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"Nobody Wants To Feel Different...But It's Just The Way It Is": Experiences Of Stigma And Other Stressors Among People Living With Psoriasis

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"NOBODY WANTS TO FEEL DIFFERENT…BUT IT'S JUST THE WAY IT IS": EXPERIENCES OF STIGMA AND OTHER STRESSORS AMONG PEOPLE LIVING WITH PSORIASIS

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DISSERTATION

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On July 17, 2015

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DEDICATION

This dissertation is dedicated to

Phyllis A. (Griebstein) Power (05.17.1924 – 01.09.2014).

To her, I was her "little professor". To me, she was my Grandmother.

She instilled in me the value of family, health, and hard work.

I learned from her the virtue of patience, humility, and gratitude.

Always greeted with "How's school, kiddo?" in visits, hand-written letters, and phone calls...

she was my number one fan, my motivation.

Before I headed east four years ago, she spoke of home and family in North Dakota

and told me, "You'll miss it. You'll miss us."

She was right. Home is missed; she is sorely missed.

There will be no visit, no hand-written letter, and no phone call

when the paper is signed and the degree completed.

Instead, a smile, a tear, and a loving memory of her, remembered forever.

I did it, Grandma.

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The successful completion of this dissertation and other requirements for the doctoral degree cannot be attributed solely to personal achievement. Rather, the journey has been a team effort. Through my tenure as a graduate student, my interest in the stress process framework has taught me an invaluable lesson: social support matters!

To my parents: If not for the selfless act of adoption, I would not be here today. With every small success along the way, I am reminded of your enduring love, support, and guidance.

To my sister, family, and friends: I am truly grateful for your patience, understanding, and motivation. Your presence in my life throughout this adventure has meant far more than you'll ever know. For that, I am humbly indebted to all of you.

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TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

ABSTRACT

“*NOBODY WANTS TO FEEL DIFFERENT…BUT IT’S JUST THE WAY IT IS*”: EXPERIENCES OF STIGMA AND OTHER STRESSORS AMONG PEOPLE LIVING WITH PSORIASIS

By

Alex R. Parkhouse

University of New Hampshire, September, 2015

It is understood that stigmatizing processes can, and do, affect multiple domains of life among people who bear a stigma label. It is also understood that sources of stress (stressors) can spill over into a variety of areas of life, impacting the health and well-being of stigmatized people. However, although both stigma research and stress research advance, little has been done to connect these two important lines of sociological inquiry. To address this gap, 23 semi-structured qualitative in-person and telephone interviews were conducted to examine the daily, lived experiences of stigma and other stressors among people living with psoriasis (PLWP), a group of people with one of the most common chronic skin conditions (CSC). A grounded theory approach to emergent narrative themes was utilized to uncover the variety of ways that stigma operates in the stress process framework, including how stigma-related stress proliferates into many domains of life, and how PLWP attempt to manage and cope with stigma and other psoriasis-related stressors. Findings revealed that the multidimensional nature of psoriasis shapes the meaning(s) PLWP attach to their CSC; psoriasis-related stigma operates as a stressor that is often chronic, permeating the daily life of PLWP and contributing to the development of an “psoriasis identity”; and PLWP utilize, to varying degrees of success, personal and social resources such as coping and social support in efforts to reduce stressful circumstances and their distressing outcomes. Data presented in this dissertation contribute to our understanding of stigma, social stress, and health processes among PLWP as well as other stigmatized groups of people suffering from chronic illness.

Keywords: stigma; stress process; PLWP; chronic illness

CHAPTER I
INTRODUCTION

Goffman (1963), Link and Phelan (2001), and Link and Phelan (2013) describe stigma as a deeply discrediting attribute, but more specifically as a social process. It is understood that stigmatizing processes can, and do, affect multiple domains of life among people who bear a stigma label. Research utilizing stress process theory simultaneously describes the effects of stressors (sources of stress) on health and well-being. Stress process researchers (Pearlin et al. 1981; Thoits 2011; Wheaton et al. 2013) note that while stressors can spill over into a variety of areas of life, personal and social resources such as mastery and social support might offer people protection from the negative consequences of stressors. However, while both stigma and stress process research advance, little research connects these two important lines of sociological inquiry.

Despite some efforts by medical researchers to examine chronic skin condition (CSC)-related stressors and the effects of such stressors on the quality of life of people living with chronic skin conditions (Basavaraj, Navya, and Rashmi 2011; Schmid-Ott, Schallmayer, and Calliess 2007), considerations of CSC-related *stigma* as a *source of stress* have been largely overlooked. Although some research suggests that stigma represents a hidden burden of illness among those with chronic conditions (Weiss, Ramakrishna, and Somma 2006), the findings tend to outline dimensions of stress that may be linked to stigma, but do not attempt to describe the daily lived experience of stigma among those who are stigmatized (Mickelson 2001). This dissertation addresses this gap by investigating the experiences of stigmatized people living with psoriasis (PLWP), which is one of the most common chronic skin conditions, to provide rich understanding of how stigma is experienced, the meanings attached to those experiences, and the ways that stigma creates stress in their daily lives.

Some sociological research on stigma and stress focuses on other stigmatized groups such as people living with HIV/AIDS. For example, findings by Herek, Saha, and Burack (2013) suggest that because of socially constructed differentness, stigmatized people with HIV/AIDS are disempowered, have limited access to resources, and have less control over their lives than the non-stigmatized. Additionally, stigmatized persons are subjected to ostracism, discrimination, and other consequences of stigma processes. Although some past studies suggest that stigma is stressful for people living with HIV/AIDS, it is likely that stigma also acts as a potent stressor in the understudied lives of other stigmatized groups, such as those living with chronic skin conditions. Psoriasis, the most prevalent non-contagious and incurable autoimmune disease in the U.S., is a condition often characterized by visible raised, scaly red patches, itchy, and painful plaques in different bodily areas, or white pustules (National Psoriasis Foundation 2014). The most recent statistics from National Psoriasis Foundation (NPF) and the American Academy of Dermatology (AAD) (2014) indicate that there are approximately 7.5 million Americans and roughly 125 million people worldwide living with psoriasis. Statistics aside, skin plays an important role in establishing interpersonal relationships. CSCs not only impact physical appearance, they can significantly influence other people’s reactions toward those with the condition (Hrehorow 2012). The prevalence of psoriasis and the nature of symptoms beckon sociological investigation of the lived experience of stigma among PLWP to highlight and better understand the intersection of stigma and the stress process among people living with chronic skin conditions.

An extensive literature search reveals very few articles addressing the potential consequences of stigma in psoriasis patients. For example, a dated article by Ginsburg and Link (1993) indicates that patients with psoriasis feel stigmatized by their disease and are rejected by others and suffer further adverse effects emotionally and in occupational daily life. This work, however, only scratches at the surface of stigma acting as a stressor among people living with chronic skin conditions. In an earlier article by Ginsburg and Link (1989:53), the authors note that the concept of stigma is valuable for understanding how individuals experience psoriasis, pointing to the multidimensionality of stigma experienced by people with psoriasis. That is, people with psoriasis, as well as people with other CSCs, might anticipate rejection, feel flawed and embarrassed, or experience a sense of guilt or shame. More broadly, Ginsburg and Link (1989) suggest that a patient's perceptions of the social and psychological impact of psoriasis can be enormous, and that stigma likely affects the course of the condition and illness experience in many ways (e.g. flare ups; stress; treatment-seeking). Other research findings suggest that perceived stigma among people with psoriasis can be potentially harmful (Richards et al. 2001), and that the chronicity of stigma might vary as the skin condition becomes more or less visible (Hrehorow et al. 2012).

Consistent with the view of Kennedy (2006) who argues that qualitative research examining psoriasis narratives (and other narratives of people with CSCs) is of great value in social science and dermatological research, this dissertation helps fill a gap in our understanding of stigma and stress by conducting a qualitative, in depth assessment of the lived stigmatized experiences of people living with a chronic skin condition. This dissertation looks deeply into the stigmatized illness experience of people living with psoriasis (PLWP) to focus on the meaning of stigma as a stressor and its implications for the lives of the stigmatized. Interview data from discussions with PLWP outlined in this dissertation will contribute to our understanding of stigma, social stress, and health processes among PLWP, but also other stigmatized groups of people suffering from chronic illness such as those living with HIV/AIDS (Rueda et al. 2012), suffering from obesity (Mustillo, Budd, and Hendrix 2013), or living with a mental illness (Perry 2011). More specifically, this dissertation highlights the variety of ways that stigma operates in the stress process, including how stigma-related stress proliferates into many domains of daily life, and how PLWP manage and cope with stigma and other psoriasis-related stressors. To that end, the presentation and discussion of findings based on interview data with 23 PLWP will speak to five research objectives:

1. Uncover meaning(s) and experiences of psoriasis and CSC-related stigma among PLWP.
2. Learn how stigma, and other stressors, may be stressful for PLWP.
3. Investigate the role of the proliferation of stigma-related stress in the daily lives of PLWP.
4. Discover how PLWP manage and cope with the stressful effects of stigma and other stressors.
5. Provide direction for future research conceptualizing stigma as stressor among PLWP as well as other stigmatized groups.

CHAPTER II
BACKGROUND

Stigma as a Social Process

In his signature text on the management of a spoiled identity, Goffman (1963:3) famously refers to a stigma as an attribute that is deeply discrediting; an attribute that has the ability to reduce a whole and otherwise usual person, to a tainted, discounted, and less desirable one. Goffman (1963) further asserts that those who possess a stigma possess an undesired differentness, or "mark" (Jones et al. 1984), that sets him or her apart from non-possessors, and subsequently they are labeled as not quite human. The fact that symptoms of CSCs often create a physical "mark" may further reinforce this notion beyond the intended symbolism. It is not hard to imagine then how stigma attached to PLWP reduces an otherwise normal person to a less desirable, tainted person, creating unique challenges for PLWP as well as their social networks.

Goffman (1963) notes that people with physical deformities, people he refers to as "blemished", are stigmatized and are avoided, especially in social (public) places. Moreover, Goffman (1963) asserts that *stigmatization* of "blemished" people is itself, a *social process*. In other words, stigma permeates the lives of the stigmatized in both interpersonal and institutional contexts, impacting the personal and social identity of PLWP. For example, PLWP might be aware of socially constructed psoriasis stigma labels, might hold the same beliefs about psoriasis and psoriasis stereotypes as non-PLWP, and experience feelings of shame and embarrassment as a result of that awareness (Goffman 1963:7). Building off of Goffman's (1963) conceptualization of stigma as a social process, this dissertation examines how stigma processes intervene in the daily lives of PLWP, affecting PLWP' perceptions of themselves and their condition (e.g.

psoriasis identity). Goffman (1963) additionally notes that “blemished” people (e.g. PLWP) employ identity management techniques as a tool to manage stigmatization. The present study also aims to highlight illustrative examples as to the ways PLWP utilize both personal and social resources to cope and manage stigma.

Link and Phelan (2001:363) argue that because there are many stigmatized circumstances and because stigmatizing processes can affect multiple domains of people’s lives (e.g. family life, relationships, employment), stigma likely has a dramatic bearing on the distribution of life chances for those who possess it (e.g. health and life circumstances among people living with psoriasis). In their seminal work *Conceptualizing Stigma*, inspired by the work of Goffman (1963), Link and Phelan (2001) emphasize not only that there are multiple dimensions to the concept of stigma, but also that stigma represents a social process. Link and Phelan (2001) identify four key components highlighting stigma as a social process: labeling; stereotyping; separation; and, status loss and discrimination. For Link and Phelan (2001), stigma labeling essentially occurs because of the social emphasis placed on particular human differences. In other words, a majority of differences, such as the color of one’s eyes, are ignored and deemed socially irrelevant. On the other hand, some differences are highly salient, and matter socially. Stigma labels attached to PLWP, for example, might be the result of the oversimplification or misconception of autoimmune skin conditions perhaps resulting from a lack of psoriasis-related knowledge. Interviews with PLWP aimed to uncover how, and in what ways, stigmatizing reactions from others contributes to stressful circumstances for PLWP. Moreover, the present investigation explores how components of stigma (labeling, discrimination, etc.) create instances where PLWP might feel *different* and experience differential (stigmatizing) treatment (e.g. not allowed in public swimming pool), in a variety of circumstances. As discussed below, the appearance of psoriasis symptoms and the meanings attached to symptoms by observers (however inaccurate), have important social implications.

CSC-related stigma likely differs according to time and place (e.g. early years of a psoriasis diagnoses versus present day diagnoses; living with psoriasis in an area with treatment facilities versus living in an area without treatment facilities). Research by Kleinman and Hall-Clifford (2009) and Yang et al. (2007) suggests there are unique cultural factors at play creating the lived worlds of stigmatized persons and the labels attached to those worlds, such that stigma may severely threaten important components of life. In other words, the social, ordered reality of daily stigmatizing experiences among PLWP likely vary, contingent on changing norms of chronic illness (Berger and Luckmann 1966). Link and Phelan (2001) also claim that stigma involves both a label and a stereotype, with the label linking a person to a set of undesirable characteristics that ultimately form a stereotype. For example, for some people, the “infected psoriasis patient” label links the described person (e.g. person living with psoriasis) to stereotyped beliefs about the grotesqueness of people with CSCs (e.g. scaly; contagious), which in turn, might lead them to create social distance from people with psoriasis. One of the crucial goals of the present study is to uncover how PLWP anticipate and experience stigmatizing labels and how the stigma labels weave intricately into the everyday lives of participants. Interviews with PLWP were constructed to reveal how and in what ways, the stereotypical beliefs about psoriasis (a likely influential factor on the chronicity of stigmatization) contribute to PLWP’ understanding of their condition.

Link and Phelan’s (2013:527) *modified labeling theory* of mental illness suggests that “labeling through treatment contact and the stigma that accompanies such labeling jeopardize the life circumstances of people with mental illness by harming their employment chances, social networks, and self-esteem." Link and Phelan (2013) argue that people develop conceptions of the mentally ill early on through socialization and form expectations devaluing a person with mental illness. Moreover, the pair argues that people who have experienced mental illness labels are at a greater risk of the reoccurrence of mental illness. Modified labeling theory, originally developed to explain stigma processes among the mentally ill, can also be applied to the ways PLWP anticipate and experience stigma. For example, psoriasis labels like ugly, scaly, and unattractive are internalized by PLWP, and because PLWP are aware of what others think of "people like that", PLWP anticipate being stigmatized. The anticipated threat of stigma can be a source of stress for PLWP, to the extent that PLWP might change the way they act and behave out of the fear of being labeled by others. Similar to the mentally ill as described by Link and Phelan (2013), psoriasis labels can contribute to PLWP acting differently. Anticipated psoriasis stigma might make PLWP uncomfortable around others and might contribute to PLWP withdrawing and isolating themselves from interactions with others (e.g. family, employers, dating partners). While anticipated stigma is not actual rejection like discrimination toward or physical distance from PLWP (experienced stigma), which also is a significant source of stress for PLWP, anticipated stigma is still burdensome for PLWP.

The third component of Link and Phelan's (2001) conceptualization of stigma as a social process is separation of "us" versus "them". Within the separation component of stigma, the linking of labels to undesirable attributes essentially becomes the rationale for believing negatively labeled persons are fundamentally different from those who do not share the label (Link and Phelan 2001:370). Applied to psoriasis-related stigma, it might be the case that for non-psoriatic people, labeling people with psoriasis as dirty and contagious, serves as a boundary maintenance mechanism, allowing non-psoriatics to justify their distance from people living with psoriasis. Others might actively or discretely treat PLWP differently once believing PLWP are "different". In other words, others might blatantly distance themselves from PLWP in public places (e.g. swimming pools), or might stare or talk under their breath when in proximity of someone with psoriasis. Differential treatment based on the rationale that PLWP are not "normal" is a source of stress (*experienced stigma*) for PLWP that likely is burdensome in both private (e.g. dating) and public (e.g. recreational activity) areas of life.

A final component of stigma as a social process is status loss and discrimination (Link and Phelan (2001). When people with psoriasis are labeled, set apart, and linked to undesirable characteristics (e.g. dirty, scaly, grotesque), a rationale is constructed for devaluing, rejecting, and excluding them (Link and Phelan 2001:371). PLWP are then stigmatized when this "differentness" leads them to experience status loss and discrimination (e.g. disadvantage in terms of life chances; income; education). However, Link and Phelan (2001) also point out that stigma is, to some extent, dependent on social, economic, and political power of the stigmatized relative to those doing the labeling. Link and Phelan's (2001) work, more broadly, extends early sociological research by Goffman (1959) and Parsons (1951), outlining how scripted, social roles and presentation of self can convey one's social status. In other words, the social status of PLWP might be dependent on their degree of compliance toward socially assigned expectations of being "sick", and their success of navigating stigmatizing experiences.

Work by Phelan, Link, and Dovidio (2008) reflects Link and Phelan's (2001) conceptualization of stigma as a social process; noting stigma can lead to disadvantaged outcomes in multiple domains of life for stigmatized persons. Phelan et al. (2008) suggest the perceived threat of stigma is especially problematic for stigmatized persons. For example, Phelan et al. (2008) would argue PLWP are vulnerable to discrimination by others (e.g. stigmatizing treatment by non-psoriatics) as a result of a degraded social status. Phelan et al. (2008) would also argue that the perception(s) of stigma among PLWP stem from societal norms and expectations of those who are conceived of as *healthy* (non-psoriatics), and those who are conceived of as "*diseased*" (PLWP). Moreover, the non-psoriatic public could come to expect less competent performances from PLWP (e.g. as employee, paying customer, or dating partner), than from fellow non-psoriatics based on the lower status (e.g. their position as a group, based on esteem and respect) of PLWP (Lucas and Phelan 2012). Stigma, or the perceived threat of stigma among people with psoriasis is therefore likely stressful, for the presence of CSC-related stigma disrupts interactions with others (e.g. in the home, public, or workplace), causing discomfort and feelings of awkwardness among both PLWP and non-psoriatics which, in turn, might lead to avoidance of interaction altogether. Narratives of PLWP discussed in later chapters of this dissertation shed light on how PLWP anticipate and experience stigma in their daily lives as a stressor; as part of their "psoriasis identity".

A more recent analysis by Link and Phelan (2013) is helpful for understanding what factors might help contribute to the severity or stressfulness of CSC-related stigma among PLWP. Link and Phelan (2013) highlight six key dimensions of stigma: concealability; course; disruptiveness; aesthetic qualities; origin; and, peril. *Concealability* refers to how apparent or detectable a characteristic is to others. This may be a particularly salient dimension for many PLWP. Although some circumstances of CSC-related stigma are concealable (e.g. covering rashes by clothing), others might not be (e.g. bodily plaques on head or face). Even when potentially concealable, CSC-related stigma can be stressful for PLWP because of the need to be vigilant about what to wear and how best to "hide" their illness. *Course* refers to the extent to which the stigmatizing circumstance is believed to be reversible. Although a psoriasis diagnosis is not reversible, it can be treated with varying degrees of success, using medical or, in some cases, non-medical, over-the-counter home/natural remedy treatments. A progressive worsening of the condition among PLWP might impact their ability to function “normally” (e.g. receiving an education; partake in job interviews; fulfill family responsibilities).

The stress of CSC-related stigma may also be influenced by disruptiveness. *Disruptiveness* is the extent to which the circumstances of the stigmatized individual strain and add to the difficulty of interpersonal interactions. Non-psoriatics, who are in the presence of someone with psoriasis with visible signs of symptom progression, might become uncomfortable and stare, comment, or create some level of distance. CSC-related stigma might be particularly stressful in this example, since PLWP might challenge the expectations of health (e.g. going out in public with bleeding plaques), making interaction with others difficult. *Aesthetics,* a dimension of stigma that refers to the extent to which different marks elicit an in instinctive or affective reaction of disgust from others, is also useful for investigating CSC-related stigma (Link and Phelan 2013). Visible, bleeding or scaling plagues are considered unaesthetic and often elicit an instinctive, negative reaction of disgust from non-psoriatics. The combination of aesthetic abnormalities (e.g. psoriasis plaques and flakes) and certain life conditions (e.g. joblessness) would likely exacerbate the stressful nature of stigma experienced by PLWP.

Origin and *peril* are two additional dimensions that are also helpful in understanding the stressful nature of CSC-related stigma. *Origin* refers to how the condition (psoriasis) came into being and the extent to which the stigmatized person’s (PLWP) behavior may have caused the condition (Link and Phelan 2013). *Peril*, on the other hand, differentiates conditions (psoriasis) according to the extent to which they induce fear, or perceived threat in others (non-psoriatics) (Link and Phelan 2013). When the stigmatizing condition (psoriasis) is perceived by others to be the result of some immoral or irresponsible behavior, the chronicity of stigma toward PLWP might increase. Or, when psoriasis is perceived to be irreversible because it's assumed psoriasis is genetic in origin, the chronicity of stigma toward PLWP might also increase. Since public knowledge about psoriasis is generally low, variation in perceived origins may influence the level of stigma experienced by PLWP. Some may view psoriasis as a result of poor hygiene or uncleanliness, and subsequently distance themself from PLWP.

In sum, stigma is likely a source of stress among people living with psoriasis. While Goffman (1963) provides initial dialogue explaining the impact of a deeply discrediting attribute on stigma-bearers, Link and Phelan (2013:528) and Chaudoir, Earnshaw, and Andel (2013) call on scholars to now identify the sources and probing mechanisms of stigma so as to deepen the understanding of stigma as a social process. This dissertation answers this call by investigating how people living with psoriasis experience stigma as a stressor in their daily lives. Stigma is utilized as a lens to uncover ways in which PLWP anticipate, experience, and deal with stress that arises from their condition. The stress process framework, a general orienting framework, will also be utilized to illustrate how stigma is stressful for PLWP; how psoriasis-related stressors affect PLWP daily, becoming chronic sources of stress; and how PLWP' personal and social resources are used to manage and cope with stress. The stress process framework is outlined in greater detail later in this chapter.

Stigma as a Stressor

In their seminal work on the stress process, Pearlin et al. (1981:341) report "there is probably general agreement that stress refers to a response of the organism to conditions that, either consciously or unconsciously, are experienced as noxious." In other words, a stressor represents a condition of threat, challenge, demand, or structural strain, that by the very face of its occurrence (e.g. stigmatization), calls into question the operating integrity of the individual (Wheaton et al. 2013). Stigma might act as a stressor, for example, by creating the possibility or expectation of harm (fear of disclosure of psoriatic condition), while simultaneously placing demands (e.g. burden or guilt) on people living with psoriasis. Stigma might also act as a chronic form of stress for PLWP. Consistent with Pearlin et al.'s (1981) conceptualization, chronic stressors (e.g. stigma) originating from a discrete life event (e.g. psoriasis diagnoses) can endanger the self-concept (e.g. mastery; self-esteem) of those who are stigmatized. Research suggests chronic stressors, which have a long-term course and are less self-limiting than forms of stress, can be especially damaging (Wheaton et al. 2013).

Studies by Miller (2006) and Miller and Major (2000) also provide a foundation for characterizing stigma as a stressor in this dissertation research. Miller (2006:21) claims stigma creates stress because other people have stereotyped expectancies about what stigmatized people are like, harbor prejudiced attitudes toward stigmatized people, and behave in a discriminatory manner toward stigmatized people. Miller (2006) finds that stigma can affect stigmatized people's access to educational and employment opportunities, the quantity and quality of health care they receive, and their acceptance by the communities in which they live. Miller and Major (2000) similarly contend that stigmatization results in outcomes such as anger, anxiety, or fear and that the lives of stigmatized people (e.g. PLWP) are subject to more daily hassles and chronic strains than those who do not possess a stigma (e.g. non-psoriatics). The qualitative investigation of stigma as a stressor in the lives of PLWP in this study contributes to early work on stress. Namely, findings presented in this dissertation highlight social processes of stress, uncovering if and how stigma manifests not only through daily hassles PLWP face, but also through constant, chronic strains for both PLWP as well as for those they are closest to (e.g.

family, peers, significant others) via stigma by association or, courtesy stigma (Martinez-Garcia et al. 2014).

In this dissertation, stigma is conceived of as a stressor that may “proliferate” into multiple areas of life for people living with psoriasis. Early work by Pearlin (1989:249) details the value and importance of a sociological investigation of stressors. Conceptualizing stigma as a stressor provides a lens for seeing the connections between the social processes of stigma, and the challenging or burdensome experiences of stigmatized PLWP. Readers will come to learn that stigma may not necessarily start as an event; rather, it may develop insidiously and continue as a problematic condition in the social environment of PLWP. Interview data from narratives of PLWP addressed in subsequent chapters of this dissertation will highlight the ways in which stigma serves as a chronic stressor in their daily lives and how stigma may proliferate to create other types of chronic strains for PLWP.

Stigma, Chronic Illness, & Health

Researchers as well as medical practitioners have acknowledged the potential impact of stigma on health. For example, Weiss et al. (2006) claim stigma is a both a feature and a cause of many health problems. Stigma becomes anticipated and or experienced by persons with stigmatizing health problems (e.g. PLWP) and is characterized by exclusion, rejection, or a sense of devaluation that results from the perception or anticipation of adverse judgment. Such experiences, in turn, can further damage health. Consistent with Weiss et al.’ (2006) work, it is plausible that the anticipation and or experience of stigma might contribute to a psoriasis flare-up for PLWP. Psoriasis is a visible condition, which might be hard, if not impossible to fully conceal or avoid stigmatizing reactions of others. Moreover, PLWP can develop co-occurring health conditions that increase severity of their psoriasis flare-ups. This, in turn, is likely to increase the likelihood of stigmatizing reactions by others. Consistent with Link and Phelan's (2001) argument, PLWP might anticipate psoriasis-related stigma because they believe discrimination will be directed at them (Earnshaw et al. 2011), even if they have not had such experiences (*anticipated* stigma). PLWP, of course, may also experience psoriasis-related stigma when they are *actually* treated differently or feel differently because of stigma labels imposed on them by others (*experienced* stigma).

While the social meanings of stigma attached to stigmatized persons change, and are influenced by various factors, stigma has a substantial impact on the experience of illness, help-seeking, and treatment of chronic conditions (Weiss et al. 2006), as well as on psychological outcomes such as shame, depression, anxiety, and avoidance, regardless of the concealability of the stigma (Pachankis 2007). Additionally, stigma research informs us that even seemingly minute daily stigmatizing experiences are harmful to those with chronic illness (Meyer 2003); stigma (whether anticipated or experienced) can be potentially harmful to the quality of life of people with chronic illness (Earnshaw and Quinn 2011); and, stigma likely contributes to the multiple disadvantaged social statuses of people with chronic illness (Struber, Meyer, and Link 2008).

Work by Hatzenbuehler, Nolen-Hoeksema, and Dovidio (2009) on stigma and health suggests that stigma is a risk factor for mental health problems, though few, if any studies have considered how stigma leads to such problems. Rather, a majority of findings have only shown that stigma conveys a devalued social identity for stigmatized groups (e.g. people with mental illness) (Corrigan et al. 2000; Corrigan, Watson, and Ottati 2003). Hatzenbuehler et al. (2009) find that because stigma "gets under the skin" of those who are stigmatized, stigmatized persons must utilize strategies or seek resources as an attempt to manage the stigma incurred. Moreover, research clearly points to stigma as a global phenomenon, impacting people with chronic illness in almost all cultures, regardless of race, age, or gender (Van Brakel 2006; Thoits 2005; and Brown 2014). In this dissertation, narratives of PLWP are used to uncover the ways PLWP attempt to cope with the challenges of CSCs, including stigma experiences, and their perceptions of how effective those coping efforts are. Additional research findings have shown that stigma places unique demands on people living with chronic illness (Miller and Kaiser 2001); impacts the quality of life of stigmatized persons (Earnshaw, Quinn, and Park 2011); and acts and means different things for different stigmatized groups (Mickelson 2001). This dissertation research simultaneously addresses the demands that CSC-related stigma places on PLWP, as well as highlights how and in what ways stigma impacts their daily lives and what it means for them and those they associate with (Dwyer, Snyder, and Omoto 2013).

Stigma, Psoriasis, & Stress

Research by Ginsburg and Link (1993) addressing the consequences of stigma among persons with psoriasis remains one of only a few articles directly highlighting stigma as a stressor for PLWP. However, there is a small body of research addressing the general issue of stigma among psoriasis patients. Work by Gupta and Gupta (1995), O'Leary et al. (2004), and Schmid-Ott et al. (2007), and others (Gaston et al. 1987; Kimball et al. 2005), indicates that psoriasis and other chronic skin conditions can negatively impact the quality of life of those suffering from a particular condition. For example, people with psoriasis might be embarrassed to go out in public during a flare-up and might be hesitant of entering sexual relationships out of fear of stigmatization. Schmid-Ott et al. (2007) additionally claim that public misunderstanding of psoriasis is tremendous, ultimately creating stigmatized feelings among PLWP with even the smallest patches of skin affected. Consistent with the potential negative effects of stigma, Schmid-Ott et al. (2007) and Gupta and Gupta (1995) find that the subjective experience of chronic illness is a meaningful determinant of the quality of life of PLWP, whereby stigma is a chronic issue for some, while a low-grade burden for others.

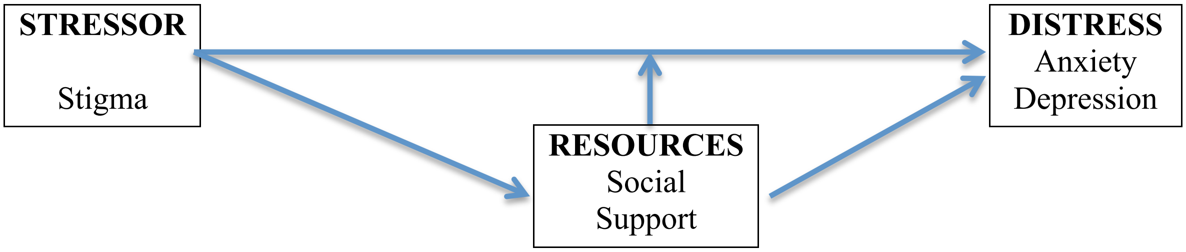
Work by Warren, Kleyn, and Gulliver (2011), Basavaraj et al. (2011), Janowski et al. (2012), and Ros, Puig, and Carrascosa (2014) suggest that the physical, psychological, and social burden of psoriasis might also have cumulative effects on PLWP. In other words, people living with psoriasis might have multiple experiences of disadvantage, such as being turned down for a job or a date, discomfort, and social rejection throughout the life course. This dissertation research investigates how stigma as a stressor may potentially play a role in creating disadvantage among PLWP in terms of attaining life goals, pursuing careers, and developing social relationships.Warren et al. (2011) suggest that the stigma of psoriasis patients is worse than other skin conditions because the lesions are often highly visible. The current research seeks to better understand how family life and social life may be "planned" around skin condition visibility, as well as how the chronicity and visibility of the condition effects the level of stigma experienced by PLWP.

Although the stigmatization of people living with chronic skin conditions (as explored through the lives of people with psoriasis) poses a real and serious threat as a stressor, there are resources such as social support that might buffer the negative stressful outcomes (Janowski et al. 2012). However, some research indicates that people with psoriasis may perceive lower social support as a result of their condition (Picardi et al. (2005) and that some must depend on personal coping strategies (Zalewska et al. 2007). This dissertation research investigates how people living with psoriasis might use social support and personal resources as tools to manage and cope with the stigma and other stressors experienced in their daily lives. Through this research then, we are not only likely to discover that there are multiple factors impacting the perception of stigma (Jowett and Ryan 1985; Ginsburg and Link 1989; and, Richards et al. 2001), but also learn the conditions that might make PLWP feel more vulnerable to the effects of CSC-related stigma (Hayes and Koo 2010).

Stress Processes of Living with Psoriasis

In attempt to articulate the experience of stigma as a stressor among people living with psoriasis, the stress process framework as a conceptual map (general orienting framework) is utilized in this dissertation as a means to investigate these daily life experiences. Applied to psoriasis narratives, the stress process model provides important clues as to how and why PLWP are exposed to stigma-related stressors, while simultaneously helping readers understand why particular stigma experiences as well as the negative consequences of stigma may differ among PLWP. Pearlin et al. (1981:337) argue the process of social stress can be seen as combining three major conceptual domains: sources of stress (stressors); mediators and moderators of stress; and, the manifestations of stress. Shown below, Figure 1 depicts the elaborated stress process model as originally outlined by Pearlin et al. (1981) applied to stigma-stress. This dissertation uncovers, through interview narratives, how and in what ways people living with psoriasis experience stigma as a stressor; how having psoriasis may increase the risk of stigmatization; and, what resources such as social support (Turner and Brown 2010; Thoits 2011) mean to PLWP and if and how they are utilized as a way to manage or lessen stigma experiences.

