanding about this population, which could be beneficial not only to women, but also to those physical and mental health practitioners who work with them. Overall, the results of the study could facilitate positive social change.

### **Research Questions**

- RQ1. What is the lived experience for women with PD who choose alternative or complementary interventions as opposed to pharmaceutical interventions?
- RQ2. How do they feel about the treatment decision they made, and what benefits have they noticed?

### **Theoretical Framework**

The theoretical framework for this study was based on two theories: self-efficacy theory (Bandura, 1997) and self-in-relation theory (Surrey, 1985). Bandura's self-efficacy theory provides a lens through which to view and understand chronic disease. Self-efficacy theory informed this study regarding how to understand a person's confidence in his or her own ability to control motivation, behavior, and the social environment (Bandura, 1997). As mentioned earlier, previous research has found that women with psoriasis tend to believe that they have some influence over their disease

(Lesuis, 2012). Self-efficacy theory informed the current study in terms of how self efficacy played a role in women's decision-making process regarding treatment options for PD.

Self-in-relation theory is specific to female development and works well with self-efficacy theory. This theory was developed by Surrey (1985), who explained this theory as addressing how women identify themselves in the context of important relationships. Being able to understand women with PD in terms of how they decide on their treatment plan in this context may yield valuable information that leads to a better understanding of the complexities of this experience and how to best serve this population. Women were the focus of this study due to the fact that women tend to suffer from a lower quality of life than men living with PD (Eder et al., 2012). Taking into account a women's perspective provides a more accurate picture of women's experience. These theories will be looked at in greater depth in Chapter 2.

### **Nature of the Study**

The nature of this study was qualitative. The qualitative approach allowed for a deeper understanding of the participants and how their thought processes worked through determining their treatment plan. It has been shown that women with PD suffer from worse quality of life than men with PD, yet little is known about how this looks in their lives (Eder et al., 2012). The specific methodology used was phenomenology, through which I sought to describe the lived experiences of these women in terms of how they went through the process of deciding on a treatment plan that did not include pharmaceutical interventions. Most of the research that had been conducted had not

sought to examine the lived experience of women with PD (Magin et al., 2009). Participants were interviewed until the data were saturated, with no new themes emerging. Phenomenology focuses on interviews (Creswell, 2014). Open-ended questions were asked to elicit the responses needed to allow for an open and thoughtful dialogue.

### **Definitions**

The following key terms are used throughout the research.

*Nonpharmaceutical interventions*: This term applies to any treatment that does not consist of prescription medications. This term has been used interchangeably throughout this paper with *natural and alternative treatments*.

*Psoriasis*: Psoriasis is the aspect of PD that affects the skin. It is a chronic inflammatory disease (Boehncke & Menter, 2013).

*Psoriatic arthritis (PsA)*: PsA is an inflammatory joint disease that does not have the blood antibodies associated with rheumatoid arthritis, which is referred to as *seronegative spondyloarthropathy* (Boehncke & Menter, 2013). At times, when the term *PsA* is used in this paper, it specifically pertains to the joint inflammation aspect of the disease and not necessarily to the skin portion of the disease. Given that researchers have often chosen to focus on either PsA or psoriasis, some information only pertains to that specific area of the disease.

*Psoriatic disease (PD)*: *PD* is a relatively new term that encompasses the various “manifestations of tissue and organ involvement observed in many psoriasis patients”

(Ritchlin, 2009, p. 1). *PD* is used throughout this paper for consistency and with the understanding that it includes psoriasis and psoriatic arthritis.

### **Assumptions**

There were a few assumptions for this study that I believed but could not prove to be true. The first assumption was that the participants were honest about their diagnosis of PD and that they had used only alternative treatments for at least the last 6 months. The assumption also existed that these people generally wanted to decrease their symptoms. Those participating in the study had the intent of improving their quality of life and reducing symptoms through the use of natural or alternative treatments. These assumptions were necessary, as it would have been difficult to have diagnoses verified along with treatment options and duration of treatment.

### **Scope and Delimitations**

The scope of this study focused on women diagnosed with PD who were treating their disease with nonpharmaceutical interventions at the time of the study and sought to understand their lived experiences when deciding on a treatment plan. This topic was meant to bring attention to this specific timeframe of the disease while examining what women take into consideration and how they come to treat their disease nonpharmaceutically. Examining personality factors and the five-factor model was a consideration at the start of the research process; however, based on the research, I decided to begin by examining the lived experiences of these women. The results of this study may lead to a closer study of personality factors in those women who choose to treat their PD nonpharmaceutically.

Women were specifically examined to better understand the impact of relational roles on the choice of treatment. Males in the same scenario might be an appropriate topic for future research, but to gather as much data as possible for one population, only women were used for this study. Women aged 18 years and older of any ethnicity were allowed to participate. This may have affected transferability, given the possible diversity of the sample. However, the scope of the study involved understanding the lived experience of women, so perhaps future research could narrow down this group if need be.

### **Limitations**

One limitation of this study was that it does not transfer to all women diagnosed with PD who are not using pharmaceutical interventions. The issue of transferability was previously discussed and was a limitation of the study. Another limitation was the interview question guide, in that it did not include all questions that needed to be asked. The final limitation was that the interviews were conducted via Facetime or using audio only. This mode may have impacted rapport building.

Biases are a common concern in qualitative research, as the researcher is the instrument. I would like to disclose that I have been diagnosed with PD and have experienced the process of deciding on a treatment plan. I was constantly vigilant of my own stance so that the words of the participants and their experiences were the center of the study. Participants were given the opportunity to review their summaries to ensure that their points were conveyed.

### **Significance**

The significance of this study is that it may help readers to understand the severe impairment that PD can create. Examining how women choose their treatment can help mental health professionals understand how to approach women with chronic conditions and understand their decision-making process when it comes to deciding on a treatment. Previous studies have shown that those with PD have a lower quality of life, but what is missing is an understanding of how and why people treat their PD in the way that they have chosen (Boehncke & Menter, 2013; Eder et al., 2012; Mease, 2012). The risk of anxiety and depression with PD cannot be ignored. The costs of treating those with PsA can reach almost \$2 billion each year (Lee, Mendelsohn, & Sames, 2010). Currently, no cure for PD exists, so symptom management and reduction are the targets, and the focus of treatment is maintaining or improving quality of life. Women were the focus of this study, as they tend to suffer from a lower quality of life than men when living with PD (Eder et al., 2012). A previous Swedish study on psoriatic patients suggested that females may be more likely than males to believe in the influence they have on their disease and therefore take greater responsibility for their disease management (Lesuis et al., 2012).

### **Summary**

This chapter laid out the study and its basis. PD is classified as an autoimmune disease that consists of psoriasis and PsA. Psoriasis is defined as a systemic inflammatory disease that affects up to 3% of the population (Velez, Wei-Passanese, Husni, Mody, & Quereshi, 2012). An estimated 10-30% of those with psoriasis will

eventually develop PsA, which is a “chronic inflammatory and progressive arthritis” (Velez et al., 2012, p. 7). PD has been shown to affect men and women at similar rates; however, the presentation of the disease can vary greatly across genders and individuals, with these differences possibly being partly attributable to social expectations of females (Eder et al., 2012).

Examining the lived experiences of women with PD and how they decide on a treatment that does not include pharmaceutical interventions may lead to a greater understanding of the thought process for female PD patients, which may help medical professionals, including mental health professionals, better care for this vulnerable population. Mental health professionals have an obligation to serve this population, given members’ increased risk of mental health issues. Because PD is often diagnosed in the early adult years and has no cure, the ability to serve this population’s mental health needs is vital.

The next chapter provides an in-depth literature review of what is currently available regarding PD, women with PD, PD treatments, and relevant theoretical frameworks.

## Chapter 2: Literature Review

### Introduction

PD encompasses the diagnoses of psoriasis and PsA. While *PD* is a relatively new term, it seeks to bring together psoriasis and PsA. A subset of those diagnosed with psoriasis will go on to develop PsA. This paper's focus was on those diagnosed with PD, not solely psoriasis. Not all research has grouped psoriasis and PsA together and identified them as PD. It was my intent to bring this research together to aid in the creation of a complete picture of PD. The term *PD* is used throughout this paper for continuity purposes and with the understanding that it includes psoriasis and PsA. At times, when the terms *psoriasis* and *PsA* are used, it should be noted that they pertain specifically to the one aspect of the disease that each represents and not necessarily to one another. Given that research has often chosen to focus on either PsA or psoriasis, some information only pertains to that specific area of the disease.

PD has often been grouped in with other chronic conditions. It may also be classified simply as a skin disease, but there is much more happening within the body than what is seen on the skin. PD is an autoimmune disease that affects roughly 3% of the world population, and currently no cure exists (Eder et al., 2012). Psoriasis usually presents itself first by attacking the skin. There are numerous types of psoriasis, including plaque, flexural, erythrodermic, pustular, guttate, and nail psoriasis (Papoutsaki & Costanzo, 2013). Each of these types has different appearances, but all cause the body to reproduce skin cells within days as opposed to weeks (Eder et al., 2012).



While the specific origin of the disease is unknown, it is believed to be caused by multiple factors, including genes, the immune system, and environmental factors (Starkebaum, 2015). Of those diagnosed with psoriasis, roughly 20%, which comes to between 14,000,000 to 42,000,000 people worldwide, will develop PsA (Boehncke & Menter, 2013; Kotsis et al., 2012). PsA involves inflammation encompassing not just the skin, but also other areas of the body, primarily joints.

Research suggests that roughly 1 million Americans currently have PsA, and the numbers are increasing (Hammadi, 2016). Little is known about the cause of PsA, which can make it difficult to fully grasp the enormity of the impact of the disease. Various sources suggest that the cause is multifaceted and includes genetics, infections, trauma, and environment (Eder et al., 2012; Liu et al., 2014; Papoutsaki & Costanzo, 2013). The purpose of this research was to examine the decision-making process of women with PD who have chosen to eschew pharmaceutical intervention in favor of natural alternatives. Understanding women's reasoning in choosing a treatment route will allow for a clearer understanding of how mental health professionals can be a support to this population whose members are vulnerable to mental health issues such as depression and anxiety (Grozdev et al., 2012; Magin et al., 2009).

This chapter explores PD in relation to its diagnosis, symptomology, and treatment, as well as how women specifically are affected in various life areas by PD and why their unique experience with PD needs to be more closely studied. The numbers for those affected with PD have been shown to be growing (Boehncke & Menter, 2013), so it is imperative that those affected are better understood and respected, no matter their

treatment choice. It is estimated that 2.5% of the North American Caucasian population is affected by PD, with males and females being equally susceptible (Eder et al., 2012; Hammadi, 2016).

Women tend to take their relational obligations into consideration when choosing a treatment. Research has shown that pharmacological options have lower efficacy for women than they do for men (Eder et al., 2012). Women with PD were chosen for this study because they have been shown to have a lower quality of life than men diagnosed with PD (Hammadi, 2016; Magin et al., 2009) and to experience complexities in their decision-making process regarding PD treatment, particularly with respect to important relationships and the impact that their treatment choice may have on those relationships. The theoretical frameworks I used for this study offered some understanding of how confident individuals may be in their ability to choose a treatment option and how women tend to view themselves and their health in relation to others.

The two theories that I used to help bring understanding of women diagnosed with PD were self-in-relation theory and self-efficacy theory. Self-in-relation theory specifically looks at women and their development and how women take into consideration important relationships that have bearing on their identity (Surrey, 1985). This variation in identity formation can be further complicated when women are faced with a chronic disease and the impact it will have on not only their lives, but also the lives of those with whom they have important relationships, such as significant others, children, aging parents, and coworkers. Bandura described *self-efficacy* as a person's confidence in his or her ability to control motivation and behavior, noting that social

environment can play an integral role in determining self-efficacy (Bandura, 1997). By applying self-efficacy theory to women with PD, I was able to gain a better understanding of how in control these women felt in relation to deciding on a treatment option and their confidence that they could carry out what was necessary.

This chapter provides clarification regarding the literature on the topic of PD, self-in-relation theory, self-efficacy theory, mental health treatment, and nonpharmaceutical interventions. The few qualitative studies that exist on PD and those that look at quality of life have neglected to fully capture the thought process in how people decide on treatment plans; rather, the focus has been on how patients feel in regard to the diagnosis and living with the disease (Magin et al., 2009; Sarilar, Koic, & Dervinja, 2011). This literature is impactful and applicable to understanding the physical and psychological effects of the disease, but it does not go far enough toward understanding how those with PD cope with the disease and live daily lives while trying to manage symptoms.

### **Literature Search Strategy**

I originally used the search term *psoriatic disease* because common sense seemed to dictate that PD was the primary focus of my study and was therefore where the literature search should begin. However, I soon discovered that this term was not at all common within the formal literature. Ritchlin (2009) disclosed that *psoriatic disease* is a fairly new term created to encompass both psoriasis and PsA. Based on this information, I conducted searches on the two separate components of the disease, which resulted in more information. Rarely did I find in existing research that information pertained to PD

as a whole without acknowledging psoriasis as well. I also found that PsA was joined with other forms of arthritis, most often rheumatoid arthritis. Although I do not discount the impact that both of these diseases have, it should be noted that they are separate diseases, and rheumatoid arthritis does not include the skin presentation of psoriasis. It is important to remember that PsA goes hand in hand with psoriasis. One cannot have PsA without having psoriasis (Boehncke & Menter, 2013; Liu et al., 2014).