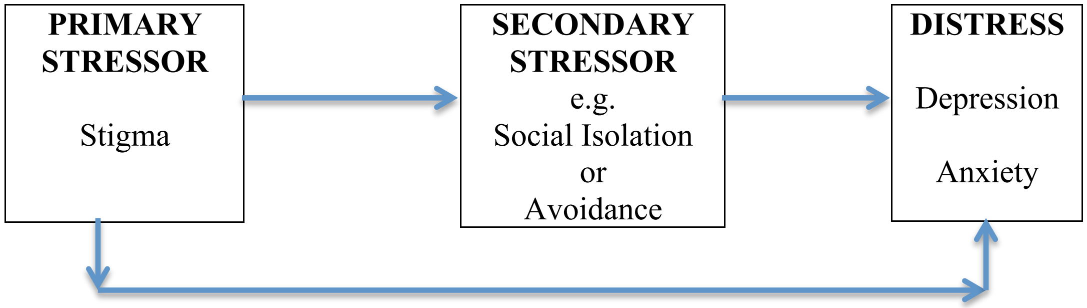
Figure 1: Elaborated Stress Process Model



In context of the stress process framework, Wheaton and Montazer (2010) argue stressors can occur in different ways. For example, stigma as a stressor can be both threatening and demanding. In other words, stigma threatens PLWP by creating the possibility or expectation of potential harm (e.g. fear of disclosure; shaming), while simultaneously placing demands on PLWP (e.g. burden or overload; guilt). Threats and demands characteristic of stigma as a stressor are likely present at life event changes (e.g. psoriasis diagnoses) and are continuous and persist as a chronic stressor (e.g. day-to-day stress). Work by Pearlin, Aneshensel, and Leblanc (1997) addressing chronic stress suggests that some groups of people are particularly likely to experience "stress proliferation". Stress proliferation essentially refers to "the expansion or emergence of stressors within and beyond a situation whose usefulness was initially more circumscribed", and or "a situation where a stressor or set of stressors penetrates the boundaries of the multiple life domains in which individuals are engaged" (Pearlin et al. 1997:223). In accordance with Pearlin et al.'s (1997) suggestion that stressors beget stressors, this dissertation qualitatively investigates the proliferation of stress among PLWP, stemming from stigma. This investigation contributes to the stress process literature by revealing how and in what ways stigma acts as a primary stressor challenging PLWP, leading to possible secondary stressors, which in turn may increase distress among PLWP.

Figure 2 provides an illustration of stigma acting as a primary stressor, leading to possible social isolation or avoidance (secondary stressors) by PLWP, thereby increasing the levels of distress among PLWP (e.g. depression; anxiety). However, CSC-related stigma as a primary stressor may also directly affect levels of distress among PLWP. In this dissertation, attempts are not made to "test" these models, but instead utilize the stress process framework as an organizing framework that helps guide interview questions, thereby uncovering the social processes of stigma and stress. In other words, "results" of this dissertation research are not constrained by the models illustrated in this chapter; the social processes around stigma and stress experiences emerge from the narratives of PLWP in the following chapters.

Figure 2: Stress Proliferation among PLWP



In general, scholars have applied the stress process framework in their sociological analyses of stressors and stress exposure in a variety of social, personal, and institutional contexts. For example, stress process researchers have explored the ways in which stressors associated with self and identity (Thoits 2013), family status (Umberson, Thomeer, and Williams 2013), and work (Tausig 2013) impact outcomes of mental health. Stress process researchers have simultaneously identified the distressing consequences of stressors stemming from economic hardship (Young and Schieman 2012), discrimination (Gayman and Barragan 2013), and physical limitation (Bierman and Pearlin 2011; Brown and Turner 2012), while indicating how stressor exposure can vary by race, socioeconomic status (SES), and gender (Turner and Avison 2003). Utilization of the stress process framework in past descriptions of findings pertaining to stressor exposure, response to stressors, on a plethora of outcomes, such as mental health, opens the door for new lines of inquiry. This dissertation research contributes to the stress process literature by shedding light on the understudied lives of people with psoriasis and their day-to-day experiences of stigma as a stressor (as well as other important stressors) and ways of coping and dealing with that stress.

CHAPTER III
METHODOLOGY

Study Design: A Qualitative Approach

This dissertation highlights the variety of ways that stigma operates in the stress process, including how stigma-related stress proliferates into many domains of daily life (interpersonal and institutional contexts), and how PLWP manage and cope with stigma and other psoriasis-related stressors. Inquiry of this nature requires a qualitative approach, for a majority of prior, mostly quantitative work, focuses solely on social stigma from society's (or the researcher's) view of stigma, rather than focusing on affected individuals' perceptions or experiences of stigma (Mickelson 2001). Employing a qualitative research design in this dissertation is useful for capturing perceptions of stigma and experiences of stressors as they occur in natural, every-day settings (e.g. on-line psoriasis groups, place of employment, activities or social events, and within family and peer interaction) for PLWP. In order to make sense of the daily stressors experienced by PLWP and how PLWP cope with the stressors, I collected data for this study by conducting twenty-three in-depth, semi-structured in-person and telephone interviews with PLWP across the United States and a U.S. Territory. I also participated in a National Psoriasis Foundation sponsored psoriasis walk in one of New England's largest cities as part of a strategy to recruit interested PLWP. I draw on interview narratives in the "findings" of this dissertation as a tool to organize key themes in the data and produce and describe a holistic, illustrative account of daily stressors experienced by PLWP participating in this study.

The format of this dissertation, more broadly, reflects an "emergent" research design. Despite the initial strategic plan for the study, phases and components of the research process (e.g. recruitment, interviews, and analysis) were modified from time to time in order to account for and adapt to emerging issues and themes in the data. For example, I revised and added questions and probes to the interview guide as the study progressed to more adequately capture apparent themes in early interview responses. By allowing the emerging data to help guide the protocol, I maintained flexibility in adjusting research strategies and procedures upon learning of potential problems, or new avenues for investigation while talking with study participants. Adapting to changes in the natural setting of those participating in this study, as well as the research process itself, was crucial for understanding participants' experiences of the day-to-day stress of living with psoriasis, for life with a CSC is not static.

To understand the on-the-ground reality of daily CSC-related stressors, and to "get close" to participants (Emerson et al. 2011), I participated in a walk to cure psoriasis and recorded ethnographic field notes. Through attendance at the psoriasis-related walk event as well as gaining membership to two online groups for PLWP, I was able to enter the social worlds of people living with psoriasis. Each component of the research design helped facilitate a deeper understanding of the daily lives (social worlds) of participants as a way to make sense of PLWP' experiences of stigma as both meaningful and important, and at the same time allowing me to utilize the stress process framework as a means to interpret these social worlds. Crucial patterns, categories, and themes from interview data were identified in a bottom up, inductive format. In other words, I worked back and forth between apparent themes in the data to specify how stigma, and other stressors were experienced and given meaning by the participants themselves. The stress process framework is used as an interpretative toolkit to unpack and make sense of the key themes from interview data and to organize the findings for the reader.

The qualitative methodology employed in this dissertation allows a more in-depth understanding of the meaning(s) attached to daily experiences of stigma and other stressors, and how and why the meaning(s) vary among the participants interviewed. Research by Kennedy (2006) suggests stigma narratives, such as those of PLWP applied here, allows the researcher to uncover illness experiences that may, in the current context, shape PLWP' "psoriasis identity". Moreover, in the final section of this dissertation, I will also suggest ways that this qualitative data might inform future quantitative *and* qualitative sociological research on stigma-related and other stressors among other groups of stigmatized persons.

Study Participants & Data Collection

Psoriasis is one of the most common chronic skin conditions. Work by Hrehorow et al. (2012:67) suggests that psoriasis markedly influences many aspects of life for PLWP (e.g. social, occupational, sexual, and also financial). The potential visibility (e.g. symptoms appearing on face, neck, extremities, etc.) and severity of symptoms (percent of body affected by symptoms) of persons with psoriasis make them particularly useful informants for understanding stigma and stress processes among people living with a chronic skin condition. In chapters to follow, I will draw on responses from interview participants to highlight, for example, how variability in symptom visibility and severity, as well as difference in social contexts, create variability in stigma-related stressors.

This study, which was approved by the University of New Hampshire's Institutional Review Board (IRB) (see appendix for official approval document) consisted of three interview recruitment phases. First, I participated in a psoriasis walk hosted by the National Psoriasis Foundation (NPF) in one of New England's largest cities early fall 2014. While attending and participating in walk events, I distributed IRB-approved fliers (see appendix for flier) advertising the study to walk participants and volunteers. The site for the psoriasis walk was selected as a venue for initial recruitment due to the large number of PLWP and their support networks that were projected to attend and because there were no psoriasis support groups in existence at the time this study was conducted. Next, I designed a second IRB-approved flier (see appendix for flier) advertising the study and posted the flier on bulletin boards of local businesses in northern New England and on the campus of a large coastal flagship state university in northern New England. Finally, I gained access to two separate online groups for PLWP, one public group (open access to public) and one private psoriasis group (access at the discretion of site administrator). On the respective sites, I posted a flier similar to those distributed to local business. The strategy behind the implementation of three recruitment phases was two-fold: one, to encourage interested PLWP to sign up for an interview, and two, to encourage interested PLWP to inform other PLWP of the study, with the intent of a snowball sample transpiring from the original recruitment pool. Although, the non-probability convenience sample of people with psoriasis makes it challenging to "control" for age, gender, and race in this sample, an effort was made to reach a diverse audience at each recruitment stage of the project.

I conducted twenty-three semi-structured, qualitative interviews (seven in-person interviews; sixteen phone interviews) with adult men and women (over age 18) living with psoriasis in the U.S. and U.S. Territories. Interview participant characteristics are located in Table 1.

Table 1. Interview Participant Characteristics (n=23)

Age	Range: Average Age:	19 Years – 78 Years 39 Years
Gender	Male: Female:	05 18
Race/Ethnicity	Black: Non-Hispanic White: Hispanic: Indian:	01 20 01 01
Relationship Status	Single: Married: Domestic Partnership:	15 07 01
Time with Psoriasis	Range: Average in Years:	08 Months – 65 Years 19.1 Years
Symptom Coverage	Range: Average Coverage:	Mild (3% Coverage) - Severe (>10% Coverage) Moderate to Moderate/Severe
State/Location	U.S. States: U.S. Territory:	15 01

Information in Table I indicates the average age of participants from 15 U.S. states and 1 U.S. Territory, from all regions of the country (North, South, East, West, and Midwest),was just under 40 years. More women than men participated in the study, and despite some variation, the sample was largely non-Hispanic, white. Table I also indicates more single PLWP participated in the study than married PLWP, and that the average length of time participants reported living with psoriasis was just over 19 years. Additionally, study participants, on average, reported the psoriasis symptom coverage on their body to be moderate (between 3% and 10% of body covered with psoriasis symptoms) to moderate-severe (10% or more of body covered with psoriasis symptoms). While Table I does not list study participant occupations, this sample of PLWP covered a wide range of professions including, but not limited to: medicine, education, service industry, and government. Furthermore, 3 study participants reported being unemployed at the time of the interview, 3 identified their occupational status as college student, and 2 were retired.

All interviews (in-person and telephone) were conducted between early fall 2014 and winter 2015, with interviews averaging just under one hour each. In-person interviews took place at locations convenient for participants (e.g. local coffee shop) and phone interviews took place at times convenient to participants based on regional time-zone differences. The interviews followed an interview guide approved by the university IRB (see appendix for full interview guide) before the project started. Participants were first asked to provide demographic information (e.g. age, gender, marital status, etc.), followed by providing responses to five general questions and a series of follow-up probes consistent with the research objectives of this study. The interview guide was flexible and was revised over time as interviews with PLWP proceeded. Participants were given a copy of an IRB-approved informed consent document (see appendix for informed consent document) prior to the interview informing them of the purpose of the study, as well as their rights and risks as a participant. In-person study participants were given a hard copy of the consent document before the start of the interview, and participants that participated over the telephone were sent a consent form electronically via email prior to the interview.

The informed consent document also asked for participant permission to audio-record the interview. At the conclusion of each interview, participants were given an IRB-approved debriefing document (see appendix for debriefing document) informing them of local and domestic resources for PLWP (NPF contact information in the U.S.), as well as contact information, in case they had questions or concerns regarding their participation in the study. Additionally, all interviewees received a $20 cash card as a token of appreciation for participating in this study. As a way to protect the identity of study participants, I assigned pseudonyms to quoted material illustrated in findings sections of this dissertation.

Creswell (2009) critically notes that triangulation of different data sources (e.g. seeking out and using multiple data sources) is important for building a coherent justification for themes in qualitative research. While findings in this dissertation are based on interview data from conversations with PLWP, discussion of these findings are informed by other sources of data (observations) to shed light on apparent themes stemming from the lived experiences of stigma-stress among PLWP. The combination of in-depth interviews with PLWP and participation in a psoriasis walk event help to inform the findings of this dissertation by highlighting CSC-related stigma as a social process. Participants living with psoriasis had the opportunity to share their experiences of the day-to-day challenges and stressors associated with their condition. Participants, all of whom have experienced psoriasis-related stress, were particularly receptive and grateful for the opportunity to share their stories. Findings from qualitative interviews with PLWP outlined in this dissertation will benefit sociologists, mental health researchers, and other scholars by informing them how stigma as a social process serves as a stressor not only for PLWP, but also other understudied stigmatized groups.

Data Analysis

As a general analytic strategy, I systematically recorded all observations and interaction with PLWP as a tool to inform the "findings" of this study. For example, as a participant in an NPF-sponsored psoriasis walk, I wrote down jottings, which were short descriptions or phrases of observations I made during the event as well as key phrases from informal conversations I had with other event participants. After participation in the psoriasis walk was complete, I transformed the brief jottings into full written accounts and detailed descriptions (ethnographic field notes) of each observation I made and each conversation I had throughout the event. Participation in the psoriasis walk event granted access to an initially unfamiliar social world of

PLWP, which resulted in the production of written accounts of that world (Emerson et al. 2011). During each of the twenty-three interviews with study participants, which were audio recorded, I similarly kept record of my observations. For example, during in-person interviews, I made notes as to the participant's dress, speech, and general demeanor. During phone interviews, I noted the tone of voice as well as patterns of response (e.g. long pauses versus quick response) of each participant. After the qualitative interviews were complete, digital audio recordings of the interviews with twenty-three PLWP were transcribed verbatim and uploaded to ATLAS.TI, a qualitative analytical software program.

The value of this qualitative study lies in the particular description of themes, which emerged from interview conversations with PLWP. In other words, particularity rather than generalizability is the staple of this study (Creswell 2009:193). Consistent with the qualitative, emergent design of this study, the following procedure for analysis of data was followed. First, data collected from twenty-three in-depth qualitative in-person and phone interviews with PLWP were transcribed verbatim. Second, interview transcripts were uploaded to ATLAS.TI for coding and analysis. I utilized an open coding procedure for analysis of interview data. In other words, interview transcripts were inductively analyzed line by line and several codes were developed. I categorized the open codes and clustered them in accordance with the respective sections of the interview guide. Once the codes were clustered by section, sub-codes developed and themes from interview data emerged. For example, I first read through each participant response to the initial question on the interview guide, *how did you become aware of your psoriasis condition?* as well as follow-up probes. Fifteen codes emerged from participant responses toward the initial question and probes. Another seven sub-codes (codes that derived from the original fifteen codes) emerged after combing through the data a second time. I then organized the twenty-two total codes based on themes that emerged from participant responses. I repeated this coding procedure in ATLAS.TI for each question and subsequent probes on the interview guide. As a general research strategy, I wrote memos while analyzing themes that had emerged during the coding phase as a way to describe my findings contextually and to make sense of the data, theoretically.

Next, two colleagues and I performed an inter-coder reliability check. Inter-coder reliability refers to the extent to which two or more independent coders agree on the coding of the content of interest while applying the same coding scheme. To check for code consistency, I distributed excerpts of participant responses to my colleagues; each then independently coded the material, which was then compared to codes I originally assigned. The exercise showed the coding scheme of interviews to be accurate and reliable; for the most part, independent coders assigned the same codes to the interview material.

Finally, I utilized a grounded theory approach (Glaser and Strauss 1967) to the analyses. Corbin and Strauss (1990:5) argue that a grounded theory approach to qualitative study is valuable because social phenomena are not conceived of as static; rather, the social phenomena are continually changing in response to evolving conditions. A grounded theory approach to data analysis accounts for changing and evolving phenomena such as, stigma-stress, allowing me to not only uncover relevant conditions in the lives of PLWP (stigma, stress, and health), but to also highlight how PLWP might react to changing conditions (e.g. new social environment) and adjust their actions (e.g. utilizing personal and social support) (Corbin and Strauss 1990). Following a grounded theory approach, I collected interview data, located key concepts in interview transcripts, and developed categories and groupings of key themes via an open-coding scheme. Open coding of data provided opportunity for adjustment and adaption to changing conditions throughout the research process. For example, I made small changes to the interview questionnaire as themes emerged from prior interviews. Moreover, throughout the analysis phase of this study, I was attentive to subtle variations in emergent themes to aid in the construction of holistic nuanced accountings of PLWP' experiences of stigma-stress.

Descriptions or themes stemming from the codes did not speak for themselves. The descriptions, accounts, and codes highlighting daily experiences of stressors among PLWP were organized with the help of the stress process framework (Pearlin et al. 1981). Corbin and Strauss (1990:11) argue grounded theory need not work alone; a sentiment shared by other contemporary grounded theory scholars (LaRossa 2005; Poteat, German, and Kerrigan 2013). In other words, applying concepts and themes that emerged from the data to an existing theory leads to new insights (e.g. stigma, stress and health), and theoretical sensitivity (demonstrated usefulness of stress process framework highlighting stigma as a stressor) (Corbin and Strauss 1990). Themes that emerged from the data speak to the larger picture of how this group of PLWP experiences stigma-related and other stressors on a daily basis. My job as a researcher was to search for patterns (themes) in the data and for ideas that help to explain why the patterns exist. The stress process framework was implemented in this study as a general orienting framework to help organize, synthetize, and make sense of themes deriving from study data; it was not used to "test" preconceived hypotheses of the social processes involved in determining stigma-stress among PLWP. Moreover, a grounded theory approach to studying stigma, stress, and health among PLWP fits well with the stress process framework, for emergent themes can be informed by or contrasted to research findings on stress-related issues. For example, past stress process research has shown how personal and social resources often help people to manage stressful conditions like job loss or marital dissolution. Findings emerging from this study can show how similar (or different) resources are utilized to manage or reduce conditions of stigma-stress.

CHAPTER IV
WHAT IS PSORIASIS?

Psoriasis is a chronic, incurable, non-contagious autoimmune skin condition effecting approximately 7.5 million Americans and 125 million people worldwide (NPF 2014). Although the exact cause of psoriasis is unknown, the two processes that comprise psoriasis (rapid skin growth and inflammation) appear equally among men and women and among all races, although, some people are genetically predisposed to psoriasis more so than others (NPF 2014; Bergstrom and Kimball 2011). As a chronic skin condition, psoriasis manifests in a variety of forms (e.g. guttate; inverse; pustular,) and symptoms (e.g. white scales, redness, swelling, itching, and painful patches or plaques). The severity of psoriasis-related symptoms waxes and wanes throughout life (e.g. increased severity of symptoms during psoriasis flare-up; decreased severity of symptoms after successful treatment) and can appear at any age without warning (Bergstrom and Kimball 2011). Literature on psoriasis (Bergstrom and Kimball 2011) indicates that, while the condition is almost never fatal, psoriasis can bring extreme discomfort, disfigurement, and disability to PLWP.

In this chapter, I draw on interview data from conversations with PLWP to describe nuanced meaning(s) and experiences of *psoriasis as a condition* among study participants. In order to create a holistic, narrative account of PLWP' experiences with and management of CSC-related stigma-stress, attention is focused first on condition-related elements of psoriasis (e.g. symptoms, triggers, etc.) that PLWP identified as the foundational make-up of their respective experiences. During interviews, study participants were initially asked, "How did you first become aware of your psoriasis condition?" I asked a series of follow-up probing questions as a strategy to uncover important condition-specific components that contributed to the overall meaning of psoriasis in participants' lives. Responses of participants generally fell under four thematic categories: symptoms and triggers of psoriasis; diagnosis and disclosure; treatment; and, psoriasis and quality of life. I provide illustrative examples from the interview data to demonstrate how and why these themes are important to study participants. The themes discussed in this chapter provide a springboard for the discussion of CSC-related stressors and stressor management presented in the next chapter.

Symptoms and Triggers

Psoriasis is a condition that is interwoven with virtually all aspects of PLWP' lives. The notion that psoriasis affects PLWP' lives in pervasive and meaningful ways was consistent with interview responses of study participants. As a way to understand what psoriasis as a CSC meant for the PLWP I interviewed, I asked participants how they first became aware of their psoriasis condition. Roughly 18 of 23 participants explicitly discussed psoriasis-related symptoms and triggers they experienced as a way to frame their experiences, a frame that served an important role in each participant's overall psoriasis narrative.

Psoriasis symptoms can appear at any age, take a variety of forms, and can differ in terms of the percentage of body-mass coverage (NPF 2014). Response of PLWP interviewed for this study reflected this whole range of psoriasis-related symptomology. I spoke with participants who have lived with psoriasis for a relatively short amount of time, like Gloria, a 42-year-old major gifts officer in Massachusetts who has lived with psoriasis for approximately 8 months, as well as with participants who have lived with psoriasis for several years, like Dennis, a 72-year-old retired professor in North Dakota who has lived with psoriasis for over 65 years. Not only did the amount of time that study participants lived with psoriasis vary considerably, so too did their experiences with psoriasis-related symptoms. For some, like Brent, a 27-year-old systems support analysis in Massachusetts, symptoms of psoriasis started out rather insidiously:

> I kind of…you know, what I remember is that I had kind of like uh…it [psoriasis] started with the scalp so, I had kind of…almost like a bruise or, umm…you know, a cut or something, umm…kind of at the top of my scalp. You know, I thought it was like a sports injury. I played lacrosse at the time and I thought maybe like my helmet was irritating my head, which I never really thought anything of it. It [psoriasis] started really small you know, and so I let it go. Umm…and then, you know, over… over the summer and then into my first year of uh school I noticed that you know, it [psoriasis] became more like dandruff and then…you know, eventually it became this kind of scaly, you know…constant flakes falling off, that you know is kind of characterized as psoriasis.

For other study participants like Molly, a 22-year-old college student in New Hampshire, psoriasis-related symptoms started insidiously, but quickly spread to many areas of her body:

> In the beginning, at first it [psoriasis] was just like small little patches. But, I vividly remember that probably after having the symptoms for 5 or 6 months, umm…it [psoriasis] was like completely everywhere on my body. It was on my scalp; it covered like every area of my skin with patches. I remember…it's kind of a disturbing story, but it was like things growing out of my head, of psoriasis patches, and I remember my parents having to literally cut the patches out of my head so I could brush my hair. It was so bad.

While psoriasis related symptoms appeared out of nowhere for participants like Brent and Molly, at least 3 participants told of their psoriasis symptoms appearing after experiencing illness. For example, Julie, a 22-year-old with long curly red hair and blue eyes reported, "it was in the end of January and I had just gotten over a cold and, umm…yeah, I had strep throat and then I got medication for it. It was almost exactly 2 weeks after I was done taking the medication that I started getting a rash. It [psoriasis] started on my neck…umm it just looked like a rash." Danielle, a 21-year-old single mother in Maryland on the other hand told of her psoriasis symptoms appearing after giving birth, "I just had my son and I started to get a flare-up on my head and my head was itching really badly. Over time it [psoriasis] got worse, and it spread to my legs and then to my stomach and now I actually have it on my back."

Whether psoriasis-related symptoms developed insidiously, quickly, or appeared after a health event (e.g. strep throat; child birth), the location of symptoms varied widely between participants. For example, for some participants, psoriasis symptoms appeared in the genital region, for others, on the head, extremities, and fingernails, and for some participants, in their joints as psoriatic arthritis. Despite location variability of psoriasis-related symptoms, many of the types of psoriasis symptoms reported were consistent across almost all PLWP interviewed for this study. Participants repeatedly cited itchiness, pain, flaking, scaling, and even bleeding as part of routine psoriasis symptoms experienced. Angelica, a 32-year-old forensic consultant from Puerto Rico referring to her psoriasis plaques, stated, "They are very, very itchy. Umm…for me, that's the worst part about it [psoriasis], that they're very itchy…it's not that it's always a problem, but they itch A LOT!" Christine, a 24-year-old South Carolina resident who was unemployed at the time of the interview and has lived with psoriasis for roughly 12 years, likewise cited her own experience with psoriasis symptoms, "Umm…most difficult symptoms would definitely be…the fact that you flake everywhere. The uncontrollable itch…the cracking…the uh…I mean the stinging… your skin stings." These types of responses were characteristic of many respondents in the study, namely that psoriasis symptoms bring significant discomfort to PLWP. As will be discussed later, such physical discomfort is often a significant source of stress in the lives of PLWP.

The severity of psoriasis-related symptoms for PLWP has generally been classified as mild (less than 3 percent of body coverage), moderate (3 to 10 percent of body coverage), or severe (more than 10 percent of body coverage) (NPF 2014). PLWP may experience temporary psoriasis symptom flare-ups or, temporary symptom relief from successful treatment. PLWP interviewed for this study reported a wide range of symptom severity. Some participants claimed they experienced mild to moderate symptom coverage of psoriasis. For example, Christine, the 24-year-old from South Carolina explained how her symptom coverage initially began as mild, though changed over time and was considered moderate. Christine stated, “My initial symptoms…I wouldn’t think they would be considered very severe at all, it was very manageable. Umm...at this point, at 24, I’d say it’s about a moderate amount.” Libby, a 53-year-old from Oklahoma who has lived with psoriasis for roughly 35 years, similarly claimed her symptom coverage type changed, though hers became less severe: “ I would say initially…umm…I can remember the plaques being much larger…and they would come off in one, like in a sheet almost. Now, it is almost like the dust. It’s not the full on plaque. It’s changed.”

While participants like Christine and Libby experienced mild to moderate psoriasis symptoms, participants like Alan and Beth experienced severe psoriasis symptoms that covered much of their body. Alan, a 36-year-old service industry worker in North Carolina who has lived with psoriasis for approximately 16 years, shared that his psoriasis covered as much as 65 percent of his body. Beth, a 44-year-old medical billing specialist in Connecticut who has lived with psoriasis for 28 years, reported 90 percent of her body was covered with psoriasis. Both Alan and Beth cited their severe psoriasis coverage created substantial discomfort in their daily lives. The physical discomfort experienced by study participants was particularly evident in a response from Rob, a 30-year-old construction worker in New York who has lived with psoriasis for roughly 11 years. Rob reflected on past and present severity level of his psoriasis and claimed:

> Early on, it [psoriasis] was just confined to my scalp. But, it was VERY severe. Umm…it pretty much followed my hairline, and the scalp psoriasis is interesting because it produces almost like a gel…umm…it was very severe, VERY severe. Very painful. I would wake up at night clawing at my head. Just a lot of blood and nastiness. Umm…lost a decent amount of hair. Umm…now, I'd say about 40% to 50% of my body is covered in plaques, and by that I mean, solid, solid plaques…not little guttate spots. My entire torso is a giant plaque. My arms and legs are similar, but the severity is not there. It isn't…it sheds a lot, but it isn't as painful; it isn't as red.

Rob not only experienced psoriasis coverage all over his body, he experienced additional discomfort after scratching affected areas and experienced bleeding. Study participants who reported severe levels of psoriasis coverage also identified how seeking medical attention can be problematic. Dennis, the 72-year-old retired professor from North Dakota shared how the severity of his psoriasis symptoms interfered with his medical specialists' ability to differentiate between psoriasis and other conditions such as cancer:

> My psoriasis is very severe. You know, when I go to see my specialist…he has a very difficult time, you know, he's always looking for cancer and he'll look at me and I look like a person who had the measles. I have it [psoriasis] all over my body…but I don't have a lot on my face. My legs are just loaded and he'll look at that and say, "my biggest problem is trying to differentiate what I should take a biopsy on" and that kind of stuff. So, I have a lot of it [psoriasis]. I have some on my hands…and different spots that come and go. Sometime I have fingernails that you know, they have psoriasis, and they have to be cut off. You know, that varies…I used to go through that all the time and in the last year, my fingernails have been fine. But, it's goofy. It's pretty severe.

Although symptoms are often severe, at least 3 PLWP experienced remission from their psoriasis symptoms. In a medical study conducted at Stanford University, roughly 40 percent of PLWP experienced condition-free periods of over 1 year. (Bergstrom and Kimball 2011). Laura, a 19 year old college student who has lived with psoriasis for 3 years, claimed the psoriasis rash on her neck has, at times gone into a remissive state where the rash dissipated, yet an itching sensation still remained. Marvin, a 78-year-old Texan who has lived with psoriasis for roughly 42 years similarly indicated that his psoriasis went through periods of remission. Marvin stated, “I have varied between uhh…really bad blow ups, uhh…to minor blow ups, to full remissions. Umm, my last remission was this year (2014) and I’m back now and I have a fairly full outbreak.” The short-lived nature of symptom remission was also evident in a response from Rebecca, a 48-year-old from Oregon who has lived with psoriasis for about 12 years. Rebecca claimed, “there was a really brief time when it [psoriasis] had nearly gone in into remission, I had a small patch on my ankle and a small patch on the back of my arm and that lasted for…a very short time. Literally like a few days and then it came back very thick and very heavy and it had been like that since.”

It is not specifically known why one PLWP may have a mild form of psoriasis and while other PLWP have severe psoriasis. However, more is know about what makes psoriasis get worse for PLWP than what makes psoriasis get better (Bergstrom and Kimball 2011:47). Psoriasis symptom triggers vary from one PLWP to the next. However, some common triggers of psoriasis flare-ups include stress, diet, changes in weather, and some medications (NPF 2014). Interview data indicated study participants experienced psoriasis flare-ups as a result of three categories of triggers: seasons, personal habits, and stress. At least 7 participants experienced the greatest number of psoriasis flare-ups during fall and winter months, and a decrease in flare-ups during spring and summer. Several participants equated fall and winter months with increased dry, cracked lesions and plaques over their bodies and increased application of moisturizer, regularly. Sarah, a 40-year-old gardener and molecular biologist who has lived with psoriasis for 30 years claimed that PLWP often endure pain from moisturizers in order to experience relief from flare-ups. Sarah spoke of her winter moisturizing routine: “Umm…for about…5 minutes after that [application of moisturizer], it’s like being fire and then it’s where the pain slowly decreases and you’re left with a warm glow of endorphins, which, is at least one nice part about it. It [flare-up treatment] sucks”.

In contrast to fall and winter months, participants shared their affinity for warm temperatures and sunshine. Molly, the 22-year-old college student from New Hampshire claimed, “I’ve always found that my psoriasis was better during the summer months when I’m outside and exposed to the sun…so, I’ve always loved the summer.” Participants shared similar sentiments as Molly about the sun and warm temperatures and also shared experiences of seasonal effects on their psoriasis flare-ups in different locations of the country. Marvin, the 78-year-old living in Texas, shared:

> I notice it [flare-ups] more in cold weather. Down here [Texas], we don’t get that much cold. When I was up north, I lived in northwest Indiana and on the real cold days I mean, like particularly on my legs, you know I couldn’t move without feeling the scales pulling at me and trying to pull apart and trying to fall off and all of that. It was uncomfortable on almost a constant basis. Down here, uhh…a cold day for us is 40 degrees. Uhh…I occasionally get a little notice of you know, the psoriasis is bothering me some. But, it’s [psoriasis] not as severe, and it [flare-ups] doesn’t last as long.

While some study participants like Marvin, resided in warmer climate areas of the country, some participants like Alan, the service industry worker in North Carolina, told of how he experienced a reduction in flare-ups after traveling to Florida during cooler months of the year in his home state. Interestingly, participants reported that the trade-off of sun exposure consisted of a reduction in psoriasis symptoms, but an increased risk for other health issues such as skin cancer.

Approximately 4 PLWP additionally identified personal habits that contributed to their psoriasis-related flare-ups. Participants like Gloria, the 42-year-old major gifts officer from Massachusetts, cited scratching as a psoriasis flare-up trigger. In the interview, she shared, “I have a terrible habit of scratching and I think it [scratching] slows down the healing process…umm what I need to do, is kind of leave it [psoriasis] alone and let my skin heal instead of you know…basically flaring up my own skin. I need to leave it [psoriasis] alone." Gloria recognized how her habit of scratching contributed to the chronicity of her flare-up and what she needed to do to help the healing process. Other participants similarly recognized how their activities contributed to their symptom flare-ups. For example, PLWP shared of how swimming in a chlorinated pool, eating a diet high in sugar, and even dying their hair contributed to increased psoriasis flare-ups. Chelsea, a 21-year-old college student with an athletic build who has had psoriasis for 3 years, shared about her hair dying routine. Chelsea reported during the interview:

> I dye my hair, and…dying it KILLS. It like, burns…I mean I do it anyways because I want to keep dying my hair. But like, I definitely shouldn't (laughs). I like sit there…like do it myself, well one of my friends helps, and I just sit there and like clench my fists because…because like it's all fine up here [points to the scalp], but that's how I know where the psoriasis is, because I can't see it, but once you get to it, it starts to burn and as you go down, it burns from when you get the chemicals on it [psoriasis] from like the hair dye (laughs).

Some participants like Chelsea, continued routines recognized as predictable triggers of their psoriasis flare-ups, whereas other participants like Christine, the 24-year-old from South Carolina experienced triggers that were more or less unpredictable. Christine shared, "I've had multiple instances where it's [psoriasis flare-ups] gotten worse. I've had two children. Both pregnancies, my psoriasis was almost unmanageable." In Christine's experience, her pregnancies led to increased psoriasis flare-ups that were particularly problematic for her. Excerpts from PLWP narratives indicated more generally that some triggers of psoriasis flare-ups among study participants were self-induced (e.g. scratching; dying hair, etc.), while other participant flare-ups appeared unpredictably, either seemingly out of nowhere, or after an event like childbirth.

The most frequently cited trigger for psoriasis flare-ups among study participants was stress. Though ambiguously defined, stress has been presented in the literature as a trigger of psoriasis symptoms (NPF 2014). At least 10 participants explicitly recognized and attributed stress to the increased severity of psoriasis flare-ups they experienced. Alan and Danielle are two PLWP that explained this notion succinctly. Alan broadly shared, “I mean I think that the overall stress level in your life is a trigger for psoriasis”, while Danielle articulated further, “I mean it’s stressful sometimes because in life you know, you go through stressful periods of time and I know stress can make psoriasis worse. So…sometimes I have to calm myself down because I don’t want another flare-up.” From excerpts in Alan and Danielle’s narratives, it’s clear that they and other study participants like them, simultaneously identified stress as a contributing factor to their psoriasis flare-ups and acknowledged stress reduction as an important mechanism in the management of symptom chronicity. Study participants claimed that stress experienced at school, at work, during certain seasons of the year, and during co-occurring health conditions, contributed greatly to increased psoriasis symptom flare-up events.

Interview data indicated that study participants often framed the nature of psoriasis-related stress and psoriasis flare-ups as cyclical. For example, Sharon, a 43-year-old unemployed Michigan resident who had both psoriasis and psoriatic arthritis, referring to the stress of having psoriasis and symptoms flare-ups, claimed:

> I’ve kind of…I’ve got bigger fish to fry than to worry about that [stresses of the world]. So, it’s mostly my personal issues with it [psoriasis] that stresses me out and I know that stressing is not good for psoriasis; it’s the one trigger that really makes mine flare. So, it’s a vicious cycle for me. I have to you know, calm down and it’s like, “you know what, it’s not worth it, you’re only making it worse” [said to self] kind of thing, so…

Sharon acknowledged daily stresses of the outside world, but found the personal concern over her own psoriasis condition (and psoriatic arthritis) was especially stressful, which contributed to her increased symptom flare-ups. Angelica, the forensic consultant from Puerto Rico similarly talked about the stress of her psoriasis and the unknowns of the condition, and said, “So, not knowing…like, what can happen to my body and that stresses me out even more and then…you know, the flare-ups do come and…and you get stressed about it. It's a vicious cycle because you know…you get stressed about it and then you get more flare-ups and then you get more stressed about it." Together, Sharon and Angelica, as well as other study participants, described stress and psoriasis flare-ups as a vicious cycle where one continuously impacted the other.

Taken together, interview data presented here indicate that PLWP share similar symptoms and triggers of psoriasis, though the chronicity of symptoms and types of triggers vary from one PLWP to another. These findings reveal that the meanings PLWP ascribe to psoriasis symptoms and triggers are shaped and patterned by a number of factors (e.g. seasons; treatment). Findings presented in chapter 5 show how psoriasis condition-related symptoms represent substantial sources of stress for PLWP, highlighting the intense nature of stressors PLWP like Sharon and Angelica face daily.

Diagnosis & Disclosure

16 PLWP explicitly cited psoriasis diagnoses and disclosure as two additional condition-related components of psoriasis that contributed significantly to their overall experience of living with psoriasis. Participants discussed whether they had been professionally diagnosed (e.g. diagnosed by a physician or specialist) and shared whether or not they disclosed their psoriasis condition with others, aside from medical professionals. Present, day, approximately 95 percent of the time, health care providers diagnose a patient with psoriasis after conducting only a visual inspection of their skin (NPF 2014). While there are no blood tests to confirm a psoriasis diagnosis, clinical practitioners typically rely on identification of similar skin changes (e.g. scaling, redness, pain, etc.) that are common among patients with psoriasis (Bergstrom and

Kimball 2011). I draw on interview data to discuss nuances in diagnoses experience of PLWP interviewed for this study.

All 23 participants interviewed for this study, at some point, received a formal, medical diagnosis of psoriasis. Participants mostly received a psoriasis diagnosis from a dermatologist, rheumatologist, or general practitioner. While all participants received a formal diagnosis, diagnoses experiences varied widely. For many participants, like Brent, a 27-year-old systems support analysis from Massachusetts, a psoriasis diagnosis was clear from the start. Brent recalled the immediacy of his diagnosis, "the dermatologist was able to kind of, right away say that it [psoriasis] was, you know… psoriasis." On the other hand, a psoriasis diagnosis was not so clear from the beginning for other study participants. Chelsea, the 21-year-old college student who provoked a psoriasis flare-up from dying her hair, recalled:

> So, I eventually went to the doctor and my primary care actually had no idea what it was. They seemed very baffled by it. So… I was initially like, "oh, it's probably just some skin condition". But, when they [doctors] didn't know what it [psoriasis] was, I was like, "oh, maybe it's something bad!" So, they [doctors] like…like tested it and they were like, "we don't know" and so they like sent me to umm…a different hospital for like a specialist to look at it [symptoms]…like a skin specialist. So, I was like, "okay". Then I went in, and the second that I went in he [dermatologist] looked at it, and he's like, "oh, this is psoriasis" and I was like, "oh, okay"…because at first I was like, "I have cancer…I'm dying…like I don't know what it is" [jokingly said to friends]. But…yeah so he told me it was psoriasis, and…and he asked if it…like he checked the rest of my body and it nowhere else beside my neck and scalp.

In contrast to Brent's swift psoriasis diagnosis by his dermatologist, Chelsea's primary care physician's ambivalence and inability to provide an accurate diagnosis contributed to her initial misunderstanding of her symptoms.

Although most study participants sought a diagnosis from a medical professional first, some PLWP received a diagnosis through an alterative route. Amy, a soft-spoken 36-year-old lecturer at a college in New Hampshire, who had lived with psoriasis for over 30 years, reflected on her early days with psoriasis. Amy grew up in rural Maine, and when her psoriasis symptoms appeared at a young age, her parents took her to visit a community health van that set up shop in a local parking lot. As an adult, Amy later sought a formal diagnosis of psoriasis from a dermatologist, for the mobile health professional did not originally classify her condition. Amy's diagnosis narrative is particularly interesting, for regional differences in availability and approach to healthcare of residents are likely to impact the probability of a timely and accurate psoriasis diagnosis. Interview data more broadly indicated that, not only did PLWP seek a variety of routes toward diagnosis, some participants consulted multiple medical practitioners simultaneously.

Data from the interviews revealed several additional diagnoses-related issues among study participants. Participants' knowledge of psoriasis, perception of modern medicine, co-occurring illnesses, and their own independent research regarding psoriasis were frequently cited. At least 7 PLWP indicated that the amount of knowledge they had about psoriasis prior to their diagnosis was very limited. Laura, the 19-year-old timid college sophomore who has lived with psoriasis for about 3 years, said, "I heard about it [psoriasis], but I didn't really know what it was because I would see like TV commercials about medicine for it…but, I never really like knew it was a skin condition or anything like that." Despite the frequency of psoriasis-related commercials on television, many participants like Marvin, the 78-year-old from Texas, did not have an idea what psoriasis was prior to his diagnosis. Marvin told of his visit to the doctor and recalled, "I went to my family doctor and he took a look and said, "You have…psoriasis!" and I said, "Okay, what's that? (laughs)." Many other study participants shared similar stories about not knowing what psoriasis was, or that different types of psoriasis existed. Amy, who originally sought help from a mobile health van, thought psoriasis "was just "that weird thing about me" and sometimes I had to put cream on it (laughs)." After receiving a formal, medical diagnosis, however, all PLWP in this study became well-informed as to what psoriasis is and what it entails.

Interview data indicated that perception(s) of modern medicine also affected participant's response to the diagnosis. Interestingly, only 2 study participants mentioned having confidence in modern medicine, or the medical model approach to psoriasis (i.e. if there's a problem, treat it medically) during the interview. Brent, the 27-year-old systems support analysis from Massachusetts spoke of his visits with his dermatologist positively, and reported:

> You know, I definitely felt comfortable with him [doctor] and I think I've always kind of felt comfortable with medical professionals just because… you know, I think a lot of people, some people might be embarrassed you know, or something like that umm….to see a physician but, umm I've always kind of respected the ah, the uh…the kind of the professional kind of nature of it [medicine]. So, I've never felt you know, any…any, I've never felt ah, kind of you know, timid about umm seeking professional help with stuff. I felt comfortable. He [doctor] also made me feel comfortable…sounded like he knew what he was doing, that he kind of uhh…he had you know, experience like this before So…yeah, that was good.

Beth, the medical billings specialist in Connecticut similarly cited trust the modern medical community and remarked that not only does she see her dermatologist and rheumatologist regularly, she complied with her doctor's orders (e.g. prescriptions, etc.) after every visit.

Far more participants cited mistrust in modern medicine of psoriasis when they addressed diagnosis-related issues in interviews. Rob, the 30-year-old construction worker from New York, did not sugar coat his perception of the medical community:

> Another thing is I have a lot of issues with the medical community. Umm, I've probably been through about a dozen dermatologists, and they're just the most useless goddamned people I've ever met. They…for the most part, don't really take the time…you get a couple different dermatologists. One thing is you go into the office and they've got the newest medication, the posters for all the newest medications up on the wall. Umm…there's no questions about history, it's very…it's tough to go to someone [doctor] who specializes in a disorder like this [psoriasis], and get no sympathy. Umm…and to then be given options that are

> TOTALLY out of your reach. That's been my general experience with dermatologists. Umm…so that's been very frustrating.

Participants similarly voiced frustration with modern medicine, specifically expressing their frustration with how medical professionals downplay their condition. Amy, the college lecturer claimed, "I know that I have been told by doctors you know, as an adult that "yeah this is mild, that it's umm…it's just a cosmetic issue, it's not really a "problem", whereas I view it as more intense then they do." Several other PLWP cited examples of mistrust in medicine, similar to the sentiments of Rob and Amy. More specifically, participants shared they did not trust certain avenues of care (e.g. for college student participants, student health services); the medical model response to their condition (e.g. physicians writing and changing prescriptions frequently); or their physician's explanation of the condition (e.g. physician couldn't affirm whether psoriasis was linked to diet or other lifestyle choices).

Interview data also pointed to the co-occurrence of illness as well as engaging in independent research on psoriasis as important factors influencing diagnosis-related responses. Study participants experienced a variety of chronic illnesses that co-occurred with their psoriasis, such as multiple sclerosis, congestive heart failure, t-cell lymphoma, and candida. Several PLWP interviewed for this study shared that not only were they living with psoriasis, they had also been living psoriatic arthritis. Marlene, a 53-year-old Mississippian who has lived with psoriasis for 33 years, spoke of her psoriasis and psoriatic arthritis: "oh my God… it's [psoriasis] horrible! I mean…it's real like patchy, scaly…I mean it will drive me crazy! Now, with the psoriatic arthritis, I have pain…I mean it will have you crying." As a way to learn more about psoriasis (and other co-occurring conditions) several participants took to the Internet in search of answers. Gloria, the major gifts officer from Massachusetts shared:

> Yeah. I mean…I definitely, you know, at first when she [dermatologist] told me, she diagnosed me…I went right back to my computer and read up on it [psoriasis]. Umm…I wasn't really interested in looking at those kind of graphic images of you know umm…but, I definitely read up on it [psoriasis] because I wanted to know why now, why you know, if there's nobody in my family that has ever been diagnosed, you know, why, why is it me? So I was a little more vigilant about what was happening and, it [personal research] also helped me as I was going into my appointment to really know what questions to ask.

Like Gloria, Susan, a 59-year-old certified life coach from New Hampshire who has lived with psoriasis for over 30 years, recounted that she searched the internet not only to learn about psoriasis in order to ask the right questions, but also as a resource to learn whether and how psoriasis is connected to other issues such as diet or conditions like leaky gut syndrome. Many study participants that experienced co-occurring conditions hypothesized that their psoriasis condition was related, or in some way(s), affected by those other conditions.

PLWP interviewed for this study talked about issues of disclosure, which appeared to meaningfully contribute to their overall experience of living with psoriasis. Participants shared whether or not they disclosed their psoriasis condition with others, aside from medical professionals, and how and when they disclosed that information. Contemporary literature on psoriasis suggests that because psoriasis has deeply personal implications for PLWP, disclosure of a psoriasis condition can be very difficult (NPF 2014). Despite the deeply personal aspects of psoriasis, at least 8 PLWP reported that they shared their diagnosis with family, friends, children, significant others, as well as employers. For some study participants, disclosure of their psoriasis condition seemed like something that "had to be done", or was viewed as a "normal" part of life with psoriasis. For example, Molly, the New Hampshire college student (who was also a youth ambassador for the NPF) spoke of her psoriasis condition openly:

> Umm… obviously I told my friends and family, but honestly, as I was growing up I didn't have anything to tell them because I didn't know. Until all of a sudden in 2010 when I had all of this information, I was telling everybody how severe

> psoriasis is, and that it's not just this rash. And so, I tend to, I try to bring psoriasis into different umm…like, I've had to do multiple papers in college, and I always have somehow, you know, made it about psoriasis.

Many participants, like Molly, disclosed their psoriasis openly. However, some participants disclosed information only after being asked by others about the condition. Dennis, the 72-year-old retired professor from North Dakota, hinted at this when he reported:

> It's one of those things where…where some people ask. A lot of people just simply say, "did you burn yourself?" The children are really good about that, they're like "What's that?!" (laughs)…they're just curious about it. It's no different from an ant crawling up your leg and saying "What's that?! What have you got there?!" you know? (laughs). I say, "it's kind of a skin problem you know, that I have here"… "Does it hurt?"… "No it doesn't hurt" and often times I'll say to the kids or people that it's just something that doesn't go away. It stays forever and ever; it's just something that I have. I have to live with it [psoriasis].

PLWP' disclosure of their condition to others appeared to be mostly successful; family and friends responded positively to disclosure. Sometimes however, disclosure of psoriasis to friends and peers created discussion of popularized "miracle cures" for psoriasis and other psoriasis myths. PLWP who chose to disclose their psoriasis condition often reported they did so as way to educate and inform others as to what psoriasis is (and is not). Molly shared this sentiment in conversation and stated, "I feel like to me, the fact that I can, you know, pass on what I know to other people…that kind of makes me feel good about the fact that I have psoriasis…that I am able to help other people." For some participants like Molly, disclosing a psoriasis condition appeared to be educational (for others) and liberating (for self) simultaneously. Study participant responses also highlighted the importance of psoriasis disclosure as an educational tool to dispel common misunderstandings and stereotypes of psoriasis. Sharon, the 43-year-old unemployed Michigan resident claimed:

> Umm…it's not always an easy conversation. It usually starts with me noticing glancing and stares and maybe a little whispering or something like that. Then, I will just approach them, and say, "Do you have questions?" and you know,

> they're all like, "No, no, no" (embarrassed) and I'm like, "No really, it's fine". I would rather educate, rather than you guys speculate as to what's wrong with me". So, a lot of times I will just say, "If you've got a question, ask". It's not going to offend me; I want people to know what it's like.

Despite study participants' mostly open dialogue of their psoriasis, some study participants claimed their willingness to disclose information was contingent on their perceptions of how others might react. For example, Amy the lecturer at a large university in New Hampshire, stated:

> I don't tell people if I feel like that will judge me and think that I'm gross. I certainly have some friends who are sort of girly friends and…I've heard them say things. I was a social worker for a while and I would drive clients around and some of them would have psoriasis and some of my colleagues would drive them around and I would hear them say "they left a bunch of flakes in my car", so I understand it's weird and gross. So yeah, those are people I might not say… "oh hey…I have that [psoriasis] too". I kind of keep that to myself.

Other PLWP kept their psoriasis diagnosis quiet, isolating themselves from the potential reaction(s) of others. Rebecca, the 48-year-old from Oregon who started a public blog about PLWP, commented on the isolated nature of psoriasis for some PLWP:

> So it's a lot of self-educating and a lot of research that I do on my own, and my blog. Otherwise, it's an isolated world because there's not…usually when you're talking to somebody about…if you're a cancer patient, you know someone who has survived and they've been cured and you talk about their options and what they did. But, when it's psoriasis, you don't have that discussion of "I've had that and I've cure it", or "here's what I did". You suffer alone as that person.

Both Amy and Rebecca's narrative excerpts outline the variety of motivations and pathways of disclosure for PLWP. Interview data presented in this section more broadly reveal that while study participants were formally diagnosed with psoriasis and disclosed their condition to others, PLWP' experience of diagnosis varied (e.g. trust in modern medicine), as did the choices and circumstances around their disclosure (who and when to tell). In chapters 5 and 6, I present interview data showing how PLWP encounter sources of stress that shape their experience of psoriasis, as well as how they cope and manage with psoriasis-related stressors. As will be discussed later, PLWP's visits to specialists and their trust (or distrust) in modern medicine appear to be shaped by the cost of their psoriasis care, and their anticipated (stigmatizing) reactions from others.

Psoriasis Treatment

Present day, there is no cure for psoriasis. However, according to the American Academy of Dermatology (2014) and the NPF (2014), there are a variety of treatment options for PLWP. Dermatologists and other health specialists have generally prescribed one of the following treatment regimens for psoriasis patients: topical treatments (medication applied to the skin); biologic treatments (medication injected intravenously); phototherapy (exposing skin to ultraviolet light), and systemic treatments (medication taken orally or intravenously to treat the body inside out). Complementary or alternative approaches to psoriasis treatment have also been available to people with psoriasis. For example, acupuncture, over-the-counter supplements, creams, and shampoos, as well as different diet and nutrition plans are a few of many alternative approaches to psoriasis treatment (NPF 2014). Literature on psoriasis treatment has shown that, while treatment options have been beneficial for some PLWP, not all PLWP experience the same degree of success (Bergstrom and Kimball 2011). Moreover, the effectiveness of treatment(s) and side effects associated with treatments vary from one PLWP to the next. Despite the number of psoriasis treatments on the market (a variety of prescription and over-the-counter medications), not all PLWP seek out, or have access to, treatment plans.

Approximately 12 PLWP explicitly cited psoriasis treatment as an additional factor that contributed meaningfully to their overall experience of living with psoriasis. I draw on interview data to discuss nuances in treatment experience of PLWP interviewed for this study. Several participants explained that they took a medical approach to treating their psoriasis symptoms; almost all PLWP reported the use of topicals, biologics, or UV-light at some point during the course of their condition. Brent, the 27-year-old systems support analysis from Massachusetts, shared that he took medication for his psoriasis not only to treat localized flare-ups, but as a preventative tool to protect against symptom-spreading to other areas of his body. Brent told of varying levels of effectiveness he experienced with his medication, but confidently reported that taking medication was an important mechanism in managing his psoriasis symptoms, as was his personal willpower. The sentiment that medication was used as a tool to manage present and future psoriasis symptoms was shared among a majority of PLWP interviewed for this study. Despite the treatment sentiment, some participants like Molly, the college student in New Hampshire and NPF youth ambassador, claimed that while medication helped alleviate psoriasis symptoms, medication did not alleviate all aspects of the condition:

> So, when I went on a medication, I guess it made me a little more confident. I mean, it just kind of got rid of the patches, but it didn't really get rid of obviously the human aspects. It just kind of cleared my skin, which makes it seems like to anybody that would talk to me…they wouldn't really notice I had psoriasis anymore. So, I guess as far as that, that's how it [psoriasis condition] changed. Just my appearance.

Study participants (including participants that tried medication) reported also taking alternative approaches to treatment of their psoriasis. At least 4 PLWP interviewed for this study claimed they had tried over-the-counter treatment products (e.g. coal tar, shampoos and lotions, creams, etc.), as well as homeopathic treatment options (e.g. meditation, yoga, exposure to sunlight, etc.). Study participations overwhelming cited cost, availability of product, and accessibility (e.g. supermarket closer than medical facility) as key factors that influenced their decision to utilize alternative approaches to psoriasis treatment. Diet was one of the most popular alternative sources of treatment for alleviating psoriasis flare-ups among participants. Tanya, a

31-year-old stay-at-home mother in Maine who has lived with psoriasis for 1 year, shared that fruits, vegetables, and other "healthy foods" are expensive, but shopping on the outside of the supermarket is less expensive for her than prescription medication for her psoriasis. Numerous participants shared the sentiment that diet has helped to manage psoriasis symptoms in diverse ways, and has been a mostly cost-effective route for treatment. Interestingly, given participants' general acceptance of alternative psoriasis treatment and healing methods, some participants were dissatisfied with what is available to PLWP. Rebecca, the psoriasis blogger from Oregon brought up the issue when she talked about her writing:

> So, my last thing was a rant and a rave on my page [blog] about how people are snake oil sellers and they try to charm you and "this is going to work for you, and you're going to feel better" because we're [PLWP] targets; we're easy victims when it comes to snake oil, because we are so desperate for anything that will help. There's this joke in the [psoriasis] community about the silliest things you've done to try to get better, and there's this one lady who was told that if she soaked her fingers in urine, it would clear up the psoriasis on her hands. So she did. Umm…we've [PLWP] all tried juice, or anything in the kitchen, that will make you quit itching and make it stop so you can sleep, you know…it's an isolated community of people with no options and little money because, economically we're devastated because sometimes you can't work with psoriasis, yet the government doesn't recognize it and social security rarely allows it to be considered it a disability.

Rebecca and other PLWP shared that because psoriasis is a condition not recognized as a disability and because of the high cost(s) of traditional (medical) psoriasis treatment, PLWP have sought unique, alternative approaches to treatment as a way to alleviate psoriasis-related symptoms.

In their response(s) about treatment-seeking, study participants frequently talked about what psoriasis treatment routine(s) entailed, as well as identified treatment side effects that they had experienced. Many PLWP talked about uncomfortable, and rather inconvenient, treatment regimens that they regularly utilized. For example, some study participants slept in full body suits, or with shower caps on as a way to topically medicate every evening. Other participants told of how they rubbed coal tar over affected areas, applied creams and moisturizers extensively, and self-injected medication, all to try to manage symptoms of psoriasis. Equally distressing as some of the treatments, were the side effects resulted from their use. PLWP interviewed for this study cited a host of disturbing treatment side effects. Burning sensation, hair loss, fatigue, drug-induced Lupus, and increased risk of cancer were only some, of a number uncomfortable, and potentially life-threating side effects reported. PLWP on biologic treatment plans indicated that they often experienced injection site complications. For example, Sharon, the 43-year-old from Michigan who didn't sugarcoat anything about living with psoriasis, recalled, "I started getting abscesses from my injections sites because you know, it [treatment] killed my immune system. So, I actually ended up in an intensive care unit with sepsis one time because of it. So, after that, he [rheumatologist] quickly yanked me off of that. I will never take it again. I'm through with biologics" (laughed). Given Sharon's experience, and similarly distressing experiences evident in the narratives of PLWP, it is no surprise that PLWP were critical of psoriasis treatments, and often burdened by everyday frustrations of their treatment routines and options.

Study participants not only explained the approach they took to psoriasis treatment (e.g. medical; alternative), the types of treatments they tried, and side effects they experienced, they also shared barriers to psoriasis treatment they experienced; in particular, barriers due to health insurance and treatment expense. The medical model approach to psoriasis treatment had physicians and specialists prescribing medications to PLWP routinely until a successful treatment was identified. Marlene, the 53-year-old Mississippian, spoke of continuous prescriptions handed to her by her physician: "I'm not saying for everyone…but they're [dermatologists] like, “let’s try this, let’s try that”. Well, you know, you can’t…financially, you can’t! I mean…like I said, everything that you get is expensive”. Study participants that had health insurance regularly paid $150 to $300 in psoriasis-related treatment co-pays per month. On the other hand, study participants that did not have health insurance reported they spent $1,000 or more per month on psoriasis treatment, and were not regularly seen by a health practitioner. While some PLWP were able to afford out-of-pocket expenses for lesser-priced psoriasis treatments, other PLWP (e.g. retired; students; unemployed) were particularly financially challenged. Sarah, a molecular biologist-turned-gardener spoke of her early years of psoriasis while in grad school:

> If they make you pay a co-pay every single time you go in for a treatment therapy that you do 2 or 3 times a week, and you’re co-pay is $25, it adds up. You know, on graduate student salary, which back then I think was 22K, umm…I was extremely lucky in that my appointments were in the hospital across the street from where I was working…and the women who ran the phototherapy lab basically let me drop in. I mean…going to a doctor’s appointment 3 times a week and holding down another job…yeah [implied it’s impossible]. So…for someone in almost any other situation than my situation, it would have been both not cost effective, and…their work wouldn’t have permitted it.

Sarah hinted in her response that the demand placed on PLWP to maintain regular treatment activity often cannot be met due to other extenuating circumstances (e.g. job) of daily life or financial status.

Interview data revealed that, despite a range of treatment options available to PLWP, treatment choices varied for PLWP. Some PLWP chose traditional treatment routes, whereas other PLWP opted for alternative treatment methods. While PLWP utilized traditional and alternative approaches to treatment as a tool to manage and reduce visibility of psoriasis symptoms, the chronicity of stress stemming from psoriasis treatment varied across respondents. In chapter 5, I discuss stressors experienced by PLWP stemming from treatment-related issues.

As will be shown, costs and side-effects of some treatments sometimes burdened PLWP financially and jeopardized their health in some instances (side effects increased risk of cancer).

Psoriasis and Quality of Life

PLWP interviewed for this study cited a fourth condition-related component of psoriasis that contributed to their overall experience of living with psoriasis: quality of life. Nearly all study participants reflected on the "human aspect" of psoriasis and discussed how life with psoriasis is a challenge; psoriasis impacted the quality of their everyday lives. According to the NPF (2014), PLWP face unique challenges in relationships, at work, in their homes, and in their personal lives as part of life with a CSC. Similarly, findings from psoriasis literature suggest that while the chronicity of challenges experienced by PLWP as a result of their condition may vary, so too may PLWP' quality of life (Bergstrom and Kimball 2011). A few researchers have similarly discussed how psoriasis can alter the course of PLWP' lives (Warren et al. 2011) because of the disruption of their day-to-day activities (Basavaraj et al. 2011).

In chapter 5, I explicitly identify and discuss stigma as sources of stress for PLWP. Here, I show how psoriasis, as a condition, is perceived by PLWP to reduce their basic quality of life. Study participants shared a variety of ways the quality of daily life was impacted by psoriasis. For example, PLWP claimed they were conscientious about the types of clothing they wore (e.g. specific colors so psoriasis flakes are not visible), social activities they participated in (e.g. avoidance of large, public places such as the beach), and network of peers they associated with (e.g. hanging out non-judgmental people). Moreover, participants reported that symptoms of psoriasis challenged their ability to function interpersonally (e.g. dating; work life) as well as psychologically (e.g. depression; anxiety). Susan, the certified life coach who has lived with psoriasis for 20 plus years, reflected on the challenges of life with psoriasis:

> I am monitoring what I'm going to be doing later, how I need to dress, how I need to be prepared, how like everything started to revolve around the psoriasis as to what I was doing or not doing on a daily basis…and we're each trying to find a place to be secure within ourselves while we're dealing with our maladies. So, it's a daily struggle. We each have our different "things", but we're all dealing with the same "thing".

Sharon, from Michigan who has lived with psoriasis for 28 years likewise claimed psoriasis was a daily challenge, mostly because multiple areas of life for her were impacted by psoriasis: "so, it's the little things I mean; they're little on their own, but when you add them all together, it's…a little daunting sometimes". Study participants all shared that daily life with psoriasis was "daunting" at times, sometimes more so than others.

Transcript data indicated PLWP interviewed for this study claimed that the reaction of others toward their psoriasis was a particularly challenging aspect of the quality of daily life with psoriasis. Nearly all study participants shared that the visibility of their psoriasis symptoms made them especially noticeable targets for outward reactions from their non-psoriatic counterparts. PLWP cited they routinely noticed staring, glancing, and whispering from others when in public as well as during one-on-one situations like dating. Jackie, the 44-year-old insurance worker from Florida recalled reactions from others as a daily challenge; she remarked, "Oh yeah. Absolutely. That's the thing [reactions] that makes you not want to go out in public. You know, you get looks…umm…if I was wearing shorts (laughs), umm…a lot of the comments were "oh, what did you fall into poison ivy?" or, "what are those, mosquito bites? Oh my gosh look at all of them!" You know, just something of that nature." In Jackie's experience, reactions she received from others toward her psoriasis seemed to be unfounded and misinformed. Participants largely attributed people's reactions to a lack of psoriasis knowledge, or, in some cases, ignorance. Rebecca from Oregon commented on the public's (non-psoriatic) general misconception of psoriasis:

> Just the public view…when people see you and don't know what it [psoriasis] is, they're scared of you. People are afraid of what they don't know, and psoriasis is very not known. The commercials on television show women in pretty dresses, walking around a garden party, and they have a big smile on their face…and they're serving food and they're laughing. That's not real life for people with psoriasis.

Overwhelmingly, participants reported that the reactions of family, friends, acquaintances (e.g. hair dressers, employers, etc.), and the general public were grounded in both misunderstanding of the condition, as well as general curiosity. PLWP participating in this study indicated that although a large number of reactions entailed negative connotations (e.g. degradation), many PLWP received empathetic reactions from others. While all study participants recognized reaction(s) of others as a daily challenge, some PLWP informed and educated those who stared, glanced, or whispered as a tool to turn psoriasis speculation into psoriasis knowledge.

In their response(s) about the quality of daily life challenges with psoriasis, study participants additionally talked about what I term, "psoriasis feelings". In other words, PLWP referred to the ways psoriasis, as a condition, impacted how they thought and felt about themselves. Marvin, the 78-year-old from Texas summated the response of many PLWP: "I am extremely self-conscious about the fact that everywhere I go, I leave bits and pieces of me behind. You know, and even with neighbors and friends, uhh…beer drinking buddies, whatever." For many study participants, symptoms of psoriasis (e.g. flaking, shedding, pain and discomfort, etc.) not only impacted their quality of life socially, but psychologically and mentally too. A number of PLWP interviewed reported bouts of depression, anxiety and times marked by low self-esteem. Moreover, study participants considered life with psoriasis equally "mentally exhausting" as it was physically exhausting. PLWP frequently attributed labels such as "gross", "dirty", and "contagious" applied to their condition by non-psoriatics, as the foundation of deep feelings of embarrassment and hypersensitive self-awareness. For some participants like Marlene from Mississippi, psoriasis profoundly challenged the way she thought of herself:

> I'm just embarrassed of my own self. It's mainly inside me, because I'm not…you know, I want to say, "I wish I was like them" [non psoriatics] and that I didn't have it [psoriasis]. If I didn't have psoriasis, I wouldn't have to worry about that. I don't feel…proud to be myself and I do, I have a problem with that. I have seen a psychiatrist about it because I just…I don't…I'm not happy with myself about it. I'm very ashamed.

The way study participants felt about themselves regularly impacted their participation in social events, family outings, as well as intimate activities. Susan, the certified life coach from New Hampshire, shared how psoriasis affected her dating life:

> I didn't date much because I was single the whole time I was raising my children, while I was going through school. So for 17 years, 15 of which were in school, 17 years were raising the children; I only dated sporadically. But that would make or break whether or not I would or not [date]. So, you don't feel at all sexy if your skin's not at least smooth. So there might have been an incentive for me to be really aggressive, get rid of it [psoriasis symptoms], so that I could feel more like a woman. I had done that in the past, but umm…yeah. It really affected all aspects.

Susan remarked that on an extremely personal level, life with psoriasis has challenged conceptualization of sex appeal, as well as her conception of herself as a woman. Other PLWP interviewed for the study similarly claimed that their conceptions of themselves routinely impacted or determined the amount of interaction they had with others (e.g. employers, friends, strangers, etc.) as well the frequency of participation in activities of daily living (e.g. going to the pool, shopping, community events, etc.). However, a number of study participants attempted to minimize exposure of symptoms as a means to reduce negative feelings about themselves by covering symptoms, or avoiding interaction altogether. Meanwhile, some participants like Libby, the 53-year-old Oklahoman, acknowledged the personal psychological, and mental challenges of life with psoriasis, and responded resolutely. Libby stated, “I mean at this point in my life you know, love me or leave me…I don’t care…I got it [psoriasis].”

In the next two findings chapters, I draw on interview data to specifically outline sources of stress experienced by PLWP as well as how PLWP manage and cope with the stress. However, findings outlined here broadly indicate that psoriasis, as a condition, is stressful PLWP. Sources of stress (stressors) proliferate and become a chronic source of stress, affecting everyday quality of life of PLWP as well as their conceptions of their condition and self. In the next chapter I shed light on stigma as a stressor (and other stressors), how stigma permeates every domain of PLWP’ lives, as well as how it shapes PLWP’s *psoriasis identity*.