Another search term that was beneficial was *autoimmune diseases* because PD falls under that umbrella. Again, much of the research on this topic addressed the efficacy of prescription drugs or how various autoimmune diseases compared to others (Lesuis et al., 2012; Papoutsaki & Costanzo, 2013; Velez et al., 2012). Rarely was information found that focused solely on the effects and presentation of PD as a whole. This search was made even more difficult when only looking at females with PD. Few studies were found differentiating between males and females in relation to PD, its presentation, and treatment (Eder et al., 2012). However, through each of these search steps, valid and appropriate information was gathered that helped to create a holistic view of PD that particularly pertained to females.

The various searches used also helped to show a gap in the literature and how exposing this gap and seeking to fill it could be beneficial to not only those living with PD, but also the professionals relied upon to treat the disease. While the minimal data that were available proved frustrating, this lack of information helped to validate that current studies had not gone far enough or served to benefit all of those diagnosed with PD. Instead, existing information had served to help a limited population of those

affected, specifically those who sought to use pharmaceutical interventions (Boehncke & Menter, 2013; Lesuis et al., 2012; Liu et al., 2014; Picchianti-Diamanti et al., 2010). The missing populations in these studies were noticeably those whose members did not fit into a neat and chosen demographic.

The primary databases used in researching the current literature included PsycINFO, PsycARTICLES, and MEDLINE. I also sought out foundations such as the National Psoriasis Foundation in the United States and the Psoriasis Association of the United Kingdom. National health sites such as the National Health Service (NHS) in the United Kingdom were used and the National Institutes of Health (NIH) of the United States. I deliberately avoided sites that were sponsored by pharmaceutical interests to maintain an objective view. In addition, sites that focused on natural remedies and cures for PD were not used because their research was not documented in a way that could withstand scientific rigor. These sources also proved worthy in locating information on the following theories.

### **Theoretical Foundation**

Choosing a treatment plan for an autoimmune disease is often an overwhelming task. This choice comes with the understanding that the treatments are designed for symptom management and will not cure the person of the autoimmune disease. Choosing a treatment option involves people incorporating their belief system and way of life into how they address their treatment. The theoretical framework for this study used self-efficacy and self-in-relation theory.

### **Self-in-Relation Theory**

Many of the theoretical frameworks previously used in PD research stemmed from findings of studies with men as the subjects. Self-in-relation theory turns the focus to women and involves the understanding that much of a woman's "experience of self is relational" (Surrey, 1998, p. 2). In contrast to theories that focus on individuality, self-in-relation theory reflects an understanding that women tend to see themselves in the context of certain relationships. This theory emphasizes relationships in regard to one's experience and developmental process (Surrey, 1998).

Surrey sought to bring to attention to the notion that women need different developmental milestones and terminology that match women's development (Pilkinton, 2007). Self-in-relation theory takes out separation-individuation, which is the expected achievement of adults becoming independent, and replaces it with relationship-differentiation. *Mutual reciprocity* specifically defines the "link between a girl and her mother through their emotional sensitivity to one another" (Pilkinton, 2007, p. 28). The need to care for others is often ingrained in a girl from an early age as she observes her mother and seeks to emulate what her mother does. It becomes a constant, albeit normal, struggle to balance one's own needs with the needs of others.

This theory was originally proposed in the 1990s and is focused on women's psychological development (Pilkinton, 2007). The core of self-in-relation theory is the idea that females do not go through developmental stages and life events in a vacuum. Rather, these stages are experienced while the woman takes into account not only her needs, but also the needs of others and how these needs can be balanced (Pilkinton,

2007). Societal pressures along with expected norms may impact how a woman responds to a given situation. Women are often seen as caretakers; for a woman, having to become someone who needs care may not change the fact that one of her main goals is continuity in the family structure.

Gilligan was one of the earliest feminist researchers to take an in-depth look at women's development (Pilkinton, 2007), and she brought to light a study conducted based on Kohlberg's moral development theory (Gilligan, 1982). In this study, an 11-year-old boy and an 11-year-old girl were asked a moral question that centered on what a husband should do if he could not afford the medicine his ill wife needed to survive. The boy often had a clear and logical thought process concerning why the husband should steal the medicine and how this choice might come with consequences, but the benefits outweighed those consequences and were worth the risk. In contrast, the girl participant often had difficulty coming up with an answer as she analyzed how each of the relationships would be affected in the short term and the long term. The girl examined the situation from a relational view as opposed to viewing each person as standing on his or her own (Gilligan, 1982). To the girl participant, the decision was not one that only the husband should make. Rather, the druggist should have seen the dire situation of the wife and helped out. Boy and girl participants both perceived that some terms of agreement would need to be reached, but where a boy used logic and law, a girl used communication in relationships (Gilligan, 1982).

Transferring this idea to healthcare, it can be seen how pursuing the treatment option as laid out by a physician is what a patient "should" do, in that the physician is the

medical professional. However, from a relational perspective, a woman may be concerned about other aspects of treatment recommendations, such as side effects of the drugs prescribed, how the side effects could impact her relationships, and the cost of these drugs. That is, her choices will have consequences for those close to her. A woman diagnosed with PD may consider how her child's lifestyle or quality of life will be affected before she contemplates the personal effects of treatment options that are available to her. Likewise, a woman may consider her career as she works to find a balance between her job and her treatment options. The decision to pursue nonpharmaceutical treatments may stem from a woman's desire to balance self-care with the care of her family and maintaining relationships that she holds dear.

Self-in-relation theory can inform studies on women and health care. Women with PsA are more likely to experience medication side effects, have poorer quality of life, and quit their medications compared to men in similar circumstances (Eder et al., 2012). Self-in-relation theory allows medical professionals to see female patients as wives, mothers, caregivers, employees, employers, or daughters (i.e., in the context of their relationships and how these can impact how they decide on a treatment option).

Examining women in this relational context of disease management can allow for greater clarity concerning how and why women choose certain treatment options. This may then provide medical professionals insight that allows them to understand and support these women. Medical professionals also need to use this insight when working with these women in their treatment. Health care professionals and those who study health-related quality of life (HRQOL) need to take into consideration that perhaps



standard assessments such as the Dermatology Life Quality Index (DLQI) are sex-neutral (Lusuis et al., 2012). Lusuis et al. (2012) even suggested that physicians may modify their risk/benefit ratio, which could affect the treatment options that the physician offers. The assessments currently used for those with PD are not specific enough to how women experience the disease. Women's responses on these assessments could negatively impact their treatment options.

### **Self-Efficacy Theory**

Self-efficacy theory is another vital framework to consider when studying chronic diseases. Self-efficacy theory addresses a person's confidence in his or her ability to control his or her own motivation, behavior, and social environment (Bandura, 1997). Bandura's original theory of self-efficacy stemmed from the premise that outcome expectations and efficacy expectations differ because an individual may very well know that a certain behavior or course will lead to a specific outcome, yet he or she may doubt his or her ability to carry out these behaviors or courses of action (Bandura, 1977). In reference to health, patients may know that a healthy diet and regular exercise will benefit their well being but may feel that they are unable to carry out these tasks on a long-term basis. The possibility exists that if self-efficacy is high enough, an individual will be able to implement the changes needed to improve his or her health.

A chronic disease such as PD can be seen as a threatening situation which, according to Bandura's theory, could affect a person's self-efficacy due to his or her emotional arousal. Bandura's self-efficacy theory indicates that a small success for a

person, such as seeing symptom reduction due to a dietary change, may then improve his or her self-efficacy, leading him or her to try another alternative treatment option.

Perhaps women who seek to treat their PD without pharmaceutical intervention have high self-efficacy, which leads them to believe that they are capable of making necessary life changes to increase their health and confidently fight their PD. Viggers and Caltabiano (2012) presented research that stressed the importance of acceptance and self-efficacy on those with chronic diseases and their ability to adapt. Given the dire diagnosis of PD and the knowledge that it is a chronic and potentially debilitating disease may help solidify the need to take charge of one's health while also being confident in one's own ability to choose the treatment path best suited for the individual, and not necessarily the one prescribed by a medical professional.

Bandura's theory can be broken down into two components: outcome expectancy and efficacy expectation. Outcome expectancy is the person's assumption that a specific behavior will lead to a specified outcome, and efficacy expectation is the conviction of the person that they can actually carry out this behavior (Bandura, 1977). Bandura's two components are applicable in the decision-making process one must undergo when deciding on a treatment plan for a chronic disease, specifically PD. Self-efficacy can be nurtured from achieving various successes in differing areas of life. A resilient self-efficacy that may benefit those with a chronic disease can be cultivated and strengthened when one is pushed and overcomes obstacles (Bandura, 1997). One's efficacy expectations determine how much effort one will expend and persist in this effort in the face of adversity or opposition (Bandura, 1977).

Decisions are not made in a vacuum. A woman tends to take into consideration a multitude of factors. The stakes are high when confronted with a chronic disease so the incentive is great to put forth effort to successfully treat one's diagnosis. Most people may assume that listening to a medical professional's advice and utilizing pharmaceutical interventions may be the best course of action, yet women who choose not to utilize pharmaceutical intervention may very well have a determined path of treatment that they feel will lead to a better outcome or provide fewer risks than pharmaceutical treatment. Understanding self-efficacy in women who treat their disease naturally can lead to an understanding of the thought process and previous experiences of these women. It is beneficial that before looking at treatments, one should first understand PD.

### **Psoriatic Disease**

Psoriasis is a chronic inflammatory skin disease (Boehncke & Menter, 2013) that results in those affected having varying skin presentations of the disease depending on the type of psoriasis. Types of psoriasis include flexural, erythrodermic, pustular, guttate, nail, and plaque. Plaque psoriasis is the most common form with an estimated 80-90% of those with psoriasis having plaque psoriasis. Plaques are pink or red with silvery or white scales and vary in size and location on the body (Papoutsaki & Costanzo, 2013). These plaques are often the center of pharmaceutical advertisements for the treatment of psoriasis.

Psoriatic arthritis (PsA) is a chronic disease that involves the inflammation of areas around the joints and surrounding ligaments (Papoutsaki & Costanzo, 2013), along with the connective tissue between tendons and bones (Liu et al., 2014). These areas

usually present with stiffness, pain, swelling, and tenderness (Papoutsaki & Constanzo, 2013). The duration, severity, and location can vary greatly (Liu et al., 2014). Some discrepancy exists about the prerequisite of having psoriasis prior to being diagnosed with PsA. There is a subset of those with PsA who have been diagnosed “sine psoriasis” with a family history of psoriasis being enough (Scarpa et al., 2003).

The literature available circles the topic of PD without ever directly landing on the topic. Studies were examined that specifically looked at those who utilized alternative treatments for various health reasons. For example, a study conducted by Su and Li (2011) sought to examine the trends in those who used complementary and alternative medicine (CAM) from 2002-2007. While their data shed light on people tending to use CAM due to restricted access to conventional care, it did not describe what diagnoses the participants had that they were trying to address. Su and Li (2011) were clear in identifying racial and ethnic differences, but there was no mention of gender differences in those who are seeking CAM.

Astin’s study (1998) was slightly different in that it looked deeper into the meaning of why people sought out alternative therapies for their health care and specifically pointed to a gender difference. The reason given for minimizing gender differences was that they were extremely close in that 41% of the female participants and 39% of the male participants reported using alternative health care (Astin, 1998), although it was worth noting that this study did not include PD. The study by Astin (1998) provided some insight, though, into why people may choose alternative health which included more education, poorer health status, and having chronic pain.

PD can involve chronic pain from arthritis, enthesitis, dactylitis, spondylitis, psoriasis, and nail disease (Mease, 2012). This is an extensive list of symptoms to attempt to control. Studies so far have looked at pharmaceutical interventions and their effectiveness (Mease, 2012; Velez et al., 2012; Papoutsaki & Costanzo, 2013; Picchianti-Diamanti et al., 2010). This has left out those diagnosed with PD and how they treat their disease naturally, and the possible effectiveness of their treatment option.

Numerous qualitative studies were found that sought to understand what it is like to have a chronic condition, including psoriasis. Aujoulat, d'Hoore, and Deccache (2006) analyzed over 55 articles focused on those with chronic conditions and patient empowerment. Strikingly, the effectiveness of self-empowerment can be dependent on the health care provider and him or her implementing a “patient-centered approach...that acknowledges the patients’ experiences, priorities, and fears” (Aujoulat et al., 2006, p. 6). Turning the focus onto the patient and validating his or her experiences, with PD and living with PD, can help open a dialogue that allows for an honest discussion of treatment options available and why a patient may consider one option over another.