Meaning(s) of Psoriasis

For PLWP, psoriasis is more than an incurable, non-contagious autoimmune skin condition; psoriasis meaningfully shapes everyday life. Psoriasis, as a CSC, is comprised of a variety of elements that individually and simultaneously impact the quality of life of PLWP. Based on interview data, it is clear that the meaning(s) of psoriasis of PLWP are shaped by a number of condition-related components. Study participants constructed their experiences of psoriasis based on their psoriasis-related symptoms and triggers; diagnosis and disclosure of their condition; symptom treatment; and, quality of life challenges faced as a result of living with psoriasis. Excerpts from study participant interviews indicate that psoriasis symptom severity and triggers vary greatly for PLWP, though both frequently result in discomfort and tend to occur in a cyclical pattern. Interview data also indicate that despite a formal (medical) diagnosis of psoriasis, PLWP are faced with a number of challenges pertaining to maintenance of care (e.g. health insurance and other expenses) and disclosure of condition-related details with others. Interview data additionally signal that PLWP utilize both traditional medical treatments and alternative methods to care of their psoriasis and have experienced varying degrees of success, as well as complications (e.g. side effects of treatment) with each avenue.

It is clear from the data that psoriasis is a difficult, multidimensional condition. However, the meanings PLWP ascribe to psoriasis are not coincidental; the meanings of psoriasis are patterned and shaped by diverse, social factors. Institutional and interpersonal context matter both for stressor exposure and stressor management by PLWP. Culturally constructed stigma-labels of psoriasis, health policy, as well as PLWP' personal and social resources shape PLWP's daily lives with psoriasis. In chapters 5 and 6, I present data in context of the stress process framework, illustrating how PLWP are burdened by stigma-stress (and other stressors), though the chronicity of stress experienced by PLWP varies, as do their response(s) to stress.

CHAPTER V
STRESSORS, STRESS PROLIFERATION, AND PSORIASIS IDENTITY

Stigma is a multidimensional, social process (Goffman 1963; Link and Phelan 2001; Link and Phelan 2013) that affects many domains of life for people who, like PLWP, bear a stigma label. For PLWP, the deleterious nature of a spoiled identity stemming from experiences of stigmatization is stressful. Stigma acts as a stressor (source of stress) in such a manner that stigma simultaneously generates stress in form of discrete daily events, while also triggering potentially long-lasting hardships (chronic strains) for PLWP. In this chapter, I draw on interview data from PLWP to describe, in context of the stress process framework, how stigma is experienced, the meaning(s) attached to those experiences, and the ways that stigma creates stress in the daily lives of PLWP, while also shaping PLWP' "psoriasis identity".

STIGMA AS STRESSOR

Stress process researchers (Pearlin et al. 1981; Pearlin 1989; Thoits 2011; Wheaton et al. 2013) define *stressors* as experiential circumstances that give rise to *stress*. Stressors, can, on one hand, originate from discrete life events (e.g. psoriasis diagnoses) and, on the other hand, can endure and become a continuous, chronic form of strain (e.g. affect daily work and family life). For the purpose of this study, I conceptualize stigma as a stressor for PLWP, whereby stigma-stress begets other forms of stress in diverse ways, affecting daily social life and activity, as well as personal and emotional well-being of PLWP. Previous scholars have recognized that the burden of psoriasis-related stigma likely contributes to the overall quality of life among PLWP, though have neglected to specifically link dimensions of psoriasis-related stress to stigma, directly. For example, past studies have found that there are positive and negative effect(s) of cumulative life course impairment on psoriasis patients' lives, given factors like personality traits and physical comorbidities (Ros et al. 2014), and that there are negative impacts of psoriasis on occupational disability of PLWP (Basavaraj et al. 2011) and sexual relationships between PLWP and other sexual partners (Schmid-Ott et al. 2007). In this section of the chapter, I draw on interview data from study participants to specifically address the lingering gap in the literature between stigma as a social process, stress, and psoriasis.

BEING DIFFERENT

All 23 study participants framed their narratives of life with psoriasis as a generally stressful experience. Despite intentional exclusion of the word "stigma" from the interview questionnaire, each study participant described stigma as a source of stress either directly (specifically using the word "stigma") or indirectly (describing experiences that reflect stigma) in conversation. Responses of study participants on the topic of stigma as a stressor were coded and categorized into two over-arching themes: being different and stigma feelings. Under each of the broad themes, sub-themes emerged from the data. Sub-themes are presented under respective sections below. The first over-arching theme that emerged from interview data was what participants described as *being different*. Being different refers to how PLWP felt abnormal (something was "wrong" with them) and perceived not to fit in with others. Participant narratives exemplified how stigma labels shaped PLWP's conceptions of being different.

Stigma Labels

Stigma labels are undesirable characteristics or attributes that set the stigmatized (PLWP) apart from "normals". Narrative findings presented below reveal stigma labels can derive *directly* or *indirectly from interactions* with others (PLWP being told they were gross or seeing others stare or act disgusted), or *anticipated interactions* (PLWP assuming that others will be disgusted). Alan, the 36-year-old service worker from New York who has lived with psoriasis for roughly 16 years spoke about being different:

> You know, you constantly feel like part of you is broken or different. Nobody wants to feel different…but it's just the way it is. That's just a natural human reaction. It's nothing we can control, but it's people's first reaction, you know…poke at it…make fun of it…of that person for being different. When you have psoriasis, you're different. You know, when your elbows and ears and face and legs are all red and scaly and gross, people don't see you as being as attractive; they don't see you as being, umm…it influences your popularity; how people interact with you. It's very stressful…it freaks you out, you know?

Alan's response, part of which serves as the title of this dissertation, captured the quintessential elements of a stigma label that became a routine source of stress for PLWP interviewed for this study. Alan attributes being different, as well being perceived as less attractive, to stigma labels which are so socially engrained in the culture that it is "natural" for other people to poke at or to make fun of someone (PLWP) or something (visible psoriasis plaques) they perceive as *different*. Similar to Alan's description of feeling "broken", at least 15 other study participants shared that stigma labels directed toward their *differentness* made them feel "disgusting", "filthy", and "deformed", among other things. Moreover, another 5 study participants shared how they had experienced strangers make an assumption they had an illness or disease such as the plague, leprosy, or syphilis. Marlene, the 53-year-old from Mississippi who has lived with psoriasis for 33 years referred to others' assumption(s) of disease: "they stare…it's like the first thing they do. You know, if they see that [psoriasis] and stare, you can feel it, you know? I'm like, "I'm sorry, but I don't have the plague, you know? It's not going to jump on you." It's like they don't want to get near you because they have no idea what it is." Like so many other participants, Marlene experienced a lack of trust from others over the "uncertainty" of her visible skin condition being contagious, which resulted in others physically distancing themselves from her.

Over half of study participants shared the sentiment that everyone has their "thing" that sets them apart, makes them different from other people. However, a few participants claimed that psoriasis-stigma labels made them feel *different* in ways that others (those with other chronic conditions) and outsiders (non-psoriatics) cannot fully understand. For example, Rob the 30-year-old construction worker from New York who has lived with psoriasis for 11 years, shared how his psoriasis made him feel different, in a unique way:

> I had an uncle once, in Florida, who is very overweight and he was going to go with some friends to the beach. He asked if I wanted to go, and I said "no". You know, I'm self-conscious…my skin is flaring and this and that…and he said, "you'll love it!...look at me, I'm fat! You know, everybody's got something…something weird with them". While that's true, it's [psoriasis] just very different. You know, you go to the beach, you're going to see a thousand fat guys running around, you know? You're not going to see a thousand guys just covered in plaque. It stands out; it draws attention.

Rob contrasted his condition (psoriasis) with that of his uncle's (obesity) to suggest that given the greater number of obese people at the beach, obese people might not expect the same level, or chronicity of stigma that people with psoriasis do. In Rob's narrative, he not only suggested that his experience of being *different* is unique from others with chronic issues, he suggested that the visibility of psoriasis symptoms contributed to him feeling different, and that he had been labeled as such, apart from his uncle. Julie, the 22-year-old college senior from New Hampshire who has lived with psoriasis for 2 years similarly reflected on the stress of stigma labels and being "different": "I don't think if you mentioned psoriasis to someone who doesn't have it, I don't think they would think there's a stigma attached. I think that people who don't really know, or have not experienced it, don't really understand how big of deal it can be, or how severe it can be and don't really understand it."

The narrative excerpts from Rob and Julie illustrate more broadly that experiences of stigma and being labeled *different* were stressful in divergent, yet similar ways for study participants. While only a couple participants in this study, like Rob, identified the stress of being different as unique to people with psoriasis, almost all participants agreed that the visible nature of their symptoms contributed greatly to others casting them as *different,* which was stressful. Interestingly, participants did not typically highlight differences in levels or chronicity of stigma labels experienced (e.g. gross, unwanted, and disabled). Rather, responses indicated that participants reported feeling different regardless of whether they had a psoriasis flare-up "just" on their hand, or symptom coverage over their entire body. The visibility of psoriasis symptoms makes PLWP easy targets for stigma labels. Jackie, the 44-year-old Floridian who has lived with psoriasis for 31 years, discussed the impact of the visibility of symptoms, stigma-labeling, and reactions of others: "That's the thing that makes you not want to go out in public. You know, you get looks. A lot of the comments were "oh, what did you fall into poison ivy?" or, "what are those, mosquito bites? Oh my gosh look at all of them!" You know?" A majority of PLWP reported experiences similar to Jackie, primarily that when out in public, people not only stared and whispered out loud, they quickly attributed the "unsightly" symptoms to other problems like a poison ivy rash, or scarring from a bad burn.

Drawing on Julie's narrative presented earlier, all study participants felt that people not living with psoriasis are unable to fully grasp the stressful nature of being conceived of as "different". Coincidentally, the perceived disconnect between psoriatics and non-psoriatics of understanding of psoriasis also proved to be stressful for study participants. Rebecca, the 48-year-old from Oregon who has lived with psoriasis for 12 years, stated:

> I always worry because there's always going to be that one person that doesn't know what psoriasis is, and act ignorantly. So it's a constant thing in the back of your mind that someone is going to bump into you or, stare at you and…it's going to be difficult, and it still happens because it [psoriasis] *is* different. You know, a lot the stares are not because the people are mean, but it's because they've never seen anything like psoriasis. They're looking and they're like, "oh my gosh, what

> is that?" or, "what's wrong with her?" You can't walk around with a board that says, "I have psoriasis and it's not contagious!" You know? [Laughs]. You can't just go around handing out pamphlets to everyone who gives you a second look. It's impractical.

While a majority of PLWP attributed stigma labeling by others to ignorance and lack of psoriasis-related knowledge, 5 participants cited curiosity and general concern over symptoms from others as explanation for perceptions of differentness. Interview data indicated that participants who had lived with psoriasis from an early age, were more conscientious of the stigma labels during younger, impressionable years of life as compared to later, present day life with psoriasis. Interview data simultaneously revealed that participants were most deeply burdened by stigma labels during the early days of their psoriasis condition. However, these findings do not suggest that PLWP in later years of life who have been living with psoriasis for many years are not stressed as a result of stigma-labels or being perceived as "different". In sections to follow, I discuss in greater detail, the stressful nature of anticipated and experienced threats of stigma among PLWP. Nevertheless, participant narratives addressed in this section clearly show the noxious consequence of being labeled "different". In fact, the repercussion(s) of stigma labels toward PLWP are deeply personal. As Beth, the 44-year-old from Connecticut who has lived with psoriasis for 28 years put it, "psoriasis is very ugly; so you feel ugly as a woman." Conceiving of ones self as "ugly", "grotesque", and so forth, is a challenge for PLWP both socially (publically) and personally (ideation of femininity and masculinity).

PLWP & Being Different

The narrative findings that comprise the theme *being different*, speak more broadly to the fact that stigma, as a social process, is stressful for PLWP. Early stigma researchers (Goffman 1963; Jones et al. 1984) assert that people who possess a stigma (PLWP) possess an undesired differentness or "mark" that sets them apart from non-possessors (non-psoriatics). In the narrative excerpts presented above, it is clear that PLWP have been considered “different” (dirty; gross; unattractive) in the eyes of others. *Labeling* and *stereotyping* of stigmatized groups (PLWP) by others are two processes of stigma that Link and Phelan (2001) argue are at the heart of any experience of stigmatization. Link and Phelan (2001) posit that while a vast majority of human differences are ignored, differences in skin appearance (scales, plaques, flakes) are highly salient and matter socially. The taken-for-granted displays of normal, “healthy” looking skin is challenged by PLWP with visible psoriasis symptoms whereby labels attached to psoriasis subsequently link PLWP to a set of undesirable characteristics. Participant narratives illustrate this process exactly: others labeled PLWP dirty, gross, and so forth, and then most often, linked those labels to the undesirable characteristic, “contagious”. Link and Phelan (2001) cite the oversimplification of particular differences as a strong contributor toward the linking of labels to stereotypes. This was the case for study participants; PLWP repeatedly shared that others either did not understand what psoriasis was, or were ignorant, which fueled the reaction(s) toward, and created stress for, PLWP.

Past research on psoriasis and stigma has failed to explicitly conceptualize stigma as a stressor for PLWP, or outline the social processes involved in shaping the burdensome nature of *being different*. For example, early and contemporary work by psoriasis scholars (Martinez-Garcia et al. 2014; Bohm et al. 2013; Verhoeven et al. 2009; Gupta and Gupta 1995; Ginsburg and Link 1993; Gaston et al. 1987) suggest PLWP are rejected, discriminated, and feel poorly about themselves, but the researchers do not articulate what stigma labels and stereotypes mean for PLWP, nor elaborate on how the labels and stereotypes create a stressful, stigmatizing experience for PLWP. Interview data in this study indicate that PLWP are deeply affected by feeling “different”. Yang et al. (2007), Chaudoir et al. (2013), and Kleinman and Hall-Clifford

(2009) suggest the lived experience of stigma is a *moral experience*, especially problematic for stigmatized persons whose stigma is visible and known (discredited stigma). Study participants routinely spoke of the visible nature of their condition and the impact stigma labels had on their self-concept. Dennis, the 72-year-old from North Dakota who has lived with psoriasis for more than 65 years said, “I have looked in the mirror and said to myself, “you look terrible; you look horrible.” If you say those things enough times, you obviously have something on your mind.” Like Dennis, a majority of participants recalled that stigma labels made them feel bad about themselves and that the labels challenged their understanding of beauty, and in a couple instances, conception of femininity or masculinity. Interestingly, while study participants did not claim to have experienced a greater level or chronicity of stigma with greater symptom coverage, all participants shared that even the smallest flare-ups were disruptive to interpersonal interactions with others (going to the beach; riding on public transportation; attending social events). Link and Phelan (2013:531) argue that disruptiveness is troublesome because it links to people’s expectations about the way things “should be”. When expectations of beauty and health (i.e. clear skin) are challenged, interaction becomes difficult between PLWP and others; a finding reflected in participant narratives above. The perceived lack of control over stigma labels might too, be a contributing factor toward the stressfulness of such labels.

STIGMA FEELINGS

Stigma, as a stressor, generated strain in the daily lives of PLWP through *stigma feelings*, a second theme that emerged from interview data. Study participants generally referred to the ways that the anticipation and experience of stigma were routinely burdensome.

Anticipated Stigma

Each participant recounted familiar stigma labels and stereotypes as a foundation for their constant awareness of and continual sense of embarrassment about their psoriasis. While, as will be discussed in the next section, PLWP do sometimes experience actual stigmatizing reactions, often stigma-related stress is generated simply by the *potential* for or *anticipation* being stigmatized. PLWP like Tanya, the 31-year-old stay-at-home mother in Maine who has lived with psoriasis for 1 year, anticipated stigmatizing responses from others arise from their knowledge of existing psoriasis labels and stereotypes (e.g. PLWP are unclean and contagious). Amy stated:

> I cover up my ears because I was afraid that like if somebody saw my ears, they would just be like, “eww, they’re gross!” like, “does she clean them?” People make judgments and they don’t know and they don’t want to ask you, “oh, what’s wrong with your ears?” because that would be weird. So, then they just, you know, formulate opinions. I just didn’t want that. I was afraid people would make snide remarks…maybe not directly to me, but to themselves at least.

From the narrative excerpt, it is clear that Amy, and other study participants whose response mimicked hers, experienced stress in part due to the anticipation of stigmatizing labels (gross), stereotypical judgments (unclean), and outward remarks (something’s “wrong” with PLWP). For Amy other study participants, the stress of anticipating (stigmatizing) reactions from others was enough of a burden that they had actively attempted to cover (e.g. with clothing; makeup) their psoriasis symptoms to minimize the likelihood of drawing attention to themselves. Ironically, interview data revealed concealment of psoriasis symptoms was in itself stressful for PLWP, a concept I discuss later in this chapter as one of the “other stressors”.

Study participants shared their reasoning as to where the anticipation of feelings of stigma stemmed from and how anticipating stigma is stressful. Rebecca, the 48-year-old unemployed Oregon resident who has lived with psoriasis for roughly 12 years, shared:

> Just the public view…when people see you and don't know what it is and they're scared of you. People are afraid of what they don't know, and psoriasis is very not known. The commercials on television show women in pretty dresses, walking around a garden party, and they have a big smile on their face…and they're serving food and they're laughing…and that's not real life for people with psoriasis. The first time we really saw people with cancer that were bald, that were sick, were cancer research commercials and real patients…really bald, really sick. They don't do that for psoriasis and until they do, it's going to be a very hidden condition. Phil Mickelson is out on the golf course and yeah cool "I'm out golfing", the worse thing in the world for someone with psoriasis to be trying to be out on a golf course…is being hot, sweaty, itchy, in pain…it's not real. Phil really has psoriasis, but…it's not a real projection of who we are, what life is like.

Almost all study participants, including Rebecca, specifically cited the public's view of psoriasis as both the source of, and foundation for, the stress that accompanies the anticipation of psoriasis-stigma. Rebecca's narrative suggests that the public's view of psoriasis is misinformed by unrealistic media depictions of what life is like for those living with the condition, which instills a burdensome fear of stigma in PLWP. PLWP in real life, are expected to act in accordance with the media portrayals of people with psoriasis (e.g. take their medication, appear happy, and remain active). Meanwhile, PLWP experience the inability to conform to these media images as stressful.

Interview data indicated that study participants generally anticipated feelings of stigma daily in social settings (pool/beach; public transportation; weddings/celebrations), in the work place (interaction with colleagues and customers/clients) and in intimate circumstances like dating. Angelica, the 32-year-old Puerto Rican who has lived with psoriasis for 11 years, spoke of the stress she had experienced in her dating life as a result of anticipating psoriasis stigma. Angelica, referring to dating, said: "That's why, if I'm going to be close to someone or someone's going to notice, I like to tell them before, just because of that fear that they might reject me." The anticipation of stigma was stressful for participants in the dating scene to the extent many PLWP felt an obligation to disclose their condition prior to, or early on during a date as a way to minimize potential stigmatizing reactions or rejection altogether. More generally, interview data also revealed that the stress of anticipated stigma affected PLWP regardless of the chronicity of a psoriasis flare-up, and that the stress forced participants to put a great amount of effort toward "prep" for entrance into the public eye (e.g. appropriate clothing; makeup to minimize symptom visibility).

Study participants shared profoundly emotional examples as to how the anticipation of stigma greatly impacted the way they felt about themselves. Beth, the 44-year-old medical billings specialist from Connecticut who has lived with psoriasis for 28 years put it bluntly, "You just don't feel good, but you have to eventually go somewhere [public space]. It's just all around misery. I've actually tried to take my life." Beth attributed feelings of misery and "not feeling good" (depression and anxiety) to her perceived threat of stigma and being viewed as "ugly"; to the extent her inability to avoid stigmatizing circumstances became a burden that led her to attempt suicide. Interview data indicate that approximately 18 study participants also framed the perceived threat of anticipated stigma as noxious. Brent, the 27-year-old from Massachusetts who has lived with psoriasis for 8 years, recalled how his perception of stigma created stress: "You know, not knowing anybody who had the condition, not knowing kind of much about it [psoriasis]. You feel alone, you feel embarrassed that umm, you know, that there's something wrong. I think for me the idea of being umm…different or you know, having something wrong, wasn't something that I had the capacity to understand. It was stressful."

Like Brent, PLWP interviewed in this study identified the perceived threat of stigma as stressful; PLWP felt isolated, alone, ashamed, and embarrassed. Interview data suggest a majority of PLWP perceived the threat of stigma as most stressful when they had limited knowledge of psoriasis, or were unaware of others living with the condition; a finding reflected in Brent’s narrative excerpt. However, at least 4 study participants indicated having general knowledge of psoriasis and awareness of others with the condition, knowledge that did not entirely exempt them from experiences of stress stemming from the threat of anticipated psoriasis stigma. Interview data simultaneously uncovered that the chronicity of perceived stigma can vary over the course of the condition, and more broadly, throughout the duration of the life course of PLWP. Sharon, the 43-year-old unemployed Michigan resident who has lived with psoriasis for 28 years recalled the stress of perceiving stigma:

> Oh, it’s [perceiving stigma] VERY stressful. Mostly I would have to say, when I first noticed it, and I was younger, it was troublesome. I also I had it [psoriasis] on my face at the time, which really bothered me. Like any young person would, I felt like I was deformed. I couldn’t hide it; I was different and that’s not always good for a younger person and for their self-esteem. That was stressful to me then. Now, the stress is also about umm…the physical pain. I know what it does and how it acts and what I have to do to fix it and I’m used to the stares. I’m used to the talking and stuff like that and it doesn’t bother me anymore…well, for the most part. There are times where I’ve just had enough and…enough is enough kind of think, you know?

Sharon’s narrative excerpt describes that in her younger years of life and at early stages of her psoriasis, the threat of stigma was especially burdensome, threatening her self-esteem and confidence in herself; she felt “deformed”. It is also clear from Sharon’s comment that despite a decrease in the chronicity of perceived stigmatization throughout her life and course of illness, her perception of stigma as an on-going annoyance, remained. Other PLWP shared similar experiences; primarily that the threat of anticipated stigma was uniquely challenging during adolescent and teenage years and early days of the condition, which they contrasted from present day, where the stress of psoriasis symptoms (e.g. pain) likewise became challenging. Interview data indicate that PLWP perceived stigma as a greater threat during younger, pubescent years in part to the heightened social emphasis on dating and exploration of their sexuality. Interview data also indicated that, after confronting stigmatization for several decades, some PLWP, became, to some extent, desensitized to their own perceptions of stigma. These findings do not suggest that dating in later years of life is not stressful for PLWP, nor do the findings suggest stigma-stress dissolves entirely as PLWP age. Rather, the findings indicate there are personal and social resources available to PLWP that lessen the stress of anticipated stigma, an area that I present in more detail in chapter 6.

Interview data uncovered that the location of psoriasis symptoms played a role in the degree of anticipated stigmatization; a finding depicted in Sharon's response. Participants reported a greater threat of stigma and more feelings of depression, anxiety, and worry when psoriasis symptoms appeared in places difficult to conceal (e.g. head, neck, and face). While none of the study participants had psoriasis symptoms on their face at the time of this study, over half of PLWP reported symptoms on their scalp, ears, or neck. Participants who had psoriasis symptoms on their head were particularly likely to experience the threat of anticipated stigma, due to the vulnerability they felt when exposing a part of the body that is crucial for first impression(s). Like Sharon, PLWP felt particularly stressed when they "couldn't hide it" [psoriasis symptoms], for they feared others would dismiss them, form opinions of the condition, and not take them seriously in conversation; psoriasis was a stressful distraction.

Experienced Stigma

PLWP not only experienced stress over the anticipated threat of stigma, but they also suffered *actual* experiences of being stigmatized. Study participants recalled having experienced general harassment, exclusion, and rejection at particular events as well as in everyday, social life. Rob, the 30-year-old construction worker from New York who has lived with psoriasis for 11 years, recounted the stress of experiencing stigma:

> I think just general harassment, or maybe exclusion from an event. You know, like I guess if I was going to go to a public pool…you know, I might be nervous

> about somebody seeing it and saying they don't want me to get in the pool because they don't know what it is and this and that…and it becomes a big issue. Situations like that…Umm, where somebody harasses us [PLWP]. So, it's things that I just avoid, things like that entirely. It is a major concern.

Narratives of all 23 study participants were similar to Rob's, each indicating general harassment in the form of outward comments (name calling, labeling), non-verbal cues (staring, gawking), or actions (removal from pool), was stressful for PLWP. In fact, all study participants in their own unique way, shared that the stress of stigmatization often led them to avoid certain situations altogether. Study participants reported avoiding school-related functions, weddings, as well as one-on-one interactions with strangers. In a later section of this chapter, I present data to frame *avoidance* as one of many manifestations of stigma as a chronic form of stress in the lives of PLWP.

Interview data revealed that, in general, experiences of stigma are stressful for PLWP, because stigma creates high levels of social discomfort and invades the privacy of PLWP. Dennis, the 72-year-old retired professor in North Dakota, recollected the stressful nature of having experienced stigmatization:

> Psoriasis affects my privacy. I mean I don't feel comfortable going down to the swimming pool with my shirt off and swimming around with other people because they all wonder what I have and react. I don't feel comfortable if I'm at the lake and it's a Sunday afternoon and you have 200 people swimming, so I have to compensate. What you do is go down there at 6 in the morning when nobody's there…and if people happen to come around and happen to see, then things change. It's a little more bothersome when you're in a crowd situation like that.

Dennis' narrative excerpt highlights one of many ways that PLWP jeopardized their personal levels of comfort to engage in "normal" activity like swimming. It is clear from interview data that experiences of stigma force some PLWP, like Dennis, to find alternative strategies to enjoy taken-for-granted seasonal activity. The inconvenience of having to take an unconventional approach (swimming at dawn) to some otherwise routine activity itself is stressful for PLWP. Interestingly, Dennis' response suggests that the chronicity of stigma-stress is greater for him when he's in the company of a crowd of people. Approximately 6 participants reported experiencing greater stigma-stress in crowds, while the remaining 16 PLWP reported that the experience of stigma was equally stressful regardless of the number of people around. For example, PLWP reported having experienced stigma both in public areas (pools or beaches; social events), as well as private domains (dating). Despite nuanced differences in chronicity of stigma-stress experienced, a third of study participants recalled experiences of stigmatization during times of severe symptoms flare-ups as well as during times of less-severe symptom visibility. These findings more broadly suggest that experiences of stigma are stressful for not only for PLWP with severe psoriasis in the company of a number of people, but also PLWP with mild to moderate psoriasis in the presence of only a few others.

Interview data revealed that PLWP experienced differential (stigmatizing) treatment. 22 of 23 study participants recalled specific instances where other people actually treated them differently or reacted in an outward, stigmatizing manner because of their psoriasis. Differential treatment occurred in public and private settings for PLWP. For Molly, the 22-year-old college student who has lived with psoriasis for 15 years, differential treatment based on her psoriasis started at an early age:

> This was probably the first time I wore a short-sleeve shirt to school: I remember this one teacher I had who, in the middle of teaching, stopped her lesson and said, "Oh my god! What's that's on your skin? Is that poison ivy?" and like everybody in the class looked at me and I was mortified. I was just like "no, it's just psoriasis not poison ivy, and it's not contagious". She just made a face, and was like "Oh…okay" and then went back to her lesson like she was just so disgusted. She didn't believe me and didn't look at me the same way she did with the other kids. I think that kind of made me want to talk about psoriasis more because I was just stressed out that she made a judgment and was like so critical of me when she

> didn't really know anything about it. It was so inappropriate because she was a teacher.

Molly's narrative excerpt illustrates that differential treatment by her teacher in the classroom created a stressful circumstance where she felt "mortified", embarrassed, and angered. Coincidentally, Molly perceived her teacher as someone she would least expect to treat her differently based on her appearance. Interview data revealed that PLWP experienced differential treatment from people they trusted, perceived as professional, more often than they would have imagined. Amy, the 36-year-old college lecturer who has lived with psoriasis for 30-plus years shared that while was on a cruise, she witnessed a pharmacist treat a fellow cruise passenger with psoriasis differently because of the psoriasis flakes on the passenger's bathing suit. Similarly, Christine, the 24-year-old unemployed South Carolina resident who has lived with psoriasis for about 12 years recalled an experience in which a phlebotomist refused to draw her blood for medical tests because the phlebotomist thought something was "wrong" with her. Participants reported identical experiences as Molly, Amy, and Christine; each believing educated professionals would be forgiving and respectful of people's health conditions. The interview data suggest that in general, differential treatment experienced by PLWP stemmed came from professionals and laypersons alike, which created a great deal of burden (anxiety, anger, insecurity) for PLWP.

Interview data simultaneously uncovered that PLWP experienced differential treatment in both public *and* private settings. Rebecca, the 48-year-old unemployed Oregon resident who has lived with psoriasis for 12 years recounted an experience she had at a convenience store:

> I was at a convenience store and a lady's daughter brushed up against me and she snatched her daughter up because she had bumped into me. She grabbed her and pulled her away and it startled me that she did that, but I know why she did. I said "you know, it's okay…she can't catch it, I'm not contagious" and then you know she looked relieved. It was an automatic response you know, you don't want your

> kids near it [psoriasis] (laughed). You know, it's difficult…and then I go out to the car and I'm in tears because I feel bad because the whole thing happened.

From Rebecca's narrative excerpt, it is clear that the act of a mother pulling her child away was stressful for Rebecca. However, because Rebecca was aware of psoriasis stigma, witnessing the act did not come as a surprise to her. Beth, the 44-year-old medical billings specialist in Connecticut who has lived with psoriasis for 28 years shared a similar experience of differential treatment in a convenience store: "I was at the gas station one day and went to give the clerk my money and she saw my hand, which was covered full-blown in psoriasis scales, and she looked at my hand, looked at me, and put my change on the counter. So, I purposely touched her hand and said, "Have a nice day!" The stress of being treated differently prompted PLWP to react to stigmatizing circumstances in diverse ways, characterized in the two narratives above: some PLWP *internalized* their frustrations and emotions, while others *externalized* their frustration aggressively, verbally. Interview data suggest PLWP experienced differential treatment at a variety of public places. PLWP recounted instances of differential treatment at public pools and beaches, hairdresser and tanning salons, as well as on public transportation (subway and bus). Additionally, interview data uncovered PLWP perceived the greatest threat of differential treatment from adults, whereas PLWP perceived children as curious, non-intrusive observers.

At least 12 study participants recalled situations where they were treated differently not solely in public domains, but in private domains of life too. Overwhelmingly, PLWP discussed examples of differential treatment pertaining to dating. Alan, the 36-year-old service industry worker in North Carolina who has lived with psoriasis for 16 years, shared an experience of dating:

> I mean for better or worse, I've had like hook-ups...and the first one I had, I tried to get the lights low (laughs) at that stage and then when we were naked, they [other person] were like "what's that?". Most the time, I have to explain it

> [psoriasis]. I've had a couple people that assume I have some sort of HIV or complications from AIDS or something like that. Pretty much every time that's ever happened, I try to talk it out. I think there was one time where the person was like "okay this isn't gonna work, gotta go, bye."

From the narrative excerpt, it is clear that Alan was aware of psoriasis-stigma, for he turned down the lights in an attempt to hide visible psoriasis symptoms. During the interview, Alan disclosed that he is gay and overweight and that he felt he was stigmatized and subsequently treated differently, more so than others who are not gay, overweight. Experiencing an intimate other attribute psoriasis symptoms to a condition like HIV/AIDS and refuse or discontinue sexual acts was stressful for Alan; he felt ashamed, unattractive, and anxious. Interview data revealed PLWP experienced cancellation of dates, discontinuation of intimate activity, and stigmatizing reactions (comments and looks) in the dating realm. For some PLWP, like Susan, the 59-year-old life coach in New Hampshire who has lived with psoriasis for 20-plus years, a spouse sought a divorce in part to problems with intimacy stemming from psoriasis. Interview data also revealed PLWP the chronicity of stigma-stress resulting from differential treatment varied slightly, dependent on type of relationship. For example, participants whose martial relationship was terminated or jeopardized reported deep emotional distress, in contrast to PLWP casually dating or involved in non-long-term relationship. However, this finding does not suggest that PLWP engaging in hook-ups and dating are not stressed after experiencing differential treatment by intimate others. Male *and* female participants openly and willing shared detailed circumstances pertaining to "problems" with intimacy because of psoriasis.