Another qualitative study that focused on those with chronic pain looked at resilience and coping strategies, and the psychological implications they had (Viggers & Caltabiano, 2012). This Australian study found that resilience played a minor role in mental well-being and that maladaptive strategies such as catastrophizing or taking on a sick person role can increase depression, anxiety, and stress, whereas coping strategies, whether positive or negative, can affect one’s HRQOL (Viggers & Caltabiano, 2012). Another study looked at a chronic condition, though not specifically PD, and was a

qualitative study aimed at understanding the strategies that women with fibromyalgia utilize (Traska, Rutledge, Mouttapa, Weiss, & Aquino, 2011). Fibromyalgia and PD have some similarities in that they can be “invisible diseases” where others may not be aware of a person’s health diagnosis. Both currently have no cure, and can be difficult to treat. Strategies were identified regarding how these women in the study coped with their disease on a daily basis. Some of these strategies included planning, being selective about activities, balance, environmental changes, and pushing themselves to accomplish what they needed (Traska et al., 2011). The findings also suggested that a lack of support from health care providers and other important people in their lives was difficult, but being able to share their experiences with others with the same disease proved beneficial.

While no studies specifically focused on women with PD, a qualitative study on those with psoriasis was conducted in 2009 by Magin et al. that resulted in the conclusion that psychological sequelae in psoriasis were definitely an issue. While the psychological issues may not be diagnosable, as they do not meet DSM-5 criteria, those feelings most prominent were shame, anxiety, depression, low self-esteem, stigmatization, and being self-conscious. Again, psoriasis can be unpredictable and unrelenting in its presentation. One cannot negate the psychological impact this disease can have. Unfortunately, the study acquired participants from a clinical setting so there is no way to decipher between those who were being treated pharmaceutically and those who were treating only with natural alternatives. Magin et al. (2009) suggested that a qualitative approach to this type of study was better suited due to the complexities of the psychological construct. This

study included psoriasis patients with a wide range of disease severity, allowing for better insight into those with psoriasis with varying degrees of presentation (Magin et al., 2009).

### **Differences in Gender**

Studies that have been conducted on PD alone have often combined males and females (Boehncke & Mentor, 2013; Grozdev et al., 2012). While the studies that have focused solely on PD have helped advance the knowledge of professionals of those living with PD, they have merely scratched the surface. These studies did not differentiate between genders. Eder et al. (2012) sought to understand the gender differences between males and females when it came to the presentation and treatment of Psoriatic Arthritis (PsA).

While PD tends to affect males and females equally, females have been shown to have symptoms that differ from males, while also having differing outcomes when treated with the same pharmaceutical interventions (Eder et al., 2012). Women tend to have multiple joints affected at one time, while men usually present with few joints affected. Females also tend to have poorer scores in patient-reported outcomes than males (Eder et al., 2012). These findings were interesting as males have more severe joint damage and women tend to endure a worse quality of life and limited functioning (Eder et al., 2012).

That same study by Eder et al. (2012) showed that females tended to experience a worse quality of life, worse fatigue, and more work disability than males with PD. Given the physical and mental toll of those with PD, it may benefit these women to have medical professionals who understand the reasoning behind how these women approach

and decide on a treatment plan. If women are more likely to discontinue the pharmaceutical route due to the negative physical, mental, and physical effects (Eder et al., 2012), it is valuable to understand what they are doing to treat the disease and why they have chosen that particular route. This same study suggested that social aspects could impact the way women and men view their health (Eder et al., 2012). Further understanding of the treatment options women utilize should be examined to ensure that treatment options are available for a diverse population. Perhaps natural alternative treatment options offer relief or fewer side effects.

Other studies conducted globally (Boehncke & Menter, 2013; Franks, Chapman, Duberstein, & Jerant, 2009; Grozdev et al., 2012) have shown that quality of life is negatively impacted by PD, thus there is a clear connection between mental and physical well-being of those living with PD.

### **Quality of Life**

Two of the ways that quality of life can be affected is with the unpredictability of the disease and the finding of a treatment option that works. As with any treatment, there is no guarantee that one treatment will work for everyone with that condition. An example of how quality of life may impact women and their relationships is when they are mothers. Remicaid® is an infusion drug used in the treatment of PD. Remicaid® requires the patient to go to an infusion clinic for at least two hours to receive the infusion about every 8 weeks with one dose costing between \$1,300-\$2,500 (Shiel, 2017). Based on these numbers a woman could potentially spend over 13 hours of her life receiving the infusion, not taking into account travel time, wait time, or a possible



reaction. The potential cost of over \$13,000 depending on health insurance and co-pays is also a real concern. Remicaid® also has the possible side effects of nausea, vomiting, back pain, and headaches which could impede one's ability to carry out his or her daily responsibilities (Shiel, 2017) and negatively impact his or her quality of life. A woman may opt out of this alternative due to time constraints and to ensure she is able to meet her parenting obligations including transportation, meetings, activities, meals, and other aspects of parenting that do not wait. Quality of life being impacted could lead to the pursuit of less constraining options such as natural alternatives. There is the possibility that she chooses a natural route for treatment so that she has fewer side effects and views it as more cost effective, including time and money.

Another way quality of life is affected is dealing with the physical aspects of the disease and being self-conscious, worrying about people noticing or commenting on the disease and fearing that it may be contagious (Magine et al., 2009; Kotsis et al., 2012). Magin, et al. (2009) defined the above aspects, as well as having an impaired self-image. Activities such as swimming, trying on clothes, or going to the salon can become battlegrounds in the mind of one with PD as these individuals need to be prepared for comments, stares, or denial of services due to the presentation of their psoriasis.

### **Diagnosis of Psoriatic Disease**

PsA is an inflammatory seronegative spondyloarthropathy that primarily affects peripheral joints (Boehncke & Menter, 2013). This definition means that PsA belongs to a family of chronic diseases that affects the joints. Symptoms of PsA are centered around the joints, but can also affect the surrounding ligaments and tendons. These symptoms

include stiffness, pain, swelling, and tenderness (Papoutsaki & Costanzo, 2013). These symptoms can be irregular and spontaneous, leaving those diagnosed with a guessing game of which joint or area of the body will be affected next and for how long. The outside and the inside of the body are susceptible, leaving the person seemingly at the mercy of the disease. The presentation of the disease can vary from person to person and day to day. Ruling out rheumatoid arthritis by performing a blood test that specifically tests for rheumatoid factor is one step used in the diagnosis of PsA. Should one present with inflammation of joints, have psoriasis or a family history of psoriasis, and have blood work that shows rheumatoid factor within normal range, he or she will often be diagnosed with PsA, even though there are currently not universal criteria for the diagnosis of PsA (Liu et al., 2014).

The Classification Criteria for Psoriatic Arthritis (CASPAR) is gaining acceptance in various healthcare settings (Liu et al., 2012). The CASPAR consists of the following five items being given certain point values: 1) current psoriasis or family history of psoriasis or nail psoriasis, 2) absence of serum rheumatoid factor, 3) current or prior history of dactylitis, which refers to the swelling and redness of a digit, 4) radiographic evidence of periarticular bone, which means it is occurring around a joint, and 5) new bone formation on x-rays of hands or feet (Velez et al., 2012).

Understanding the different symptoms and diagnosis of psoriasis and PsA is important as it allows for those with psoriasis to know that they could be at risk for developing PsA. Psoriasis is often the first to be diagnosed as the symptoms will usually present ten years before PsA develops (Boehncke & Menter, 2013). Psoriasis can be

diagnosed by a physical examination, a family history of psoriasis, and a general history of the patient and if he or she has recently been sick, been on any different medications, or has had a stressful life event. Psoriasis is often seen and managed in a family practice environment (Magin et al., 2009). Those that practice in a family practice environment need to understand that those diagnosed with psoriasis are susceptible to developing PsA, given that up to 20% of those with psoriasis could develop PsA (Boehncke & Menter, 2013). Misdiagnosing or mistreating these symptoms can cause permanent damage if left untreated, as PsA is progressive. Symptomology, diagnosis, and treatment are all aspects of PD that are vital. Gender differences that arise in these areas need more attention.

PD has no signs of slowing down in progression or numbers of those diagnosed. Thus, the job of the medical community, including mental health professionals, should be to meet these patients where they are at the time of presentation. Unfortunately, much of the current literature is vague on separating PD from rheumatoid arthritis, chronic pain, or those with psoriasis. Other arthritis or chronic pain diagnoses do not have the added skin symptoms that accompany PD. Psoriasis alone brings its own long-term impact on physical and psychosocial health (Velez et al., 2012), but PD needs to be able to stand alone in research given the impact it has on a person's overall wellbeing.

### **Treatment Options**

Treatment options can include pharmaceutical interventions, along with natural options. Unfortunately, there is no treatment that is guaranteed to work for all symptoms for any length of time on every person diagnosed with PD. The incurable aspect of the disease can wreak havoc on those affected, along with the seeming unpredictability of the

disease (Magin et al, 2009). The purpose of current treatment options is to minimize symptoms. The treatment does not only have to work for these symptoms, but has to also work in congruence with the responsibilities and relationships a woman has.

### **Pharmaceutical Options**

Most pharmaceutical treatments seek to minimize or eliminate symptoms, which may also negatively impact quality of life (Papoutaski & Costanzo, 2013). PD is a chronic disease, whose course waxes and wanes. Any treatment options provided are for symptom management, to minimize and slow joint deterioration, improve physical abilities, and reduce the risk of death (Liu et al., 2014).

A brief list of pharmaceutical treatment options includes corticosteroids, nonsteroidal anti-inflammatory drugs (NSAIDs), disease modifying antirheumatic drugs (DMARDS), and anti-tumor necrosis factor agents (TNF inhibitor), with each of these options carrying with them their own risks and side effects (Liu et al., 2014; Papoutsaki & Costanzo, 2013). Corticosteroids and NSAIDS are the initial treatment for those diagnosed with PD; however, they are meant to reduce symptoms and not slow progress. Once these two options are not benefiting the patient a DMARD may be added to their treatment (Liu et al., 2014).

Thus, a patient may be prescribed multiple, different medications for his or her treatment of PD with no guarantee of results. Moving to a DMARD poses more health risks, such as hepatotoxicity, which is liver damage that is drug induced. DMARDS are a more ideal treatment for those with mild PsA as opposed to NSAIDS or corticoid steroids, as these latter two treatment options will not slow down joint damage

(Papoutsaki & Costanzo, 2013). Other DMARDs include Cyclosporine, Leflunomide, and Sulfasalazine. Liu et al. (2014) noted that Cyclosporine has proven more effective when combined with a biological therapy, adding yet another drug into the life of a patient.

TNF inhibitors are known as biological therapies created to have more targeted treatments, and while a noteworthy endeavor, these biological therapies carry their own risks. Papoutsaki and Costanzo (2013) laid out clear requirements for those who are prescribed biological therapies. The recommendations include a physical and history of the patient needing to be conducted prior to starting treatment, along with liver function tests, platelet counts, and tuberculosis testing (Papoutsaki & Costanzo, 2013). Patients taking biological treatments need to be regularly monitored, and severe infections could lead to the temporary or permanent discontinuation of the treatment. Those who watch television may be familiar with a few common biological treatments that are regularly advertised, such as Humira®, Enbrel®, Remicade®, and Stelara®. Most treatments for PD suppress the immune system, which makes the patient more vulnerable to infection and certain diseases, including cancer (Boehncke & Menter, 2013).

These treatment options can affect men and women differently, with studies showing that anti-TNF agents are more likely to be discontinued earlier by females than males due to possible less effectiveness in females than males (Eder et al., 2012). European studies (Magin et al., 2009) have also shown that females may suffer a higher number and worse side effects from these drugs than their male counterparts. A study conducted in 2012 resulted in a noticeable difference in the males prescribed biological

agents than females, while the females showed significantly higher scores on the DLQI (Lesuis et al., 2012). The DLQI is an assessment on how the effect of the skin disease affects one's health related quality of life (HRQOL). The scores can range from 0-30 with the higher the score representing worse HRQOL (Lesuis et al., 2012). This particular study showed that women have a greater score than men, by more than 10 points, even though men showed more psoriasis according to the Psoriasis Area and Severity Scale (PASI). Thus, one needs to carefully weigh the costs and benefits of living with the symptoms of the disease vs. the side effects of the drugs.

Side effects are most prevalent for those who treat their PD with anti-TNF- $\alpha$  agents. Anti-TNF- $\alpha$  agents have significantly changed the treatment of PsA over the past 15 years as they have been shown to be effective in controlling symptoms and preventing joint damage (Eder et al., 2012). However, women have been shown to quit this treatment option earlier than males and have seen a more inferior response to treatment than their male counterparts. Females tend to have more adverse side effects as well, which contributes to early termination of the drug. Eder et al. (2012) suggest that sex hormones and musculoskeletal performance could explain why females tend to not respond as well as males do to anti-TNF- $\alpha$  agents; however, no formal studies have been found to support this idea.

### **Alternative Treatments**

While not as popular or well-advertised, alternative treatment options do exist for those with PD. Some of these treatment options include diet, supplements, exercise, acupuncture, and lifestyle changes (Astin, 1998). Astin (1998) conducted a survey to

help determine why patients use alternative medicine for their health care treatment. The reasoning was not so much a negative concept of pharmaceutical intervention, rather, it was because alternative treatments better aligned with certain patients' values and beliefs. Astin's findings (1998) suggested that those seeking alternative treatments for their healthcare appreciated the connection between mind, body, and spirit, and have had some transformative event in their lives that has significantly changed their world view. While this study did not specifically mention any type of medical condition, it is reasonable to suggest that being diagnosed with a chronic, potentially life-altering disease such as PD can be classified as a transformative event in one's life. Astin (1998) also presented that for those who have struggled with their health, it is their continuing suffering that has led them to seek alternative treatments. Perhaps the suffering and the unpredictability of PD can cause one to lose hope in treatment options or to continually be searching for a treatment option that will reap the most benefits with the fewest amount of costs, financial or otherwise.

Investigation into alternative medicine may give people with PD hope that perhaps a cure exists. Yet when the patient goes to the doctor he or she will be told that it is not curable, but may go into remission. The physician, however, can give no reasoning as to how or why some people go into remission. Prescriptions will be discussed as a way to improve symptoms associated with PD. This reasoning may work well for some patients, but others may leave their doctor's office less than satisfied. Further research is needed in the area of alternative medicine to know more clearly its efficacy and possible interactions with pharmaceutical interventions (Su & Li, 2011).

Patients that choose alternative routes need to determine which alternative route to take, what information to trust, and how much they are willing to invest in the process. While alternative medicines may be cheaper than prescription drugs, many insurance companies do not cover alternative treatments, such as diet protocols, supplements, or therapies such as acupuncture. The patient now has to decide if the out-of-pocket cost is worth the chance of becoming symptom free, with fewer side effects. The United States Food and Drug Administration's (FDA) oversight of prescription medications may make them appear safer. Oversight of supplements and alternative medicine usually is less stringent, and often results rely heavily on testimonials. While a debate can be made about this subject in and of itself, the patient needs to decide for him/herself which option better aligns with personal values and identity.

It can become a difficult choice when side effects are negatively impacting quality of life when, ironically, they are expected to help improve one's quality of life. While pharmaceuticals may indeed slow the disease, the cost/benefit ratio regarding quality of life is an important factor for patients to consider. The Australian study by Magin et al. (2009) suggested that just the physical symptoms cannot be treated, rather an approach that focuses on the patient and his or her coping and active involvement in treatment decisions could help alleviate the negative psychological impact. These researchers further noted that these results may not carry over to those that do not utilize pharmaceutical interventions. Reaching out to those with PD who are not seen at a clinic would give a clearer and more accurate picture of the range of treatments utilized by those living with PD.



The participants in the study by Magin et al. (2009) showed a theme of feeling a lack of control over the disease. As they were recruited from doctor's offices and thus receiving pharmaceutical intervention, it begs the question of what psychological themes are present in those who are treating their PD with natural alternative treatment options. Examining quality of life in those with PD has shown repeatedly that quality of life is negatively impacted (Boehncke & Menter, 2013; Eder et al., 2012; Grozdev et al., 2012). Understanding decision-making and life experiences of those affected by PD has the potential to benefit health professionals in the incorporation of therapies that meet the needs of the patient. A general approach used on all patients as if they were the same just because of a similar diagnosis may show to be an outdated approach.

### **Quality of Life**

Males and females are shown to have the same rate for being diagnosed with PD, yet women have been shown to suffer from a lower quality of life due to the disease (Hammadi, 2016; Magin et al., 2009). PD is a physical disease that also comes with a high risk of psychological comorbidity (Magin et al., 2009). Ample studies have shown that chronic conditions affect one's quality of life. However, few have sought to better understand treatment options and if treatment options can impact quality of life (Eder et al., 2012; Boehncke & Menter, 2013; Grozdev et al., 2012). Resiliency has also shown to be an important factor when dealing with chronic pain (Viggers & Caltabiano, 2012); however, chronic pain does not fully encompass the physical appearance that accompanies a disease like PD. The unpredictability over psoriasis outbreaks and knowing it is a chronic condition can be some of the most burdensome factors of the

disease (Grozdev et al., 2012). The erratic presentation of PD is a complex area, as having participants complete assessments while in a remission or during a severe outbreak could affect how they respond.

PD is a disease that severely impacts many, if not all, areas of one's life. While males and females are affected at similar rates, treatment options have shown better efficacy with males than females. Given there is currently no cure or proven prevention, empowering females to live full and productive lives is vital. This starts with working to understand women with the disease and how their perspectives, values, and beliefs can influence interpretation, coping, and treatment choices of these women. The psychological impact cannot be underestimated and should be part of the treatment plan. Many psoriasis patients are seen in a family practice setting. Perhaps it is not enough to seek specific medical professionals such as a general practitioner, dermatologist, and rheumatologist for disease monitoring and management. It would likely be beneficial to have psychological management and monitoring as well as part of routine care.

Medical professionals may need to adjust and work to better understand the patients' point of view and take into consideration the psychological impact of the disease and the negative impact it can have on one's life (Grozdev et al., 2012). While the physical symptoms may be predominant, it cannot be the sole factor when determining severity.

Viggers and Caltabiano (2012) began this endeavor with the examination of how psychological functioning can impact adults with chronic pain. This study helped unite mental and physical health and change the focus of care to caring for the whole person.

The stance of the researchers was resiliency and how coping strategies impacted psychological functioning on Australian adults with chronic pain (Viggers & Caltabiano, 2012). This begged the question about the participants and their choice of treatment. Researchers need to take into consideration the multifaceted areas of disease and how each of the physical and psychological areas need to be treated, and that it is just as important not to overlook areas, such as the psychological impact of a disease (Grozdev et al., 2012).

The use of alternative medicine is increasing in those with various health issues including cancer, depression, chronic pain, and diabetes (Astin, 1998). A holistic approach is starting to gain momentum as researchers continue to find significant comorbidities in systemic inflammatory diseases like psoriasis (Velez et al., 2012). Comorbidities can also include psychological diagnoses such as depression and anxiety, so including mental health professionals on the treatment team creates a more holistic approach (Magin et al., 2009). While PD is a chronic condition and is often accompanied by chronic pain, it should not be under the same umbrella as other chronic diseases or with a general term such as chronic pain (Kotis et al., 2012).

Studies exist looking at the effectiveness of pharmaceutical interventions and effects on quality of life, but few, if any, studies look at quality of life for those who treat their PD with natural alternative treatment options. Understanding the lived experience of women who treat their PsA non-pharmaceutically could help various health professionals reach out to this population and better understand and support their treatment choices.

### **PD and Mental Health**

It has been shown that PD can negatively impact one's quality of life (Papoutsaki & Costanzo, 2013). The impact PD has on women especially can be multifaceted. Not only are these women faced with a physical battle that is not always visible, there is also a psychological battle. They must contend with a society that can be unforgiving of physical flaws and where appearance can impact employment and appropriate compensation (Stork, 2015). Research has shown that PD is associated with numerous mental disorders and negatively impacts psychological and psychosocial functioning (Ferreira et al., 2016; Kurd, Troxel, Crits, & Gelfand, 2010; Lee et al., 2010). An important point is that PD is not a one-way street where this disease leads to an increase in risk of mental disorders and increased stress. Rather, research has shown that stress and depression can also greatly increase the risk of the development of PD (Leavitt, 2015).

Much of the research that is available has again centered on the use of pharmacological intervention to help combat depression. While the purpose of these treatments is to help restore serotonin levels, as well as decrease inflammation, there are still risks involved. As mentioned earlier in this chapter, some medications available to treat PD also block TNF-alpha's disruption of serotonin, which has shown to improve these patients' mental functioning and moods (Leavitt, 2015). The drawback with this approach is it is a costly treatment that women with PD may choose to avoid. As the realization of the economic burden of PD is realized, policy makers need to understand the various treatment options available and the holistic approach that needs to be taken in

the treatment of PD (Lee et al., 2010). The concern was that this study largely focused on pharmaceutical approaches to the treatment of PD in all its forms, whether physical or psychological. Reasons for this avoidance were previously discussed in this chapter and included financial cost, time burden, and lowered immune system. These studies have shown what pharmacological interventions can be utilized to combat mental health diagnoses such as depression, this then leaves out those who choose a non-pharmacological approach to treatment of their PD.

Stork (2015) reported that a key component in the mental health treatment of those with PD is to reinstate some sense of control. PD is an unpredictable disease that currently has no cure. These two factors can greatly impact the view a person has pertaining to the life that is capable of being lived. While men are frequently taught to solve their own problems and be independent, women are not always raised with this sense of being in control of their future (Stork, 2015). The National Psoriasis Foundation conducted a survey of almost 5,000 patients with psoriasis that showed 20% of these women considered psoriasis a large problem in their everyday lives, as opposed to 12% of men (Stork, 2015). Medical professionals should also educate women with PD on the mental health impact of the disease and include it in the treatment plan (Leavitt, 2015). It has been recommended that patients would be served best by a psychodermatologic approach (Ferreira et al., 2016). The psychodermatologic approach seeks to emphasize the mind-body relationship. Ferreira et al. (2016) conducted a systematic review to examine the link between psoriasis and mental health disorders. While gender was not a focus of this study, their results indicated several studies had shown females have a

higher risk for secondary psychiatric comorbidities (Ferreira et al., 2016). Had they included PsA in this study, perhaps a stronger link could have been made between psychiatric conditions associated with PD. Regardless, the study suggested that the treatment of either the physical or psychological aspect of psoriasis could impact the other (Ferreira et al., 2016). Based on the psychodermatologic approach, PD should be treated from a biopsychosocial model that treats the whole person (Leavitt, 2015). The participants for this study included males and females who had been diagnosed with psoriasis. The study did not clarify what percentage of these participants also had PsA. Leavitt (2015) stressed that patients need to be aware of their moods and possible changes, so that they can reach out for help in a timely manner. A study conducted in 2002 had two groups of participants with psoriasis (Leavitt, 2015). Leavitt noted that one group completed six weeks of group therapy that taught coping skills, and strategies on how to overcome negative thoughts, while the other group did not have this opportunity (2015). It was found that after six months over 60% of the participants in the group therapy had over 75% improvement in their psoriasis, compared to 23% in the control group (Leavitt, 2015)! Stork explained the extent of women's suffering, especially as they cope with a society that highly values physical attractiveness. Women tend to adjust their clothing choices based on the presentation of the psoriasis. This approach works when the psoriasis is not visible on parts of the body not normally covered but is near impossible on areas of the body such as face, neck, and hands that are normally visible. A major component of mental health treatment is acceptance. Acceptance of a disease that has no known cure and no predictable pattern.

Acceptance can be a portion of mental health treatment. Approaches, such as cognitive-behavioral therapy (CBT) and Acceptance and Commitment Therapy (ACT) work to empower clients (Leavitt, 2015; Hulbert, Storey & Wilson, 2015). ACT works to have clients develop valued directions that help drive their decision-making. Rather than have clients work to eliminate negative thoughts, they work to accept them as just that, thoughts (Hayes, 2006). The study by Hulbert et al. (2015) looked at the application of ACT on patients diagnosed with cancer. Cancer is similar to PD in that it can be a life-threatening and chronic condition. ACT seeks to increase the psychological flexibility of a person, so as to improve their ability to cope in stressful situations (Hulbert et al., 2015). This translates over into PD, as clients can make the switch to view their disease as just that, a disease. PD is not their identity, but it is part of who they are. This concept may not be an easy one to internalize due to the impact it may have. CBT is another approach that has been useful in the empowerment of women (Stork, 2015). Teaching coping strategies, such as mindfulness meditation, may help empower these women and increase their psychological well-being (Leavitt, 2015). Mental health treatment could also be of benefit for those with a genetic predisposition to PD. Due to the heightened risk of psychological comorbidity, researchers have suggested that patients with a diagnosis of psoriasis be assessed for depression, anxiety, and suicidality (Kurd et al., 2010). Learning coping skills and having strong emotional health would be beneficial prior to the potential development of PD.

## Summary

Psoriasis affects an estimated 2-3% of the world population with a wide range of 6-30% of these individuals going on to develop PsA. While males and females are equally afflicted with the chronic disease, it has been shown that presentation and effects of the disease can vary widely between genders, with women experiencing lower quality of life and less drug efficacy than their male counterparts. This chapter explained the reasoning behind the organization of the research and the study. The purpose of this research was to understand the lived experience of women diagnosed with PD and how they decided on a non-pharmaceutical treatment plan. It was important to convey the seriousness and complexities that go into this process with the understanding that these are not numbers, rather they are mothers, partners, employees, bosses, teachers, and others that the general public is likely to interact with daily.