Interview data indicated that PLWP experienced differential treatment through the non-verbal and verbal reactions from others. Brent, the 27-year-old systems support analyst from Massachusetts who has lived with psoriasis for 8 years, shared, "There was this lady who was sitting next to me somewhere and I was minding my own business and she would look over at me, and then look at her nails, and then look at mine. It felt like an eternity and it was just like, I felt angry, like you know, I really felt kind of this, this swell of stress, emotion at that point." Brent referred to the pitting on his fingernails from psoriasis and framed the non-verbal reaction from the stranger sitting next to him as a stressful situation. Marlene, the 53-year-old from Mississippi who has lived with psoriasis for 33 years likewise recalled how non-verbal reactions at the beach (and other places) were stressful for her:

> At the beach, you know, you don't want to get out there [sit on the beach; swim] because that's the first thing people notice [psoriasis]. You can feel em' lookin' at you. So you're not very uncomfortable there, you know? Anywhere that it's an outing or something like that where there's people…that's when you know. You know exactly. You can feel that they're talking about it [psoriasis] and you can hear em' sometimes. Sometimes I'll ask em', "do you have a question about what's wrong with me?" you know, "I'll tell you". Of course it embarrasses them, but they know I'm sitting over here…you know, I feel very insecure because here I am, I have this issue, you know? I don't mean to have it, but it's the way God made me I guess.

Marlene's narrative excerpt depicts how she "felt" the non-verbal reactions of others (in various contexts), and portrays how those experiences were stressful for her; specifically, she felt uncomfortable and insecure.

Interview data revealed that PLWP recognized the permanence of their condition, but given the stigmatizing reactions they received, PLWP wished they could get rid of psoriasis as a way to avoid reactions from others. Interestingly, Marlene attributed her condition to "the way God made her", which indicated a perceived lack of control over her psoriasis as well as the reaction(s) it drew from others. Interview data also uncovered that some PLWP put "a wall up" when it comes to dating and social interaction with others, in part due to the stress experienced from prior stigma-reactions. However, Marvin, the 78-year-old Texan who has lived with psoriasis for 42 years was the exception. Marvin stated, "I'm sure there some people who maybe shied away a little bit or reacted for whatever reason, but I was never aware of it. I mean it wasn't an open shunning or anything like that. To me, if they see it, they see it. If I cover it up, I cover it up. I do wear long pants and a long-sleeve shirt though, so there's very little anybody can see". While the data did not suggest the chronicity of psoriasis symptoms impacted the intensity of the reactions from others, PLWP experienced non-verbal (and verbal) reactions when symptoms were visible. Marvin may not have recognized reactions from others, but he was aware of psoriasis-stigma; he attempted to cover up his symptoms to minimize the stressfulness of the situation.

Study participants also experienced verbal, outward stigmatizing reactions from others. Beth, the 44-year-old Connecticut resident who has lived with psoriasis for 28 years recounted her experience and response to stigmatizing reactions from others: "They'll snicker and say, "oh my God, look at her legs…what is that leprosy or something?" and I'll turn around and say, "NO! ITS FUCKIN' PSORIASIS, YOU IDIOT!" You know what I mean? Things like that; I hear everything. It's like I am more tuned in to what people say because I'm so afraid they're talking about me." Beth's narrative excerpt indicates that the reactions of others were stressful for her, to the extent that she reported having a heightened sense of awareness of others' remarks. For Beth, the stress she experienced was manifested in an externalized response toward the stigmatizers, a manifestation characteristic of responses of a few study participants. Sarah, the 40-year-old molecular biologist-turned gardener in New York who has lived with psoriasis for 30 years succinctly put it, "as long as twits will be twits, there will be an issue".

Interview data indicate that over half of study participants experienced reactions from others in the form, or combination of, negative comments, soft-spoken whispers, and curious or disrespectful questioning or gestures. Others would routinely attribute PLWP' visible psoriasis symptoms to disease, and point and stare. Interview data simultaneously uncovered PLWP experienced displays of verbal, outward stigmatizing reactions from others in public places (shopping malls; parks; work), private dwellings (home; neighborhood). The stress created from the differential treatment of others left study participants feeling self-conscious, embarrassed, and angered. Study participants, like Jackie, the 44-year-old Floridian who has lived with psoriasis for 31 years, attributed the insensitive response of others to a lack of knowledge about psoriasis.

Interview data additionally suggest the chronicity of stigma-stress did not vary by location of where differential treatment occurred (public or private spaces), but was perceived less of a burden when PLWP had support of family and friends. Tanya, the 31-year-old stay-at-home mother in Maine who has lived with psoriasis for 1 year spoke of the benefits of support: “If I was single, and I didn’t have a family, then yes I’d have a ton of stress and I would be very worried about what other people think or say and whether I could go out in public or on a date and all of that stuff. But that’s not the case for me.” However, data indicated that perceived social support of PLWP did not entirely eliminate the threat of stigma-stress from reactions of others. In chapter six, I present findings illustrating the ways PLWP utilize both personal and social resources to cope and manage the stress of living with psoriasis. Interview data also indicated at least 5 PLWP felt the reactions of others were not as severe when those asking questions out of curiosity, knew someone with psoriasis. Roughly 12 study participants who experienced stigmatized reactions subsequently framed the circumstance as an opportunity to educate others and to dispel myths about psoriasis.

Stigma Feelings & PLWP

Interview data indicate PLWP' perceptions of stigma contributed to stressful experiences of presentation of self and impression management. Amy, the 36-year-old college lecturer recounted how presenting herself to her students in the classroom required strategy:

> When I'm teaching and I'm not wearing sleeves, I make sure my back is to the back wall and everyone else is in front of me. In fact if I have to walk down an isle, I'll walk sideways because that's not where that patch is. But, I typically don't walk back to everyone in the class and that's absolutely because of having psoriasis. So, I walk strangely perhaps, at times. I take perhaps, that "long route" sometimes just in an effort, just to minimize the possibility that they're spotting it.

Amy's narrative excerpt depicts that her perception of anticipated stigmatizing reactions from her students determined her navigation around the lecture hall. Interview data simultaneously revealed some PLWP were required to be in the presence of others (e.g. teacher), while PLWP, like Marlene, the 53-year-old Mississippian, avoided interaction with others. Marlene recalled, "Sometime, I just I may go out by myself, you know? Or go where there's nobody, but I don't go a lot of places because of my psoriasis. I mean I stay mostly to myself or, just go a select few places. I won't get around a bunch of people; I'm too embarrassed." At least 16 participants disclosed that they conceived of their psoriasis as an "eye sore" and felt embarrassed about their external appearance in the workplace, in front of their children, and in public places (grocery store; restaurant). Interview data additionally uncovered that PLWP took psoriasis medication(s), tried homeopathic treatments, and regularly applied lotion, make-up, and cream to minimize, or to cover the appearance of visible psoriasis symptoms. Interestingly, efforts to minimize psoriasis symptoms (e.g. coal-tar baths; full-body medicated suits) for an "acceptable" appearance, alone, were stressful emotionally *and* financially for PLWP. Work by Goffman (1959:19) would suggest public (e.g. workplace) and private (e.g. intimacy) performances (interactions) are stressful for stigmatized persons (PLWP) because their “mask” (conception of self) is challenged by the expectations of others.

Health & illness scholars (Earnshaw et al 2011; Earnshaw and Quinn 2011; Mickelson 2011) and psoriasis scholars (O’Leary et al. 2004; Richards et al. 2001; Ginsburg and Link 1989) have recognized that the anticipation and experience of stigma have a negative impact on the quality of life of patients with chronic illness and PLWP. For example, findings by Earnshaw et al. (2011) suggest that people living with chronic illness anticipate stigma and expect others will devalue them based on their condition, a devaluation that also affects caregivers of people with chronic conditions via courtesy stigma (Mickelson 2011). Earnshaw et al. (2011) find that people living with a chronic illness anticipate stigma from family, friends, colleagues, and strangers, and socially isolate themselves in part due to past experience with and current perceptions of stigmatization.

O’Leary (2004) and Ginsburg and Link (1989), similarly argue that the anticipation and experience of stigma leads to poorer levels of quality of life (and higher levels of depression) among PLWP, but add that feelings of stigma can create triggers for subsequent psoriasis flare-ups. While prior, mostly quantitative literature on chronic illness and psoriasis establishes a link between stigma and outcomes of health (quality of life) generally, researchers have neglected, qualitatively, to address how stigma feelings are stressful for PLWP. Clear from illustrative examples above, findings in this study align and build on prior literature. PLWP do feel different from and devalued by others, and in some cases isolate themselves from others, but both the chronicity of stress and the chronicity of *anticipated* and *experienced* stigma vary by factors like expectations of PLWP based on unrealistic media images, knowledge of condition and awareness of other PLWP, and severity and location of psoriasis symptoms. Later in this chapter

I elaborate on the ways that stigma feelings spill over and proliferate to create other stressors in PLWP's lives.

The narrative findings illustrating *experienced stigma* speak broadly to the fact that stigma, as a social process, is stressful for PLWP. Link and Phelan (2001:370-371) identified "discrimination" as a component of stigma processes; suggesting stigmatized persons are disadvantaged in terms of life chances and general well-being, for stigmatized persons are excluded and treated differently from those who do not possess a stigmatizing attribute. Interview data affirmed PLWP are discriminated against (treated differently); discriminated against in both individual *and* institutional contexts. Study participants experienced differential treatment in public places (classroom; beach; hairdresser), and in private domains (at home; in intimate relationships). Similarly, PLWP were denied disability benefits in places of employment and in some instances, were not allowed in public pools due to policies pertaining to contagious illness.

Link and Phelan (2001), Brown (2014) and other stigma and health scholars (Struber, Meyer, and Link 2009; Earnshaw and Quinn 2011) find that experiences of differential treatment pose a serious threat to the well-being of stigmatized persons, but these prior inquiries have neglected to investigate stigma-stress experienced by the stigmatized; specifically, PLWP. Earnshaw and Quinn (2011) and Struber et al. (2008) argue stigma-discrimination adversely impacts health in a number of ways: stigmatized persons internalize stigmatized reactions, suffer repeat illness symptoms, and experience barriers to proper care. Interview data indicate findings applied to PLWP reflect findings of prior work. For example, stigmatized PLWP internalize the experience of differential treatment as stressful (feel depressed, anxious, embarrassed), suffer symptom flare-ups in a cyclical manner, primarily as a result of stress, and experience barriers to care that non-stigmatized persons typically do not (e.g. phlebotomist refusal to draw blood from PLWP).

Research on other stigmatized groups has shed light on the deleterious nature of stigma-discrimination, though has similarly neglected to outline the ways stigma-stress impacts the daily lives of PLWP. Studies findings pertaining to obesity (Mustillo et al. 2013), HIV/AIDS (Herek et al. 2013), and mental illness (Perry 2011), suggest cultural standards are such that groups socially exclude people who are different; greater visibility of condition equals stronger stigma labels; and, stigmatized people with chronic illness are more vulnerable to on-going rejection and discrimination from both acquaintances *and* strangers. Interview data both align with and digress from these prior findings. First, PLWP are perceived of as different for a variety of reasons, namely because of factors like the visibility of symptoms. Cultural standards of health and inaccurate stereotypes of PLWP fuel the division between psoriatics and non-psoriatics; PLWP are cast as disabled, ugly, and incapable. Second, in contrast to prior work, interview data suggest greater visibility of psoriasis symptoms *did not* equal greater chronicity of stigma-labels, or stigma-stress. Instead, PLWP experienced differential treatment and subsequent stigma-stress regardless of the severity of symptoms. However, PLWP perceived the stigma labels and threat of differential treatment to be less severe when others had some knowledge of psoriasis, or knew someone with the condition. Last, although this study did not "test" the relationship between perceived vulnerability to stigma labels and distress, interview data did indicate that PLWP often felt differential treatment by both strangers and intimate others, which was linked to feelings of shame, embarrassment, and anxiety. PLWP developed strategies to reduce the future possibility of differential treatment (e.g. educated people to dispel psoriasis myths), though PLWP felt that negative reactions by others were inevitable. Coincidentally, stress process researchers (Brown and Turner 2012; Gayman and Barragan 2013) suggest prolonged stress exposure and on-going discrimination can be detrimental. Findings in this study indicate that PLWP seek personal and social resources to cope with and manage the stigma-stress experienced in their daily lives; a finding I present further evidence for in chapter 6.

Narrative findings comprising the over-arching theme *stigma feelings*, demonstrate that stigma is in fact a source of stress for PLWP. The *separation of "us" from "them"* and *status loss,* two processes of stigma identified by Link and Phelan (2001), lie at the heart of the anticipation and experience of stigmatization. Link and Phelan (2001:371-371) claim stigmatized individuals construct a rationale for believing they're fundamentally different from others based on (stigmatizing) treatment, a differentness that reduces PLWP' status in the eyes of the stigmatizers. Interview data sheds light on these two processes of stigma. PLWP believe they are "deformed", "ugly", and "unattractive" given the nature of their condition and their inability to conform to (unrealistic) expectations of PLWP set by others (especially the media). Simultaneously, people stigmatizing PLWP are unsure of, and in some case, do not take PLWP seriously in conversation; others expect less of a competent performance from PLWP. Miller and Major (2000) and Miller (2006) find that stigma increases the frequency and intensity of threats to self; a finding shared in this study. Namely, that the anticipation and experience of stigma (stigma feelings) contributed to feelings of embarrassment, shame, and even depression; stigma was a stressful, burdensome for PLWP. However, the findings outlined above also contribute to literature on stigma and stress, by demonstrating that stigma feelings create stress among PLWP (referred to as "peril", by Link and Phelan 2013) and that levels of stress experienced by PLWP are not static; the chronicity of stigma-stress can be greater in some circumstances than others.

OTHER STRESSORS

CONDITION-RELATED SYMPTOMS AS STRESSOR

Stress process scholars have demonstrated that people can experience multiple sources of stress (Pearlin et al. 1981; Pearlin 1989). Interview data in this study reflected the prior research finding; aside from stigma, three additional stressors burdened PLWP: condition-related symptoms, cost of care, and symptom concealment. Approximately 17 PLWP identified the physical aspects of condition-related symptoms as an additional source of stress. Study participant narratives depicted ways in which their condition-related symptoms created stressful circumstances in four general areas: social settings, recreational activity, purchase(s) of goods, and care and treatment.

Social Settings

Brent, the 27-year-old Massachusetts resident who has lived with psoriasis for 8 years, recalled how his condition-related symptoms were stressful in a social setting: “I would say my psoriasis has kind of brought me a lot of anxiety in a lot of social situations, to be honest. You know, let’s say I went to the grocery store; I am very anxious about being there. Having to interact with others is just stressful. You know, I have a lot of anxiety about it. If I didn’t have this [psoriasis], the grocery store wouldn’t be a bad place.” Brent attributed the stress (high levels of anxiety) he experienced while grocery shopping to having psoriasis; stress he claims would not otherwise be present had he not had psoriasis. Although Brent does not explicitly refer to the anticipated threat of stigma in this narrative excerpt, it might be case that Brent’s perception of stigma contributes to the chronicity of the stress he experienced at the grocery store because of his condition. The other 16 study participants reported that their psoriasis symptoms created stressful circumstances at proms, weddings, summertime gatherings, and other social or work-related events that otherwise would not have been problematic in the absence of their condition. Rob, the 30-year-old New York resident who has lived with psoriasis for 11 years recounted:

> It's funny, like I've said before I'm not a social person to begin with. So, I don't really like going to parties or bars. I don't like doing that anyway, but the psoriasis makes it worse…it makes it, you know, that much more difficult. So, it's kind of like if someone invites me to a party, immediately I'm not really going to want to go, and then on top of that…you know, before even going, I'm self-conscious about my psoriasis. If I do go, I won't be able to drink…and then people want to know why I'm not drinking and then I have to get into this whole thing.

Rob's narrative excerpt indicates psoriasis, as a condition, can be a source of stress for both extroverted PLWP, as well as introverted PLWP. Stressful feelings of anxiety and embarrassment are exacerbated in social settings during interaction and being questioned as to what's "wrong"; feelings that study participants shared would not exist if it weren't for their condition.

Recreational Activity

Interview data also showed how PLWP experience pain and discomfort of their condition-related symptoms as a source of stress when engaging in recreational activities. Participants shared stressful situations attributable to their condition while exercising/working out, playing sports, practicing yoga, and riding ATVs (all-terrain vehicles), to name a few. Christine, the 24-year-old South Carolina resident who has lived with psoriasis for 12 years, portrayed her psoriasis symptoms as a source of stress when it came to swimming: "Swimming, as an activity is mentally difficult because swimming leaves a lot more skin exposed…which will bring stress on you. Especially if you're going to a swimming pool, the chlorine physically burns! Without this [psoriasis], swimming anywhere wouldn't be a problem." Interview data indicate PLWP experience stress in part to physical issues with their condition (pain, irritation). 6

participants had both psoriasis *and* psoriatic arthritis, and were subsequently limited in their ability to participate in recreational activity. For Marvin, the 78-year-old Texan who has lived with psoriasis for 42 years, psoriasis and psoriatic arthritis has been especially stressful:

> My psoriasis of course led to the psoriatic arthritis…that screwed up my knees, and walking for any distance or length of time or when I go to the health club, I can only use the recumbent bike. Walking on a treadmill or using a stepper is totally out of the question. Oh, and my fingers…yeah, very much a problem. I've always had, always prided myself in my younger years of my handwriting. Now, it's tough to hold a pencil properly and along with that, the fact that I don't write, I use the computer to do everything anymore. My handwriting has gone to hell.

Interview data revealed that for participants like Marvin, psoriasis (and psoriatic arthritis) creates stress and feelings of pain and discomfort for PLWP when recreational activity is limited or no longer a part of their lives. While psoriasis created stressful circumstances in recreational activity, data uncovered PLWP experienced greater levels stress when their condition-related sypmtoms altered their ability to engage in, or perform the activity. In fact, 1 study participant sought professional help from a psychologist to make sense of the burden induced by ceasing activity because of psoriasis.

Purchase of Goods

PLWP additionally framed their condition-related symptoms as a source of stress when purchasing goods. Interview data revealed PLWP's symptoms contributed to stressful circumstances when purchasing clothing, automobiles, work attire, and personal products (pantyhose; underwear). Gloria, the 42-year-old major gifts officer in Massachusetts who has lived with psoriasis for less than 1 year recalled how psoriasis determined the types of clothing she bought:

> I used to wear a lot of dark colors clothing-wise all of the time. And now, as I go shopping, umm…you know, when I used to gravitate toward buying something black, I now have to stop and think, "unless this clears up, black is probably not the best color to wear" and gravitate toward light colors. So, I have to wear

> clothes that are lighter in color so that you know, that if I'm having flakes or anything like that, it's not showing.

Interview data indicate PLWP reported purchasing clothing based on color, as well as style (long sleeves and pants to cover psoriasis symptoms). Gloria's narrative excerpt illustrates that she experienced stress stemming from her condition-related symptoms (e.g. limited clothing options), as well as anticipated stigma-stress stemming from psoriasis symptoms (flaking). Gloria, and 9 other study participants envisioned clothes shopping to be a fun experience, rather than stressful, in the absence of their condition. Amy, the 36-year-old college lecturer who has lived with psoriasis for 30-plus years shared that the stress she experienced as a part of her condition similarly affected other material purchases. Amy was restricted to purchasing vehicles with tan interiors and purchasing light-colored furniture for her home because of her psoriasis; she wanted to reduce the visibility of flaking.

Interview data revealed that Amy, and at least 5 other PLWP experienced strong feelings of frustration and helplessness when making such purchases. The data also revealed PLWP contrasted the stress they experienced from that of their non-psoriatic consumer counterparts. Study participants felt their friends and family could make purchases "on a whim", whereas participants lamented that they had to conscientiously consider how their condition would determine (e.g. flare-ups; remissions) the appropriateness of the item in question. PLWP reported heightened levels of stress when purchasing clothing for work and important social events like weddings. Based on findings in this study, it's plausible, however, that greater stress experienced by PLWP is attributable to anticipated or perceived stigma, past stigmatizing experience, and the overall importance of successful impression management. Interestingly, 2 study participants framed the stress created by their condition-related symptoms different than the stress from other health "conditions" when purchasing goods. Danielle, the 21-year-old stay-at-home mother in

Maryland perceived clothes shopping based on her psoriasis as a stressful experience, whereas she perceived clothes shopping based on her pregnancy, as an exciting experience.

Care & Treatment

Interview data also uncovered PLWP experienced stress created from the anticipation of symptoms and flare-ups in the future. Dennis, the 72-year-old retired professor who has lived with psoriasis for 65-plus years recalled:

> This is a futuristic thought, but I really get concerned about being older and being incapacitated and I've talked to my doctor many times about what's going to happen if I have to go to the nursing home and bed ridden, what's going to happen to me? I'd be scratching and bleeding and lying there and maybe have Alzheimer's, maybe I don't, maybe I just can move around or whatever. Who is going to take care of my symptoms? I know doggone well nobody is because they haven't the capacity to deal with those issues, so that gnaws away at my psychologically.

For Dennis, the worry and anxiety over his psoriasis symptoms stemmed from his fear of the unknown (e.g. Dennis wondered who will take care of those symptoms should he become incapacitated). While no other participant focused on issues of aging and psoriasis like Dennis, it's likely an issue many, if not all PLWP will face at some point over the course of their lives. More generally, interview data indicate PLWP experienced reductions in stress during periods of successful treatment application and during stages of remission. However, the findings do not suggest that PLWP experienced no stress when PLWP were temporarily clear of psoriasis symptoms.

Coincidentally, while PLWP experienced varying levels of success with psoriasis treatment (e.g. periods of remission; clear skin), in some instances, psoriasis treatment(s) created stressful circumstances for PLWP. Interview data revealed 13 study participants experienced stress attributable to condition-related symptom treatment. Molly, the 22-year-old college student who has lived with psoriasis for 15 years, recalled the stress of psoriasis treatment:

> It wasn't necessarily the psoriasis itself that was stressful for me; it was the treatment that interfered too. I used to do this one treatment where I would have to put shampoo in a shower cap and I would have to keep it in for 3 hours, or I would do the one with steroid cream and I would have to be in a special suit for 4 hours and I would have to be home and it was uncomfortable to move. I couldn't get homework done, so it was more of the treatments that restricted me more than anything. It wasn't just the psoriasis itself.

Molly perceived psoriasis treatment as an inconvenience; a routine that limited her ability to perform daily tasks like homework. Study participants similarly shared that treatment regimens such as medicated "sauna suits", psoriasis night gloves, and medication compliance, regularly interfered with their social *and* work lives, as well as their at-night sleep habits. Interview data uncovered PLWP likewise utilized non-medical treatments, which also created stressful circumstances for study participants. Beth, the 44-year-old from Connecticut who has lived with psoriasis for 28 years recalled, "I completely love the ocean…I truly do. I will put the water in squirt bottle and it does help dry out my psoriasis, but if I were to go in the ocean, it feels like a zillion little needles poking me all over my lesions because it just burns SO BAD…makes me want to just rip off all of my skin." For Beth, traveling to the ocean was a blessing and a curse; she experienced temporary relief from salt water, but could not treat her entire body due to physical pain induced by the salt water. Interview data uncovered PLWP experienced greater stress if they experienced side effects from condition-related symptom treatment. Study participants reported both minor treatment side effects (e.g. medication odor; small reaction) and major side effects (e.g. injection site abscesses; drug-induced lupus; increased risk for other health conditions like cancer). However, the findings do not suggest that PLWP, who experienced similar side effects, experienced the same degree of stress.

Interview data also revealed PLWP experienced stress from attempts to find the “right” condition-related symptom treatment. Libby, the 53-year-old from Oklahoma who has lived with psoriasis for 35 years shared her experience of looking for the right treatment:

> I’ve tried a million things. You know, I…a million home remedies, or somebody said “try this” “try that”…I’ve tried it. I mean yeah…we’re all looking for the magic bullet… whether it’s apple cider or I mean I even went so far as for a while to use…it was actually it’s a Native American shaman technique for psoriasis and it was like cayenne pepper and baby oil and then wrap your head in cellophane. Kept it on there until I couldn’t stand it any longer. That just makes you really uncomfortable for about 45 minutes and it didn’t do a dang thing for the psoriasis. So, what do you do? You try it again (laughs)…you know in 2 days…maybe it needs a second application! Then you think, what the hell was I thinking…cayenne pepper and baby oil. So yeah, I wish there was a magic bullet. I will say over the years, dermatologists would say, “try this stuff, if it works…order some more right away because I have a feeling it’s going to get pulled off the U.S. market”. Low and behold I tried it, it worked with AMAZING results…and I ordered another bottle and when that was gone, it was banned from import into the U.S. Supposedly it had a super potent steroid in it that was undisclosed.

Libby tried a variety of in-home remedies and barely-legal medications to try to treat her psoriasis. It is clear from Libby’s narrative excerpt that the search for the “magic bullet” psoriasis treatment is stressful and entails great investment of both time and money for PLWP. More broadly, interview data indicate PLWP experienced greater stress from psoriasis treatment options that were not practical financially (out of budget), nor readily available (U.S. market). These findings are important in light of the ever-changing pharmaceutical and over-the-counter medication marketplace. Treatment options available one year might not be available the next, leaving PLWP with limited paths to travel toward relief from their psoriasis symptoms.

COST OF CARE AS STRESSOR

Approximately 15 PLWP reported *cost of care* as a second, additional source of stress. Participants generally referred to stress experienced from expense(s) related to psoriasis medication or treatment, and health insurance. Gloria, the 42-year-old from Massachusetts who has lived with psoriasis for less than1 year, recalled the stress she experienced from the cost of care of her psoriasis:

> It absolutely has been stressful. It has been a financial burden. Because you know, here I have spent a considerable amount of money this year on treatments, on over the counter meds, you know? It is a monthly cost in terms of all the different prescription medications that I have to go and get. So it has been stressful; I have put a significant amount of money into trying to treat this.

Gloria framed the cost of care as stressful; attributing the stress to financial strain she experienced partly because of the cost of multiple medications. Interview data revealed that Gloria wasn't alone when it came to experiences of stress from the cost of care. 8 other PLWP cited medication expense(s), physician fees, and deductibles as stressful circumstances, which similarly proved financially burdensome. For some PLWP, the stress of the cost of care required them to re-think their approach. Dennis, the 72-year-old from North Dakota who has lived with psoriasis for 65-plus years, shared that the cost of psoriasis medications in the U.S. and challenges with Medicare Part D led him to purchase psoriasis medication from South America and Canada, which somewhat alleviated him and his wife from the financial burden of the otherwise high costs of psoriasis medicine in the U.S. While Dennis and his wife had the resources to lessen the stressful burden of the cost of care by purchasing medication from outside the country, other PLWP did not have the resources to do so. In fact, some PLWP experienced greater stress because of the cost of care of psoriasis. Rebecca, the 48-year-old from Oregon who has lived with psoriasis for 12 years framed the cost of care as the reason she did not have any money at the time of the study, as well as the reason she could no longer support her kids; her children lived with a sibling of hers at the time of this study.

Study participants reported costs of psoriasis care ranging from under $100 per month, to over $1,000 per month. Contingent on medication type, insurance, and deductible or over-the-counter expense, PLWP expected to pay between $1,200 and $12,000 annually for psoriasis care. For 6 study participants, costs of psoriasis care included the "hassles" PLWP dealt with regarding health insurance. Christine, the 24-year-old from South Carolina who has lived with psoriasis for 12 years, recounted the stress of the costs of care and insurance:

> Expensive medication and insurance are both a humongous source of stress. I've had two different insurance companies drop me because the psoriasis is deemed as a pre-existing condition. As far as medications, I remember my mother taking to me the pharmacy for the first time long ago; it was for a foam medication with steroids in it and I put it on my scalp when they first decided it was psoriasis. It was supposed to be a week's worth of medication, and it was $234 because we didn't have insurance.

Christine's narrative excerpt indicates health insurance companies have characterized psoriasis as a pre-existing condition in some cases, and dropped PLWP. At the time of the study, Christine did not have health insurance and reported paying $400 a month for her steroid foam out-of-pocket. At least 3 PLWP recounted similar experiences being dropped from insurance plans, and subsequently were unable to receive care from a specialist. Interview data revealed that despite the intuitive benefits of health insurance (lower healthcare costs; minimal deductibles), some PLWP framed health insurance as a *cost of care*, given the limitations they experienced. Interview data also uncovered that despite having insurance, at least 2 PLWP completely avoided a medical approach to care of their psoriasis, given anticipated costs and perceived hassles of expense.

Interview data simultaneously uncovered that for at least 15 PLWP, the stress of the cost of care of psoriasis was *chronic*; the stress permeated and created strain in other areas of daily life (financial; interpersonal conflict). Interview data revealed that the chronicity of stress created by the cost of psoriasis care was greater for PLWP who sought care from multiple specialists, who did not have health insurance, or, who had co-occurring illness. However, the findings do not suggests that PLWP who seek care from one specialist, who have health insurance, and who do not have other health conditions are free from stress created by costs associated with psoriasis care. On the other hand, the data also indicate PLWP who paid for less-expensive over-the-counter psoriasis remedies (oils; creams), who sought natural paths to care (e.g. meditation; yoga), or who had received free care advice from a doctor, experienced less-severe stress related to the cost of care. As issues of managed care and health care costs remain a central focus of health care consumers in the U.S., limited findings pertaining to costs of care as a stressor among PLWP in this study will require further attention by future health and stress process scholars.

SYMPTOM CONCEALMENT AS STRESSOR

Interview data indicate *symptom concealment* was a third additional source of stress for PLWP. Each of the 23 study participants referred in some manner, to stressful circumstances created by psoriasis symptoms, treatment, and symptom-concealment. Amy, the 36-year-old college lecturer succinctly recalled the stress she experienced pertaining to her psoriasis symptoms, "what's stressful is the not knowing where the symptoms are going to appear next". Rebecca, the 48-year-old from Oregon, shared similar thoughts, "the most stressful thing is not knowing from day to day what the symptoms are going to be like and not being able to control it." Narrative excerpts from both Amy and Rebecca indicate that the unpredictability of location and chronicity of symptom flare-ups created feelings of anxiety and worry; symptom appearance was perceived to be out of their control. For at least 15 PLWP, stress not only stemmed from the unpredictability of psoriasis symptoms, but also from the visibility and nature of the symptoms. Jackie, the 44-year-old Floridian who has lived with psoriasis for 31 years recalled:

> It is stressful. It's hard to explain it; for part of the day, you tend to forget about it [psoriasis] because you're busy, so your mind isn't on it until something like, I'll look down, and I'll see flakes on my desk, or around my desk. Or, I'll go into the bathroom and realize, "oh lovely, I've been talking to so and so and there's this

> huge flake hanging down from my eyebrow!" (laughs), you know? So you get that kind of stress factor and then you just get the whole itching, or if it hurts, because sometimes it will hurt.

While Jackie did not think about her psoriasis all day, she experienced stress when her psoriasis symptoms were visible to others and when her symptoms hurt, or were painful. Interview data revealed PLWP generally felt most stressed from their *visible* psoriasis symptoms while engaging in sexual activity, visiting other people's homes, and in public places. It is possible however, that the perceived threat of stigma from others contributed to the chronicity of stress experienced.

Interview data uncovered that for 22 of the 23 study participants, symptom concealment attempts created stressful circumstances for PLWP. PLWP purposefully covered psoriasis symptoms in many ways: clothing, make-up, long hair, and with household items like a Band-Aid. Gloria, the 42-year-old from Massachusetts who has lived with psoriasis for less than 1 year recounted her attempts to cover her psoriasis symptoms, "I just wear longer clothing. I try not to wear things that, you know, show my legs. If I wear a skirt, I generally tend to wear ones that are long. I've never been one to wear shorts and short skirts. But, when it's really hot out, I do want to wear a sun dress, or you know, I want to wear a skirt that shows my shins, but in the summer time I just don't." Interview data revealed Gloria was not alone when it came to the purchase of clothing to conceal psoriasis symptoms. PLWP routinely purchased clothing not designed for certain seasons of the year (e.g. long pants during hot summer months) to hide their symptoms. Interview data also revealed PLWP covered their psoriasis regardless of the chronicity of the symptoms to avoid reactions from others. The findings suggest PLWP experience stress not only from the discomfort of certain concealment methods, but PLWP also experience stress from the anticipated and or perceived threat of stigma from others.

Interview data indicate that both the “need” to conceal, and the chronicity of stress of concealment, varies for PLWP. For Molly, the 22-year-old college student in New Hampshire, the desire to cover psoriasis symptoms changed as she went through school. Molly said, “I think at first, when I was in elementary school, I never really covered it [psoriasis] up that much because in elementary school people were like “okay”. But once I got to middle school, I definitely used to wear long sleeve shirts and pants just to try to cover it up. But then, eventually after high school I was like, “you know what, I don’t know why I was covering up.” Molly perceived the necessity and stress of concealment at its peak during middle and high school. Based on findings presented earlier in this chapter, it might be that Molly, and other PLWP, are more overtly concerned about the impressions of others during the formative years as opposed to the early and later years of life. Not only then, is the act of concealment stressful for PLWP, so too is the perceived threat of stigmatization from others.

Interview data also revealed PLWP experienced greater stress from concealment attempts when preparing for work, job interviews, and social events like weddings and barbeques. Study participants perceived interaction with potential employers as a “high stakes” encounter and attempted to present an “acceptable” appearance. This finding does not suggest though, that casual interactions with neighbors, family, and friends were not stressful or did not require PLWP to perceived the need to hide their symptoms. For participants like Marvin, the 78-year-old retired Texan, the perceived need for and stress of concealment was minimal as he aged, given his strong sense of self. Marvin said, “I think I feel fairly sure of myself. I know I’m reasonably intelligent, probably about the average and so why should I feel bad about something that I can’t control? I can try to cover it you know, at times and at social events. But, I really can’t control it. I’m not going to start hiding in the house and staying away from people because

I have an autoimmune problem." For Marvin, his positive perception of himself and his perceived lack of control over psoriasis, positively impacted, minimalized stress and steered him away from isolation. In chapter six, presentation of findings will illustrate the role of personal mastery in managing the stress of stigma and the other stressor discussed in this chapter.