Researchers have recently been able to specifically look at PD with its full clinical presentation. Numerous studies have also looked at the psychological effects PD can have (Eder et al., 2012; Liu et al., 2014). The statistics we do have bring vital points about the psychological sequelae of PD, but it noticeably excludes those who are not treating their disease with natural alternative treatment options and why they are choosing to do so. The lack of resources on women who treat their PD with natural alternative treatment options is unacceptable. The implications these findings can have on mental health treatment are significant, given the impact PD has on psychological well-being. Studies have shown the harsher side effects of current pharmaceutical treatment options (Eder et al., 2012), yet little research has been conducted on these women and their



experiences with choosing a non-pharmaceutical path. It is also lacking a patient-centered approach to patients in an effort to reduce psychological co-morbidity (Magin et al., 2009). Velez et al., (2012) suggested further study on the impact of a holistic approach to help improve quality of life and health care efficiency. Understanding the lived experience of these women with PD who treat naturally helps to better understand this concept. Given the psychological impact of PD, mental health professionals need to understand the complexities and psychological impact of PD. The research method described in Chapter 3 will be used to understand the lived experiences of these women who choose to treat their PD with natural and alternative treatments. This phenomenological study consisted of interviews with women who have been diagnosed with PD and who are currently not utilizing pharmaceutical interventions. The complete layout of the research and design, along with ethical considerations are described next.

## Chapter 3: Research Methodology

### **Introduction**

The examination of the decision-making processes of women with PD who have decided on a nonpharmaceutical treatment plan may allow researchers and healthcare providers to better connect with these clients in a supportive role. Previous studies have highlighted the lower quality of life in people diagnosed with PD, but it is yet to be determined how those diagnosed with PD come to the decision of how they treat their disease and why they choose a specific course, specifically alternative treatments (Boehncke & Menter, 2013; Eder et al., 2012; Mease, 2012). This study was conducted using a qualitative approach, specifically transcendental phenomenological research. This chapter details the design of the study, including why it was chosen, how it was used, the role of the researcher, and ethical considerations.

### **Research Design and Rationale**

The methodology for this study was qualitative because the primary purpose was to explicate the meaning and essence of lived experience pertaining to a specific phenomenon (Christensen, Johnson, & Turner, 2010). Qualitative researchers not only seek to understand the lived experience of a person regarding a specific phenomenon, but also attempt to make sense of the meaning that this phenomenon brings to the person (Creswell, 2013). The purpose of this study was to closely examine the decision-making process of women with PD who have chosen to treat their disease with natural alternative treatment. The research questions for this study were able to be more accurately examined and answered through a qualitative approach.

Feminist research aligns well with qualitative research. As discussed in Chapter 2, self-in-relation theory was one of the frameworks used for this study due to this theory taking into account how women view the world, with the notion that much of their view is relational. Feminist researchers seek to enhance the voice of women by understanding that all descriptions of experience and reality are made from a particular standpoint (Willig & Stanton-Rogers, 2011). This stance coincides well with phenomenology and with my aims as the researcher in this study. It was my intent to be able to convey to the audience the experiences of these individuals from their unique perspectives.

Another advantage of phenomenology is that there exists a general understanding that a relationship exists between the mind and the world (Howell, 2017). Using phenomenology, I sought out the description of the lived experiences of these women in how they decided on a treatment plan that did not include pharmaceutical interventions. With such little existing research on the topic, this qualitative approach was intended to create a foundation that could help lead researchers to better understand this decision-making process. Further study on the topic will allow for more attention on the treatment of not only the disease, but also the person who has the disease.

Phenomenology was chosen over other qualitative approaches because phenomenology is used to describe lived experiences. Bloor and Wood (2011) described how Amedeo Giorgi stressed that the role of psychological researchers was to gather specific descriptions of a specific event and then look for the meanings of these phenomena. Within phenomenology, it is important for the researcher to ask questions

that produce information as to what the experience of the phenomenon was like for the person who encountered it (Bloor & Wood, 2011).

Phenomenological research involves asking participants open-ended questions in an attempt to elicit descriptions of specific events; in this study, I sought information on choosing treatment options pertaining to PD. From this information, I was able to describe the structure of the experiences through reflection and interpretation (Moustakas, 1994). The goal of this process was to determine the meaning of these experiences and to develop more general meanings. This methodology allowed for the participants to describe their experiences in their own words. Open-ended questions made it possible for the participants to verbalize their experiences from their perspectives.

With limited knowledge of women diagnosed with PD who treat their disease naturally, phenomenological research assisted in laying a solid foundation in developing themes and meanings from these participants' stories. The foundation will potentially lead to further research in this area and help health professionals develop a greater understanding of this population and how best to serve them. I was able to generalize and present the data collected in a way that encouraged readers to become emotionally engaged (Bloor & Wood, 2011). Below are the research questions that were the focus of this study.

RQ1. What is the lived experience of the decision-making process for women with PD who choose alternative or complementary interventions as opposed to pharmaceutical interventions?

RQ2. How do they feel about the treatment decision they made, and what benefits have they noticed?

### **Role of the Researcher**

Using a qualitative approach required me to first seek to understand the workings and purposes of the qualitative method. Qualitative research requires the researcher to have self-knowledge and awareness. Perhaps the most challenging aspect of qualitative research is that, as Janesick (2011) observed, in order for participants to trust the researcher, the researcher needs to trust him- or herself. Janesick went on to say that the researcher then must have “solid knowledge of the self” (2011, p. 4). This is a powerful idea in that it suggests that it is not just the interviewing of others that is important, but also the relationship of the researcher with herself. Each of the participants in this study shared a common thread, yet each participant brought her own perspective, experiences, and self-awareness.

My role as the researcher was decided after much consideration. Husserl, a German philosopher who is credited with founding phenomenology, emphasized the importance of first-person perspectives (Howell, 2017). It was my intent to be able to present the experiences of women who had been diagnosed with PD and had to decide what course of treatment to pursue and what this process was like for them. It should be noted that I have been diagnosed with PD and have also experienced and continue to experience the process of deciding on a treatment plan. Phenomenology posits that the researcher should work to bracket his or her experience so that the data collected will be viewed from a fresh perspective (Creswell, 2013).

While it would be ideal to have only this fresh perspective, all people experience events in accordance with their own beliefs and past experiences. Assuming a phenomenological attitude requires the researcher to bracket his or her own beliefs and experiences. The researcher also works to take the experience as a phenomenon for the person, not necessarily a reality in the world (Giorgi & Giorgi, 2011). These are two heavy expectations to have of any researcher, yet by reaching for these ideal standards, a researcher may stand back from his or her understanding and interpretation (Ladkin, 2014). The importance of the researcher viewing data collection from this vantage point is that it has the potential of enabling the researcher to hear other experiences in a way that is new, allowing for various perspectives to be taken.

I was constantly vigilant in my awareness of my own biases and experiences and how these had been handled throughout the research process. I disclosed my diagnosis and treatment choice to each participant. My diagnosis of PD brought a wealth of knowledge to the table, in that I was able to empathize with those being interviewed because I had experienced similar struggles, feelings, and emotions. One is never free from one's own perceptions and past experiences; this can hamper one's efforts to fully understand another's experience (Howell, 2017). However, it is possible to be aware of one's own experiences and perceptions while also seeking to understand another's.

## **Methodology**

### **Participation Selection Logic**

The population that was used for this study consisted of women who had been diagnosed with PD and were currently using nonpharmaceutical treatment options. The

purpose of criterion sampling was to select cases that met a specific set of criteria. Using criterion sampling for this research ensured that those interviewed all had the same general background. The criteria were not extensive. However, the criteria were meant to ensure that the data collected came from sources that were similar.

Four selection criteria were applied. The first was that the participant needed to be a biological female who identified as a female, which helped to ensure that the participants were similar in gender and gender identification. The second criterion was that all participants needed to have been diagnosed with PD by a physician. Each participant had experienced psoriasis and symptoms of PsA. The literature described the varying symptoms that can be experienced by those with PsA, as well as the degree of severity and the differing presentations of psoriasis (Boehncke & Menter, 2013; Liu et al., 2014; Papoutsaki & Costanzo, 2013). I was concerned only that the participants had been diagnosed with PD. The various presentations of the disease were described but were not part of the criterion. The next criterion was that the participants had been using only nonpharmaceutical approaches for at least 6 months. This time limit helped give some stability to the participants. Those who had recently gone off of medications might still have felt effects that may have inhibited accurate insight. Ensuring that timeframe also allowed for the participants to have a chance to better gauge their perception of their choice. The last criterion was that the participant spoke and understood English and had access to the Internet and a computer. I applied these criteria solely for the purpose of accurate data and accessible participants.

One criterion that was not chosen was that the participant would only have used nonpharmaceutical treatment options. This criterion would have prohibited data from being gathered from those who may have chosen a pharmaceutical route at some point in their treatment and brought further insight into their choosing of non-pharmaceutical interventions. Another criterion that was eliminated was age. While I was seeking a lived experience of a similar population, the ideal study also sought to be diverse in allowing for varying perspectives. This same reasoning was also used when eliminating race, ethnicity, and country of residence. The far reach of the Internet allows for those across the globe who share the same experiences to be able to connect. The common experience for this study was that women who had been diagnosed with PD were able to share how they came to decide to treat their disease nonpharmaceutically.

### **Setting and Sample**

The participants were located through two Facebook support groups for those with PD. One of the support groups had a primary focus on being supportive to all those with PD and the daily struggles of this disease, along with peer advice concerning medications and treatments. The other Facebook group focused on the nutritional aspect of a person's health while trying to navigate life with PD. It was my intent that a diverse sample be sought. Online support groups allowed me to reach individuals with PD who might not have been accessible at medical clinics. After the approval of the site administrators, an advertisement was posted that requested participants for the study. The advertisement included the purpose of the study, the requirements of being a participant, and a small biography of the researcher (see Appendix A). Those who



responded to the advertisement were given a brief description of the study and asked to sign an informed consent.

The number of those to be studied varied, as the research concluded when the data were saturated. Qualitative research does not place requirements on the number of participants, with a general rule being to interview participants until the data becomes repetitious so that no new themes are emerging. For this study, I sought to acquire 20 potential participants who met the criteria and were willing and able to be interviewed. The participants were interviewed by their availability. Even though the target sample was 10 participants, saturation was reached after seven participants. It was communicated via electronic mail that should a participant be unable to complete an interview within a given timeframe, the participant would be removed from the study. This only happened in one instance.

### **Instrumentation**

Within qualitative research, the researcher is often a vital instrument, so ensuring that the researcher is well-prepared is invaluable. The researcher carries the responsibility of recruiting participants, collecting data, analyzing data, and reaching conclusions. Organization is important so that there is a clear protocol that will be followed and can be replicated if needed. I started by preparing an open-ended interview that included all questions to be asked of all participants (see Appendix C). Patton (2002) clearly stated that the quality of the information garnered relies heavily on the interviewer.

The interviews that I conducted were audio recorded and were then transferred to my personal computer. My computer is password protected, and the data have been stored in a file that is discrete. The information has been stored using a numbering system so that participant names are not attached to the data. The data will be stored for 7 years.

### **Data Collection and Explication**

The data collected for this study consisted of one-on-one open-ended interviews. Consistent open-ended interviews allow for a specific set of questions, which is beneficial for a few reasons. First, consistent questions ensure that the same questions are asked of each participant, which allows for easier inspection by those who will use the study. Next, consistent questions help to ensure a highly-focused interview and the most efficient use of time. Also, the analysis was easier to complete afterward as responses were easier to find and compare (Patton, 2002). The consistent questions also helped to ensure that the necessary questions were asked. Open-ended questions were asked with the exact wording and sequence of questions being predetermined. I used my discretion to ask follow-up questions when I determined that additional information would be beneficial to the research.

Some of the questions asked were as follows: How long have you been diagnosed with PD? How long did it take you to get diagnosed, once you realized something was wrong with your health? What treatment options were presented to you after you were diagnosed? How did you become aware that treatment options besides pharmaceutical interventions were available? How do you stay current on what treatment options are

available to for PD? What was your thought process when deciding that pharmaceutical treatment was not what you wanted? What were the contributing factors in the decision? How do you feel about the choice you made? Did you discuss your decision with your doctor? How did your doctor respond? Do you regularly go to a medical doctor for disease management? Do you see any other medical professionals, such as a naturopathic physician?

That being said, bracketing was used so that I could put aside my experiences and approach the participants' experiences with a fresh perspective. Bracketing, or *epoche*, which is an ancient Greek term, is a suspension of judgement (Howell, 2017). This is an important aspect of phenomenology. *Epoche*, which can also be referred to as *transcendental phenomenology*, entails looking at these lived experiences just as they are, without interference.

### **Explication**

*Explication* was used in place of the word *analysis* because explication has the connotation of researching a phenomenon while keeping the context whole, whereas analysis has the implication of seeking to break the data apart (Groenewald, 2004). Explication of the data was conducted using the following five steps: bracketing and phenomenological reduction, delineating units of meaning, clustering of units of meaning to form themes, summarizing each interview, and extracting general and unique themes from all interviews and making a composite summary.

Bracketing, as previously mentioned, is a deliberate step in which the researcher sets aside his or her own experiences and takes the data as being new information, with

no opinion being formed. Groenwald (2004) suggested that listening to interview recordings repeatedly to become familiar with the data can help one embrace the participant's experience. These interviews were transcribed on my personal computer. Delineating units of meaning involves separating the information that specifically showcases the phenomenon. This stage was used in conjunction with bracketing as I needed to work to see the data without my perceptions and draw out what was important based on the data and the research purpose.

The next step, clustering of units of meaning to form themes, requires the researcher to use his or her "artistic judgment" (Groenwald, 2004, p. 19). The clusters were created by me grouping the units of meaning together and the researcher identifying significant topics. NVivo was not needed for this step. Each summarized interview included the themes discovered in the data. This step involved reaching out to the participants to see if they were interested in reviewing the summary to ensure the participant's information was correctly conveyed. This step helped ensure validity (Groenwald, 2004).

The last step called for me to look for the common themes as well as the individual themes that emerged. This required me to be familiar enough with the data to be able to separate common themes if differences occur. The above steps revealed what was gleaned from the data. These steps brought these everyday descriptions into a scientific language that was able to lay the foundation for theorizing, no matter how small (Groenwald, 2004).

### **Issues of Trustworthiness**

Having research that is valid was my intent. Qualitative methodologies have criteria that researchers follow to ensure that the issue of trustworthiness is addressed. These criteria are credibility, transferability, dependability, and confirmability (Morrow, 2005). Credibility involves the researcher acquiring thick descriptions from the participants that not only include the phenomenon, but the context and culture as well (Morrow, 2005). Addressing credibility requires the researcher to take time with the participant during the interview and to check back with the participant afterwards. Sharing the summary of the interview with the participant allowed me to hear feedback from the participants and ensure that the participant's experiences were conveyed accurately. A potential drawback was that the participant may not be willing to participate or available at this step. Fortunately, only one participant did not respond to the summary, As previously mentioned, it benefited me that I was familiar with the data, which aided in me using my judgement to understand the participant's experience.

Transferability can prove to be a difficult task as it is not same as generalizability, as known in quantitative studies. Rather, transferability is achieved with the researcher being transparent and open about the research. I provided the information on myself as the instrument along with context, processes, participants, and relationships, which allowed the reader to decide how these findings can be transferred to a more general population (Morrow, 2005). It was not the intent that these findings will be generalized to other populations or settings, nor should the reader assume this.

Dependability can be accomplished by the researcher documenting the process, from the designs to data collection to analysis. Morrow (2005) stressed the researcher use a log to keep detailed records of activities, processes, influences, emerging themes, categories, and analysis notes. I had a notebook used to document dates and thoughts on the research and the steps taken. This allowed for others to fully understand this research and enable them to repeat this study if they should choose to do so. The last criterion is confirmability. Confirmability is based on the premise that research is never fully objective (Morrow, 2005). However, there are ways to address this issue. Reflexivity was used, as I disclosed my biases and necessary experiences that were mine. Ensuring confirmability was an ongoing process of keeping detailed records and constantly being aware of personal biases at all stages of the research. It is through these four areas that this research maintained high standards. Trustworthiness can be a constant influence, as well as ethics, which will be described next.

### **Ethical Procedures**

The purpose of this study could have unintentionally led to the participants experiencing reactions that they may have had difficulty coping with. The researcher took this risk seriously and sought to have the participants be as educated as possible about the research and what it entailed. This began with recruiting participants in a respectful and transparent manner. The Facebook pages previously mentioned as sources for locating participants have strict guidelines for soliciting. I prepared a document to be sent to the page administrators detailing the researcher and my study (see Appendix A). Once these administrators agreed, an agreed upon post was created and posted for

potential participants (see Appendix A). Given the anonymity of the internet, private messages were encouraged for initial contact with phone number exchanges to follow.

Prior to the interview participants were able to ask any questions they may have had for me. I explained the research to the participants prior to them signing the informed consent form. Participants were informed that they may opt out of the research at any time and for any reason. Participants were then asked in the interview how they were feeling and were made aware prior that should they begin to feel intense emotions to notify the interviewer. If a situation arose where the participant felt she needed to speak to a mental health professional, I would have directed the participant to mental health professionals in the area in which she lives, if she was not currently in therapy with a mental health professional. Fortunately, this was not a concern for any participant involved in this study.

Confidentiality was treated with the highest regard. Each participant was assigned a number, and that number was how they were identified in the research, as well as how the interviews were identified. I know the identities of the participants, but will not share the information without the participant's consent. The participant was informed of this confidentiality prior to the interview as well as how her data were to be stored and used. The participants were informed that data was to be stored on the researcher's personal computer. They were also made aware that my personal computer is password protected and that the information will be stored using numerical identifiers, rather than the participants' names. Participants were also informed that per APA guidelines, data

will be stored for 7 years. Participants had until the follow-up communication to pull out of the research. None of the participants chose to be removed from the study.

The researcher is the sole person with the number and identity key. That being said, those with access to the raw data include myself, dissertation committee, and only necessary Walden staff, such as the IRB. Raw data will be destroyed by being deleted from my personal laptop after seven years. Participants were provided the option of being notified when their data are to be deleted. All participants denied this option.

### **Summary**

This chapter laid out how the research was conducted, stored, and analyzed. Information was also provided on how the participants would be recruited, informed, and interviewed. The researcher as the instrument was carefully described in hopes of conveying the importance of being that instrument and the necessary responsibilities.



## Chapter 4: Results

The purpose of this study was to examine the lived experience of women with PD who had chosen to treat their disease with natural alternatives as opposed to pharmaceutical interventions. Through this research, I sought to fill a gap in the literature on how women make decisions in regard to treatment of PD. Another purpose of the study was to provide greater understanding of this population, which could be beneficial not only to women, but also to practitioners who work with them. The research questions were the following:

- RQ1. What is the lived experience of women with PD who choose alternative or complementary interventions as opposed to pharmaceutical interventions?
- RQ2. How do they feel about the treatment decision they made, and what benefits have they noticed?

In this chapter, I examine the setting of the study and how participants were recruited. I look at how the participants differed in how they were chosen and their demographics. Participant information is provided, including the number of participants, duration of interviews, and variations from the original research plan. I also explore the four areas of trustworthiness mentioned in Chapter 3: credibility, transferability, dependability, and confirmability. Finally, I present the findings of the research and address saturation, nonconforming data, and how I approached each research question.

### **Setting**

The original research plan called for the use of two Facebook support groups for PD to locate participants. While three Facebook support groups were contacted, only one

approved the request. The only group to approve the advertisement was a site that promoted natural alternative PD treatments. Although all participants were recruited from one Facebook group, it was confirmed that participants in this group also belonged to other Facebook support groups, including those through which I had unsuccessfully sought permission to recruit participants. No reason was provided for the denial of the advertisement on the two other Facebook groups.

The administrator for the cooperating Facebook group was eager to help by spreading word of the study. The study was reintroduced two more times after an original posting to acquire more participants. Previous participants commented about the study on the group's page and encouraged others to participate. The administrator of the Facebook page forwarded all questions regarding the study to me and provided my contact information to those who expressed interest.

### **Demographics**

To ensure participant anonymity due to the number of members in the cooperating Facebook group, I asked only broad demographic questions. Of the seven participants, one was from the United Kingdom, one was from Canada, and five were from the United States. Of the five participants from the United States, one was from the East Coast, and four were located in the Western region of the United States. One participant reported being on disability due to her PD. Six of the seven participants reported having children, and one of those participants had three children under the age of 7. Two of the participants reported being married. One participant stated that she was the primary caregiver for her elderly parents.

### **Data Collection**

Each participant completed the interview questions as laid out in Chapter 3. The seven interviews each lasted approximately 30 minutes. The interviews were recorded using a personal recording device. The interviews were then uploaded onto my computer, where they were labeled with “Participant 1,” “Participant 2,” and so forth. The data were then transcribed using Rev, an online transcription service. I completed two of the interviews using FaceTime and the other five interviews by phone. The original plan was to use video chat; however, this proved difficult due to issues of technology and convenience.

While adhering to the protocol presented in Chapter 3, I found myself frequently checking my emotions in response to what the participants shared. I frequently checked in with myself to ensure that I maintained the role of researcher throughout the duration of each interview. In addition, three of the participants inquired about my treatment method and diagnosis. While I answered directly and honestly, I felt pangs of inadequacy and a need to defend my current treatment options.

The consistent presentation of open-ended questions proved effective and allowed the scope of the study to remain in focus. Due to the vast experiences of those affected by PD, it would have been easy to slip into countless conversations about various aspects of the disease. The interview questions helped to align my focus to where it needed to be. It was also important that the analysis be clear, and that I was able to find and compare themes and data with ease (Patton, 2002). I used my discretion to ask follow-up questions as needed. This helped to ensure that participants provided the necessary

information and that I understood what they expressed. At times, participants became caught up in a topic and needed to be guided back on track.

### **Data Analysis**

The questions that I asked included the following: How long have you been diagnosed with PD? How long did it take you to get diagnosed, once you realized something was wrong with your health? What treatment options were presented to you after you were diagnosed? How did you become aware that treatment options besides pharmaceutical interventions were available? How do you stay current on what treatment options are available for PD? What was your thought process when deciding that pharmaceutical treatment was not what you wanted? What were the contributing factors in the decision? How do you feel about the choice you made? Did you discuss your decision with your doctor? How did your doctor respond? Do you regularly go to a medical doctor for disease management? Do you see any other medical professionals, such as a naturopathic physician?

Bracketing was used so that I could put aside my experiences and approach the participants' experiences with a fresh perspective. Bracketing, also known as *epoche*, involves suspension of judgment (Howell, 2017) and is an important aspect of phenomenology. Through *epoche*, researchers attempt to look at lived experiences just as they are, without interference from biases.

As I went through the data, themes began to emerge. First, there was a common feeling of self-empowerment among the participants. While not always able to identify the feeling, the participants noted a "gut feeling" that there was more that they could do

aside from taking pharmaceuticals. Participant 2 noted, “I really in my heart felt that it was the wrong thing to be taking for my body.” She made this statement after 1 month of trying a pharmaceutical to address her PD. Many of the participants had been health conscious prior to their diagnosis and had used alternative treatments for other conditions. Participant 4 reported how her refusal to take the pharmaceutical route was the first time she had gone against medical advice. On the other hand, Participant 5 frequently disclosed her distrust of medical professionals and their lack of knowledge in regard to autoimmune diseases. Regardless of their stance toward medical professionals, all participants researched other alternatives and sought to engage in a treatment plan in which they could feel confident. Even when they started treatment plans, they continued to assess and modify their treatment as they went along.

Another theme that emerged from the research was medical professionals’ first line of treatment being a pharmaceutical intervention. None of the participants reported that their medical professionals had broached the subject of alternative treatments or dietary changes. Participants reported that although their healthcare providers might not have been against dietary changes, they did not see such changes as viable treatment for PD. Participant 4’s rheumatologist clearly stated to her that she would see her in 6 months, as if the dietary changes she was making would not be beneficial to her. Participant 7 reported that it was difficult for her to maintain medical appointments due to her not accepting pharmaceutical treatment options.

An alarming finding across the participants was how many ran the risk of no longer being under the care of a rheumatologist because of their treatment options. It

became apparent in the data that medical professionals had little to offer patients who decided against pharmaceutical interventions. A few of the participants simply attended appointments as “check-ins” so that they would not lose their providers. A common fear among the participants was the possible progression of PD. Very few had completely sworn off pharmaceutical interventions; rather, they wanted to pursue such interventions only as a last resort.

Many of the participants had sought the services of alternative medical professionals, such as naturopaths and acupuncturists. The participants were methodical in their research on alternative treatments and in seeking alternative sources of reputable help. They were willing to try various alternatives. One participant pursued a Chinese formula. She stated Chinese formulas are supplements and herbs chosen specifically for the individual. All participants made dietary changes that involved eliminating foods that they thought might trigger their symptoms. Participant 3 noted that she wanted not just to eliminate trigger foods, but also to incorporate anti-inflammatory foods. Participants were in tune with their bodies and noticed small changes in pain and swelling. Participant 3 was specific about the foods that she had eliminated; most participants were able to identify which foods led to certain symptoms.

No two participants had the exact same treatment plan. While all participants also incorporated supplements, they all had their own regimens. Just as with their diets, they adjusted their supplements as needed and paid close attention to their bodies.

### **Evidence of Trustworthiness**

Qualitative methodologies involve criteria that researchers attempt to meet to ensure that their work is trustworthy. These criteria are credibility, transferability, dependability, and confirmability (Morrow, 2005).

Credibility involves the researcher acquiring thick descriptions from participants that include not only the phenomenon of interest, but also the context and culture (Morrow, 2005). I gathered such descriptions in the interviews as clients discussed where they were located and what treatment looked like in their communities. For example, Participant 4 discussed how widespread alternative treatments were in Oregon where she lived. Participant 5 referred to the area she lived in as a “killing field.”