Other Stressors & PLWP

Contemporary psoriasis literature cautions readers (PLWP and the general public) to the challenges associated with life with psoriasis, challenges including stress. Yet, the National Psoriasis Foundation (2014) and popular psoriasis scholars like Bergstrom and Kimball (2011) have neglected to identify the threat condition-related symptoms, the cost of care, and symptom concealment explicitly pose to PLWP. Findings from other psoriasis *and* stress process scholars have likewise neglected to shed light specifically on the role of stressors such as those presented in this section pertaining to PLWP. However, two prior studies, one by Jowett and Ryan (1985) and another by Kimball et al. (2005) scratched at the surface, suggesting psoriasis as a condition, is stressful for PLWP, especially for employment and courtship activity, respectively.

Interview data uncovered PLWP experience a "constellation of stressors" (Pearlin 1989) (stigma and other stressors, simultaneously) that, together, create stressful circumstances in both interpersonal and institutional contexts. The data revealed PLWP's social, recreational, and consumer behavior is patterned and shaped by psoriasis. PLWP are not only limited emotionally (anxiety; worry) by their condition, PLWP are also limited physically (mobility) in some instances. The data also indicate the cost of care PLWP endure is stressful. PLWP are burdened with medication and treatment expense(s) and health insurance bureaucracy. For PLWP, the cost of care not only determines access to care (skin specialist) and treatment choices (medical or alternative treatment), the cost of care for some PLWP, also affects family sustainability (support for children).

The data additionally indicated the unpredictability and visibility of psoriasis symptoms lead PLWP to take often-inconvenient measures to hide symptoms to "pass" (Goffman 1963) as a *normal* person. While symptom concealment of psoriasis symptoms in public (social spaces; work) and private (dating) settings is a burden for PLWP, symptom concealment coincidentally helps to minimize the overall experience of psoriasis stigma-stress. Findings of prior stress process research suggest people experience stress disproportionately or unequelly so (Bierman and Pearlin 2011; McLeod 2013; Rosenfield and Mouzon 2013; Williams, Costa, and Leavell 2010; Brown et al. 2013). Though this study did not "test" the chronicity of stressors presented here, a future investigation might decipher whether the stressors presented above are *more* or *less* burdensome for PLWP, given their socioeconomic status, gender, or race.

STRESS PROLIFERATION

Stress process researchers (Pearlin et al. 1981; Pearlin 1989; Wheaton and Montazer 2010) have established that stress does not occur in a vacuum; rather, stress occurs along a continuum whereby (primary) stressors beget other (secondary) stressors. Stress experienced from an event (e.g. stigmatizing reaction from others), can spill over and "proliferate" to create additional chronic strains, affecting multiple areas of daily life (e.g. employment; social life). Interview data revealed that at least 18 PLWP experienced stigma and other (primary) stressors presented above, proliferate to create new independent sources of stress in a variety of social roles PLWP occupied (e.g. employee, parent, friend, neighbor). Analysis of participant response(s) captured nuanced experiences of stressor proliferation, which were coded into two emergent categories: *daily functioning* and *peer and family networks*.

Daily Functioning

Interview data indicate the stress of stigma and other stressors interfered with PLWP' daily functioning at work, participation in social and recreational activity, relationships, and personal goals. For example, Gloria, the 42-year-old from Massachusetts who has lived with psoriasis for less than 1 year, recounted her concern over her future job performance: "I mean, I guess there's this distant concern that if this [psoriasis] gets really bad, am I going to be able to continue to do the job that I do?...which is an external facing job. The fear is there now, but when it gets really, really bad, how will it effect my work?" Gloria shared that because her job required her to be in front of people all day, the anticipated threat of stigma was a daily hassle; a hassle she feared might eventually force her to quit her job in the event her psoriasis symptoms worsened. Gloria's concern about future job performance in and of itself was stressful, as she was unable to focus on tasks at hand without worrying. Interview data revealed about 12 PLWP experienced stigma-stress as well as symptom-related stress as a constant, daily burden in their role(s) as an employee. The anticipated and perceived threat of stigma by co-workers, clients, and bosses coupled with the daily stress of symptom concealment to "save face" daily, drove PLWP to their emotional limits (e.g. anxiety; worry).

Interview data revealed that at least 2 PLWP reported difficulties with job interviews because of their psoriasis, but no PLWP explicitly reported being fired from or leaving a job because of conflict created by psoriasis-related stress. Interview data also revealed that the 12 PLWP who explicitly cited stigma and other sources of stress as a daily hassle in their role as an employee, each held a position that required frequent interaction with co-workers and clients. Though study participants in this sample were employed in positions that required routine interaction with others, other PLWP employed in positions that require little interaction (e.g.

telecommuters) might not perceive the threat of stigma and other stressors as a chronic source of stress in their role as an employee in the same way.

Interview data additionally uncovered PLWP framed the physical act of going to and from work as an independent, additional source of stress. Brent, the 27-year-old systems support analyst from Massachusetts, shared that the commute to and from work everyday alone, was burdensome. Brent recalled, "I think the hardest part for me was public transit. Going to and from work was very hard. I would be commuting via rail and be very anxious about it you know, what if somebody's looking? or what if this, and what if that? My mind kind of ran wild." For Brent, stigma-stress interfered with what would otherwise be a routine commute to work. Utilization of public transportation became an additional source of stress whereby, in some instances, the stress of commuting led Bent to travel during off-peak hours.

Study participants similarly experienced the proliferation of stigma and other stressors as a chronic strain in daily social and recreational activity. For example, Beth, the 44-year-old Connecticut resident who has lived with psoriasis for 28 years recalled, "There's been times when I didn't go to a friend's wedding, or a picnic, you know bbq's at a friend's house. It [psoriasis] really limits you; it limits a lot of things…it sucks!" For Beth, the stress of psoriasis (as a condition) as well as stigma-stress, contributed to her avoidance of social events, and she subsequently missed out on major life events in her friend's lives. Interview data uncovered that at least 13 PLWP attempted to avoid or isolate themselves from social and recreational activity because of psoriasis-related stress. Avoidance and isolation as secondary stressors were an additional independent source of stress for PLWP. For Rob, the 30-year-old from New York who has lived with psoriasis for 11 years, avoidance of the beach was routine:

> The beach is a perfect example. If I think about the reactions [from others], I kind of get myself worked up. I had several times where I would drive 20 minutes, I'd

> be getting close and I would see the crowds and I would just go back home. I just stressed myself out. I would get so anxious over the possibility that you know, God forbid, they'll stare at me, or have somebody say something to me.

Stigma-stress as well as stress from the condition and symptoms of psoriasis proved to be a chronic strain in Rob's life. Rob frequently was inconvenienced by the stress (turning car around), which contributed to his avoidance of places like the beach altogether. While some participants avoided social and recreational activities completely, others like Marvin, the 78-year-old Texan, attended events, but isolated themselves from certain activities. Marvin recounted:

> A couple of my neighbors have pool and they throw pool parties. I never go and swim. I don't swim anymore at all even though at one time I was a decent swimmer. Mainly because if I go in with bathing trunks, I'm going to look like hell and it's the case where I can see the crowds of people moving away from me because I look like I'm diseased. So, I don't swim anymore. I go to pool parties, but I just go to drink beer (jokes).

Marvin attended pool parties hosted by his neighbors, but isolated himself from the crowd of people who swam. The stress of looking "diseased" contributed to Marvin's avoidance of swimming, an activity he once enjoyed. Interview data revealed PLWP avoided and isolated themselves from playing volleyball, volunteering in their community and their children's parent-teacher organization, dating, as well as social outings to the park or retail shops. The self-imposed isolation was, itself a stressor for PLWP. Interview data also uncovered that PLWP in some instances, isolated themselves from their past and present goals. Jackie, the 44-year-old Floridian who has lived with psoriasis for 31 years recounted abandonment of a goal of hers; Jackie said, "My sister and I, years ago, had this idea of opening our own little like bakery. Would I feel comfortable doing that? No. Because, people are uncomfortable with differences and I would be worried about getting flakes in people's food. If I went into to somebody's restaurant and saw that, I would be uncomfortable. So, why wouldn't somebody else?" Jackie isolated herself from the once-likely opportunity of opening a bakery with her sister because of the stress from of psoriasis condition and symptoms, as well as from the perceived threat of others' reactions. Interview data more broadly uncovered that PLWP' public *and* private areas of life were affected by the recurring strain of stigma and other stressors. It is clear from participant narratives, that the pervasiveness of stigma and other stressors in PLWP' daily functioning is far-reaching.

Peer & Family Networks

Interview data simultaneously indicated that the stress from stigma and other stressors created on-going strain in PLWP' interaction(s) in peer and family networks. This strain represents an additional stressor that created distress for PLWP independent of the (primary) stigma-related stress. Brent, the 27-year-old from Massachusetts who has lived with psoriasis for 8 years recalled how psoriasis-related stress shaped his role as a friend to others; Brent said, "I would say having a heightened level of anxiety has been constant. Let's say somebody wants to do something, maybe I don't want to do something. So it effects them [friends] in that way, and maybe they don't get the full experience of who I would be without it [psoriasis] you know?" Brent recalled that the constant burden of psoriasis-related stress contributed to his avoidance of activities with friends, a burden that restricted who he was or was not able to be around his friends. At least 4 study participants attributed having a smaller group of friends, which in and of itself was stress producing, to the stress they experienced regularly from psoriasis, and the reactions the symptoms fueled.

Furthermore, PLWP attributed some of the conflict experienced in peer interaction to a lack of psoriasis knowledge among and unsolicited "advice" from their friends. Gloria, the 42-year-old from Massachusetts who has lived with psoriasis for less than 1 year framed the unsolicited “advice” from friends, colleagues, and family as an “annoyance”. Likewise, for Molly, the 22-year-old college student in New Hampshire, being referred to as “the flaky roommate” by her dorm mates wasn’t an endearing sentiment. More generally however, interview data revealed PLWP’ interaction with peers and friends was somewhat of a paradox: peer interactions exacerbated psoriasis-related stress in some instances, while lessening the burden of psoriasis-related stress for other PLWP. In chapter six, I present findings illustrating the value of social support (family; friends) toward managing the stress of psoriasis.

For at least 5 PLWP, psoriasis-related stressors challenged daily interaction with family members. Rebecca, the 48-year-old from Oregon who has lived with psoriasis for 12 years, recalled an instance where the psoriasis-stigma she experienced affected her son; Rebecca said, “When it comes to things like the first day of registering for high school for my son, he worried everyone would see me, so it’s [stigma-stress] still in the back of their [her kids] minds.” Rebecca’s narrative excerpt illustrates that the stigma that burdened her, also burdened her children as a *courtesy stigma*, which is stigma experienced by others who are in the presence of the stigmatized person (Goffman 1963). Interview data revealed that aside from courtesy stigma, which was only reported by one participant, PLWP also perceived the threat of stigma-stress to have an impact on spousal sexual relationships. For Beth, the now-divorced 44-year-old in Connecticut who has lived with psoriasis for 28 years, the stress of spousal intimacy was great; Beth said, “I will not get completely naked, ever…there will never be a time where I will do it [sex] during the light.”

Both male *and* female PLWP reported that the anticipated threat of stigma was a burden; even with spouses they trusted and have been married to for several years. Interview data also revealed that stress PLWP experienced from the cost of care of psoriasis influenced PLWP’ decisions that pertained to family vacations and monthly purchases like groceries. Marlene, the 53-year-old Mississippian who has lived with psoriasis for 33 years recounted the cost of care for psoriasis dictated everything that she purchased, down to the diet coke 2-liter she purchased before the interview. The chronicity of daily stress from the cost of care of psoriasis was exacerbated for some PLWP, especially those who were expecting children or who were unemployed at the time of the study. Though stigma and other stressors created daily strains in family life for PLWP, family as a type of social support, helped to lessen the burden of psoriasis-related stress; a finding I present in greater detail in chapter 6.

Stigma, Stress, & Health

Interview data presented here clearly illustrate stigma-stress and stress from other sources (condition-related symptoms, cost of care, symptom concealment) penetrates the boundaries of multiple domains of PLWP' lives, often creating additional, independent sources of stress involving social roles and relationships. Stigma and other stressors have the power to disrupt and challenge PLWP' daily activities and relationships; the stressors, in some instances, become a chronic source of stress for PLWP. Coincidentally, while prior studies have addressed the deleterious effects of stigma on health (Pachankis 2007; Van Brakel 2006; Weiss et al. 2006;) and the negative impact of psoriasis on the quality of life of PLWP (Basavaraj et al. 2011; Ros et al. 2013; Bohm et al. 2012), prior work has not uncovered the way(s) in which stress proliferates to affect the daily lives of PLWP. Addressing this gap, findings presented above shed light on the process of stress proliferation in the lives of PLWP, specifically illustrating that the processes of stress, stress proliferation, and distress experienced by PLWP. For example, PLWP feel "different" and anticipate stigmatization (stigma-stress itself is stressful for PLWP), isolate themselves from, or avoid social events and interaction with peers or family members as a result (isolation and avoidance becomes an additional source of stress for PLWP), and PLWP subsequently feel anxious, embarrassed, as well as depressed. The anxiety, embarrassment, and depression felt by PLWP then triggers subsequent psoriasis-related stress and, in some instances, psoriasis symptom flare-ups.

Pearlin (1989:246) framed chronic illness as an *ambient strain*, a strain that cuts across roles and envelops people with a chronic illness. Findings presented above illustrate that the ambient strain(s) of psoriasis affect not only PLWP, but also people they are close to and associate with. Stress process scholars (Pearlin et al. 1997) and stigma scholars (Dwyer et al. 2013) have found that the demands and burden felt by people with a chronic illness affect people close to those with the illness (e.g. caregivers; family; friends) as do the stigma labels. Findings presented above are consistent with results of prior work; namely, people close to PLWP (e.g. children, spouses) share some of the burden (courtesy stigma; restricted sex life) of psoriasis. Furthermore, according to Pearlin (1997:224), stress proliferation is not uniformly experienced by all individuals confronting the same life circumstances. Pearlin's (1997) assertion was reflected in responses of PLWP in this study. PLWP did not all experience stigma-stress and other sources of stress to the same degree and not were equally distressed by it. Rather, PLWP utilized and had access to different personal and social resources that influenced the extent to which challenges were experienced as stressful and whether those stressors lead to distress. In chapter 6, I present findings specifically outlining how personal and social resources helped PLWP cope and manage the stress life with psoriasis.

PSORIASIS IDENTITY

Pearlin (1989:249) argued that a careful study of stressors should provide a researcher with the opportunity to learn something about social life as it bears on individual functioning, the organization of people's lives. Thoits (2013) added to Pearlin's (1989) assertions, positing that in order to comprehensively understand the intersection of stress and stressors in people's lives, research must consider issues about self and identity. Interview data in this study revealed a nexus between the calls of stress process scholars like Pearlin (1989) and Thoits (2013): stressors contributed to PLWP' *psoriasis identity*. I refer to *psoriasis identity* here as the ways PLWP conceived of their condition and self in context of experience(s) of psoriasis-related stressors.

Participant responses generally were categorized into two "outcomes": positive-neutral perception of condition and self *or* negative perception of condition and self. For example, Amy, the 36-year-old college lecturer in New Hampshire, recalled how psoriasis and psoriasis-related stressors have shaped her acceptance of her condition:

> I've come to accept it…I'm this person who has been shaped by this experience of having something that is unpleasant. Not only to feel, but to look at. Do I think I'd be a more confident person just body image wise without psoriasis? Absolutely. I mean feeling comfortable in your own skin…it really means something to me. I think I would generally like myself better if I didn't have this creepy thing that happens. If I could just make it disappear, yeah I would…that would be a great thing for me. So, am I glad that I went through you know, the struggle with it all those years? No! But, it has helped me say that "we all have our flaw, we all have our issue", and I just need to accept that this is my issue. This is my thing that I have to deal with.

The narrative excerpt illustrates that while Amy perceived her condition as "creepy", she framed her experience of psoriasis and psoriasis-related stress as something that contributed positively toward her understanding of her own "flaw". Though Amy did not choose a life with psoriasis, she accepted her condition. Interview data revealed 6 PLWP similarly framed their psoriasis identity either positively or positive-neutrally. Molly, the 22-year-old college student who has lived with psoriasis for 15 years recounted how, without psoriasis, she wouldn't be the same:

> I honestly I've never been ashamed of it [psoriasis]. I've always kind of taken it [psoriasis-related stress] and been like "yeah, I have psoriasis". If I could do it all over again and not have psoriasis, I wouldn't, I would still have it because to me,

> it's like that is just part of who I am. I don't know…I've never wished I didn't have it. I mean, honestly, I wish there were times that my skin wouldn't be painful, naturally, but I never wanted to know, take that way…because to me, I wouldn't be me without this. You know?

Despite the stress Molly has endured as part of her condition, she reported not only that she has never felt ashamed, but also that psoriasis has become deeply engrained as part of who she is, to the extent that if she didn't have psoriasis, she would not be herself.

The other 4 PLWP attributed their psoriasis identity "outcomes" to the lack of control over reactions of others and of the condition overall, as well as attitude. For example, Libby, the 53-year-old in Oklahoma who has lived with psoriasis for 35 years succinctly recalled, "I was brought up with good self-esteem, you know? I'm comfortable. I know what goes on in my brain. I accept that I cannot control what goes on in other people's brains." It's clear that Libby's psoriasis identity was molded by her perceived strong sense of self-esteem and her lack of ability to control other people's (stigmatized) perceptions of psoriasis. However, the narrative excerpt indicates Libby likely had resources (e.g. social support) growing up, which also contributed to the positive sense of self-esteem and perspective of condition she held. For other PLWP, like Angelica, the 32-year-old from Puerto Rico who has lived with psoriasis for 11 years, attitude played a role in shaping PLWP' psoriasis identity. Angelica recalled, "throughout the years, I've grown to embrace the condition instead of…you know, be sad or depressed all of the time. You have to come to terms with the fact you're going to have it [psoriasis] and that you can live with it, and it's something that a lot of people have lived with. So, I try to see the silver lining in everything."

In the narrative excerpt above, it's clear that Angelica had an optimistic attitude (looked for silver lining) toward her condition and positive view of herself living with psoriasis in part, because of her awareness of others "surviving" life with the condition. For Sarah, the 40-year-old in New York who has lived with psoriasis for 30 years, the stress of psoriasis is a big part of who she is, but psoriasis and psoriasis-stress are not the focus of her life. Sarah's attitude was likewise apparent in her narrative:

> It's not the focus of my life. I'm bothered by it when it's painful. I'm bothered by it occasionally when watching commercials for women's shaving products, because my legs are gross. I'm bothered occasionally when someone gives me the stink eye on the subway. I'm bothered when I'm having a crappy day and the 17th person wants to tell me about their great aunt Agatha who treated hers with coconut oil and eggs. But it's not every day; it's not all of the time.

Sarah described the stress of life with psoriasis, but framed her general attitude as such that psoriasis-related stress did not define her as a person, or become focus of her daily life. Interview data revealed that PLWP whose psoriasis identity was not negatively impacted by psoriasis-related stress, generally lived with psoriasis for at least 10 years, recognized the permanence of the condition, and utilized resources that aided PLWP to positively re-frame daily life and circumstances that would otherwise be construed as negative.

Interview data uncovered that at least 11 PLWP described a psoriasis identity that was negatively shaped by experiences of psoriasis-related stress. For example, Susan, the 59-year-old life coach in New Hampshire who has lived with psoriasis for 20-plus years, recalled the constant embarrassment of her psoriasis and how that embarrassment has shaped her experience of life with psoriasis:

> I am constantly embarrassed of the fact that I cannot walk around in short sleeves and shorts and be okay. When you see a man walking down the street and he has gout in his legs, which are all purple and bruised and inflamed and swollen…do you not look? And do you not go "oh my god, that guy has gout"? I don't need anybody talking about me. It's bad enough I have to hide from what I deal with [psoriasis stress] emotionally, so it's kind of like some parts of me that are really bold and brazen and real, and then there's the other part of me [psoriatic] that is secretive and I hide and nobody knows what goes on behind the mask.

In the narrative except, Susan framed her daily life in a dichotomous, paradoxical manner; on one hand, she was "bold and brazen", while on the other, she was insecure about herself. Susan recounted how she routinely hid her backstage burdens of life with psoriasis to "pass" as a normal person in the public eye. Interview data revealed that PLWP' conception of the condition and their self-concept was negatively impacted by the shame they experienced as part of psoriasis-related stress. For some PLWP, like Gloria, the 42-year-old from Massachusetts who has lived with psoriasis for less than 1 year, acceptance of life with psoriasis was a challenge. Gloria said:

> I don't want to accept that this the way it's going to be. I hope it can get back to the way it was [before psoriasis]. You know, I don't want to be on medication forever. I don't want this and I'm hopeful that this won't be something that I have to live with on a daily basis. You know, I hope it's something I can treat and get better. So that's what I'm hopeful about. But, I guess there is still a feeling of a little bit of denial that I have to live with this. That this is a permanent condition and this is the best it's going to get.

Gloria, who had lived with psoriasis for a relatively short amount of time at the time of this study, expressed how life with psoriasis equated to denial. Gloria's conception of life with psoriasis was tarnished by the fear of the unknown (medication dependence, remission). Interview data revealed PLWP whose psoriasis identity was negatively impacted by psoriasis-related stress had lived with psoriasis anywhere from less than 1 year to more than 20 years. Interview data suggested that the permanence of the psoriasis and perceived lack of control over symptoms contributed toward PLWP' perceptions of hopelessness and denial.

Interview data also pointed to the visibility and nature of symptoms of psoriasis as contributing factors in PLWP' psoriasis identity. For example, Rob, the 30-year-old from New York who has lived with psoriasis for 11 years, attributed his embarrassed to the negative reactions of others. Rob recalled, "I'm put in a circumstance where I'm just hanging out and I've got people eyeballing me…and I know why. But, there's nothing I can do about it. It's embarrassing." The narrative excerpt indicates that Rob's inability to escape the reactions of others has shaped his mostly negative perceptions of psoriasis. Interview data indicated at least 5 PLWP similarly reported that the deleterious impact of reactions (stigma labels) from others made them feel poorly about themselves. PLWP felt judged and subsequently perceived themselves as undesirable or unattractive. For Julie, the 22-year-old college student who has lived with psoriasis for 2 years, her civilian *and* military life was affected by her psoriasis. Julie recalled how in the Army, she had to prove that she wasn't a "sick person" even though she had visible psoriasis symptoms and had to take medication with all the other military officers that were "sick". PLWP whose psoriasis identity was negatively impacted by psoriasis-related stress generally attempted to utilize resources to help positively re-frame some aspects of daily life with psoriasis. In chapter 6, I present findings explicitly illustrating how personal and social resources were utilized by PLWP to manage psoriasis-related stress.

Illness and identity research is not unfamiliar territory for scholars. Parsons (1951) hypothesized people with chronic illness are *deviant* and adopt a "sick role", whereby the sick person is released from obligation of other social roles (e.g. parent; employee), but held accountable for their return to health. The Parsonian framework of the sick role however, is considered by other scholars (Pierret 2003; Turner 1995; Charmaz 1989; 1993) to be overly deterministic; Parsons (1951) neglected to acknowledge that people with an illness have *agency* in constructing their illness experience and identity (Lively and Smith 2013:506). Rather, scholars have accepted Charmaz' (1983) conceptualization of illness, identity, and agency, whereby agency refers to how people begin to redefine what it *means* to be "sick" or what it means to be a parent, friend, or colleague and so forth, with an illness (e.g. psoriasis). The findings presented above are not meant to provide evidence to support or refute prior claims; rather, the findings presented here broadly shed light on the *psoriasis identity* of PLWP. How participants developed a *psoriasis identity* was influenced by both social (expectations of others; stigma labels) and individual (attitude; sense of control) factors.

Sociological scholars Berger and Luckmann (1966) posited that social reality is a *social process*; social reality is a highly ordered, on-going reality that is human made and experienced (socially constructed). Participant narratives not only illustrated that the social reality of life with psoriasis is ordered (e.g. diagnoses; treatment regimens; interaction with others), findings also emphasized PLWP interpreted that social reality to make it their own (perceptions of their condition and self). PLWP' conception of their condition and themselves were meaningfully influenced by psoriasis-related stressors. Some PLWP accepted their condition and had a positive self-image, while other PLWP had difficulty with acceptance of condition and had a less positive self-image. Interview data also uncovered that stigma and other stressors experienced by PLWP (discrete *and* chronic) shaped PLWP' performance of social roles; psoriasis-related stress challenged PLWP as parents, employees, and sexual partners. Goffman (1959) argued that social roles, pre-established by society, guide our expectation(s) of behavior for those who occupy a given role. It is no coincidence then, that an unsuccessful performance by PLWP as a parent, friend, and even as a person with psoriasis, can have long-term consequences toward their psoriasis identity.

CHAPTER VI
STRESSOR MANAGEMENT AND PSORIASIS AWARENESS

Life with psoriasis can be stressful. However, stressors do not necessarily lead to the same stressful outcomes for all PLWP. Stress process researchers (Pearlin et al. 1981; Pearlin 1989; Turner and Brown 2010; Thoits 2011; Ross and Mirowsky 2013) suggest that people utilize *personal* and or *social resources* to moderate or "buffer" the stressful impact of life problems (e.g. stigmatization). Personal and social resources help PLWP to redefine stressful circumstances and/or better handle them when they occur, reducing the threat and negative impact of stress. In this chapter, I draw on interview data from PLWP to describe how PLWP cope with and manage stigma and other psoriasis-related stressors. Findings presented in this chapter also illustrate how PLWP' use of resources shape PLWP's goals for raising psoriasis awareness, and PLWP's outlook for future psoriasis research.

PERSONAL RESROUCES

Stress process scholars generally consider personal resources to include two core individual-level factors: *mastery* and *coping*. Mastery refers to the sense of personal control, the belief that one can control or shape important life outcomes (Ross and Mirowsky 2013:379). Thus, those who are high in mastery generally feel that they have the power to control stressful circumstances. Coping, on the other hand, refers to the things that people do to avoid being harmed by life-strains (Pearlin and Schooler 1978). Coping serves to either *change the situation* from which stressors arise, *manage the meaning* of the situation to reduce the threat of stress, or to keep the *symptoms of stress within manageable bounds* (Pearlin and Schooler 1978; Pearlin

1989:250). Interview data revealed that 13 of 23 participants identified ways that personal resources were used to manage the stress of stigma and other psoriasis-related stressors.

MASTERY

Interview data indicated that 8 PLWP had a strong sense of mastery or "perceived personal control" over psoriasis-related stress. Christine, the 24-year-old from South Carolina who has lived with psoriasis for 12 years, recalled how a strong sense of mastery shaped her perception of control over her psoriasis; Christine said, "I think I have a very strong sense of self-being. I'm very self-aware and I'm very comfortable with myself, and I know when things are going badly and I need to adjust myself and distract myself." Libby, the 53-year-old from Oklahoma who has lived with psoriasis for 35 years likewise recounted her perception of control over stress she experienced, "You know, you choose happiness or not. For some reason I have this ailment and I've just got to deal with it. You can either control it you know, or let it control you. I'm not going to let it control me." Narrative excerpts from Christine and Libby indicate that strong sense of mastery positively contributed to perceived ability to "adjust" to uncomfortable, stressful circumstances. A strong sense of mastery also appeared to influence the extent to which psoriasis-stress created negative or positive attitudes or outlooks (i.e. happiness or depression).

Interview data also revealed that at least 4 of the 8 PLWP with a strong sense of mastery approached psoriasis-related stress with coping strategies like a sense of humor and sarcasm. For example, Sharon, the 43-year-old from Michigan who has lived with psoriasis for 28 years, shared that her sense of self-esteem contributed to her management of psoriasis-related stress through joking and laughter. Sharon said:

> I have a pretty normal sense of self-esteem. I mean, I'm not conceded by any means. I've had psoriasis for so long, I've had to develop a sense of humor about

> it. It's one of those things that if I don't laugh about it, I'm going to cry about it kind of thing. So, I've found that it's easier to laugh at my psoriasis and make jokes about it. Like, if a new lesion shows up somewhere where it hasn't been before, I'll be like, "oh, lookie there" (laughs) you know? Or, "It's a red-letter day, I got another one" (laughs). I'd rather joke about my psoriasis and laugh and you know, feel good for a second or two whether it's misplaced or not, rather than sit down and cry for half an hour about it like, "Oh my God, I found another spot on me". In the big picture, is one more spot going to make a big difference? No, it's not going to make a big difference.

It is clear from the narrative excerpt that Sharon was aware of the alternative to humor and laughter (crying, sadness) in regard to her approach to stressor management. Sharon claimed that the length of time she had lived with psoriasis required her to develop a sense of humor to deal with stressful circumstances. Interview data revealed PLWP with a strong sense of mastery had lived with psoriasis anywhere from less than 1 year, to over 65 years. Interview data simultaneously indicated that PLWP with a strong sense of mastery generally "accepted" their psoriasis (symptoms *and* stress) rather than denied the condition. Study participants, like Gloria, the 42-year-old from Massachusetts who has lived with psoriasis for less than 1 year, refused to "succumb" to psoriasis; rather, they chose to embrace their condition. However, interview data did not suggest that PLWP with strong mastery or perceived control are untouched by psoriasis-related stressors. In fact, it is clear from participant narratives above that PLWP do experience stress from stigma and other psoriasis-related stressors, though the perceived threat of stress appeared to be less chronic for these 8 study participants.

Interview data indicated at least 5 PLWP had a weak sense of mastery and perceived having less control over psoriasis-related stress. Rob, the 30-year-old from New York who has lived with psoriasis for 11 years, shared how his perceived lack of control over psoriasis-related stress contributed to feelings of agitation; Rob said:

> With the stress…there's just really nothing I can do. You know, I get very agitated if I feel like somebody is looking at me. This might sound terrible, but I

> tend to compare it to a woman with big breasts. You're talking to somebody and they keep looking down…and they keep looking down, and a lot of times I'll be having a conversation with somebody and I'll catch their eyes shooting to my arm. Or, this or that, and you know, that'll stress me out more, and I'll get agitated, and maybe I'll get a little angry with the person. That's not really good management for the stress, but that's just kind of what happens. I think I used to try to relax myself and say it doesn't matter, but like I said, you get those glances and you're talking and making eye contact with somebody and you just see them glance and it gets VERY stressful. I still haven't found a good way to deal with the stress. I really haven't.

It is clear from the narrative excerpt above that Rob's perceived lack of control and sense of helplessness contributed to a vicious cycle of stress. Rob noticed (stigmatizing) reactions from others (which were beyond his control), became agitated, and then experienced stress, stress that further fueled his agitation. Interview data revealed that co-occurring mental health issues, like depression, contributed to PLWP's perceived lack of control over psoriasis-related stressors. Susan, the 59-year-old from New Hampshire who has lived with psoriasis for 20-plus years shared how her perceived lack of control contributed to emotional fatigue; Susan said:

> Every now and then I get really tired [emotionally]. It's an awful lot of energy spent in hiding…I just get really tired. I mean, it's no different with my depression, but it's kind like this: I said to my son, "I think I want to come out of the closet" with the depression, because I'm exhausted, and it's no different than with the psoriasis. I'd like to come out of the closet with the psoriasis, but can't; I'm exhausted!

Interview data uncovered that PLWP who had perceived a lack of control over psoriasis-related stress felt "trapped" and routinely isolated themselves by avoiding interaction with others. In the narrative excerpt above, it is clear that Susan's emotional fatigue restricted her capacity to reach out and "come out of the closet with psoriasis". Interview data also uncovered that PLWP with low mastery had lived with psoriasis anywhere from less than 10 years to over 20 years. Furthermore, data suggested that PLWP with low mastery in this study were especially likely to experience stress proliferation. This finding is not surprising in context of Pearlin et al.'s (1981) "stressors beget stressors" analogy. In other words, stigma and others stressors (presented in chapter 5) proliferate into multiple areas of life for PLWP. The chronicity of stressors then is most severe for PLWP with a perceived lack of control, sense of mastery.

Past stress process scholars have found that perceived control (mastery) varies by gender (Ross and Mirowsky 2002), Age (Shaw & Krause 2001), and race (Pearlin et al. 1997). However, rather than examining how PLWP's perceived control differs by these factors, data analysis in this study aimed to uncover the ways in which PLWP utilized personal resources like mastery, as a tool to manage and deal with the stress of psoriasis. Ross and Mirowsky (2013) argue that some social conditions rob people of control over their lives and increase a sense of powerlessness. Findings presented above indicate that while some PLWP feel powerless in the face of psoriasis-related stress (e.g. stigmatization), other PLWP utilize their perceived sense of control to minimize stress (e.g. through humor). Stigma and health scholars Miller and Kaiser (2001) posit that when people with a chronic illness are stigmatized, they either *accept* their condition or *disengage* and avoid stressful situations. Findings presented above align with Miller and Kaiser's (2001) findings; PLWP who perceived having control generally *accepted* their condition and were able to manage the stress of stigma and other stressors, whereas PLWP who perceived a lack of control generally *isolated* themselves and avoided stressful circumstances.

COPING

Interview data revealed that aside from personal mastery, PLWP utilized coping strategies to minimize the burden of stigma and other stressors. Coping is a well-studied concept among stress process scholars (Pearlin and Schooler 1978; Pearlin et al. 1981; Pearlin 1989) and stigma scholars (Link and Phelan 2013; Miller and Major 2000; Miller 2006). Pearlin and Schooler (1978) posit that coping generally occurs in three ways: people *change the situation* from which stressors arise, *manage the meaning* of the situation to reduce the threat of stress, or keep the *symptoms of stress within manageable bounds*. The three types of coping outlined by Pearlin and Schooler (1978) were reflected in study participant responses and are presented below.

Changing the Situation

Concealment of psoriasis symptoms was a coping strategy most frequently used by study participants to change the stressful situation (i.e. stigma and other stressors associated with psoriasis). At least 15 PLWP explicitly recalled concealing (covering or hiding) symptoms of psoriasis as a way to manage and deal with the stress they experienced. Sharon, the 43-year-old from Michigan who has lived with psoriasis for 28 years put it bluntly, “it’s like if I’ve got to get something done [out in public] and I really don’t have time to deal with the negativity, it’s better to just cover it up and avoid the situation to begin with, that way it’s not gonna happen.” It’s clear that for Sharon, concealment of her psoriasis symptoms was a strategy she practiced to avoid stressful, negative (stigmatizing) reactions from others. Interview data indicated that PLWP concealed symptoms of psoriasis not only to avoid stressful circumstances, but also to build or restore confidence in themselves. Christine, the 24-year-old from South Carolina recounted her efforts to restore confidence in herself by concealing her symptoms; Christine said, “If my shirt isn’t covering it [symptoms], I’m likely to be constantly looking at the psoriasis myself, and you know, it [covering] helps me keep from scratching it or messing with it. There are times where you know, despite being okay with my psoriasis, there are days I’m not confident with my psoriasis showing and covering it up helps with that emotional stress as well.” For Christine, concealment of her psoriasis symptoms reduced her urge to scratch affected areas, thereby reducing the likelihood of a subsequent symptom flare-up. Christine also concealed her psoriasis symptoms as a way to minimize or reduce the amount of emotional distress she experienced from stigma and other stressors.

Interview data uncovered PLWP concealed visible psoriasis symptoms with clothing, make-up, lotion, or creams, as well as with long hair (covered symptoms that appeared on ears or neck). Interview data also uncovered PLWP concealed symptoms in a variety of contexts, including public (beach, office, social events) as well as private (intimacy) domains. The 15 PLWP that shared accounts of symptom concealment overwhelming reported doing so as a way to minimize worry over what others think. Angelica, the 32-year-old from Puerto Rico who has lived with psoriasis for 11 years recalled:

> I think it [concealment] helps with the stress because you’re not worried about people looking at you. They might have questions, and comments, and they might wonder what you have…but they can sound mean. So…by wearing those things [clothes to cover symptoms], you don’t have that happen as much. I don’t get stressed. If I don’t get that stressed, it helps control the symptoms and the flare-ups and all of that.

It is clear from Angelica’s narrative excerpt that concealment of her psoriasis symptoms helped lessen the anticipated and perceived threat of stigma from others. It is also clear that like Christine, Angelica concealed symptoms of her psoriasis not only to avoid stressful circumstances (stigmatizing reactions of others), but to “control” her psoriasis flare-ups. Interview data revealed that PLWP utilized medical and alternative approaches to minimize appearance of, or to “control” psoriasis symptoms. Study participants took medication(s) (e.g. Enbrel, Methotrexate), practiced yoga and other stress-relieving exercises, and in some instances, changed their diet(s) to control flare-ups and avoid stress by altering stressful situations. Coincidentally, though concealment of symptoms aided in PLWP’s ability to manage and deal with psoriasis-related stressors, symptom concealment can be stressful for PLWP. In chapter 5, I presented findings that indicate that the cost, time, and effort necessary for symptom concealment burdened PLWP. The findings indicate that the “trade-off” of symptom concealment is an issue all study participants dealt with.

Manage the Meaning

Positive comparison to others was a coping strategy most frequently used by study participants to manage the meaning of the stressful situation so that it was perceived as less problematic. At least 16 PLWP explicitly compared their psoriasis condition to others with psoriasis or to other conditions that PLWP perceived as “worse”. For example, Danielle, the 21-year-old from Maryland who has lived with psoriasis for 2 years, recalled that she felt better about the *chronicity* of her psoriasis after having visited a public Facebook page for people with psoriasis. Danielle said:

> Looking online [at others with psoriasis] didn’t make me feel as bad about mine [psoriasis]. I also learned I wasn’t the only one to have it [psoriasis]. I actually joined the Facebook group and I felt so much better about my psoriasis because I realized my psoriasis wasn’t half as bad as some of the others on there. Not that that I’m trying to make them feel bad or anything like that, but it just makes me feel good about myself that I’m managing it well enough that it’s not *that* bad.

Interview data revealed that PLWP also compared the *location* of their psoriasis symptoms to the location of other PLWP’ psoriasis. Brent, the 27-year-old in Massachusetts who has lived with psoriasis for 8 years, recalled comparing the location of his symptoms, to more “problematic” locations of symptoms on other PLWP. Brent said, “You know, I never had coverage anywhere on the rest of my body. It [psoriasis] just started on my scalp and it mainly remained there. So, I was always kind of grateful for that because I knew that looking it up online, it could always be worse…ah, you know, people have it on their face.” Interview data revealed that PLWP not only compared the chronicity and location of their symptoms to other PLWP that had it “worse”, PLWP also compared the *concealability* of their symptoms to other PLWP. Tanya, the 31-year-old in Maine who has lived with psoriasis for 1 year recounted, “I’ve seen pictures of people with psoriasis where they have it in really noticeable areas, so it may be harder for them. But for me, the primary areas are covered up with clothes [laughs] so it's not as bad." Findings suggest that PLWP compared their psoriasis (chronicity, location, and concealability) to other PLWP to minimize stress associated with the condition, as well as perceived the burden of stress as less chronic than those who were "worse off".

Interview data uncovered that PLWP simultaneously compared their psoriasis to others with "worse" or "more severe" conditions. For example, Molly, the 22-year-old college student who has lived with psoriasis for 15 years recounted, "I used to say that you know, my psoriasis was nothing in comparison to my friends that had leukemia or other conditions. People would treat them differently for sure, because their things were more life threatening in their eyes and, to me, people thought of me as just having a rash. I never really thought I was going to be treated differently because of it [psoriasis]." For Molly, contrasting her condition from friends that had leukemia weakened the anticipated threat of stigmatizing reactions of others, given she had "just a rash". Susan, the 59-year-old from New Hampshire who has lived with psoriasis for over 20 years likewise compared her psoriasis to her friend that had a severe mold infection on her face; Susan recalled:

> The woman that let me know about this study deals with a mold infection. She developed the mold infection 25 years ago and was really sick for a good 2, 3 years and had to change her entire diet. She's on rice based everything and she's been to a ton of physicians trying to figure out how she can function. God, what I deal with is nothing, it's nothing compared to her. She walks around and it's [mold infection] on her face, and her skin is scaling so bad. So, I'm thinking, "what are you complaining about, you can hide" [refers to self].

Interview data revealed that PLWP compared their conditions to a variety of others with "worse" conditions (e.g. brain aneurism; cancer) to put stress they experienced in "perspective". However, interview data indicated that not all study participants positively compared their condition to others. Jackie, the 44-year-old from Florida who has lived with psoriasis for 31 years said, “Some people are lucky. They have you know, a thick skin and it doesn’t bother them to be out in public and have something [condition] or that people are looking and it doesn’t bother them. I’m the opposite. I probably wear jeans and a long three-quarters sleeve shirt year-round because it [visible psoriasis symptoms] bothers me. To go out in public…I just don’t even want to. I try to hide it.” For Jackie, albeit her efforts to conceal, the visible nature of her psoriasis symptoms prevented her from being comfortable in public places. Interview data uncovered that PLWP who compared their condition to others as a tool to manage and deal with psoriasis-related stress, did so more often based on *appearance* and *threat* of condition, rather than the *course* of the condition (curable or incurable).

Managing Symptoms of Stress

Research findings by stigma, health, and psoriasis scholars suggest that coping behaviors vary. Work by Hayes and Koo (2010) suggests some PLWP turn to smoking and alcohol to manage the symptoms of stress once they occur. Work by Rodkjaer et al. (2011) on the other hand suggests people with chronic illness disclose their condition to others as a way to cope. Interview data did not indicate that PLWP in this study engaged in smoking and drinking or disclosing their condition as a way to manage the symptoms of psoriasis-related stress. However, interview data did reveal that PLWP utilized personal hobbies (e.g. reading, crafting, exercising, listening to music, and tinkering with small electronics) as a mechanism or tool to help manage the symptoms of stigma and other psoriasis-related stress. These types of strategies helped PLWP to relax or be distracted from the negative feelings and physical discomfort arising from psoriasis-related stress. For example, Dennis, the 72 year-old from North Dakota shared that after his retirement, he volunteered in local and state organizations to manage the symptoms of psoriasis-related stress:

> I've been so busy and lucky enough, both of us [Dennis' wife], to have some health I volunteer in North Dakota and help the legislative volunteer program and help line up people to push senior citizen issues in the state. I was also on the city council after I retired. I got involved in stuff like that…and I'm on the hospital board. So, you just don't have time to even worry the stress, or about poor me [laughs]. Once in a while though I get frustrated and say, "gee I'm getting tired of this shit!" [Volunteer work] (Laughs).

Furthermore, findings here more broadly revealed that while PLWP utilized personal resources (defined by mastery and coping) with varying degrees of success, the use of personal resources did not appear to make stigma-stress and other psoriasis-related stressors disappear entirely from PLWP' daily lives. In fact, coping strategies like *concealment of symptoms* was a source of stress for PLWP. This finding is congruent with Miller's (2006) claim that coping is not a panacea, and that coping can "cost" stigmatized people. In other words, PLWP are faced with a "trade off" between the benefits (minimization of stress) and limitations (contribution toward stress) of coping strategies.

SOCIAL RESOURCES

Stress process scholars identify *social support* as another resource people use to minimize or "buffer" the noxiousness of stress. Though conceptual definitions vary to some extent among scholars, social support generally refers to one's social bonds, social integration, and group relations that protect people from the effects of stress (Turner and Brown 2010). Like stigma, social support is a multifactorial construct. Social support is comprised of several *dimensions* (perceived, received, and structural support) (Turner and Brown 2010); serves a number of *functions* (emotional, informational, instrumental assistance) (Thoits 2011); and, is found in both *institutional* and *social contexts* (occupation, family, medical system and elsewhere (Pearlin et al. 1981; Pearlin 1989). Interview data revealed that participant narratives of 21 of 23 PLWP reflected ways social support played a role in PLWP' management of stigma-stress and other psoriasis-related stressors.

Perceived & Received Emotional Support

Interview data indicated that 15 PLWP perceived a strong sense of social support. Perceived support is the subjective belief that one belongs to a communicative and caring social network (Lakey and Scoboria 2005). A narrative excerpt from Laura, the 19-year-old college sophomore from New Hampshire who has lived with psoriasis for 3 years, illustrates the general sentiment of PLWP that perceived a strong sense of social support. Laura said, "It's just nice to have someone to tell like if something's bothering you. Doesn't have to be psoriasis, just anything in daily life. It's just nice to tell people about it, just someone to talk to, really. It's nice to have that because they [friends and family] don't get grossed out or anything. They'll listen to me." The anticipation that others would be there in time of need, whether psoriasis-related or not, helped Laura, and other PLWP, calm the burden of stigma and other psoriasis-related stress. Interview data revealed PLWP generally perceived having the support of family, friends, intimate others (spouses, dating partner) when dealing with psoriasis-related stress.

The support PLWP received, or the actual help others extended to PLWP, contributed to PLWP' perception of support as well as PLWP's ability to manage and deal with stigma-stress and other psoriasis-related stressors. For example, Dennis, the 72-year-old retired professor from North Dakota who has lived with psoriasis for over 65 years, recounted how his family supported him; Dennis said:

> My wife is just a beautiful, accepting, person and doesn't complain about anything. We'll get up out of bed and I'll say, "I gotta brush the scabs out of here…the scales or whatever you call them". She doesn't complain about stuff and she's supportive in any way possible. She doesn't tease, doesn't…you know,

> just treats me like that's the package I got and that it's just the way it is. My kids basically ask, "how are you doing?" or "your legs are looking better, dad"…they are supportive in a positive manner. "No big deal dad, we love ya" they'll say.

PLWP received support not only from family, but also friends and neighbors. Marvin, the 78-year-old retired Texan who has lived with psoriasis for 42 years recalled:

> It's [stress from psoriasis] not something that we talk about or fret about. My good neighbors, my good friends…uhh, they know I have it. They help me just by not looking at it, not pointing to it, not snickering behind my back. You know, so people outside of the family help by not paying that much attention to it. Inside the family, they tell me "God, you know, we commiserate with you…but there's nothing we can do. If you want me to rub that topical on your back, I'm more than willing to do it". You know, and what more can I ask for? My family and all my friends, and my great neighbors…there is no problem there. They all know how I feel about it, they all know I have it, and they all feel sorry for it, but they don't sit around and say, "Geez, you have to do something about this"…they know I'm doing whatever I can.

From narrative excerpts from both Dennis and Marvin, it is clear each received support from family, friends, and neighbors through interaction (asking how they can help) and action (applying medication to affected areas). Interview data uncovered that PLWP received emotional support (caring of loved ones and close ones), informational support (advice from friends and family on how to deal with stress), as well as instrumental support (prescribed psoriasis treatment regimens from health care providers) from others in their social networks.

Perceived *and* received support was an especially important factor in PLWP' management of stigma and stress. Interview data revealed PLWP felt a sense of belonging and worth (i.e. emotional support). For example, Sharon, the 43-year-old from Michigan who has lived with psoriasis for 28 years recounted how her family and friends restored her self-esteem and confidence; Sharon said, "They [family and friends] tell me that I'm still the same person I was before all these things showed up on my skin. You know, just the fact that they're trying to make me feel better and they love me no matter what helps make it better. They'll build me back up…and help me feel beautiful, not ashamed.” The content in Sharon’s narrative was similarly reflected in the narratives of other PLWP, namely that support of friends, family, and work colleagues, discouraged isolation as a response to stigma and other stress, and encouraged participation in daily activities. Interview data revealed 10 PLWP explicitly shared that structural support, in the form of social participation and contact with network members, helped reduce stress. PLWP participated in joint activity with others (volleyball team, nursing class, fellow crafters) which reduced stress by aiding PLWP in “taking their minds off of psoriasis”. Interview data simultaneously revealed that for at least 5 PLWP, family pets (dogs, cats) also provided support, comfort in times of stress.

Not all PLWP perceived a strong sense of social support from others. In fact, interview data uncovered 6 PLWP perceived a weak sense of social support. Jackie, the 44-year-old Floridian who has lived with psoriasis for 31 years, shared that psoriasis is something her and her family do not talk about. Jackie recalled, “I rely mostly on myself. I tend to keep to myself. I’m not a big social person. You know, my family just kind of ignores it [Jackie’s psoriasis]. They’ve seen it, and they might be like “oh it’s gotten better or worse or something” or some comment, but other than that, it’s really not a topic that is discussed.” Rather than receiving support from her family, Jackie’s family ignored issues related to Jackie’s psoriasis, leaving her with no one to turn to should she have elected to reach out. Brent, the 27-year-old from Massachusetts who has lived with psoriasis for 8 years, also recounted how support from his family was weak; Brent said, “I would say my family has not really, not directly been there for me. You know, maybe indirectly by me telling them how I feel and then them being blasé about it and saying, “well, okay that’s alright.”

Narrative excerpts from Jackie and Brent indicate that some PLWP perceived their psoriasis-related stress as bothersome or annoying to family members. For PLWP like Gloria, the 42-year-old from Massachusetts who has lived with psoriasis for less than 1 year, dealing with the stress of psoriasis was something they had to manage on their own. In other words, interview data revealed the perceived lack of support from others often created feelings of isolation, and detachment from others. PLWP were, in some instances, left to deal with stigma and other stress related to psoriasis alone. However, PLWP who perceived a lack of support did not necessarily receive zero support from others. Rather, the data indicated that PLWP did not perceive the little support they received as beneficial or useful for managing psoriasis-related stress.

Social Ties

Interview data additionally revealed that 16 PLWP recalled ways in which social ties (structural form of social support) did *and* did not contribute to the management of stigma and other psoriasis-related stress. Structural support generally refers to the organization of individuals' ties to one another, involving contact with members within a social network (Turner and Brown 2010). While there were no active psoriasis support groups at the time of the study, 10 PLWP belonged to online spaces for PLWP (e.g. Facebook groups), or had participated in events for PLWP hosted by the National Psoriasis Foundation in select cities across the U.S. (e.g. 5K walk to cure psoriasis). The 10 study participants shared that active engagement online and in person helped them to manage the stress of psoriasis because they felt they were a part of a *community* of fellow PLWP and PLWP supporters. Brent, the 27-year-old from Massachusetts recalled:

> So, I would say that the National Psoriasis Foundation is the biggest formal psoriasis community. You know, there are a lot of online forums where you can find information, and find others who have the condition or similar conditions and how they're dealing and coping with psoriasis and hear their stories. I think that's

> the whole thing, you're not alone. For me, that was definitely the biggest help. Umm…and then to physically meet people at the national psoriasis foundation walk and meet them and shake their hands and say "hey I'm going through what you're going through" and we know what this is about and what you're going through. That was really big for me.

In data presented above, Brent perceived a lack of support from his family. However, in Brent's follow-up response directly above, it is clear that Brent drew on social ties to other PLWP participating in the NPF for support. Interview data revealed PLWP that were engaged online and in-person with psoriasis groups shared similar experiences of meeting others with psoriasis, becoming aware of opportunities for psoriasis networking, learning tips and tricks of psoriasis treatment from others, and embracing their condition, positively. For, Marlene, the 53-year-old Mississippian who has lived with psoriasis for 33 years, online and in-person psoriasis support had helped bridge the gap between newly diagnosed PLWP, and PLWP that have lived with psoriasis for years:

> The Facebook group has been helpful for me. It also has helped me because there's people that I can relate to that are younger that are asking questions, you know? You know, "does this work?" or "does that work?" So for me, it [participation in the group] makes me feel like I can give them [other PLWP] some insight as to what I feel and I know how they're feeling. So, that's where I'll tell 'em, and I'm straight up about everything. I don't sugar coat anything because I know it's something that may or may not work for them.

In the narrative excerpt above, it is clear that for PLWP like Marlene, offering advice and support was equally beneficial for dealing and managing psoriasis-related stress as receiving support from others. Interview data revealed that for at least 3 participants, providing support to fellow PLWP through online groups or via the NPF helped PLWP develop a "sense of purpose" and a sense of "mattering". Molly, the college student in New Hampshire, became a youth ambassador for the NPF and Brent in Massachusetts was creating the first psoriasis support group in the Northeast at the time of this study.

Not all PLWP perceived on-line and in-person psoriasis groups as a resource for support when dealing with stress. Interview data revealed at least 6 PLWP did not perceive social tie-related support from others in psoriasis groups as a helpful resource for stressor management. For example, Rebecca, the 48-year-old from Oregon who has lived with psoriasis for 12, years spoke of her (negative) perception of the concept of a psoriasis support group; Rebecca said:

> People in support groups for people with cancer…survive cancer. Umm…you know it's kind of like this commonality that you have in a support group of survivors. We [PLWP] have yet to survive it; we're still dying from it. So…it's just kind of impossible. It just can't happen because we're not…none of us are at a point where we can talk about our experience as being positive and having anything we want to share that is good, because it's not good.

In the narrative excerpt above, Rebecca's unfavorable impression of psoriasis support groups contributed to her far-reaching generalization that *all* PLWP are uncomfortable with their condition. While findings presented in this dissertation suggest that not *all* PLWP conceive of themselves as "dying" from psoriasis, Rebecca's narrative illustrates that the perceived lack of support from others can have a profound impact on PLWP' *psoriasis identity*. In fact, interview data indicated that for some PLWP, online psoriasis groups were, in some instances, a source of stress. For example, Alan, the 36-year-old from North Carolina said:

> I tend to get extremely frustrated with the online groups, or any of them in general, but the online ones are particularly frustrating because people are stupid. You know they [participants of the group] say things like, "I've heard if you put coconut oil in your mouth and swish it for 30 minutes it'll cure your psoriasis" and like the modern pre-occupation with Dr. Oz , which is complete bullcrap. They are always grabbing at straws. And I know what it's like because in my early 20's, I spent a small fortune on "cures" for psoriasis and none of them worked. So yeah, I don't spend a great deal of time in those groups. I just can't stand it.

Alan's narrative excerpt indicates that failed attempts with psoriasis remedies in the past, and a lack of trust in other's opinions, led to a perceived lack of support from others in psoriasis groups and his distaste for such outlets. For participants like Amy, the 36-year-old in New

Hampshire, the lack of support from psoriasis networks left her feeling like a "lone soul". Interview data also uncovered that PLWP who did not utilize psoriasis network groups as a resource to manage stress, instead sought resources such as books and on-line medical sites for psoriasis facts and statistics as a way to compensate for psoriasis knowledge sharing in psoriasis networks. PLWP who disengaged from fellow PLWP and psoriasis supporters generally dealt with psoriasis-related stress in isolation, independently. However, PLWP who did not find support from psoriasis groups, did not necessarily lack support from other sources (e.g. family, friends). The findings suggest that PLWP actively seek resources (support) to help manage the stress of psoriasis, even if prior attempts have proved unsuccessful.

Social Support & PLWP

Social support is a widely studied construct among stress process scholars. Prior research findings have shown that there are several *dimensions* of social support (Turner and Brown 2010). Research findings presented above indicate that perceived and received emotional support varied among PLWP, though generally, PLWP with greater support coped and managed the stress of stigma and other psoriasis-related stressors. In contrast, PLWP with weaker support tended to isolate themselves when dealing with the burden(s) of psoriasis without assistance from others. Past research has also shown that there are a number of *functions* of social support (e.g. emotional, instrumental) (Thoits 2011). Findings outlined above likewise illustrated that love and care from family, advice from friends, and prescribed treatment by health specialists helped PLWP manage the stress of psoriasis by increasing PLWP' sense of worth and sense of belonging. Thoits (2011:148) argues that knowing who we are to others (*mattering*) provides purpose and meaning in life, which in turn guards against anxiety and despair. However, not all PLWP experienced emotional or instrumental assistance from others. Stress process scholars have also found that social support derives from a variety of institutional and social contexts (Pearlin et al. 1981; Pearlin 1989). Study findings presented above align with prior research. PLWP received support from family, friends, neighbors, as well as colleagues at work and in psoriasis networks. Not all PLWP benefited in similar ways from the sources of support, however.

Social support is also not an unfamiliar construct to both stigma and psoriasis scholars. Mickelson (2001) has posited that for stigmatized persons, the stress of stigma can, on one hand, lead to the mobilization of social support resources, and on the other hand, stigma can erode social support resources for the stigmatized over time. Data in the study indicate that PLWP utilized social support resources as a response to stigma-stress (mobilization) by seeking out help from others, including other PLWP and psoriasis supporters. However, PLWP that perceived the stress of stigma (and other stressors) as all encompassing generally avoided reaching out to others and dealt with the stress alone. Interestingly, Brown (2014) argues that stigmatized people (PLWP) that perceive the threat of stigma as most chronic benefit the most from social support. PLWP in this study who had support, perceived the stress from stigma and other psoriasis-related stressors as manageable.

Psoriasis scholars (Janowski et al. 2012; Picardi et al. 2005) have likewise suggested that social support might improve the quality of life of PLWP as well as increase a sense of security. However, psoriasis scholars have neglected to qualitatively assess how PLWP utilize social support and how resources like social support impact PLWP's capacity to manage stress and shape PLWP' psoriasis identity. Findings presented above suggest that the quality and nature of the relationships PLWP have with others uniquely shapes the meanings PLWP ascribe to psoriasis related stress. For example, PLWP who perceived healthy social relationships and ties with others generally accepted the condition and dealt successfully with psoriasis-related stress. On the other hand, PLWP who perceived having weak ties and a lack of control over their condition generally disengaged from others and dealt with their condition in isolation. The findings are consistent with work by Umberson et al. (2013) and Tausig (2013), who both showed that the *quality* and *nature* of relationships (e.g. marital, employment-wise) matter in terms of stress, even for other groups like the "mentally ill".

Psoriasis Awareness & Future Outlook On Psoriasis

There are approximately 7.5 million Americans and 125 million people worldwide living with psoriasis (NPF 2014; AAD 2014). The sheer number of PLWP domestically *and* globally beckons public awareness and scientific attention. At the conclusion of interviews with PLWP, participants were asked to share anything about life with psoriasis that they thought was important; issues that were not brought up during conversation. Interview data revealed two emergent themes from participant narratives: *psoriasis awareness* and *future of psoriasis*. Psoriasis awareness refers to PLWP' aspirations for broad dissemination of psoriasis awareness information to dispel psoriasis myths. Future of psoriasis refers to PLWP' outlook on the future of psoriasis, pertaining especially to treatment and cure, and the practice of healthcare.

De-stigmatization

Each of the 23 study participants expressed sincere appreciation for the study and gratitude for the opportunity to share their story. Of the 23 participants, 12 PLWP explicitly shared that because psoriasis has affected their lives in such intense and meaningful ways, the creation and diffusion of psoriasis awareness was a top priority. PLWP anticipated that psoriasis awareness would contribute to both the de-stigmatization of psoriasis and empowerment of PLWP. Angelica, the 32-year-old in Puerto Rico who has lived with psoriasis for 11 years recalled how for her, knowledge and awareness of psoriasis was an important factor in the de-stigmatization of psoriasis:

> I think that I've always known about psoriasis because my mother has psoriasis, but I've found that not many people know about it. More people know now than before, but not that many people know *exactly* what the condition is about…and maybe you say "psoriasis" and they think it's something else like dermatitis or something else. I think there should be something done in order to explain the condition to people. So…I think that awareness and maybe the explanation to people what the condition is about is important, because MANY people think that it's contagious. Awareness is something that would really help everyone who has the condition.

The narrative excerpt above indicates that for Angelica, the de-stigmatization of psoriasis, meant life for PLWP could perhaps entail less stress. At least 7 PLWP suggested that educating the public about psoriasis through media outlets, like television, might be a great tool to disseminate facts about psoriasis. It is not surprising that PLWP often attributed misconceptions of psoriasis to ill-informed TV commercials. For example, Sharon, the 43-year-old from Michigan who has lived with psoriasis for 28 years said:

> I wish there was more information out there. Not just for people who have psoriasis, but for people who might not understand it. You see commercials for Humira or Enbrel and they're showing how it works for psoriasis, but it doesn't really explain to the general public what psoriasis is. You know, "take this pill, you'll feel better", which is great for the people who know what psoriasis is…but there's not a lot of information out there for people who don't. I mean, everybody knows what a heart attack is whether they've had one or not. Everybody knows what cancer is, whether they've had it or heard about it, you know? It's just something that is commonplace in society, and conditions like psoriasis just aren't. It's like the dirty little secret nobody's ever heard of. I wish it were more out there in the public so people see it and that way they could learn about it and they could understand it.

Sharon's narrative excerpt depicts psoriasis as society's "dirty little secret", a condition that is hidden, not "commonplace" in the public eye. Interview data revealed that aside from TV, PLWP aspired to spread psoriasis awareness through posts online, brochures and pamphlets at doctor's offices, and in their local communities as well as through daily, informal conversation with others. PLWP generally felt that the de-stigmatization of psoriasis required persistent, continuous, and educated dialogue about the “facts” of psoriasis. At least 5 PLWP posited that stereotypes and misinformation about psoriasis are likely to persist as long as people remain ignorant.

PLWP-Empowerment

PLWP in the study believed that increasing psoriasis awareness would not only de-stigmatize the condition, but would also function to empower PLWP. Empowerment was generally referred to as PLWP having *confidence* in themselves and *control* over their condition. Molly, the 22-year-old college student, who is also a youth ambassador for the NPF, explained why engagement in psoriasis-related activities and awareness was important to her:

> I talk about psoriasis all the time. Talking about it motivates me to continue and to help others. I feel like to me, it’s really important that people understand that psoriasis isn’t *just* a skin rash. You know, it’s a lot more than that and it affects people in a really big way. It can lead to a lot of other different health problems and I feel that a lot of people hear “psoriasis” and think its eczema or they think its you know, like a rash that you get from eating something you shouldn’t. So to me, it’s just honestly really important that people understand psoriasis.

For Molly, spreading psoriasis awareness gave her confidence and inspired her to help others (PLWP *and* PLWP supporters). Participants at the NPF-sponsored walk I attended in the fall of 2014 shared similar sentiments about psoriasis awareness; particularly that PLWP-empowerment is a critical tool to instill hope in PLWP and PLWP supporters. For at least 3 PLWP, PLWP-empowerment was perceived as a means to not only encourage informed conversation about psoriasis, but also to encourage PLWP and others to be vigilant about their bodies, and of their health.

However, findings presented in chapter 5 showed that not all PLWP perceived a strong sense of control, personal mastery. In fact, for PLWP like Rebecca, the 48-year-old from Oregon who has lived with psoriasis for 12 years, psoriasis has, in some instances, stripped PLWP of the simple joys of daily life. Rebecca recounted:

> Life with psoriasis can be really difficult, and even meeting people can be difficult because it can be physically painful. Hugging your spouse is supposed to be exciting, but it might hurt. You know, the kids will come up behind me and put their arms around my shoulders because they're taller than me now and it's an endearing thing, and my son will come up and put his hand on each one of my shoulders…but it's really painful and I have to say, "don't do that, it hurts" and they get tired of hearing that. They feel bad because they've hurt you. You start to be in this little bubble of "don't touch me because it's going to hurt" and that gets frustrating because you miss that contact. I miss the hugs and cuddles. I miss not being able to have my kids on my lap. The touch part of life is gone for me.

For Rebecca, symptoms of psoriasis have limited her ability to enjoy the "touch part of life" that she once valued. Experiences like Sharon's provided incentive for PLWP's desires to spread psoriasis awareness and restore experiences of daily life that were present before PLWP' psoriasis diagnosis.

Treatment & Cure Outlook

Beyond the topic of psoriasis awareness, at least 11 PLWP explicitly shared their hope and expectation(s) for the future of psoriasis. Interview data revealed PLWPs' outlook on the future of psoriasis centered on treatment and cure issues and the healthcare industry. All 11 PLWP shared that they wanted affordable treatment options and a cure for psoriasis. Marvin, the 78-year-old in Texas who has lived with psoriasis for 42 years said:

> I'd like to see an easily available, low-priced drug, or injection…whatever they've got. You know, they can't tell me that a $2000 injection right now is reasonable. With the cost off treatment the way it is, I just sort of bang my head against the wall a couple of times. What can ya do? (laughs). So yeah, a reasonably priced alternative to the high priced stuff that's out there right now is needed. So you go get to a nice, high position in pharma when you're done and tell them to start making this for a buck a shot for us (laughs).

Marvin was not alone in his plea for low-cost treatment options. Interview data revealed that due in part to the high cost of psoriasis treatment, at least 5 PLWP shared that they "couldn't afford to be sick”. Data also revealed that participants hoped to see treatment available in the future that was not as “harmful” (side-effects) as some of the treatments on the market at the time of the study. Data presented in chapter 5 illustrated that the cost of care of psoriasis (including psoriasis treatment) is a stressor for PLWP. It is no surprise that PLWP hoped to see more affordable treatment options (medical and alternative), for lower priced treatment would ease the burden of other monthly expenses (e.g. groceries) for PLWP. PLWP with co-occurring medication conditions shared that the additional cost of psoriasis treatment forced them to have to choose which medications to take regularly, a decision that could have severe consequences.

PLWP additionally hoped for a cure for psoriasis in the future. Libby, the 53-year-old from Oklahoma who has lived with psoriasis for 35 years, shared her desire for *and* skepticism of a cure for psoriasis:

> They’ve gotta find a cure. But…there’s too much money in treatment. If there’s a cure, we’re not repeat customers. And, I guess that’s what really truly bothers me, that the world is driven by money and you know, as long as there’s more money in treatment, I’m afraid there won’t be a cure. Like diabetes…if diabetes was cured tomorrow, I mean drug companies would lose billions of dollars. You know, I’m sure it’s kind of a conspiracy theory like thing, but that’s just my person thought.