Addressing credibility also requires a researcher to take time with participants during interviews and to check back with them afterward. Sharing a summary of an interview with a participant allows a researcher to hear feedback from the participant and ensure that the participant’s experiences are conveyed accurately. I wrote summaries to address the research questions as well as other areas that I thought were pertinent to the participants’ experiences. I emailed each participant a copy of the summary, but only one participant asked that changes be made. Four participants did not respond to my email. I sought to become familiar with the data by listening to the interviews numerous times to convey the participants’ experiences.

Transferability can prove difficult to achieve. It is not the same as *generalizability*, a term used in quantitative studies. Rather, transferability is achieved by researchers being transparent and open about their research. In order to offer

transparency, researchers provide information on themselves as the instruments in their research, along with appropriate information on the research context, processes, participants, and relationships. This information allows readers to decide how the findings may be transferred to a more general population (Morrow, 2005). It is not my intent that these findings be generalized to other populations or settings.

There were numerous times throughout the interviews that I felt connected to my participants. The participants shared many relatable experiences with me, and I sometimes found myself struggling to remain objective. The stories about which I found it perhaps the most difficult to separate my personal experiences were those in which participants described feeling dismissed by a medical provider. Each time a participant shared an experience of not feeling supported by a medical provider, I went back to my own experience of being dismissed. Women with autoimmune diseases sometimes report symptoms that do not make sense to the medical community. When a medical provider is able to make a diagnosis and the patient does not agree with the treatment options, the interaction may not go well. However, the strength of these participants was evident as they continued to research treatment options and determine for themselves their best course of action.

Dependability can be accomplished by a researcher documenting the process of research, from design to data collection to analysis. Morrow (2005) stressed the need for a researcher to use a log to keep detailed records of activities, processes, influences, emerging themes, categories, and analysis notes. I used a notebook for documenting dates and thoughts on the research and the steps being taken. Notes were also taken on



the interview forms. I listed dates, emotions felt, new questions raised, and developing themes. Referring back to these notes was beneficial, in that I was able to see clearly how I had conducted the research and what my thought process had been. This information may allow for others to better understand this research and enable them to repeat this study if they choose to do so.

The last criterion, confirmability, is based on the premise that research is never fully objective (Morrow, 2005). To address this issue, I used reflexivity, disclosing my biases and experiences. I disclosed my diagnosis of PD and treatment options when asked by participants. Four participants inquired about my treatment options. Only one participant responded in a way that made me question my qualifications for conducting research on a population to which I did not belong. However, this discomfort was short lived, as I went back through my research and considered why I had sought this topic out initially. Ensuring confirmability was an ongoing process of keeping detailed records and constantly being aware of personal biases at all stages of the research. It required me to frequently check in with myself and spend time understanding my biases while seeking to understand the lived experiences of the participants.

## **Results**

RQ1. What is the lived experience for women with PD who choose alternative or complementary interventions as opposed to pharmaceutical interventions?

The information provided by the participants indicated that these women felt capable of taking control of their health. There was a sense of resolve on the part of the

participants in the choice to pursue natural treatment options and forgo pharmaceutical interventions. Participant 4 referred to herself as her own “advocate,” as did Participant 5. Participant 5 stated she was “angry” with Western medicine and her experiences with medical professionals. She noted that a previous health issue had led to a “severe healing crisis.” This previous experience had helped give her the confidence that she could take control of her treatment of PD. Others disclosed a “gut feeling” that pharmaceutical options were not for them. While many of the participants reported not feeling supported by their medical providers, they still pursued alternative treatments. They had all conducted research on these options and were continuing to seek information. Not one of the participants suggested that the treatment she selected was the only appropriate option.

Perhaps most impressive was how attuned the participants were to their bodies. They were able to notice small changes in their physical well-being and could attribute these to minor changes they had made, whether these were medicinal or food related. Participant 2 noted that she was “desperate to be well.” This desperation led her to try various diets until she was able to fine-tune what worked for her. Participant 1 and Participant 2 stressed the importance of self-care in their treatment of PD. Participant 6 reported stress as a trigger for her PD symptoms. She noted that she had learned over time to pay attention to her body emotionally and physically.

One theme that surprised me was that none of the participants had permanently ruled out pharmaceutical intervention. Each participant expressed concern about the PD progressing and about permanent joint damage. Participant 3 stated that she knew that at some point she would have to resort to pharmaceutical treatments. However, she noted

that she felt she had “some control” over her diagnosis and “you are what you eat.” The participants had an understanding that the treatment of PD was to be multifaceted. Each participant took a scaffolding approach in which she had a system of where she wanted to start with treatment. This scaffolding approach involved the participant looking toward the future and how she would add to her treatment. Participant 4 stated that she was satisfied with her current treatment option. No participant stated that she would eschew natural treatment options to pursue pharmaceutical interventions.

The motivation for these participants was to avoid possible side effects that could be life-threatening. Numerous participants stated they were concerned about the side effects of prescription treatments. Participants noted their distrust of the medical providers in how quickly the medical providers sought to prescribe medications with such serious side effects. Participant 7 stated she was specifically scared of the increased risk of cancer that accompanies pharmaceutical interventions for PD. In addition to the fear of cancer, Participant 1 reported she was also concerned about the side effects of medications that include hair loss or even death. Participant 2 described taking pharmaceutical treatments as “poisoning my body.” She went on to describe herself as “not a very cooperative patient.”

RQ2. How do they feel about the treatment decision they made, and what benefits have they noticed?

None of the participants took lightly the severity and unpredictability of the disease. Rather, they looked at the long-term effects of the disease and their treatment options. Every participant conducted her own research to determine a treatment plan that

worked for her. Participants 2, 4, and 7 reported seeing a naturopath. Participant 5 stated her acupuncturist brought to her attention specific Chinese formulas. Participant 3, who resides in England, reported she sees an osteopath and a physiopath. While each participant reported being currently satisfied with her treatment choice, a few stressed that they wanted to ensure that they exhausted all avenues prior to using pharmaceutical interventions. Participant 3 noted that she felt “good at the moment” about her treatment option. Participant 1 boldly stated that while she was “okay” with her current treatment regimen, “Pain changes my mind.” These two comments illustrate the unknown of PD and the underlying fear of the unknown.

A noticeable aspect of their treatment options that was missing was support from their medical providers. Participant 5 described her rheumatologist as “bored” when he gave her the diagnosis of PD. She noted he was also callous in his description she would have to deal with this disease for the remainder of her life. Participant 4 stated she felt that her rheumatologist was not “vested” in her. However, she noted her dermatologist was “amazing” and worked to advocate for her treatment choice. Those with PD may see various medical personnel that includes a rheumatologist, dermatologist, and primary care provider. Participant 3 stated she did not feel there was good coordination between her medical providers which further led her to seek out her own treatment route. Most of the participants reported their medical providers strongly suggested biologics or methotrexate. Few participants informed their medical providers of their treatment plan. Participant 4 was told by her medical provider she would be back after she explored dietary options. Participant 2 stated she wished that medical providers know more about

the impact of nutrition. She noted her medical provider eventually agreed to her natural approach. Participants 6 and 7 stated they continue to see their medical providers as mere check-ins due to insurance and a desire to stay on the patient load. There was concern on the part of some participants that should their PD progress, they would not be able to be seen by a medical provider. Participant 1 stated she felt dismissed by her medical provider. She noted she had made an effort to improve her attitude and listen to her body. The general consensus among the participants was how they approached their PD treatment each day. All participants reported this as an ongoing process in which they stick with what works and adjust when needed. Each participant understood the importance of the short-term and long-term effects of treatment options. Participants 1 and 2 stated they felt that their natural treatment choices were less harmful and potentially better than what medical providers prescribed. Participant 3 noted she understands she needs to put in the effort to treat her PD. The participants were all willing to make sacrifices in giving up certain foods. They also all worked to incorporate appropriate supplements, vitamins, and exercise. Based on their statements, once they resolved to treat their PD non-pharmaceutically, they pursued this avenue with zeal and determination.

### **Summary**

This chapter laid out the themes and findings from the research. Each interview portrayed the empowerment of these participants and their confidence that they knew how to treat PD. While few of the participants felt supported by their medical professionals, this perceived lack of support did not deter them from pursuing what they

felt was right for them. Their willingness to conduct research on their own and try various treatment options demonstrated their drive and resolve to treat themselves naturally.

The following chapter provides interpretations of the findings of the research. In addition, Chapter 5 lays out the limitations of this study. Finally, implications for social change, directions for future research, and recommendations for practice are provided.

## Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to examine the lived experience of women with PD who have chosen to use alternative treatments as opposed to pharmaceutical interventions. In this study, I sought to fill the gap in the literature as to how women make decisions about their treatment of PD. Another purpose of the study was to provide increased understanding of this population, which could be beneficial to those diagnosed with PD and the physical and mental health practitioners who work with them. I used a qualitative approach to allow for a deeper understanding of the participants and their thought processes through determining their treatment plans. The specific methodology was phenomenology. With the phenomenological approach I sought to describe the lived experiences of these women in terms of how they went through the process of deciding on a treatment plan. Most of the research that has been conducted in this area has not examined the lived experience of women with PD (Magin et al., 2009). Participants were interviewed until I reached data saturation.

This study showed that women are not generally supported by medical professionals when they choose nonpharmaceutical approaches. These participants trusted themselves enough to know that even without this support, their knowledge of their health and values was enough for them to pursue alternative treatments. They researched on their own and developed treatment plans that were unique to them. Perhaps the most profound finding was that the treatment is an ongoing process. All of the participants noted that they were continually researching treatment options and

paying attention to their bodies. They adjusted their treatment as needed. In addition, it was not that pharmaceutical treatment was to not be utilized; rather, patients sought to use pharmaceutical interventions as a last resort due to the risks associated with pharmaceutical interventions.

This final chapter integrates the research findings with the current literature. I also discuss limitations of the study and recommendations for further research. Chapter 5 concludes with a description of the positive social change that may result from this study.

### **Interpretation of Findings**

I chose women with PD for this study because they were shown to have a lower quality of life than men diagnosed with PD (Hammadi, 2016; Magin et al., 2009). Self-in-representation theory was used for this study with the understanding that women look at themselves relationally. From this perspective, women deciding on a treatment plan are likely to take into account how their relationships may be impacted by their treatment plan. However, few women in the study mentioned their relationships. One participant who disclosed that she had young children clearly stated that her being a mother of young children was an important factor when she decided on a treatment plan. While others talked about themselves relationally in regard to work and family, few clearly stated that was an integral factor in their choices. Rather, the applicability of self-efficacy theory was evident, as each participant felt competent enough to pursue the treatment option of her choice. Some of these options included strict diets. Each participant was committed to her treatment plan, knowing that it allowed her to live the life she desired, regardless of her diagnosis.



Research has shown that pharmacological options have lower efficacy with women than they do with men (Eder et al., 2012). Astin's (1998) study indicated that people may be more likely to choose alternative therapies if they have more education, poorer health status, and experience chronic pain. In this study, level of education was not asked; however, each participant sought out resources to educate herself on PD, the treatment options available, and potential side effects of pharmaceutical interventions. Some of the participants had previous health crises and were already informed about treatments. This helped give them insight and confidence in determining what they wanted. Many participants researched attacking the root cause of the symptoms as opposed to solely treating the symptoms. While the cause of PD is not yet known, participants researched on their own and felt that gut health, allergies, and stress were contributing factors to be targeted. In addition, Aujoulat et al. (2006) specifically mentioned that effectiveness of self-empowerment can be dependent on the health care provider providing a patient-centered approach. The research in this current study indicated that the health care provider's approach was not relevant to how the participant chose to treat her PD. Rather, the participants had felt secure in their decisions to forgo pharmaceutical interventions. The medical professionals' approaches were not influential in that respect. However, the medical professionals' approaches impacted the participants' views and trust in their treatment providers. Participants reported that they were more apt to switch medical providers than pursue pharmaceutical interventions. Many participants reported that their primary purpose in continuing with their medical care providers was to stay in the system should they need further care in the future. They

reported that they did not seek out their physicians' approval and instead simply informed them of their treatment option.

### **Limitations of Study**

Limitations of the study included transferability, interview quality, and biases. Due to the qualitative approach, few participants were used in this study. It is impossible to say that their experiences would reflect all women who pursue alternative treatment for PD. In addition, some of the participants had experienced other health concerns that not all of those with PD encounter. The interview questions may also have lacked sufficient scope. I was limited by the interview guide. While this helped to keep interviews consistent and structured, it left information missing. Perhaps the most important factor was the lack of questions directly pertaining to relational impact and educational level. The interview method did not appear to be a limitation. While Facetime did not consistently work, I felt that audio calls allowed for rapport to be established and did not interfere with the quality of the interviews. The most prominent limitation may have been my bias. While I was aware of biases given my journey with PD, it was difficult for me to discuss my treatment option with participants. I experienced a feeling of inadequacy. However, I could also relate to many of the participants' stories and understood the importance of conveying the participants' experiences from their unique perspective. I frequently checked this bias, and the participant's review of the summaries was a vital component in eliminating this bias. Only one participant did not reply to the summary reviews.