It is clear that Libby perceived a need for a cure for psoriasis, though Libby believed a cure is not as lucrative as treatment. While other PLWP did not share Libby’s “conspiracy”-like hypotheses about a cure for psoriasis, PLWP generally believed a cure would bring relief to psoriasis sufferers. For Rob, the 30-year-old from New York, a cure for psoriasis equated to preventative measures for psoriasis, which would relieve other (future) PLWP from the daily hassles of the condition. Rob believed a cure for psoriasis would unlock the underlying “root causes” of the condition. Participants did not specify how soon they expected a cure for psoriasis, nor did participants comment on whether or how psoriasis awareness would contribute to a cure.

Healthcare Practice

Interview data revealed that 9 PLWP shared concerns about healthcare practice, broadly. Susan, the 59-year-old from New Hampshire who has lived with psoriasis for more than 20 years shared her concerns about the healthcare industry:

> I think that the medical industry…practitioners [dermatologists] especially, need to start dealing with other issues like diet for people with psoriasis. They need to be partnering up with nutritionists, and other doctors who have been in the field of psoriasis. Big pharma, that's also the problem…controlling what doctors prescribe. So, it's people like me that have to find their own way to get to the information that is needed about other conditions. Sometimes I'm at it good. Sometimes I'm not.

Given Susan's perception of the restrictive nature of "big-pharma" on her doctor's treatment prescription, she felt she had been forced to independently search for answers to connect the dots. Susan was not alone in her desire for more comprehensive care (team of specialists; connection of health issues). Tanya, the 31-year-old in Maine who has lived with psoriasis for 1 year, likewise shared her belief that medical practitioners must look for connections between psoriasis and other conditions. Tanya said:

> I would like to see more medical research on psoriasis, but…I'd also like to see the medical community make a connection between issues like candida for example, and psoriasis. My medical community of doctors sort of thinks the holistic approach to candida is up in the air and not really substantiated. That's sort of what I'm getting from the medical community in my experience. But I'd like them you know, to look a little bit more seriously at other conditions and say, "Well, maybe this does have an impact on psoriasis after all". So, I definitely think the medical community can do a better job with that with respect to psoriasis in the future.

Participants believed that linkages between psoriasis and other conditions may serve as a tool for PLWP to manage and control symptoms that might otherwise be prevented or minimized by things like diet. Coincidentally, no PLWP shared desires for alternative forms of care for psoriasis. The finding is particularly interesting given that study participants sought medical *and* alternative approaches to care to manage psoriasis symptoms. PLWP also neglected to discuss issues of health insurance and healthcare policy when talking about their outlook on the future of psoriasis. This finding too, is interesting given that PLWP often experienced stress associated with the cost of care because of poor health insurance coverage and policy.

Schnittker (2013:83) argues that anti-stigma campaigns have become more common and that the missions of the various campaigns to “reduce stigma directed towards stigmatized groups” have remained consistent despite wavering effectiveness of the campaigns. The findings presented above do not explicitly illustrate that PLWP are taking part in psoriasis-specific anti-stigma campaigns. However, findings do indicate that PLWP’s current and future efforts to spread psoriasis awareness reflect their motivations to help de-stigmatize psoriasis. Consistent with findings by Thoits (2011:14), PLWP in this study “challenged” the misconceptions and stereotypes of psoriasis and PLWP by educating, confronting, and engaging others to dispel psoriasis myths. PLWP in this study also hoped for increased availability of lower-priced, less-harmful treatment options and comprehensive care of their psoriasis. Ironically, no PLWP in this study explicitly called attention to future efforts for research to address stress experienced by PLWP. In chapter 7, I present concluding remarks on the implication(s) of these findings for future psoriasis, stress, and health research.

CHAPTER VII
CONCLUSION

STIGMA, STRESS, & PLWP

Study findings in this dissertation bridge the gap in our understanding of stigma and stress among PLWP in three crucial ways. First, study findings uncovered meaning(s) and experiences of psoriasis as a condition among study participants. Interview data revealed PLWP ascribe meaning to their psoriasis based on four condition-related elements: psoriasis symptoms and triggers, diagnosis and disclosure, treatment, and quality of life associated with the condition. The elements identified by PLWP make it clear that psoriasis is a difficult, multidimensional condition. The meanings PLWP ascribe to psoriasis are patterned and are shaped by diverse social factors in both institutional and interpersonal contexts, including modern medicine and work and dating life. For PLWP, psoriasis is more than an incurable, non-contagious autoimmune condition; psoriasis shapes the everyday lives of PLWP.

Second, study findings uncovered how stigma is stressful for PLWP; how stigma and other stressors proliferate and permeate the boundaries of everyday life; and how stigma and other stressors shape PLWPs' psoriasis identity. Interview data revealed that stigma, as a social process, generates strain in discrete daily events, as well as triggers long lasting chronic strain(s) for PLWP. Stigma labels deriving both directly and indirectly from interactions with others, contribute to PLWP' perception of being different from other non-PLWP. Both anticipated and actual experienced stigma creates stressful circumstances for PLWP: PLWP regularly anticipate threats of stigma and are treated differently both in public and private domains because of their condition. Interview data indicate that condition-related symptoms, cost of care, and symptom concealment are additional sources of stress for PLWP. The constellation of these stressors create challenging circumstances in interpersonal and institutional contexts, shaping PLWP' social, recreational, and consumer behavior. Additionally, interview data showed that stigma and other stressors often proliferate to create new independent sources of stress in a variety of social roles that PLWP occupy. The chronic strain created by these stressors permeates daily functioning in social (work, relationships, and recreation) and personal (personal goals) areas of life, as well as creates problems in PLWP' interaction(s) in peer and family networks. Depending on PLWP' access to personal and social resources, stigma and other stressors contributed to PLWP' psoriasis identity, the way PLWP perceive and understand their condition, and their ideals of "self".

Third, study findings uncovered how PLWP cope and manage the stressful effects of stigma and other stressors as well as uncovered PLWP' aspirations for psoriasis awareness and PLWP' future outlook on psoriasis. Interview data indicate that PLWP utilize personal resources (mastery and coping) and social resources (social support) to help them buffer (lessen, reduce) the stressful impact of stigmatization and other stressors. PLWP with strong perceived control (mastery) are more likely to accept the condition and adjust to stressful circumstances, whereas PLWP with low perceived control are less likely to accept and adapt to their condition and often disengage to avoid stressful circumstances. PLWP also utilize coping strategies in efforts to a) change the situation (e.g. conceal psoriasis symptoms), b) manage the meaning of a situation to make it seem less burdensome (e.g. positive comparison to other PLWP), and c) keep the symptoms of stress within manageable bounds (e.g. reduce anxiety arising from stressors by participating in activities and hobbies). Interview data additionally revealed that PLWP utilize social resources (social support) to minimize the noxiousness of stress. PLWP who perceive and receive emotional social support managed the stress of stigma and other psoriasis-related stressors more effectively than PLWP with weaker support who tend to isolate themselves from social situations and relationships. Study findings additionally indicate that PLWP engaging in more "formal" support-related activities (online groups and blogs; NPF-sponsored walks) often expressed motivation to de-stigmatize psoriasis and encourage PLWP-empowerment. Moreover, while PLWP are skeptical about a psoriasis cure, PLWP genuinely hope to see lower-cost treatment options, comprehensive psoriasis care, and fair health insurance and disability policy down the road for PLWP everywhere.

Prior, mostly-quantitative scholarship on stigma, chronic illness, and psoriasis, focused almost entirely on quality of life issues of PLWP, without directly specifying dimensions of stress that are linked to stigma. The findings presented in this dissertation connected two important lines of sociological inquiry (stigma and stress), describing in rich detail the variety of ways that stigma and other stressors operate in the daily lives of PLWP. Findings analyzed and presented in context of the stress process framework link stigma *and* stress as a multidimensional social process. The threat of stigma and other stressors pattern PLWP' public and private lives in similar ways, though the chronicity of stigma and other stressors vary among PLWP, given available personal and social resources. The findings more broadly illustrate that psoriasis-related stress deeply impacts the lives of PLWP; a stark contrast from overly simplistic media portrayals of psoriasis and stereotypical psoriasis stigma labels.

Findings presented in this dissertation also tell us more about the social processes of stigma and how stigma plays a role in the everyday lives and identity of PLWP. Stigma researchers (Goffman 1963; Link and Phelan 2001; and Link and Phelan 2013) have argued that stigmatized, "blemished" people are labeled and set apart from "normal" people. Moreover, research by these scholars has shown that stigma is a multidimensional concept affecting the lives of the stigmatized in both interpersonal and institutional contexts. We now know that stigma shapes PLWP's conception of their condition and self (psoriasis identity). The stigmatized identity of PLWP often results in compensatory behaviors by PLWP (e.g. covering and concealing) which can influence subsequent health outcomes including psoriasis flare-ups, anxiety, and depression. As a result, stigma and stress can occur in a cyclical pattern for PLWP, whereby visible flare-ups result in stigmatizing labels from others, and those stigmatizing experiences in turn increase stress for PLWP, leading to further flare-ups.

We also learned from study findings that the "passing" techniques (Goffman 1963) utilized by PLWP (attempts to appear normal to others) in of themselves are a source of stress for PLWP. PLWP face unique challenges when purchasing material goods (furniture and automobiles) given the nature of their symptoms, as well as face high costs of treatment which could potentially minimize PLWP's visible symptoms. Lively and Smith (2013:512) suggest that the stigmatized (PLWP) develop their identities from the social positions or social roles they occupy within the social structure. In the eyes of stigmatizing others, PLWP occupy a lower social position which might serve as a justification for stigma labeling. Occupying a disadvantaged status too is stressful for PLWP, for PLWP derive meaning about their selves and their surroundings based on their social position. It is no wonder that PLWP at times, feel hopeless and avoid and withdraw from activity, work, and family out of fear of stigmatization.

Furthermore, study findings suggest that avoidance, withdraw, and perceived hopelessness among PLWP can stem from the anticipation and or experience of stigmatization. PLWP are aware of and internalize psoriasis stereotypes (e.g. dirty, contagious, scaly), which in turn are burdensome for PLWP in daily social interactions. The anticipation of stigmatizing reactions from others can instill in PLWP a fear of rejection, discomfort, and can damage PLWP's perceived sense of control (personal mastery). In other words, in addition to experienced stigmatization (e.g. discrimination, differential treatment), which PLWP also are confronted with, anticipated stigmatization is itself a source of stress for people with psoriasis. As sources of stress, both anticipated and experienced stigmatization can influence important personal and social resources (e.g. reduced sense of control; less social support) for PLWP, which in turn can impact PLWPs' ability to effectively manage stigma-stress.

BENEFITS & LIMITATIONS OF THE STUDY

In-person and telephone interviews with PLWP provided valuable accounts of daily, lived experiences of stigma and other stressors in the lives of PLWP. Each of the 23 study participants were grateful for the opportunity to share their story. A narrative excerpt from Amy, the 36-year-old college lecturer in New Hampshire who has lived with psoriasis for over 30 years, captures PLWP's overall interest in and gratitude for this study:

> I think it's really interesting that you're doing this. I think it's interesting that you're asking these questions…I've never been asked them before. So, it's [interview] prompted some thinking in me that I haven't done before. So, I guess I want to say thank you for getting me to think about it [psoriasis] in this way. I think the fortunate thing is you probably want to do a follow up study now that you've asked these questions [laughs].

For participants like Amy, this study gives a voice to PLWP who have otherwise dealt with their condition in silence. Interview questions inspired participants to recall deeply personal and emotional aspects of psoriasis-related stress, uncovering meanings PLWP ascribe to their CSC and depicting how PLWP experience and manage stress. Narratives of PLWP in this study might inspire other PLWP to participate and share their stories and experiences in future psoriasis and stress research studies.

This study advances stigma, stress, and health research by demonstrating how two areas of research and theory: social stigma and stress process, can each inform the other. Prior stigma research has generally shown that the anticipation of stigma among stigmatized people contributes to problems in functioning. Moreover, the stigmatized often experience discrimination and challenges to quality of life. Yet, stigma research has not explicitly conceptualized these social processes as stress processes. Findings from this study highlight that stigma is itself a far-reaching and often chronic source of stress. Importantly, stigma-stress proliferates to multiple areas of life, interfering with daily functioning at work and straining interaction between PLWP and their peer and family networks. Findings also show how the intensity and chronicity of stigma-stress can be reduced or "buffered" for PLWP by a strong sense of control (mastery), a variety of coping strategies (directed at changing the stressful situation, changing the meaning of the situation, or managing stress symptoms), and receiving strong emotional support from others. PLWP are not exposed to or damaged by stigma-stress equally: some PLWP are unable to deal with stigma-stress and isolate themselves, while other PLWP successfully cope with and manage stigma-stress. Thus, the stress process framework, applied to stigma, allows us to see how the impact of stigma on stigmatized individuals is contingent on a variety of social contexts and personal resources. On the other hand, stress process research, while emphasizing the importance of stress exposure for health and well-being, has not typically incorporated stigma experiences in conceptualizations of stress. Findings from this study inform stress process research by documenting, for example, how stigma-related stress experienced by PLWP varies by dimensions of stigma (e.g. concealability, disruptiveness) and by aspects of stigma that shape self-perceptions (e.g. anticipated labeling; differential treatment, psoriasis identity).

Qualitative findings presented in this dissertation are one of, if not the first, to explicitly illustrate stigma as a stressor in the lives of stigmatized people with a chronic condition. This study utilized the stress process framework to uncover social processes involved in stigma and stress among PLWP, and may be of value to scholars interested in people with other types of stigmatized chronic illness. For example, obese people, the mentally ill, and people living with HIV/AIDS are stigmatized groups of chronically ill people that likely experience stigma as a chronic strain in their daily lives. The current study suggests that qualitative studies on these populations might similarly uncover ways that those suffering from these chronic illnesses attach meaning to their condition and cope with and manage condition-related stress.

Despite a diverse sample of PLWP (participants from all regions of the U.S. and a U.S. territory; variation in length of time with psoriasis and symptom severity; age), study findings presented in this dissertation are not characteristic of *all* PLWP, and therefore findings cannot be assumed to be generalizable to all individuals living with CSCs. In other words, PLWP that differ from the study sample in some important way(s) (i.e. age, race, and symptom severity) might experience sources of stress that were not uncovered in interview data. Moreover, people with different types of chronic skin conditions (CSC) might experience sources of stress that are not experienced by PLWP, or were not uncovered in this study. However, the qualitative research design of this study was designed to uncover nuanced experiences of PLWP, the meanings they attached to those experiences, and how they managed stress, rather than test or compare PLWP's experiences to others with CSCs. Despite a relatively small number of interviews (23), there did appear to be saturation with respect to the themes that emerged.

Recruitment of study participants was limited to PLWP who engaged in psoriasis-related activities (e.g. NPF 5K walk), participated in online psoriasis discussions (e.g. Facebook psoriasis page), or who happened to pass by a recruitment flyer in their local community. While the recruitment efforts for a convenience sample were multifaceted, PLWP who are isolated, unwilling or are uncomfortable sharing their story, highly distressed, or whose condition is particularly disabling, may have been less likely to volunteer to participate. As a result, the sample may exclude PLWP who experience the greatest levels of stigma and other stressors and/or who possess the least social and personal resources. Therefore, despite the large number and intensity of stressors uncovered in this study, they may represent a conservative estimate of stress exposure and its consequences among individuals with this condition. Also, recruitment efforts excluded PLWP under age 18. Based on interview data, PLWP often recalled that the anticipation of stigmatization was most severe during middle and high school years of life. Given exclusion of PLWP-minors from the study, findings may not adequately represent how stigma-stress experienced is experienced at younger ages.

Finally, findings were limited to data obtained by self-reports of experiences of psoriasis-related stress. At the time of this study, no formal psoriasis support groups existed. Ethnographic participation in a psoriasis support group in the future would provide deeper immersion into the social worlds of PLWP, allowing greater exploration of the daily challenges faced by PLWP not discussed in participant interviews. Greater exploration of other groups of PLWP (e.g. by age, mobility, and willingness to talk) may uncover further clues about how PLWP experience stress stemming from stigma and other psoriasis-related stressors.

FUTURE PSORIASIS RESEARCH & IMPLICATIONS OF FINDINGS

This study opens the door to sociological inquiry exploring stigma, stress, and PLWP. Future research utilizing the stress process framework to investigate the understudied lives of PLWP should further examine the impact of stigma and other stressors on the social roles of

PLWP. For example, while findings of this study initially revealed that stigma and other stressors are burdensome for PLWP in intimate domains of life (e.g. dating, sexual relationships), findings did not explicitly reveal whether and how the chronicity of stigma and other stressors vary for PLWP in different intimate settings (casual hook-up or spousal partner). Future research addressing stigma-stress, intimacy, and PLWP should seek to uncover more nuances in stress exposure by important factors such as symptom severity, age, gender, and race. Future research should also investigate, in greater depth, the impact of stigma on other social roles like parent, peer, or employee in order to better specify the ways that stigma-stress permeates the boundaries of these roles to shape PLWP' psoriasis identity.

Future research should also explicitly investigate the role of other stressors identified in this study in the lives of PLWP. Study participants overwhelmingly claimed that the cost of care of psoriasis is stressful for PLWP. Given rising costs of healthcare in the U.S. and influence of the pharmaceutical industry on the practice of medicine, future research must address how the rising costs of care (treatment, health insurance deductibles) shape PLWP' experience of psoriasis-related stress and uncover what resources are most useful for reducing or buffering cost of care related-stress. Future investigations may better reveal why PLWP utilize a medical and or alternative approach to psoriasis care, as well as uncover how the chronicity of psoriasis-related stress varies for insured PLWP *and* non-insured PLWP. Future research investigating stress created by condition-related symptoms and symptom concealment may also provide clues as to which PLWP are most likely to seek medical or alterative treatment, and how personal and social resources shape PLWP' acceptance or denial of their condition.

The current study suggested how PLWPs' portrayal in the media (e.g. pharmaceutical sponsored television commercials) can have damaging effects on PLWP and their social relationships; changing the ways that the media portray PLWP may be critical for generating psoriasis awareness and PLWP empowerment. Study participants talked about how portrayal of psoriasis and PLWP in pharmaceutical advertisements, for example, tended to *minimalize* the “problems” of psoriasis (e.g. social discomfort, isolation, physical and emotional pain). That is, unrealistic images of PLWP in the media mischaracterize what *actual* life with psoriasis is like, underestimating the stressful nature of psoriasis in personal and social contexts. Misconceptions of psoriasis provided through media to the public can make PLWP feel inadequate since they are not “handling” psoriasis as well as those depicted in the commercials, and the misconceptions can strain social relationships, as friends and family might make unrealistic and unhelpful suggestions about how PLWP might “fix” their condition. Thus, the mischaracterization and oversimplification of psoriasis as a condition by the media itself can represent a source of stress for PLWP.

Findings presented in this study have practical implications for psoriasis advocates, health practitioners, and policy makers. Given the sheer number of PLWP both domestically and globally, psoriasis as a chronic health condition demands public attention and awareness. Efforts by national organizations like the National Psoriasis Foundation to reduce psoriasis stigma and promote psoriasis awareness have included public events (5K walks), community outreach (informational brochures and website), and fundraising for research targeting psoriasis treatment and cure. However, interview data revealed a discrepancy between the goals of organizations such as the NPF and the goals of PLWP. For example, PLWP recognize and are grateful for the efforts of psoriasis advocate organizations like the NPF, though perceive the organizations’ goal to be too focused on fundraising and less focused on dispelling psoriasis myths in the public arena (e.g. television commercials and internet ads).

As a strategy to increase public awareness of psoriasis and promote de-stigmatization of the condition, psoriasis advocate organizations can utilize data presented in this study to structure anti-stigma campaigns in such a way that the campaigns address stigma and stress experienced by PLWP. In other words, dissemination of psoriasis awareness aimed at stigma reduction (via media and internet outlets, etc.) must speak to the many ways stigma permeates the lives of PLWP, and inform public audiences as to available resources effective in helping PLWP cope and manage psoriasis-related stress. Public education about psoriasis sponsored by organizations like the NPF will not only aid in dispelling misconceptions of psoriasis and reduce stigma labeling, psoriasis education will help facilitate psoriasis empowerment of PLWP by inspiring PLWP *and* PLWP supporters to share their stories. PLWP belonging to organizations like the NPF might also consider starting support groups in their local communities. The purpose of these formal support groups would be to educate PLWP and non-PLWP about misconceptions of psoriasis, as well as provide stress-relief support for PLWP and PLWP supporters in local and regional areas.

Research findings presented in this study also have implications for psoriasis practitioners. Interview data revealed that each of the 23 study participants received a formal, medical diagnosis of psoriasis. However, not all PLWP routinely sought advice and care of a psoriasis practitioner (e.g. dermatologist). Interview data indicate that PLWP who avoid routine medical care for psoriasis, do so in part because of a lack of trust in psoriasis practitioners, and the high costs associated with psoriasis treatment medication(s) and healthcare coverage. In fact, PLWP often utilize alternative approaches to psoriasis care as a cost-effective strategy to lessen the burden of psoriasis treatment expenses. In order to gain trust with patients, psoriasis practitioners should consider having conversations with PLWP that include dialogue pertaining to the sources and cycle of stress and symptom flare-ups PLWP experience. In other words, practitioners should utilize a comprehensive approach to psoriasis care, addressing the individual needs and concerns of PLWP, rather than treating all psoriasis patients similarly, regardless of their unique circumstances.

Interview data reveal that PLWP often deal with issues of psoriasis, including stress, in isolation from others. Trust building between practitioners and PLWP becomes a crucial element for psoriasis care, as PLWP perceive practitioners as the only people they can confide in to discuss psoriasis-related concerns. Comprehensive care provided by practitioners targeting both psoriasis-related stressors and psoriasis symptoms will simultaneously build trust between practitioners and PLWP (a stressor management resource for PLWP) and provide treatment options to minimize visible symptoms, reducing stigmatizing reactions of others while providing relief to PLWP. The restoration of trust in modern healthcare practitioners on a case-by-case basis between PLWP and their doctors will likely encourage PLWP to seek routine care for their psoriasis and maintain a consistent treatment regimen. Furthermore, medical and specialized training addressing social and personal aspects of patients' lives should be incorporated in medical school and health curricula. Health curricula designed for comprehensive care of patients (including PLWP) implemented during training stages will grant practitioners the ability to assess a condition, like psoriasis, holistically (attention to the multidimensional components of condition) and to provide referral to patients that adequately serve their needs, even if the practitioner him/herself is unable to provide those services. Practitioners trained to take a comprehensive approach to psoriasis care will treat not only condition-related symptoms, but also related health needs (e.g. diet, exercise, co-occurring illness, and stress).

Findings of this study indicate PLWP are concerned about health insurance coverage and current health care cost which were perceived to significantly add to the burden of having psoriasis. At the time of the study, some study participants shared that having health insurance contributed to lower direct healthcare costs (i.e. affordable deductibles), while other PLWP shared that, in some circumstances, they were excluded from insurance plans (psoriasis considered a pre-existing condition) and were ineligible to claim disability benefits for their condition. Insurance and healthcare policymakers should interpret the findings presented in this study as a call to action, re-considering costs of insurance and exclusion of people with chronic illnesses like psoriasis in context of healthcare policies. PLWP should interpret these findings as an incentive to seek out non-discriminatory insurance options, insisting fair coverage. Comprehensive healthcare coverage and policy reform should prioritize patient safety and well-being, one of many factors included in the contemporary chronic care model studied by public health scholars.

Successful comprehensive reform efforts founded on patient safety and well-being will reduce costs associated with psoriasis care, restrict the influence of big pharma on delivery of care, and support PLWP physically unable to work. Comprehensive and fair healthcare coverage and policy for PLWP (and others with chronic illness) will minimize cost of care stress and contribute to improvements in the quality of PLWP' daily lives. Provisions of the recent Affordable Care Act (ACA) will likely have a positive impact on the healthcare coverage of PLWP in the future. For example, under the ACA, there's cost assistance available to people in need to purchase health insurance; people cannot be dropped from their insurance for pre-existing conditions; insurers are restricted to fair rates; and, patient interest is protected, making new benefits available regardless of health status. For PLWP, rights afforded by the ACA may better allow PLWP to seek out affordable and fair treatment options with reduced fear of discrimination simply based on having a chronic condition. Future research should explore how the ACA impacts clinical-community linkages pertaining to psoriasis, as well as other chronic conditions. Such investigations will help to determine the extent to which access to psoriasis care and treatment has improved with the ACA and where further improvement may be needed. A renewed interest in the rights of patients will hopefully not only inspire better quality of care for conditions like psoriasis, but also encourage illness prevention and management strategies that help to reduce stigma and stress, and that increase quality of life for those living with psoriasis.

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APPENDIX

University *of* New Hampshire

Research Integrity Services, Service Building
51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

09-Apr-2015

Parkhouse, Alex R.
Sociology, McConnell Hall
305 Kent Place
Newmarket, NH 03857

IRB #: 6078
Study: Nobody Wants to Feel Different...But It's Just The Way It Is: Experiences of Stigma and Other Stressors Among People Living with Psoriasis
Approval Date: 12-Sep-2014

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b). Approval is granted to conduct your study as described in your protocol.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects.* (This document is also available at http://unh.edu/research/irb-application-resources.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson
Director

cc: File
Turner, Heather

UNIVERSITY *of* NEW HAMPSHIRE

INFORMED CONSENT LETTER

DATE

Dear Participant:

I am a doctoral graduate student in the department of sociology at the University of New Hampshire, and I am conducting a research project to learn how people experience living with psoriasis. I am writing to invite you to participate in this project. I plan to interview approximately 25 to 30 participants in this study. You must be at least 18 years old to participate.

If you agree to participate in this study, you will be asked a series of interview questions regarding your experience of living with psoriasis. The interview will take approximately 1 to 1 1/2 hours of your time. With your permission, the interview will be audio recorded for the sole purpose of transcription of interview dialogue. This will help me to remember our conversation after the interview is over. As a token of appreciation for your participation in this study, you will receive a twenty-dollar cash card after the interview is completed.

There is minimal risk, if any, to you as a participant in this study. Other than the $20 cash card, you will not receive any direct benefits for your participation. However, the knowledge gained from this study will help researchers and providers to better understand the needs of people living with psoriasis. We find that participants often enjoy the opportunity to share their experiences in the interview.

Participation in this study is strictly voluntary. If you refuse to participate, you will not experience any negative consequences. If you agree to participate, you may refuse to answer any question and/or if you change your mind, you may stop the interview at any time. Participants withdrawing from, or not completing the interview, will not be eligible to receive a $20 cash card.

I seek to maintain the confidentiality of all data and records associated with your participation in this research. Only I and my dissertation advisor professor Heather Turner, will have access to the data for this research project. There are, however, very rare instances when I would be required to share personally identifiable information. For example, in response to a complaint about the research, officials at the University of New Hampshire, might access research data. Audio recordings of interviews will be stored securely on my computer. Interviews will be transcribed and coded for data analysis purposes, but your name will never be included within the transcript. Audio-recordings will be destroyed after the research project has concluded. I will report data from interviews using only pseudonyms; no identifying information will ever be used. The results of this study may be used in my dissertation, presentations, and publications.

If you have any questions about this research project or would like more information, you may contact Alex Parkhouse (ari89@wildcats.unh.edu) or his dissertation advisor, professor Heather Turner (heather.turner@unh.edu). If you have questions about your rights as a research subject, you may contact Dr. Julie Simpson in UNH Research Integrity Services at 603-862-2003 or Julie.simpson@unh.edu to discuss them.

I have enclosed two copies of this letter. Please sign one indicating your choice and return in the enclosed envelope. The other copy is for your records. Thank you for your consideration.

Sincerely,

Alex R. Parkhouse
PhD Candidate

Yes, I, ______________________________consent/agree to participate in this research project.

No, I, ______________________________do not consent/agree to participate in this research project.

________________________________ ____________________
Signature Date

INTERVIEW GUIDE

Researcher:	Alex R. Parkhouse	**Institution:**	Univ. of New Hampshire
Interview Date:		**Department:**	Sociology

INTERVIEW QUESTIONS

***Background*:**

I'd like to start by asking a couple of background questions so that they can be a part of our interview information.

Age: __________

Gender: __________

Race or ethnicity: __________

Marital Status: __________

How long have you been living with Psoriasis? _______________

***Core Content*:**

I. How did you first become aware of your psoriasis condition?

Probes:

- At what age did you first experience symptoms of psoriasis?
- How severe would you say your psoriasis symptoms are?
- What are the most difficult symptoms that you have experienced?
- Has the severity and types of symptoms changed over time? Gotten worse or better?
- Did you ever receive a formal diagnosis of psoriasis? What age? From a dermatologist?
- Are you receiving treatment? What type(s)? How effective has it been in reducing or eliminating symptoms?
- How have you told people about your condition, people other than health care providers?
- Who have you told and at what point? Are or were there people in your life that you

avoid telling about your condition?

II. Have you ever found living with psoriasis to be stressful? What is stressful about it?

Probes:

- Have you ever had relationships or interactions (maybe with martial or dating partners, friends, acquaintances, classmates, or co-workers) that were affected in some way by living with psoriasis? In what ways were they affected?
- Have you ever had problems or difficulties at school, work, or at home because of your psoriasis? How so? Examples?
- Are there any specific events or activities that are particularly stressful for you, given your psoriasis? Why are they stressful?
- Have you ever attempted to cover up or conceal your psoriasis symptoms? In what contexts?
- What other aspects of living with psoriasis are particularly stressful? (e.g. medication/treatment expense and insurance?)

III. Were you ever concerned that people would react or treat you differently because of your psoriasis? In what ways?

Probes:

- Has concern about other people's reactions to your psoriasis ever been a source of stress for you? In what ways?
- Were there any times when you felt that people *actually* reacted to you or treated you in a negative way because of your psoriasis? Can you give examples?
- Have people's reactions toward your psoriasis ever influenced how you feel about yourself? In what ways?
- Have you ever felt embarrassed or ashamed of your psoriasis? In what contexts? What are the circumstances that most create these feelings?
- Have you ever avoided certain situations because you were concerned about others reactions to your psoriasis? Please explain.
- Do you think that concern over other people's reactions has ever affected how you function at work, in romantic relationships, or in other types of social interactions? In what ways?
- Have people's reactions toward your psoriasis ever affected those close to you, such as your family, friends, or significant other (like made someone close to you embarrassed or angry)? Can you give me any examples?

IV. How have you attempted to protect yourself from (or manage) the stress of living with psoriasis?

Probes:

- In what ways have treatment medication(s) helped you to manage the stress of living with psoriasis? Examples?
- In what ways has wearing certain clothing or altering your appearance to "hide" symptoms of your psoriasis helped you to manage the stress? Examples?
- Have friends, family, or other people close to you helped you to cope with the stress of

living with psoriasis? In what ways or contexts?

- Are there things that you yourself do to manage, or protect yourself from others' reaction toward your psoriasis? Please explain.
- What other things might you do to help lessen the stress of living with psoriasis? (e.g. hobbies, spiritual/faith practices, having household pets?) Please elaborate.
- Have you participated in support groups for people living with psoriasis or other skin conditions? In what ways have such groups helped dealing with psoriasis-related stress?
- Are you aware of any friends, family, or colleagues that are living with psoriasis? How has that helped you respond to psoriasis-related stress?

V. Conclusion of Interview

- Is there anything in particular you would like to see future research address for people like you who are living with psoriasis?
- Is there anything else about living with psoriasis that you think is important, that we haven't talked about in our conversation?

*** Thank interviewee for their time and participation.**

*** Distribute a debriefing document at the conclusion of the interview.**

Date

Dear Participant,

Thank you for sharing your experience of living with psoriasis with me today. Your time, participation, and response to interview questions are greatly appreciated. As a token of my appreciation, please accept the enclosed cash card to use as you desire. Below, I have also included contact information of the National Psoriasis Foundation, should you choose to explore the resources, tools, discussions, and events that the foundation sponsors. All information is free and available to people living with psoriasis, supporters, and the general public. Additionally, if you have any questions about your participation in today's interview, please do not hesitate to contact. Please see my contact information at the bottom of this document.

Regards,
Alex R. Parkhouse

National Psoriasis Foundation

Mission: To Drive Efforts to Cure Psoriatic Disease and Improve the Lives of Those Affected

Website	Phone
www.psoriasis.org	800-723-9166

Researcher Contact Information

Alex R. Parkhouse
Ph.D. Candidate
Email: ari89@wildcats.unh.edu

University of New Hampshire
Department of Sociology
McConnell Hall Room 303
15 Academic Way
Durham, NH 03824

Are You Living with Psoriasis?

Source: pilladvised.com

If you are 18 years or older and live with psoriasis, please consider sharing your experience! Eligible persons are needed for a new study investigating the day-to-day difficulties and ways of coping with psoriasis. Interviews last approximately 1 hour and can be scheduled at a time and place convenient for you. Contact Alex, a researcher at the University of New Hampshire to set up your interview today! All eligible participants will receive $20 for participating.

INTERESTED?

Contact:

Alex Parkhouse

Email: ari89@wildcats.unh.edu