### **Recommendations and Implications**

Recommendations based on this study are focused on the advancement of supporting women with PD who pursue alternative treatments. Papoutsaki and Costanzo (2013) described the negative impact that PD can have on a person's quality of life. There is an unpredictability with PD that is stressful and alarming. The participants eloquently stated their fear of the unknown with PD. Professionals in the mental health community need to be aware of this population and their susceptibility to anxiety and depression. The first recommendation would be to study how to support these women within the mental health community. Mental health professionals should consider how best to reach this population and how to effectively support its members. Further research specifically targeting the mental well-being of this population would be valuable. This future research should focus on whether this population seeks out mental health services. Future research could also examine if this population has found support within the mental health community. This research will allow for a better understanding of this population's perspective and what its members need from mental health professionals. The members of the mental health community need to know where they can be of most assistance to those diagnosed with PD who treat without pharmaceutical interventions. Supporting their mental well-being could help improve their quality of life, as well as their self-efficacy. Self-in-relation theory suggests that women's relational perspective ought to be a central focus. Mental health professionals have the ability to lend a safe and supportive environment for these women to sort through the

impact that PD has had on them as a whole. This mental health treatment should encompass relational and personal impacts.

Another recommendation is to take a proactive approach to examining PD. While the cause of PD is unclear and multifaceted, it is known that emotional well-being can impact the development of PD (Leavitt, 2015). Further research in the etiology of PD is vital. The mental health community could play a significant role in conducting such research. The mental health community is needed to not only provide support for those with PD, but also to study how PD develops and what conditions may precede its development. One percent to 3% of the world population is affected by PD (Eder et al., 2012). There is no definitive cause or cure for this disease. As previously mentioned, mental health issues can precede and accompany PD. A social change implication of this research is that it could provide help for mental health professionals to become more aware of this vulnerable and frequently overlooked population. If those who treat their PD naturally do not feel support in the medical community, perhaps the mental health community can help to bridge this gap. The findings of this study indicated that these participants do not feel supported by their medical care providers. In addition, they reported feeling dismissed by medical providers who they turned to for help. They had taken it on themselves to determine their treatment plans and to monitor this process. These results may lead mental health professionals to look more closely at this population, understand its members' vulnerability, and determine approaches to actively seek them out. This population can be reached on social media platforms or in the community. Mental health professionals can lead workshops to bring attention to the

comorbidity between PD and mental disorders. These workshops can help bring attention to the comorbidity of mental disorders and PD. This study brought to attention the lack of support that this population feels from the medical community. Raising this awareness will provide necessary knowledge of what to look out for in their mental well-being and how to seek appropriate interventions. It will also show this population that the mental health community is supportive of their treatment choice and ready to assist as needed, according to the needs of the person.

### **Conclusion**

I conducted this study with the intent of bringing a voice to those who have not been heard. When society seeks to support the vulnerable, the population of women diagnosed with PD who treat naturally cannot be overlooked. At this point in time, people are more willing to seek out natural alternatives as a way to regain control of and maximize their health (Astin, 1998). This study has come at an appropriate time to bring attention to this plight. Perhaps most impactful will be making mental health professionals aware of this population and spurring them to seek out ways to engage them and promote their self-efficacy and mental well-being.

## References

- Astin, J. A. (1998). Why patients use alternative medicine: Results of a national study. *The Journal of the American Medical Association*, 279(19), 1548-1553.
- Aujoulat, I., d'Hoore, W., & Deccache, A. (2006). Patient empowerment in theory and practice: Polysemy or cacophony? *Patient Education and Counseling*, 66(1), 13-20.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191-215.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York, NY: W.H. Freeman.
- Bloor, M., & Wood, F. (2006). Phenomenological methods. In *keywords in qualitative methods*. (pp. 129-130). : Sage. doi: 10.4135/9781849209403.n40
- Boehncke, W. H., & Menter, A. (2013). Burden of disease: Psoriasis and psoriatic arthritis. *American Journal of Clinical Dermatology*, 14(5), 377-388.
- Christensen, L. B., Johnson, R. B., & Turner, L. A. (2010). *Research methods, design, and analysis* (11<sup>th</sup> ed.). Boston, MA: Allyn & Bacon.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4<sup>th</sup> ed.). Thousand Oaks, CA: Sage.
- Dudlettes, S. (1986). *Defense mechanisms and stress responses of women with psoriasis*. Unpublished PhD thesis, Pacific Graduate School of Psychology, Palo Alto, CA.

- Eder, L., Chandran, V., & Gladman, D. D. (2012). Gender-related differences in patients with psoriatic arthritis. *International Journal of Clinical Rheumatology*, 7(6), 641-649.
- Ferreira, B. I. R. C., Abreu, J. L. P. D. C., Reis, J. P. G. D., & Figueiredo, A. M. D. C. (2016). Psoriasis and associated psychiatric disorders: A systematic review on etiopathogenesis and clinical correlation. *The Journal of Clinical and Aesthetic Dermatology*, 9(6), 36–43.
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University.
- Giorgi, A. P., & Giorgi, B. (2011). Phenomenological psychology. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 165-178). London, England: SAGE.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1).
- Grozdev, I., Kast, D., Cao, L., Carlson, D., Pujari, P., Schmotzer, B., & Korman, N. J. (2012). Physical and mental impact of psoriasis severity as measured by the Compact Short Form-12 health survey (SF-12) quality of life tool. *Journal of Investigative Dermatology*, 132(4), 1111-1116.
- Hammadi, A. A. (2016, January 21). *Psoriatic arthritis*. Retrieved July 12, 2017, from <http://emedicine.medscape.com/article/2196539-overview#a3>
- Howell, K. E. (2017). *Aspects of phenomenology. An introduction to the philosophy of methodology* (pp. 55-74). London, England: SAGE.

- Hulbert-Williams, N. J., Storey, L., & Wilson, K. G. (2014). Psychological interventions for patients with cancer: Psychological flexibility and the potential utility of acceptance and commitment therapy. *European Journal of Cancer Care, 24*(1), 15-27.
- Jafferany, M. (2011, December 9). Psychodermatology: When the mind and skin interact. *Psychiatric Times, 28*(12).
- Janesick, V. (2011). *"Stretching" exercises for qualitative researchers* (3rd ed.). Thousand Oaks, CA: SAGE.
- Kelly, C. G., Cudney, S., & Weinert, S. (2011). Use of creative arts as a complementary therapy by rural women coping with chronic illness. *Journal of Holistic Nursing, 30*(1), 48-54.
- Kotsis, K., Voulgari, P. V., Tsifetaki, N., Machado, M. O., Carvalho, A. F., Creed, F., . . . Hyphantis, T. (2012, October). Anxiety and depressive symptoms and illness perceptions in psoriatic arthritis and associations with physical health-related quality of life. *Arthritis Care & Research, 64*(10), 1593-1601.
- Kurd, S. K., Troxel, A. B., Crits-Christoph, P., & Gelfand, J. M. (2010). The risk of depression, anxiety, and suicidality in patients with psoriasis. *Archives of Dermatological Research, 146*(8), 891-895.
- Leavitt, M. (2015, May 28). *The link between psoriatic disease and mental illness*. Retrieved from <https://www.psoriasis.org/advance/link-between-psoriatic-disease-and-mental-illness>



- Lee, S., Mendelsohn, A., & Sarnes, E. (2010). The burden of psoriatic arthritis. *Pharmacy and Therapeutics*, 680-689.
- Lesuis, N., Befrits, R., Nyberg, F., & van Vollenhoven, R. F. (2012). Gender and the treatment of immune-mediated chronic inflammatory diseases: Rheumatoid arthritis, inflammatory bowel disease and psoriasis: An observational study. *BMC Medicine*, 10(1), 82.
- Liu, J. T., Yeh, H. M., Liu, S. Y., & Chen, K. T. (2014, September 18). Psoriatic arthritis: Epidemiology, diagnosis, and treatment. *World Journal of Orthopedics*, 5(4), 537-543.
- Magin, P., Adams, J., Heading, G., Pond, D., & Smith, W. (2009). The psychological sequelae of psoriasis: Results of a qualitative study. *Psychology, Health, & Medicine*, 14(2), 150-161.
- Mease, P. (2012). Update on treatment of psoriatic arthritis. *Bulletin of the NYU hospital for Joint Diseases*, 70(3), 167.
- MedlinePlus, updated by: G. A. Starkebaum, MD and reviewed by D. Zieve, MD, MHA on 4/20/2013. Accessed 2/28/2014 – <http://www.nlm.nih.gov/medlineplus/ency/article/000413.htm>
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52(2), 250-260.
- Moustakas, C E. (c1994). Phenomenological research methods. SAGE: Thousand Oaks, Calif.

- Papoutsaki, M., & Constanzo, A. (2013). Treatment of psoriasis and psoriatic arthritis. *Biodrugs*, 27(1), 3-12.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks: SAGE.
- Picchianti-Diamanti, A., Germano, V., Ferlito, C., Migilore, A., D'Amelio, R., & Laganà, B. (2010). Health-related quality of life and disability in patients with rheumatoid, early rheumatoid and early psoriatic arthritis treated with etanercept. *Quality of Life Research*, 19(6), 821-826.
- Pilkinton, M. W. (2007). Self-in-relation theory: A model for helping. *The Journal of the Doctoral Students of the University of Houston*, 5(1), 28-31.
- Ritchlin, C. T., Kavanaugh, A., Gladman, D. D., Mease, P. J., Helliwell, P., Boehncke, W. H., . . . Taylor, W. J. (2009). Treatment recommendations for psoriatic arthritis. *Annals of the Rheumatic Diseases*, 68, 1387-1394.
- Sarilar, M., Koic, E., & Dervinja, F. (2011). Personal experiences of the psoriasis and its relation to the stressful life events. *Collegium Antropologicum*, 35, 241-243.
- Scarpa, R., Cosentini, E., Manguso, F., Oriente, A., Peluso, R., Atteno, M., Ayala, F., D'Arienzo, A., & Oriente P. (2003). Clinical and genetic aspects of psoriatic arthritis "sine psoriasis." *Journal of Rheumatology*, (12) 2638-2640.
- Shiel, W. C. (2017). Remicade for rheumatoid arthritis. Retrived from eMedicineHealth: [https://www.emedicinehealth.com/remicade\\_for\\_rheumatoid\\_arthritis\\_treatment/article\\_em.htm](https://www.emedicinehealth.com/remicade_for_rheumatoid_arthritis_treatment/article_em.htm)
- Stork, A. (2015). Women and the heavy toll of psoriasis. National Psoriasis Foundation.

- Su, D., & Li, L. (2011). Trends in the use of complementary and alternative medicine in the united states: 2002-2007. *Journal of Health Care for the Poor and Underserved, 22*, 295-309.
- Surrey, J. (1985). Self-in-relation: A theory of women's development. Retrieved August 7, 2015, from [http://www.wcwonline.org/pdf/previews/previews\\_13sc.pdf](http://www.wcwonline.org/pdf/previews/previews_13sc.pdf)
- Traska, T. K., Rutledge, D. N., Mouttapa, M., Weiss, J., & Aquino, J. (2011). Strategies used for managing symptoms by women with fibromyalgia. *Journal of Clinical Nursing, 21*, 626-635.
- Velez, N .F., Wei-Passanese, E. X., Husni, M. E., Mody, E. A., & Qureshi, A. A. (2012). Management of psoriasis and psoriatic arthritis in a combined dermatology and rheumatology clinic. *Archives of Dermatological Research. 304*(1), 7-13.
- Viggers, L. C., & Caltabiano, M. L. (2012). Factors affecting the psychological functioning of australian adults with chronic pain. *Nursing & Health Sciences, 14*(4), 508-513.
- Willig, C., & Stainton-Rogers, W. (2008). Phenomenological psychology. In Willig, C. & Stainton-Rogers, W. *The SAGE handbook of qualitative research in psychology* (pp. 165-178). SAGE. doi: 10.4135/9781848607927.n10

## Appendix A: Confidentiality Agreement

CONFIDENTIALITY AGREEMENT**Name of Signer:**

During the course of my activity in collecting data for this research: “Examining the lived experience of women with psoriatic disease who choose to treat their disease without pharmaceutical intervention” I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

***By signing this Confidentiality Agreement I acknowledge and agree that:***

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant’s name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.

7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

*Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.*

**Signature:**

**Date:**

## Appendix B: Interview Questions

### Lived Experience of the Decision-making Process in Women with Psoriatic Disease

#### Regarding Natural Alternative Treatment Options Questions

##### A. Questions Related to the Lived Experience of the Decision-making Process in Women with Psoriatic Disease Regarding Natural Alternative Treatment Options

1. What treatment options were presented to you after you were diagnosed?
2. How did you become aware that treatment options besides pharmaceutical interventions were available?
3. What is your current treatment plan?
4. How do you stay current on what treatment options are available to for PD?
5. What was your thought process when deciding that pharmaceutical treatment was not what you wanted?
6. What were the contributing factors in the decision?
7. How do you feel about the choice you made?
8. Did you discuss your decision with your doctor?
9. How did your doctor respond?
10. Do you regularly go to a medical doctor for disease management?
11. Do you see any other medical professionals, such as a naturopathic physician?